Passage of the

Patient Rights (Scotland) Bill 2010

SPPB 158
Passage of the

Patient Rights (Scotland) Bill 2010

SP Bill 42 (Session 3), subsequently 2011 asp 5

SPPB 158
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Foreword

Purpose of the series

The aim of this series is to bring together in a single place all the official Parliamentary documents relating to the passage of the Bill that becomes an Act of the Scottish Parliament (ASP). The list of documents included in any particular volume will depend on the nature of the Bill and the circumstances of its passage, but a typical volume will include:

- every print of the Bill (usually three – “As Introduced”, “As Amended at Stage 2” and “As Passed”); 
- the accompanying documents published with the “As Introduced” print of the Bill (and any revised versions published at later Stages); 
- every Marshalled List of amendments from Stages 2 and 3; 
- every Groupings list from Stages 2 and 3; 
- the lead Committee’s “Stage 1 report” (which itself includes reports of other committees involved in the Stage 1 process, relevant committee Minutes and extracts from the Official Report of Stage 1 proceedings); 
- the Official Report of the Stage 1 and Stage 3 debates in the Parliament; 
- the Official Report of Stage 2 committee consideration; 
- the Minutes (or relevant extracts) of relevant Committee meetings and of the Parliament for Stages 1 and 3.

All documents included are re-printed in the original layout and format, but with minor typographical and layout errors corrected. An exception is the groupings of amendments for Stage 2 and Stage 3 (a list of amendments in debating order was included in the original documents to assist members during actual proceedings but is omitted here as the text of amendments is already contained in the relevant marshalled list).

Where documents in the volume include web-links to external sources or to documents not incorporated in this volume, these links have been checked and are correct at the time of publishing this volume. The Scottish Parliament is not responsible for the content of external Internet sites. The links in this volume will not be monitored after publication, and no guarantee can be given that all links will continue to be effective.

Documents in each volume are arranged in the order in which they relate to the passage of the Bill through its various stages, from introduction to passing. The Act itself is not included on the grounds that it is already generally available and is, in any case, not a Parliamentary publication.

Outline of the legislative process

Bills in the Scottish Parliament follow a three-stage process. The fundamentals of the process are laid down by section 36(1) of the Scotland Act 1998, and amplified by Chapter 9 of the Parliament’s Standing Orders. In outline, the process is as follows:
• Introduction, followed by publication of the Bill and its accompanying documents;
• Stage 1: the Bill is first referred to a relevant committee, which produces a report informed by evidence from interested parties, then the Parliament debates the Bill and decides whether to agree to its general principles;
• Stage 2: the Bill returns to a committee for detailed consideration of amendments;
• Stage 3: the Bill is considered by the Parliament, with consideration of further amendments followed by a debate and a decision on whether to pass the Bill.

After a Bill is passed, three law officers and the Secretary of State have a period of four weeks within which they may challenge the Bill under sections 33 and 35 of the Scotland Act respectively. The Bill may then be submitted for Royal Assent, at which point it becomes an Act.

Standing Orders allow for some variations from the above pattern in some cases. For example, Bills may be referred back to a committee during Stage 3 for further Stage 2 consideration. In addition, the procedures vary for certain categories of Bills, such as Committee Bills or Emergency Bills. For some volumes in the series, relevant proceedings prior to introduction (such as pre-legislative scrutiny of a draft Bill) may be included.

The reader who is unfamiliar with Bill procedures, or with the terminology of legislation more generally, is advised to consult in the first instance the Guidance on Public Bills published by the Parliament. That Guidance, and the Standing Orders, are available free of charge on the Parliament’s website (www.scottish.parliament.uk).

The series is produced by the Legislation Team within the Parliament’s Chamber Office. Comments on this volume or on the series as a whole may be sent to the Legislation Team at the Scottish Parliament, Edinburgh EH99 1SP.

Notes on this volume

The Bill to which this volume relates followed the standard 3 stage process described above.

Volume 2 (incorporating Annexes B – E) of the Health and Sport Committee’s Stage 1 Report was originally published on the web only. This material, including the written and oral evidence taken by the Committee and the reports of other committees, is included in full in this volume.

The Scottish Government made a written response to the report of the Subordinate Legislation Committee at Stage 1, in addition to the Government’s general response to the Stage 1 Report of the Health and Sport Committee. At its meeting on 30 November 2010, the Subordinate Legislation Committee noted the response without debate. No extracts from the minutes or the Official Report of that meeting are, therefore, included in this volume. Relevant papers for that meeting, including the Scottish Government’s response, are, however, included.
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Schedule—Health care principles
Patient Rights (Scotland) Bill

[AS INTRODUCED]

An Act to make provision about the rights of patients when receiving health care; and for connected purposes.

Patient rights

1 Patient rights

5 (1) It is the right of every patient that the health care received by the patient be as described in subsection (2).

(2) Health care is to—

(a) be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs,

(b) have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing,

(c) allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing,

(d) have regard to the importance of providing such information and support as is necessary to enable the patient to participate in accordance with paragraph (c) and in relation to any related processes.

35 (3) It is the right of every patient to make complaints and otherwise raise concerns and give feedback about health care received.

(4) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify subsection (2).

2 Patient rights: further provision

(1) In construing the right of a patient under section 1(1), the matters set out in subsection (2) below must be taken into account.

(2) The matters are—

(a) the rights of other patients under section 1(1),

(b) the desirability of action delivering health care being proportionate, and otherwise appropriate, to the circumstances of each case,
3 Duty to have regard to certain rights and principles

(1) For the purposes of the rights conferred by section 1, each relevant NHS body must—
   (a) in performing its health service functions, have regard to the health care principles in so far as they are relevant to the function being performed, and
   (b) ensure that any person with whom it enters into a contract, agreement or arrangements to provide health care has regard to the health care principles in so far as they are relevant to the service being provided.

(2) For the purposes of this Act, a “relevant NHS body” is—
   (a) a Health Board,
   (b) a Special Health Board,
   (c) the Common Services Agency for the Scottish Health Service (“the Agency”).

4 Health care principles

(1) In this Act, “health care principles” are the principles set out in the schedule.

(2) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify the schedule.

5 Health care principles: guidance and directions

(1) A relevant NHS body must, for the purposes of section 3, have regard to any guidance issued by the Scottish Ministers in relation to the practical application of the health care principles.

(2) Before providing guidance in relation to the health care principles, the Scottish Ministers must consult such persons as they consider appropriate.

(3) The Scottish Ministers may give a relevant NHS body directions as to the practical application of the health care principles; and a relevant NHS body must comply with any such direction.

Treatment time guarantee

(1) In pursuance of the right conferred by section 1(1), an eligible patient is to start to receive an agreed treatment within the maximum waiting time.

(2) The guarantee described in subsection (1) is to be known as the treatment time guarantee.

(3) A Health Board must take all reasonably practicable steps to ensure that it complies with the treatment time guarantee.

(4) Those steps include, in particular, steps for—
   (a) monitoring each treatment time guarantee,
(b) making the necessary arrangements for the agreed treatment of the patient to start in accordance with the treatment time guarantee either—
   (i) within its area, or
   (ii) if it is unable (or anticipates it will be unable) to treat a patient in its own area, through another Health Board or a suitable alternative provider of the treatment.

7 Treatment time guarantee: further provision

(1) The Scottish Ministers must by regulations make the further provision about the treatment time guarantee specified in subsection (2).

(2) The further provision is—
   (a) the descriptions of patients which are eligible for the treatment time guarantee, and
   (b) how waiting time is to be calculated (in particular, specifying the circumstances in which days are not to be counted towards a maximum waiting time).

(3) The Scottish Ministers may by regulations specify—
   (a) treatments and services (including categories of treatments and services) in respect of which the treatment time guarantee does not apply,
   (b) action that a Health Board is to take to ensure that it complies with a treatment time guarantee,
   (c) circumstances in which the maximum waiting time for a patient may be extended or recalculated (and how such extension or recalculation is to be done),
   (d) circumstances in which responsibility for a treatment time guarantee may transfer to a different Health Board,
   (e) the information that a Health Board is to provide to patients about the treatment time guarantee, including—
      (i) how waiting times are calculated,
      (ii) the circumstances in which the maximum waiting time may be extended, recalculated or suspended,
      (iii) such other information as the Scottish Ministers consider appropriate.

(4) The Scottish Ministers may by order—
   (a) amend the duration of the maximum waiting time for the time being specified in section 10,
   (b) specify such different period of time to be the maximum waiting time under section 10 in relation to any treatment or services specified in such order.

8 Breach of the treatment time guarantee

(1) This section applies where a Health Board has not complied with a treatment time guarantee.

(2) The Health Board must—
   (a) make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity,
(b) provide an explanation to the patient as to why the treatment did not start within the maximum waiting time,
(c) give the patient details of—
   (i) the advice and support available (including in particular the patient advice and support service described in section 15), and
   (ii) how to complain.

(3) In making the arrangements mentioned in subsection (2)(a), the Health Board—
   (a) must not give priority to the start of any treatment where such prioritisation would, in the Health Board’s opinion, be detrimental to another patient with a greater clinical need for treatment,
   (b) must have regard to the patient’s availability, and
   (c) must have regard to other relevant factors.

9 Treatment time guarantee: guidance and directions

(1) Health Boards must, when taking steps to start the treatment of eligible patients, have regard to any guidance issued by the Scottish Ministers which relates to the treatment time guarantee (and in particular, Health Boards’ compliance with it).

(2) The Scottish Ministers may direct a Health Board to take specified action in relation to its compliance with the treatment time guarantee (including, in particular, the steps it must take).

(3) The Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such period as they consider necessary.

10 Treatment time guarantee: key terms

For the purposes of this section and sections 6 to 9—
   “agreed treatment” means a specific treatment agreed between an eligible patient and the Health Board;
   “eligible patient” means a patient of a description specified in the regulations to be made in pursuance of section 7(2)(a) as being eligible for the treatment time guarantee;
   “Health Board” includes the National Waiting Times Centre Board;
   “maximum waiting time” is the period of 12 weeks beginning with the date on which the patient agrees to the agreed treatment;
   “treatment” means a surgical or medical intervention ordinarily provided by the Health Board (other than such treatments or services as may be specified in regulations made in pursuance of section 7(3)(a));
   “treatment time guarantee” has the meaning given in section 6(2).

Complaints and other feedback

11 Complaints

(1) The Scottish Ministers must ensure that each relevant NHS body has adequate arrangements in place for the matters described in subsection (3).
(2) A relevant NHS body must ensure that each of its service providers has adequate arrangements in place for the matters described in subsection (3).

(3) The matters are—

(a) handling complaints made—

(i) by or on behalf of patients, and

(ii) by or on behalf of such other persons as the Scottish Ministers may specify by regulations made under subsection (4)(a),

(b) publicising how complaints are to be made and handled,

(c) giving a person who makes a complaint details of the advice and support available to patients,

(d) publicising the details of the advice and support available to patients (and, in particular, the patient advice and support service serving the relevant NHS body),

(e) monitoring the complaints received with a view to—

(i) identifying any areas of concern, and

(ii) improving the performance of its functions.

(4) The Scottish Ministers may—

(a) by regulations make provision about the—

(i) arrangements mentioned in subsections (1) and (2),

(ii) matters described in subsection (3),

(b) give a relevant NHS body directions about such arrangements or matters.

(5) In this section, a “service provider” is any person who provides health services for the purpose of the health service under a contract, agreement or arrangements made under or by virtue of the 1978 Act.

(6) The powers conferred on the Scottish Ministers by virtue of this section are without prejudice to their powers under the 1978 Act.

(7) Nothing done under or by virtue of this section is to preclude an investigation under the Scottish Public Services Ombudsman Act 2002 (asp 11) in respect of any matter.

**12 Patient feedback**

(1) A relevant NHS body is to encourage patients to raise any concerns or give feedback on health care.

(2) Patients may raise such concerns with or give such feedback to—

(a) the relevant NHS body, or

(b) a Patient Rights Officer.

(3) Where a concern is raised with or feedback is given to a Patient Rights Officer, the officer may pass such concern or feedback to the relevant NHS body (but may do so only with the consent of the patient).

(4) The relevant NHS body must consider all concerns raised and feedback received with a view to improving the performance of its functions.
(5) The Scottish Ministers may give a relevant NHS body directions about the performance of the duties under subsections (1) and (4).

13 Repeal of the Hospital Complaints Procedure Act 1985

The Hospital Complaints Procedure Act 1985 (c. 42) is repealed.

Patient advice and support service

14 Patient advice and support service: establishment and funding

(1) In the 1978 Act, in section 10(1) (Common Services Agency), after “section” insert “and section 10ZA”.

(2) After section 10 of that Act insert—

“10ZA Provision of patient advice and support service

(1) The Agency must secure the adequate provision of the patient advice and support service described in section 15 of the Patient Rights (Scotland) Act 2010 (asp 00) in relation to each relevant body.

(2) In exercising its function under subsection (1), the Agency must have regard to the desirability of the service being provided in the most efficient and effective manner possible.

(3) There may be more than one provider of the patient advice and support service.

(4) The patient advice and support service is not to be provided by—

(a) a Health Board,

(b) a Special Health Board,

(c) the Agency.

(5) Each relevant body must make to its provider of the patient advice and support service, in respect of the provider’s expenses (as respects its activities relating to the service), payments of such amounts, and at such times, as the Scottish Ministers may direct.

(6) For the purposes of this section, a “relevant body” is—

(a) a Health Board, and

(b) any other body that the Scottish Ministers may by order specify.”.

15 Patient advice and support service

(1) The patient advice and support service to be secured by the Agency under section 10ZA of the 1978 Act is to provide advice and support services to patients and other members of the public in relation to the health service.

(2) In particular, the patient advice and support service is to—

(a) promote an awareness and understanding of the rights and responsibilities of patients,

(b) advise and support persons who wish to make a complaint, raise concerns or give feedback about health care,
(c) provide information and advice on such matters as it considers likely to be of interest to persons using the health service,

(d) provide such—

(i) other advice or support,

(ii) reports on its activities,

as the Agency may specify.

(3) The persons who carry out the advice and support functions of the patient advice and support service are to be known as Patient Rights Officers.

(4) For the purposes of subsection (2), a reference to the rights of patients is a reference to the rights of patients under this Act.

(5) For the purposes of subsection (2), the responsibilities of a patient include the responsibility of the patient—

(a) for the patient’s own health and wellbeing, and

(b) to behave appropriately in the receipt of health care.

(6) The Scottish Ministers may by regulations make further provision about the patient advice and support service and in particular about the services it is to provide.

16 Patient Rights Officers

For the purposes of section 15(3), the activities that a Patient Rights Officer may undertake include (in particular)—

(a) providing information and advice about—

(i) the services that the patient advice and support service provides,

(ii) the health service, including its organisation, procedures and specific services that it provides,

(b) explaining the options available for (and the procedures involved in) making complaints, raising concerns or giving feedback,

(c) providing assistance and support to persons making a complaint, raising a concern or giving feedback,

(d) making persons aware of and directing persons to—

(i) other sources of advice and support, or

(ii) persons providing representation or advocacy services,

(e) publicising the patient advice and support service in such a manner as is likely to bring it to the attention of patients and other persons likely to be interested in the service.

17 Duties to share information

(1) A relevant body must (where reasonably practicable and otherwise appropriate) give providers of the patient advice and support service information about—

(a) the relevant body (and the health service generally) including its organisation, procedures and specific services that it provides,

(b) any changes to the information mentioned in paragraph (a), and
(c) such other relevant matters as the patient advice and support service may reasonably request.

(2) A provider of the patient advice and support service must give the relevant body information about—

(a) the services that it provides,

(b) such other relevant matters as the relevant body may reasonably request.

(3) No information is to be given under subsection (1) or (2) which would infringe patient confidentiality.

(4) For the purposes of this section “relevant body” has the same meaning as in section 10ZA(6) of the 1978 Act (provision of patient advice and support service).

**Protections and limitations**

18 **Protections and limitations**

(1) Nothing in this Act prejudices—

(a) the exercise of clinical judgement,

(b) the effective and efficient use of the health service organisation and resources,

(c) any other enactment or rule of law.

(2) Nothing in this Act gives rise to—

(a) any liability to pay damages,

(b) any right of action for specific implement,

(c) any right of action for interdict,

(d) any right of action for suspension.

**General**

19 **Interpretation**

(1) In this Act, unless the contrary intention appears—

“the 1978 Act” means the National Health Service (Scotland) Act 1978 (c. 29);

“the Agency” has the meaning given by section 3(2)(c);

“health care” means services provided under the health service;

“health care principles” has the meaning given by section 4(1);

“the health service” means the health service established in pursuance of section 1 of the National Health Service (Scotland) Act 1947 (c. 27);

“health service function” means any function under or by virtue of the 1978 Act which is a function concerned with, or connected to, the health service;

“patient advice and support service” is to be construed in accordance with section 15(1);

“relevant NHS body” has the meaning given by section 3(2).

(2) In this Act, unless the contrary intention appears, terms used in this Act and the 1978 Act have the same meaning as they have in the 1978 Act.
Ancillary provision

(1) The Scottish Ministers may by order make such consequential, supplemental, incidental transitional, transitory or saving provision as they consider necessary or expedient for the purposes of, or in consequence of, or for the purposes of giving full effect to, any provision of this Act.

(2) An order under this section may modify any enactment, instrument or document.

Orders, regulations and directions

(1) Any power conferred by this Act on the Scottish Ministers to make an order or regulations—
   (a) must be exercised by statutory instrument,
   (b) may be exercised so as to make different provision for different purposes (including different areas),
   (c) includes power to make such consequential, supplemental, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient.

(2) No order is to be made under—
   (a) section 1(4) or 4(2), or
   (b) section 20 containing provisions which add to, omit or replace any part of the text of an Act,
   unless a draft of the order has been laid before, and approved by resolution of, the Parliament.

(3) Any other statutory instrument containing an order or regulations under this Act (except an order under section 22(3)) is subject to annulment in pursuance of a resolution of the Parliament.

(4) Any power to make directions under this Act includes power to vary or revoke such directions.

(5) Any power to make directions under this Act may be exercised—
   (a) generally or to meet the circumstances of a particular area or matter,
   (b) either in relation to all cases to which the power extends, or in those cases subject to exceptions, or in relation to any specified cases or classes of case, and
   (c) subject to such other exceptions or conditions as the Scottish Ministers think fit.

Short title and commencement

(1) This Act may be cited as the Patient Rights (Scotland) Act 2010.

(2) This section and sections 20 and 21 come into force on Royal Assent.

(3) The remaining provisions of this Act come into force on such day as the Scottish Ministers may by order appoint; and different days may be appointed for different purposes.
SCHEDULE
(introduced by section 4(1))

HEALTH CARE PRINCIPLES

Patient focus

1. Anything done in relation to the patient takes into account the patient’s needs.
2. Patients are treated with dignity and respect.
3. Privacy and confidentiality are respected.
4. Health care is provided in a caring and compassionate manner.
5. Support necessary to receive or access health care is available.
10. The patient’s abilities, characteristics and circumstances are considered.

Quality care and treatment

7. Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.
8. The range of options available in the patient’s case is considered.
15. Health care is based on current recognised clinical guidance.

Patient participation

10. Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing.
11. Patients are provided with such information and support as is necessary to enable them to participate in accordance with paragraph 10 and in relation to any related processes (general or specific).
12. Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect.

Communication

13. Communication about a patient’s health and wellbeing is clear, accessible and understood.
14. Communication about general services and processes and decisions is clear, accessible and understood.

Complaints

15. Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures.

Other

16. Waste of resources in the provision of health care is avoided.
Patient Rights (Scotland) Bill
[AS INTRODUCED]

An Act to make provision about the rights of patients when receiving health care; and for connected purposes.

Introduced by: Nicola Sturgeon
On: 17 March 2010
Bill type: Executive Bill
PATIENT RIGHTS (SCOTLAND) BILL

EXPLANATORY NOTES

(AND OTHER ACCOMPANYING DOCUMENTS)

CONTENTS

1. As required under Rule 9.3 of the Parliament’s Standing Orders, the following documents are published to accompany the Bill introduced in the Scottish Parliament on 17 March 2010:

   • Explanatory Notes;
   • a Financial Memorandum;
   • an Executive Statement on legislative competence; and
   • the Presiding Officer’s Statement on legislative competence.

A Policy Memorandum is printed separately as SP Bill 42–PM.
EXPLANATORY NOTES

INTRODUCTION

2. These Explanatory Notes have been prepared by the Scottish Government in order to assist the reader of the Bill and to help inform debate on it. They do not form part of the Bill and have not been endorsed by the Parliament.

3. The Notes should be read in conjunction with the Bill. They are not, and are not meant to be, a comprehensive description of the Bill. So where a section or schedule, or a part of a section or schedule, does not seem to require any explanation or comment, none is given.

SUMMARY OF THE BILL

4. The Patient Rights (Scotland) Bill provides that it is the right of every patient that the health care received is patient-focused, which means that the provision of health care takes into account the patient’s needs. The Bill also provides that the health care received has regard to the importance of providing the optimum benefit to the patient’s health and wellbeing, allows for patient participation in decisions about their healthcare and provides appropriate information and support to allow them to do so.

5. The Bill introduces a guarantee (to be known as the treatment time guarantee) that eligible patients will start to receive treatment within 12 weeks of the treatment being agreed.

6. The Bill also provides for the right of every patient to make complaints and provide feedback and to have access to support to do so. The Bill provides for the Common Services Agency of the NHS in Scotland to secure the provision of a patient advice and support service, and for there to be Patient Rights Officers.

COMMENTARY ON SECTIONS

Section 1: Patient rights

7. Subsection (1) sets out the right for every patient that the health care they receive is to be provided in a certain way, as described in subsection (2).

8. Subsection (2) describes the way in which that health care should be provided. It should be patient focused, which means regard must be had to the patient’s needs, to the importance of providing the optimum benefit to the patient’s health and wellbeing and the patient should be encouraged to play an active part in decisions relating to their treatment and health care, and they should be provided with appropriate information and support to be able to participate in such decisions. In practice, this might mean:

- A healthcare professional listening to a patient’s experience of coping with a long-term condition, and taking this into account when considering the best treatment options.
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

- A patient being encouraged to take their medication regularly or to become more active in order to lose weight and improve their health.
- A deaf patient being provided with a British Sign Language interpreter so that they can discuss their illness and treatment with their doctor, and make an informed decision as to their preferred treatment.

9. Subsection (4) enables Scottish Ministers to modify subsection (2), following appropriate consultation. For example, bodies that might be consulted could include Health Boards, healthcare workers professional bodies, and members of the public.

Section 2: Patient rights: further provision

10. This section provides that meeting the rights of an individual patient should be balanced with the effect on the rights of other patients in receiving healthcare and should take into account the resources available and should be subject to the exercise of clinical judgement and the effective and efficient use of health service organisation and resources.

Section 3: Duty to have regard to certain rights and principles

11. Subsection (1)(a) places a duty on the bodies specified in subsection (2), (which are Health Boards, Special Health Boards and the Common Services Agency for the Scottish Health Service) to have regard to the health care principles set out in the schedule when providing health care, and where those principles are relevant to the service being provided. For example, it might be relevant for a hospital consultant to have regard to all of the principles in the schedule when discussing with a patient their diagnosis and treatment. Or, it might be relevant for a healthcare practitioner to check back with a patient that the patient has understood how to keep a dressing dry.

12. Subsection (1)(b) means that bodies specified in the subsection must also have regard to the health care principles which enables the Bill to be relevant to, for example, cleaning and catering services in hospitals where they have patient contact and to services provided at a primary care level, such as GP practices that are contracted by Health Boards. For example, it might be relevant for a member of catering staff to treat patients with dignity and respect when serving them food. However, ensuring that health care is based on current clinical guidance would not be relevant to a member of catering staff as they would not provide health care.

Section 5: Health care principles: guidance and directions

13. Subsection (1) provides that any body with a duty under section 3 must have regard to any guidance issued by Scottish Ministers about the practical application of the health care principles. Subsection (2) provides that Scottish Ministers must consult relevant people or organisations before giving that guidance. For example, Scottish Ministers may provide guidance about practical ways to implement Health Care Principle 5 “Support necessary to receive or access health care is available”, which might include ensuring patients are aware that they can have a third party with them to support them, such as a friend, relative or partner etc, or ensuring that patients are aware of translation, interpreting and communication support services and how to access them.
14. Subsection (3) provides that Scottish Ministers may give the bodies directions on how the health care principles should be applied in practice.

Section 6: Treatment time guarantee

15. Section 6(1) and (2) establishes a maximum waiting time for eligible patients, known as the treatment time guarantee. The maximum waiting time is set out in section 10. Eligible patients should start to receive that treatment within 12 weeks of the treatment being agreed between the patient and the Health Board.

16. Subsection (3) provides that Health Boards must take all reasonably practicable steps in order to comply with the treatment time guarantee and subsection (4) gives examples of actions a Health Board must take to deliver the treatment time guarantee for its eligible patients. Health Boards must monitor the guarantee, make arrangements for the agreed treatment to start within its area or if it is unable to treat the patient in its own area, make arrangements either with another Health Board, with the National Waiting Times Centre Board or with another suitable provider such as the NHS in England or a private healthcare provider.

Section 7: Treatment time guarantee: further provisions

17. Subsection (3) gives Scottish Ministers power to make regulations providing for other matters relating to the treatment time guarantee, including the treatments and services and categories of treatments and services in relation to which the guarantee will not apply.

18. Subsection (4) allows Scottish Ministers to change the length of the treatment time guarantee by order. For example, this could be to make the maximum waiting time shorter, as services become more efficient. Different periods could be specified for different treatments, for example if some treatments should be delivered within a shorter time.

Section 8: Breach of the treatment time guarantee

19. This section sets out what will happen if a Health Board does not deliver the treatment time guarantee. Subsections 8(2)(a) and subsection (3)(a) mean that the Health Board will be required to offer the patient treatment in a way that will ensure the patient is admitted quickly for treatment but will not distort the clinical priority of patients whose condition requires more urgent treatment. Subsections 3(b) and (c) provide that the patient’s availability and anything else that is relevant should also be taken into account when making arrangements for the patient to be treated at the next available opportunity.

Section 9: Treatment time guarantee: guidance and directions

20. Section 9(1) provides that that Health Boards must have regard to any guidance issued by Scottish Ministers in terms of the treatment time guarantee.

21. Section 9(2) provides that Scottish Ministers may direct a Health Board to take action specified in the directions in relation to the guarantee.
22. Section 9(3) allows Scottish Ministers by direction to suspend the treatment time guarantee in exceptional circumstances. For example, an exceptional circumstance could be a public health emergency that required the treatment time guarantee to be suspended for a short period, to allow Health Boards to respond to the situation and concentrate all resources on dealing with the emergency, such as in the case of a severe outbreak of pandemic flu.

Section 10: Treatment time guarantee: key terms

23. This section defines the key terms referred to in sections 6 to 9 including specifying that the maximum waiting time for eligible patients for an agreed treatment is 12 weeks. The period of 12 weeks runs from the date on which the patient agrees the treatment to the date on which the treatment begins.

Section 11: Complaints

24. Subsection (1) provides that Scottish Ministers must ensure that each Health Board, Special Health Board and the Common Services Agency for the Scottish Health Service has: a suitable complaints process; publicises this process; tells the complainant about the advice and support available to patients; publicises the advice and support available; and monitors complaints.

25. Subsection (2) provides that those bodies must also ensure that anyone providing a health service on its behalf (such as GPs) must have suitable complaints processes in place to identify any areas of concern.

26. Subsection (3) sets out the matters which these complaints processes must deal with.

27. Subsection (4) gives Scottish Ministers power to give directions to NHS bodies and make regulations about the complaints processes which must be in place, including a specific process arising from a complaint. This enables Scottish Ministers to direct a Health Board to take appropriate actions. For example, if a particular Health Board had not been publicising its complaints process adequately, Scottish Ministers could direct the Health Board to publicise the complaints process via a series of posters and leaflets situated in hospitals and health centres.

28. Subsection (5) sets out what is meant by a “service provider”. For example, a “service provider” could be a GP practice.

29. Subsection (7) provides that nothing done in terms of section 11 relating to the complaints processes excludes the Scottish Public Services Ombudsman’s (SPSO) right to carry out investigations, and the right of complainants to go to the Ombudsman. A complainant will normally still have had to exhaust (or at least invoke) the complaints mechanism provided before seeking a SPSO investigation.
Section 12: Patient feedback

30. This section provides for Health Boards, Special Health Boards and the Common Services Agency for the Scottish Health Service to encourage patients to raise concerns or give feedback on healthcare, and that patients can give feedback to a Patient Rights Officer, or to the relevant body. This section is also intended to ensure that when feedback is given to a Patient Rights Officer (PRO) that the PRO must make sure that the feedback is passed back to the relevant body. For example, if a patient felt more comfortable about giving feedback about their health care to a person who sits outwith the Health Board, there is a way for them to do this (via the PRO) and for Health Boards to be informed of that feedback.

31. Subsection (3) establishes that feedback should only be provided to the relevant body with the patient’s consent.

32. Subsection (4) means that NHS bodies must consider all complaints and feedback to see how they could improve the delivery of their services.

Section 13: Repeal of the Hospital Complaints Procedure Act 1985

33. This section repeals the Hospital Complaints Procedure Act 1985 in full. The provisions of this Act are replaced by the measures around complaints and feedback outlined in the Bill.

Section 14: Patient advice and support service: establishment and funding

34. Section 14 amends the National Health Service (Scotland) Act 1978 by inserting a new section 10ZA. The functions of the Common Services Agency for the Scottish Health Service are extended to its new functions under section 10ZA. This, read with section 10(7) of the National Health Service (Scotland) Act 1978, means that there is a specific provision which states that in carrying out its functions the Agency shall act subject to, and in accordance with, such directions as may by given by the Scottish Ministers.

35. Section 10ZA requires the Common Services Agency for the Scottish Health Service to secure the provision of a patient advice and support service in relation to each Health Board, and any other body that Scottish Ministers specify in an order. In order to do this, the Agency will procure the service from a provider or providers. The service may be supplied by more than one provider, but not by a Health Board, a Special Health Board or the Agency itself.

Section 15: Patient advice and support service

36. Section 15 outlines the services that the patient advice and support service will provide to patients and members of the public and provides that the people who deliver that service will be called Patient Rights Officers.

37. Subsection (2)(a) and (b) place a duty on the patient advice and support service to promote awareness and understanding of the rights and responsibilities of patients and to advise people who want to complain about healthcare. In practice, this might mean, for example, advising a patient who wanted to complain about their GP how to do so, and providing guidance
to the patient as to whether the complaint is a matter for the GP practice complaints system, or whether it is a regulatory matter that should be referred to the regulatory body.

38. Subsection (2)(c) and (d) provides that the patient advice and support service may also provide other information and advice on subjects that might be of interest to people using the health service.

39. Subsection (5) sets out the patient responsibilities of which the patient advice and support service is to raise awareness and understanding. An example of such a patient responsibility might be to attend an agreed appointment or to cancel if necessary, well in advance, so that an appointment can be offered to another patient.

**Section 16: Patient Rights Officers**

40. Paragraphs (a), (b), (c) and (d) set out the types of activities that a Patient Rights Officers may carry out. These include explaining the services provided by the patient advice and support service; explaining the services, organisation and processes of the health service; helping and supporting people to make complaints or provide feedback. It also includes explaining the options available and advising people of any other sources of help and advice, including services providing advocacy or representation or, for example, other forms of support, such as translation, interpreting and communication support services.

41. Paragraph (e) provides that Patient Rights Officers must also publicise the patient advice and support service in a way that ensures that patients and others are aware of the services and how to access them. For example, this might include distributing leaflets in GP surgeries, or producing information in alternative formats such as easy read, so that all patients are aware of the services provided.

**Section 17: Duties to share information**

42. Section 17 subsection (1) places a duty on relevant bodies (such as Health Boards) to share information with the patient advice and support service, and allows the patient advice and support service to ask for any other information that it would find helpful. For example, the patient advice and support service might seek clarification on procedures or services offered in a particular area.

43. Subsection (2) means that the patient advice and support service must give information on its services to the relevant bodies. It also means that these bodies can request information from the patient advice and support service. An example might be a Health Board asking its local patient advice and support service for statistical information on the numbers of women and men using the service because it wanted to compare that with the gender profiles of patients in the Health Board area.

44. Subsection (3) requires that when sharing information, patient confidentiality must be respected.
Section 18: Protections and limitations

45. Subsection (1) provides that the Bill does not prejudice the exercise of clinical judgement; the effective and efficient use of the health service organisation or resources or any relevant legislation or rule of law.

46. Subsection (2)(a) provides that the rights set out in the Bill are not of a nature that will impose any liability on any person to pay damages. This means that a patient could not claim damages from a Health Board for an alleged failure to deliver health care in the manner set out in the Bill.

47. Subsection 2(b), (c) and (d) provide that no person could enforce the rights set out in the Bill by an action for specific implement, interdict or suspension. This does not, however, alter or affect a person’s rights under any other law, for example a right to claim damages in the case of medical negligence, because of the provisions of section 18(1)(c).

Section 19: Interpretation

48. This section provides legal definitions for key terms that have been referred to in the Bill.

Section 20: Ancillary provision

49. This section gives Scottish Ministers the power to make consequential, supplemental, incidental, transitional or saving provisions by order for the purpose of giving full effect to the Bill.

Section 21: Orders, regulations and directions

50. Section 21(1) provides that all regulations and orders under the Bill are to be made in the form of a statutory instrument and that regulations and orders may make different provisions for different purposes.

51. Section 21(2) provides that orders made under sections 1(4), relating to changes in how healthcare is delivered, or 4(2) relating to changes in the healthcare principles and any order made under section 20 amending primary legislation, are to be subject to affirmative procedure.

52. Section 21(3) provides that any other statutory instrument made under the Bill (apart from under section 22(3), relating to the date that the provisions come into force) is to be subject to negative procedure.

53. Section 21(4) and (5) make provision for the way in which Scottish Ministers can exercise their powers of direction under the Bill.

Section 22: Short title and commencement

54. Subsection (2) means that that sections 20, 21 and 22 will come into force on the date of Royal Assent. The remaining provisions will come into force on a date or dates appointed by Scottish Ministers.
Schedule: Health care principles

55. The schedule sets out the health care principles. Section 3 places a duty on Health Boards to take into account these principles when delivering healthcare. The principles should ensure that health services are provided in a way that places the patient and their needs and experiences at the centre of an interaction with health services, and which also ensures that patients are encouraged and provided with support to participate in decisions about their treatment and health care.
FINANCIAL MEMORANDUM

INTRODUCTION

56. The Patient Rights (Scotland) Bill provides that the healthcare which patients receive should meet certain criteria. It also establishes a right to make a complaint, legislates for a patient advice and support service and Patient Rights Officers and establishes a 12-week treatment time guarantee.

57. The financial impacts of the Bill have been summarised in the following table. All figures are given in full and references are provided in the first column to the relevant paragraphs of this Memorandum, where more information and a breakdown of particular aspects can be found. A table at Annex A shows the information broken down on a recurring and non-recurring basis, what the funding is for and whether the funding is new or redirected.

<table>
<thead>
<tr>
<th>Area (and paragraph references)</th>
<th>2010-11 Recurring costs</th>
<th>2010-11 Non-recurring costs</th>
<th>2011-12 Recurring costs</th>
<th>2011-12 Non-recurring costs</th>
<th>2012-13 Recurring Costs</th>
<th>2012-13 Non-recurring costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principles in provision of services (para 59)</td>
<td>-</td>
<td>112,000</td>
<td>-</td>
<td>860,000</td>
<td>-</td>
<td>810,000</td>
</tr>
<tr>
<td>The treatment time guarantee (para 80)</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Support and recourse (paras 104 and 119)</td>
<td>-</td>
<td>750,000</td>
<td>2,581,000</td>
<td>250,000</td>
<td>2,581,000</td>
<td>250,000</td>
</tr>
<tr>
<td>Total £</td>
<td>-</td>
<td>862,000</td>
<td>2,581,000</td>
<td>1,110,000</td>
<td>2,581,000</td>
<td>1,060,000</td>
</tr>
</tbody>
</table>

* The treatment time guarantee will be delivered by NHS bodies as part of the 18 weeks referral to treatment target (RTT) which is the whole patient journey maximum waiting time from general practitioner referral to commencement of treatment. Overall funding for the 18 weeks RTT is a cost outwith the Patient Rights (Scotland) Bill (see paras 80 to 91 below).

58. The figures in the table include funding currently spent in this area which is being redirected from the Scottish Government and the NHS in Scotland to this work. The new money being allocated to this area is £784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13.
FOR HEALTH CARE TO BE RECEIVED IN A PARTICULAR MANNER AND THE PRINCIPLES TO WHICH PROVIDERS OF SERVICES HAVE TO HAVE REGARD

59. The financial impacts of this area are summarised below. Costs on the Scottish Administration are subdivided into two lines relating to staff education and development materials (paragraph 64) and public awareness raising (paragraph 69).

<table>
<thead>
<tr>
<th>Principles to which providers of services have to have regard</th>
<th>2010-11 Recurring costs</th>
<th>Non-recurring costs</th>
<th>2011-12 Recurring costs</th>
<th>Non-recurring costs</th>
<th>2012-13 Recurring costs</th>
<th>Non-recurring costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scottish Administration</td>
<td>-</td>
<td>94,000</td>
<td>-</td>
<td>800,000</td>
<td>-</td>
<td>800,000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>18,000</td>
<td></td>
<td>60,000</td>
<td></td>
<td>10,000</td>
</tr>
<tr>
<td>NHS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Local authorities</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other bodies</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total £</td>
<td>-</td>
<td>112,000</td>
<td>-</td>
<td>860,000</td>
<td>-</td>
<td>810,000</td>
</tr>
</tbody>
</table>

60. The Bill establishes that it is the right of every patient that the health care they receive is patient-focused, has regard to the importance of providing the optimum benefit to the health and wellbeing of the patient, allows for patient participation as fully as possible, allows for information and support and allows for concerns or complaints to be raised. This is underpinned by a schedule of health care principles to which health care bodies should have regard.

Costs on the Scottish Administration

61. The principles that are being made explicit through the Bill are embedded in good practice and in current policy and strategies, for example through staff governance, statutory UK professional standards, national (Scotland) standards for healthcare support staff, online development programmes for new graduate Nurses, Midwives and Allied Health Professionals, and the forthcoming NHSScotland Quality Strategy. As these programmes of work are already established and underway they have no additional cost. As part of the support mechanisms, which will also help underpin the principles on support, participation and communication, additional funding is being made available; this is covered at paragraphs 119-134.

62. The Scottish Government intends to support the Bill with the development of training and education materials, integrated into existing programmes of staff training, and an awareness raising of patient rights. These materials will form the basis of a workforce educational development plan, developed by NHS Education for Scotland (NES) that will be linked to other priorities, such as educational strategies to improve patient safety and clinical skills.

63. It is envisioned that a curriculum adopting an iterative approach, starting from induction and building through Continuous Professional Development (CPD), will be developed in
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

partnership with key stakeholders. There may also be opportunities to integrate learning into existing resources and courses, as well as developing new educational resources.

64. NES will undertake this work including the recruitment of staff where necessary, commissioning activity, developing educational materials and delivering training in a wide range of settings. The financial impacts below are firm projections based on NES’s experience of undertaking similar national programmes of work, for example in patient safety, and are as follows:

<table>
<thead>
<tr>
<th>Staff Education and Development materials (para 61)</th>
<th>2010-11</th>
<th>2011-12</th>
<th>2012 - 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity</td>
<td>Costs</td>
<td>Activity</td>
<td>Costs</td>
</tr>
<tr>
<td>Commissioning and development of educational resources</td>
<td>-</td>
<td>800,000</td>
<td>Completion, implementation and evaluation of educational resources</td>
</tr>
<tr>
<td>Scoping study</td>
<td>34,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Communications and awareness raising</td>
<td>60,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total £</strong></td>
<td><strong>94,000</strong></td>
<td><strong>800,000</strong></td>
<td><strong>800,000</strong></td>
</tr>
</tbody>
</table>

65. Initial planning work required to develop a specification to undertake an NHSScotland staff scoping study that will inform this 3 year programme of work is already underway and includes development of the tendering specification, risk assessment, equality impact assessment and identification of relevant partners. This is costing around £25,000 in 2009-10 and is being met from existing NES funding (not shown in the table above). The scoping study will survey a range of staff groups in a representative sample of Health Boards.

66. NES will develop and deliver a communications and awareness raising plan for staff. To ensure alignment of messages and to support the development of learning materials, NES will work with key partners.

67. Communications and awareness raising will include face-to-face awareness raising with Health Boards as part of the ongoing delivery of their Patient Focus Public Involvement work, which aims to ensure that patients and the wider public are able to fully participate in how local services are developed and delivered. NES will develop and pilot awareness raising materials for NHSScotland staff in preparation for enactment of the Bill. These materials will be developed in parallel with the public facing information being developed by Health Rights Information Scotland (see below), but will be targeted specifically at the needs of different staff groups.
Materials will include communications for NHSScotland newsletters, NHSScotland staff handbooks, posters and leaflets.

68. Consultation with patients, stakeholder organisations and the public will lead to the production of a Patient Rights information package. The Scottish Government aims to make draft examples of some of the information that might be in such a package available during Stage 1 consideration of the Bill.

69. Health Rights Information Scotland, part of Consumer Focus Scotland, currently receives Scottish Government funding to provide public information on health rights. In recognition of the need to raise awareness of the rights contained in the Patient Rights (Scotland) Bill, and to bring clarity to the full range of patient rights, Health Rights Information Scotland’s workplan will focus on this new work as a priority. The Scottish Government has estimated the cost of the work for the development and dissemination of public facing material. The cost for 2010-11 will be afforded within the current funding package. The future of the project has not yet been decided and other methods of obtaining this service or providing public information on health rights will be considered and appropriate funding provided. Nevertheless, indicative costs for 2011-12 and 2012-13 are provided in the next table. It is anticipated that these costs can be afforded within current budgets. These are firm projections from Health Rights Information Scotland based on experience of similar activity.

<table>
<thead>
<tr>
<th>Public Awareness Raising (paras 66 to 73)</th>
<th>2010-11</th>
<th>2011-12</th>
<th>2012 - 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation with stakeholder organisations</td>
<td>2,500</td>
<td>Production and dissemination of public information</td>
<td>60,000</td>
</tr>
<tr>
<td>Draft and test public information and design</td>
<td>15,500</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total £</strong></td>
<td><strong>18,000</strong></td>
<td><strong>60,000</strong></td>
<td><strong>10,000</strong></td>
</tr>
</tbody>
</table>

70. £2,500 will allow for 6 days consultation work from Health Rights Information Scotland staff with stakeholder organisations. The Scottish Government anticipates that the drafting and testing of public information would occur late in the 2010-11 financial year and is likely to cost around £15,000. This figure is based on 7 days work from Health Rights Information Scotland staff and commissioned work on user testing. In addition, an estimated £500 would be spent on commissioning initial design ideas.

71. The subsequent figures for 2011-12 and 2012-13 are indicative. Around £30,000 for 2011-12 for production and dissemination is based on design costs, Plain English checking, translation costs and £30,000 for printing and dissemination of the material – posters, leaflets,
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010 factsheets – and to provide it online. Around £3,000 for 2012-13 will allow for a review of the information, further consultation with stakeholders, any revisions necessary and around £7,000 for further dissemination of the material. The printing and dissemination figures could be amended upwards or downwards depending on the quantity of material required. These figures are currently under 10% of the funding provided to Health Rights Information Scotland and, as noted above, this can be afforded within current budgets.

72. Also supporting public awareness raising of patient rights is NHS Inform - the new national health information and support service being led for NHSScotland by NHS 24. In addition, the Scottish Government is developing a national communications campaign which will include patient rights as part of a broader package of promotion on quality, patient experience and patient information. Costs for these are outwith the Patient Rights (Scotland) Bill.

73. Patient Rights Officers will promote and encourage awareness and support for patient rights across Health Board areas, amongst other tasks. Costs for Patient Rights Officers are covered in the support and recourse section at paragraph 104.

Costs on the NHS in Scotland

74. The Scottish Government does not anticipate any additional direct costs arising from these rights and associated principles for the NHS in Scotland. Funding that will also help to underpin the principles of support, participation and communication is covered in the support and recourse section.

75. The Scottish Government anticipates that there will be indirect costs in raising staff awareness of patient rights and training. As noted above (at paragraph 67) staff awareness raising will be delivered through a variety of mechanisms including being incorporated into team meetings, messages to staff, e.g. newsletters, and a range of supporting information materials. The intention to incorporate information on patient rights into other training development and training delivery, especially into induction, means that this will be absorbed as part of the professional development of staff. Our discussions indicate that there is not a standard cost for releasing staff and managers are expected to incorporate training in their budgets. NHS Education for Scotland will build this into their business plan for 2010-11 and the Scottish Government will then agree milestones for measuring performance.

Costs on local authorities

76. The Scottish Government does not anticipate any additional costs arising for local authorities as a result of this legislation, as this Bill applies to NHS in Scotland services.

Costs on other bodies, individuals and businesses

77. The Scottish Government intends to support patient and public awareness through Scottish Government funding for Health Rights Information Scotland (see above at paragraph 69) and through NHS Inform. These costs, where relevant, are covered under costs to the Scottish Administration at paragraph 72.
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

78. It is noted that it is common for independent acute hospitals to attempt to meet the same standards as NHSScotland; no funding is available for this.

Savings
79. The Scottish Government does not anticipate any direct savings as a result of having regard to the health care principles.

THE TREATMENT TIME GUARANTEE
80. The Scottish Government does not anticipate direct financial impacts in this area. This is explained in the following paragraphs.

81. The Bill establishes a treatment time guarantee of 12 weeks for eligible patients. It is intended that this apply to elective or planned treatment where the patient receives that treatment on an inpatient or day case basis. The treatment time guarantee sits within the overall 18 weeks referral to treatment target, which is the whole patient journey maximum waiting time from general practitioner referral to commencement of treatment. This wait includes any outpatient consultations, diagnostic tests and treatment. The referral to treatment target will have a tolerance and will not therefore apply to all eligible patients. Some services/treatment not covered by the 18 weeks will be covered by the treatment time guarantee. The treatment time guarantee will apply to eligible patients once the treatment has been agreed between the patient and the clinician.

82. There will be no right to financial compensation for a treatment time guarantee that is not met.

Costs on the Scottish Administration
83. Taking forward the treatment time guarantee for inpatient and day case treatment is part of overall ongoing work on waiting times standards and targets and the monitoring of these. There are no additional costs to the Scottish Government.

Costs on the NHS in Scotland
84. Funding was given to Health Boards to deliver on the 18 weeks referral to treatment target. As the 12 weeks treatment time guarantee sits within that, it is to be delivered within that funding allocation. The initial Spending Review 2007 allocation for delivery of the 18 weeks referral to treatment target was £270,000,000, covering a period of 3 years (£90,000,000 for 2008-09, 2009-10, 2010-11). To reflect the reductions in funding across public sector services this was reduced by £20,000,000 in 2009-10 - the revised recent allocation is £70,000,000 for 2009-10 and £70,000,000 for 2010-11. There is no additional funding to Health Boards for the treatment time guarantee arising from the Bill.

85. The current waiting times performance is measured at census points on the last day of each month. On 31 December 2009 (latest data) showed that 101 patients had waited more than 12 weeks for inpatients and day case treatment. However, as the treatment time guarantee relates to the individual, it will have to be met by Health Boards on a continuous daily basis, not just at
the end of the month. The Scottish Government does not foresee any additional costs to the
NHS in Scotland in the delivery of the treatment time guarantee.

86. Where a patient is treated outwith their own Health Board area and/or outwith local
service agreements and there are transport and accommodation requirements that would
otherwise not have been incurred for the patient and his/her clinically necessary escort or carer,
the Health Board with the primary responsibility for the patient must resource that transport and
accommodation. It must be ensured that costs for accommodation and transport for patients in
this situation have been necessarily and reasonably incurred. The Health Board is not required to
resource transport and/or accommodation if the patient has requested to be treated elsewhere for
personal reasons (e.g. a relative living nearby). Patients treated at the National Waiting Times
Centre are already covered in this way, so this measure means that other patients who are treated
outwith their ‘home’ Health Board or outwith local service agreements are on the same footing.
The National Waiting Times Centre operates the Golden Jubilee National Hospital and the
Beardmore Hotel. The hospital consists of the West of Scotland Heart and Lung Centre and on
providing activity to ensure Health Boards deliver waiting time standards. The waiting time
activity target for 2009-10 is 22,268 procedures - which consists of inpatient and day case
surgery and diagnostic imaging and scopes.

87. Any additional costs incurred in covering necessary and reasonable expenses for the
minority of patients who are treated outwith their home Health Board or outwith local service
level agreements are expected to be absorbed by the individual Health Boards. This should
already be happening, as the New Ways of defining and measuring waiting times\(^1\) guidance states
that any travel arrangements for patients, and carers if necessary, should be resourced by the
patient’s Health Board. On accommodation, this will depend on distance and again should
already be happening. The cross boundary flow between Health Boards in Scotland and
elsewhere in the UK was around 14% for 2008-09, a figure similar to previous years. This
equates to around 78,000 patients being treated outwith their Health Board area. The Scottish
Government does not hold figures on the amounts currently spent by Health Boards in this area.
Since the treatment time guarantee should have very little impact on the movement of patients,
the Scottish Government does not anticipate additional costs, as a result of the Bill, to those
currently incurred.

88. As Health Boards should be keeping patients informed of their waits under the 18 weeks
referral treatment time, the Scottish Government expects that any costs should be minimal in
explaining any failure to meet the treatment time guarantee, apologising, alerting patients to the
patient advice and support service (see below) and scheduling appointments.

Costs on local authorities

89. The Scottish Government does not expect local authorities to incur any additional costs as
a result of the introduction of a treatment time guarantee.

Costs on other bodies, individuals and businesses

90. The Scottish Government does not expect any other bodies, individuals or businesses to
incur any additional costs as a result of the treatment time guarantee.

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\(^1\) New ways of defining and measuring waiting times: http://www.isdscotland.org/isd/4536.html
Savings

91. It is not anticipated that there will be any direct savings as a result of the treatment time guarantee. However, as explored in paragraphs 37 – 39 and Annex A of the Regulatory Impact Assessment to the Patient Rights (Scotland) Bill, benefits to patients can accrue through earlier treatment.

SUPPORT AND RECOUSE

Complaints

92. The Bill establishes a right to make a complaint, revokes the existing hospital complaints process legislation and brings it within the Patient Rights (Scotland) Bill.

93. It is not anticipated that there will be any direct financial impacts in this area. This is explained in the following paragraphs.

Costs on the Scottish Administration

94. There may be an initial increase in enquiries to the Scottish Government about the NHS in Scotland’s complaints process as a result of ensuring that the provisions of the Bill are made known. It is expected that the majority of such enquiries will be dealt with through providing written information and signposting people to the independent patient advice and support service and methods of feedback, such as Health Boards’ complaints processes, where appropriate. It is intended that this will be absorbed as part of ongoing Scottish Government work on patient rights, and that policy staff time involved in the Bill development will be turned towards its subsequent implementation, where appropriate.

95. The Scottish Government intends that the right to make complaints will be included as part of the overall package for raising awareness of patient rights and patient information. Costs for this are given at paragraph 69.

96. Methods of formal feedback of patients’ experience and associated costs are covered at paragraph 135 below, under evaluation and monitoring. The Scottish Government will be working on methods of informal feedback following the Making It Better\(^2\) report. The Scottish Health Council (SHC) has undertaken a scoping exercise to identify the range of current approaches undertaken by Health Boards to offer patients and the public opportunities to feedback their experiences of their services informally.

97. New approaches and evaluation of existing approaches to informal feedback will be developed by the Scottish Health Council. This will be done in partnership with NHSScotland Patient Focus Public Involvement (PFPI) staff, hospital complaints officers and the Better Together Patient Experience Programme, which gathers information on patients’ experiences of the NHS in Scotland and supports Health Boards to use this information to design and deliver high quality care and services. Costs for the evaluation of new and existing approaches to informal feedback is outwith the Patient Rights (Scotland) Bill. Further information about PFPI is provided at paragraph 67.

\(^2\) Making It Better: Complaints and Feedback from Patients and Carers about NHS services in Scotland: published July 2009, based on research commissioned by the Scottish Health Council (SHC)
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

Costs on the NHS in Scotland

98. As noted above, there may be an initial increase in enquiries about the complaints process and possibly an increase in complaints through raised awareness as a result of the Bill; staff of the patient advice and support service and Health Boards’ complaints officers will be the main recipients of this increase in enquiries and complaints. Any additional costs incurred as a result will be met from within existing budgets.

99. Health Boards and Primary Care Services contractors (such as GPs) should have systems in place to deal with complaints. The Scottish Government anticipates that the introduction of the patient advice and support service and Patient Rights Officers will assist people making enquiries about complaints to use other more appropriate and accessible routes to offer feedback or to find a resolution to their issue and it is therefore expected that the enhanced patient advice and support service will absorb much of the initial increase in enquiries about complaints.

100. It is expected that there will be minimal additional pressures on family health services (primary care) complaints officers. For example, there are approximately 1,025 GP practices and 2,740 “high street” dentists in Scotland. In 2008-09, 3,175 family health service complaints were received in total across medical (2,621), dental (526) and family health administration (28) services. It is, therefore, evident that the average number of complaints received per GP practice or dentist on an annual basis is low and it could be speculated that any additional pressure on the NHS complaints procedure, through increased awareness as a result of the Bill, is likely to have a minimal impact on the ability of family health services to respond to such complaints.

Costs on local authorities

101. It is not anticipated that there will be any costs on local authorities as a result of establishing a right to make complaints in the NHS in Scotland.

Costs on other bodies, individuals and businesses

102. The Scottish Government does not expect any other bodies, individuals or businesses to incur any additional costs as a result of the right to make complaints.

Savings

103. The Scottish Government does not anticipate any savings in this area.

Patient Rights Officers and the patient advice and support service

104. The financial impacts of this are based on current funding for the Independent Advice and Support Service, an Health Board funded advice service which helps people raise concerns or complaints about their healthcare. Redirected funding and new money, and are as follows:
105. The Bill provides for the establishment of a patient advice and support service which will replace and enhance the current Independent Advice and Support Service (IASS), which is funded by local Health Boards and delivered by the Citizens advice bureaux across Scotland. It aims to support patients, their carers and relatives in their dealings with the NHS in Scotland and in other matters affecting their health. It is intended that the NHS in Scotland’s Common Services Agency (CSA) will be required to secure a package of patient advice and support services, to enable greater consistency in the provision across Scotland.

106. The new patient advice and support service will build on the assistance, information, advice and support functions of the IASS. It will also promote an awareness and understanding of patient rights and responsibilities, provide advice and support in relation to local resolution, signpost people to advocacy and other sources of advice and support, and report annually to Health Boards.

107. There will be at least one Patient Rights Officer (PRO) per Health Board (although these may not be full time), based on an assessment of needs undertaken by individual Health Boards. The PRO will not be limited to supporting patients only from their own geographical Health Board but should also support patients in their dealings with Special Health Boards or Health Boards outwith their own region, where treatment has taken place in another Health Board area or where the patient finds it easier to meet with a PRO in another Health Board area. It is intended that the PROs will be employed by the patient advice and support service.

**Costs on the Scottish Administration**

108. In introducing the Independent Advice and Support Service, the Scottish Government agreed to fund Citizens Advice Scotland to provide a central support function to the Citizens Advice Bureaux consortia that currently provide the service for Health Boards. The Scottish Government intends from 2011-12 to redirect the £134,000 per annum for this to Health Boards to support PROs and the patient advice and support service.
109. The Scottish Government also intends from 2011-12 to dedicate £116,000 from within its Healthcare Policy and Strategy Directorate budget towards funding for PROs and the patient advice and support service.

110. In addition, in order to support the new emphasis on patient rights and responsibilities, £1,000,000 of new recurring funding from 2011-12 will be provided for PROs and the patient advice and support service. This is in addition to the core budget that Health Boards receive and from which they presently are expected to fund the current Independent Advice and Support Service. The timing of the contracting and specification process for the PROs and for the patient advice and support service will mean that no additional funds for the enhanced service will be required in 2010-11.

111. Here, the Scottish Government estimates that the additional funding package of £1,250,000 (made up of £134,000 from paragraph 108, £116,000 from paragraph 109 and £1,000,000 from paragraph 110) will provide for around 40-50 new full-time equivalent Patient Rights Officers, based on the current salary of an Independent Advice and Support Service specialist/caseworker of between £20,000-26,000 plus £5,000 on-costs. Alternatively, the patient advice and support service may consider that it wants to provide a central support function and that would mean a small reduction in the number of officers, of perhaps around 5.

Costs on the NHS in Scotland

112. The Independent Advice and Support Service is currently commissioned, in line with guidance issued in 2006 (HDL (2006-13)), by each of the 14 territorial Health Boards, through the Citizens Advice Bureaux (CABx) network. The current contracts run until March 2011. The level of service is based on an assessment of local need and is funded through the Health Boards’ general allocations. The estimated total spend (i.e. all Health Boards) during 2009–10 is expected to be around £831,000. The Scottish Government expects Health Boards to continue this level of funding in relation to the new patient advice and support service. Additional central funding (as outlined at paragraph 111 above) will be provided to support the appointment of PROs and the enhanced service provision proposed under patient advice and support service.

113. The caseworker functions of current IASS specialists/caseworkers will be replaced by PROs. As the letting of any contract for the provision of the advice and support service will prescribe the refocused functions, it is not anticipated that there will be any additional costs as a result of this refocusing and expected salary levels would be similar.

114. The total funding for the patient advice and support service is expected to provide for around 65-80 full-time equivalent PROs.

115. The NHS in Scotland’s Common Services Agency will incur costs in procurement of the PASS. This type of procurement is part of the function of the CSA. This contract is included in their workplan, however, funding of £60,000 was provided in 2009-10 to secure dedicated resource to work on the contract.

Costs on local authorities

116. It is not anticipated that there will be any costs on local authorities as a result of establishing PROs or the patient advice and support service in the NHS in Scotland.
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

Costs on other bodies, individuals and businesses

117. The contractor that provides the PASS and PROs will be expected to provide the service within the terms of the contract and thus will not incur costs higher than the funding provided. The individual Citizens Advice Bureaux that are contracted by individual Health Boards to provide the Health Board’s existing Independent Advice and Support Service, and Citizens Advice Scotland, who currently provide a central support function to the Bureaux that provide the advice and support services, were contracted on a fixed time basis, with contracts due to end in March 2011. Any implications of the ending of these contracts in relation to staff terms and conditions and any costs involved will be covered in the negotiation of the new contract and are outwith the Patient Rights (Scotland) Bill.

Savings

118. The Scottish Government does not anticipate any substantial savings as a result of legislating for the patient advice and support service. The removal of the current administrative burden on Health Boards to negotiate individually with Citizens Advice Bureaux in their area through contracting centrally through the CSA may release some small savings, although the Scottish Government does not hold information on administrative costs of individual negotiations.

Advocacy

119. The Bill will place a duty on the PRO to direct people to other sources of advice and support or persons providing representation or advocacy services, where appropriate. In light of the potential impact of this, the Scottish Government is providing additional funding for advocacy provision. See the table below:

<table>
<thead>
<tr>
<th>Advocacy</th>
<th>2010-11 Recurring costs</th>
<th>2011-12 Recurring costs</th>
<th>2012-13 Recurring costs</th>
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</thead>
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<tr>
<td></td>
<td>Non-recurring costs</td>
<td>Non-recurring costs</td>
<td>Non-recurring costs</td>
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<tr>
<td>Scottish Administration</td>
<td>230,000*</td>
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<td>500,000 230,000*</td>
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<tr>
<td>NHS in Scotland</td>
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<td>Other bodies</td>
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<td>Total £</td>
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<td>500,000</td>
<td>500,000 500,000</td>
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* The Scottish Government currently provides funding for the Scottish Independent Advocacy Alliance (SIAA) and this is likely to continue, although the amount may vary according to the work plan. The purpose of the SIAA is to promote, support and defend independent advocacy in Scotland. It has an overall aim of ensuring that independent advocacy is available to any person in Scotland who needs it.

Costs on the Scottish Administration

120. As this directing provision could result in increased demand for advocacy services, and as a result of consideration of the potential impact of the Patient Rights (Scotland) Bill across a range of equality groups, the Scottish Government will provide a non-recurring £500,000 in 2010-11 to allow Health Boards to fully assess the needs and provision in their area, building on
the Scottish Independent Advocacy Alliance advocacy map and Health Boards’ advocacy plans. The Scottish Independent Advocacy Alliance is currently updating the Map of Advocacy across Scotland. This will provide an updated picture of the advocacy provision across Scotland and this work will help the NHS in Scotland identify any potential gaps in provision.

121. The Scottish Government will then provide £500,000 per annum of recurring new money from 2011-12 to support advocacy services to help those who need assistance in exercising their rights to access appropriate support. This will be provided through an uplift to Health Board allocations based on the National Resource Allocation formula (which is used to calculate the share appropriate for each Health Board) and will provide around a 10% increase in advocacy provision across NHSScotland. The Scottish Government Health Directorates currently provide core funding to the Scottish Independent Advocacy Alliance to provide central support to the advocacy movement, which is also shown in the table above. This was £230,000 in 2009-10.

**Costs on the NHS in Scotland**

122. Health Boards currently commission and fund advocacy services jointly with local authorities. Health Boards also commission advocacy for other service users who need this to support them in their dealings with the NHS in Scotland. The Scottish Government anticipates that the majority of those who would be directed to advocacy services might already be covered by the provision in the Mental Health (Scotland) Act 2003 but are making available additional funds to cover the proposed provision in the Patient Rights (Scotland) Bill; see above at costs to the Scottish Administration.

**Costs on local authorities**

123. The duty in the Patient Rights (Scotland) Bill with regard to advocacy relates to the patient advice and support service and is not being placed on local authorities so local authorities should not incur additional costs.

124. It is expected that the patient advice and support service would monitor the level of referrals onto advocacy services, although the lack of definitive baseline information prior to the Patient Rights (Scotland) Bill on this aspect of the (current) advice and support service makes it difficult to assess current impact on advocacy services and difficult to monitor additional costs, if any. The level of spend by local authorities on advocacy services is also not held centrally.

**Costs on other bodies, individuals and businesses**

125. The Scottish Government anticipates that there may be additional demands on advocacy services through legislating for signposting to advocacy, even though NHSScotland and the current advice and support service already uses advocacy services. Additional funding is being made available to Health Boards (see above at costs to the Scottish Administration) to invest in the provision of additional independent advocacy services.

**Savings**

126. The Scottish Government does not anticipate any direct savings through investing in advocacy services.
Translation, Interpreting and Communication Support (TICS)

127. The Bill will place a duty on PROs to direct patients to relevant support services where appropriate; there is also a principle on availability of support necessary to receive or access health care. It is likely that one of the main services to which patients will be directed is to Translation, Interpreting and Communication Support (TICS). It is proposed that additional funding would be provided to NHS Health Scotland to support the development of TICS.

128. The financial impacts are as follows:

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<thead>
<tr>
<th>TICS</th>
<th>2010-11</th>
<th>2011-12</th>
<th>2012-13</th>
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<td></td>
<td>Recurring</td>
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<td>costs</td>
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<td>NHS in Scotland</td>
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<td>Other bodies</td>
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<td>250,000</td>
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129. The NHS in Scotland publicly commits to arrange TICS where it is possible and reasonable to do so. This currently costs Health Boards in the region of £3.5 million per annum. NHS Health Scotland is leading a programme of development work in partnership with a range of NHS and non-statutory organisations, guided by a NHS TICS strategy and action plan. The Scottish Government anticipates that this will offer scope for a more uniform approach in the provision of TICS. Costs, and any savings, are covered outwith the Patient Rights (Scotland) Bill.

Costs on the Scottish Administration

130. A range of development activity will be undertaken to support NHSScotland to meet the potentially increased demands of translation, interpreting and communication support services as a result of the Bill. In light of this, the Scottish Government will provide £250,000 per annum of new non-recurring money from 2010-11 through to 2012-13 to support TICS. This will be provided to NHS Health Scotland to provide support resource and guidance materials, research on needs, procurement and service standard work, community engagement and marketing, communication events and extended partnership work.

Costs on the NHS in Scotland

131. As noted above, Health Boards currently fund TICS from within their allocation. The Scottish Government are making additional funds available to cover the further development of the services (see above at costs to the Scottish Administration).

Costs on local authorities

132. It is not anticipated that there will be any costs on local authorities as a result of increasing support for TICS within the NHS in Scotland.
**Costs on other bodies, individuals and businesses**

133. The Scottish Government anticipates that there may be additional demands from the NHS in Scotland on translation, interpreting and communication support services through a better understanding of the needs of individuals. The NHS in Scotland will continue to fund those services it procures.

**Savings**

134. The Scottish Government does not anticipate any direct savings through investing in TICS. Nevertheless, in the longer term, better engagement of NHSScotland patients who most require these services may have a positive impact on health outcomes and service design which could generate indirect savings, but these would be problematic to quantify and ascribe solely to increased TICS provision.

**EVALUATION AND MONITORING**

135. The Scottish Government is considering how compliance with patient rights legislation might be monitored where hard targets are not being set on specific aspects. It is anticipated that the Scottish Government will be able to extrapolate data from other sources to assess compliance, and will also be able to reflect on measures developed to support the implementation of the Quality Strategy to assess compliance and progress with the aims of the Bill.

136. *Better Together:* Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focussed services by Health Boards, which reflect the principles raised in the Bill. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so. Also, the effects of the Bill will be monitored through the “Participation Standard”, which is the new tool that will be used from 1 April 2010 by the Scottish Health Council to measure how Health Boards in Scotland are involving patients and the public in developing local services.

**Costs on the Scottish Administration**

137. As the Scottish Government intends to monitor the effects of the Bill through programmes of work that are already in place, no additional costs are anticipated in terms of monitoring and evaluation.

**Costs on the NHS in Scotland**

138. Monitoring arrangements for compliance with Patient Rights could be through either the Staff Governance Standard monitoring arrangements or through the Annual Review process. Implementation of the Staff Governance Standard is monitored through the annual Self Assessment Audit Tool (SAAT) returns from Health Boards and the results from the NHSScotland staff survey which is held every two years. This information is then used to inform the workforce reports which are prepared and fed into the Annual Review process for each NHSScotland Board. The Scottish Government does not anticipate any cost impact.

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3 The Quality Strategy aspires to create high quality person-centred, clinically effective and safe healthcare service that is world-leading in approach. It will be published in 2010.
These documents relate to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

Costs on local authorities
139. It is not anticipated that there will be any costs on local authorities as a result of monitoring and evaluating patient rights in the NHS in Scotland.

Costs on other bodies, individuals and businesses
140. The Scottish Government does not expect any other bodies, individuals or businesses to incur any additional costs as a result of monitoring and evaluation of the Patient Rights (Scotland) Bill.

Savings
141. The Scottish Government does not anticipate any savings in this area.
### ANNEX A: PATIENT RIGHTS (SCOTLAND) BILL: FINANCIAL SUMMARY

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<td>0</td>
<td>2,581,000</td>
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EXECUTIVE STATEMENT ON LEGISLATIVE COMPETENCE

142. On 17 March 2010, the Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon MSP) made the following statement:

“In my view, the provisions of the Patient Rights (Scotland) Bill would be within the legislative competence of the Scottish Parliament.”

PRESIDING OFFICER’S STATEMENT ON LEGISLATIVE COMPETENCE

143. On 16 March 2010, the Presiding Officer (Alex Fergusson MSP) made the following statement:

“In my view, the provisions of the Patient Rights (Scotland) Bill would be within the legislative competence of the Scottish Parliament.”
INTRODUCTION

1. This document relates to the Patient Rights (Scotland) Bill introduced in the Scottish Parliament on 17 March 2010. It has been prepared by the Scottish Government to satisfy Rule 9.3.3(c) of the Parliament’s Standing Orders. The contents are entirely the responsibility of the Scottish Government and have not been endorsed by the Parliament. Explanatory Notes and other accompanying documents are published separately as SP Bill 42–EN.

BILL OVERVIEW

2. The Patient Rights (Scotland) Bill will provide that the health care that patients receive should meet certain criteria, according to a set of health care principles. The Bill will legislate for a patient advice and support service and Patient Rights Officers, for a treatment time guarantee, and will establish a right to make complaints.

POLICY OVERVIEW

3. The Scottish Government wants Scotland to become a world leader in person-centred health care, to improve patient experience and support people in participation in their health care. The Patient Rights (Scotland) Bill is intended to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland.

CONSULTATION

4. The consultation on the Bill proposals was launched in September 2008 and closed in January 2009. The Scottish Government sought to ensure that the consultation document was widely circulated and also made available as an easier-read summary version. An external company organised and facilitated national events and focus groups, and analysed the consultation responses. Health Boards were invited to submit a bid for funding to advertise, organise and facilitate local consultation events. Six Health Boards sought additional funding, other Health Boards funded events out of their own budgets. Further details of the national events and focus groups are in the consultation analysis.

5. The consultation proposals gave background on patient rights and entitlements; the document then covered 8 areas (access, respect, safety, communication, information, participation, privacy, and independent support and redress), with patient rights, entitlements and responsibilities in each section. Specific questions were asked in relation to each area, and respondents could also suggest other key rights which they would like to see included in the Bill. A 12-week waiting time guarantee was noted under the access section and a possible no-fault compensation scheme was noted under the independent support and redress section.
6. There were 230 written submissions in response to the consultation. In addition, 102 people attended the national events and 68 people participated in the focus groups. Hundreds of people also attended events organised by Health Boards and Public Partnership Forums, which is one of the main structures for Community Health Partnerships\(^1\) to involve patients, carers, the public and voluntary groups in the work that they do. Further details of responses are available online and in the consultation analysis.

7. The Patients’ Rights Bill Consultation Analysis Report, the Consultation Analysis Research Findings, the Scottish Government Response to the Consultation Analysis Report and quick read summaries can be accessed at the following links:


8. There was broad support for the proposals from all groups of respondents. There were also concerns raised, in particular from those organisations who will be involved in implementing the rights and by people who felt that the proposals did not cover their particular issues. The Scottish Government response to the consultation explored work in other areas which may resolve some of these issues.

9. One of the concerns raised by consultation respondents was that legislation is unnecessary. However, the Scottish Government believes that patient rights are extremely important and that they should be given the prominence and priority that primary legislation affords.

10. The consultation proposals said there would be provision for a Charter of Mutual Rights. The feedback received on this was muted although there was enthusiasm for the concept of mutual rights. It was decided to take this forward in a different way, through a set of principles and through implementation plans.

11. Since the end of the formal consultation period, officials have continued to meet with stakeholders and to consider research on a range of issues related to patient rights.

**BACKGROUND**

12. Existing legislation places general duties on Ministers and Health Boards to provide health care according to population need. Health Boards are expected to plan strategically, to

\(^1\) Community Health Partnerships provide a focus for the integration between primary care and specialist services and with social care, and ensure that local population health improvement is placed at the heart of service planning and delivery.
assess the impact of their work and to see that the delivery of it is suitable to the needs of their local population.

13. Previous policies, strategies and legislation laid the policy groundwork for the principles in the Patient Rights (Scotland) Bill. The Bill builds on these and implementation of it will work in conjunction with existing and developing work, such as the NHSScotland Quality Strategy\(^2\) and the Better Together patient experience programme\(^3\).

14. Patient rights are not a new concept or exclusive to Scotland. Internationally, there has been a move towards considering patient rights in an explicit form. The Australian Charter of Healthcare Rights was adopted in 2008 and in England the Department of Health published its NHS Constitution (which sets out the rights and responsibilities of patients and staff when using the NHS in England) in January 2009, and has since consulted on additional rights. The UK Government’s Health Act 2009 places a duty on providers and commissioners of NHS services to have regard to the NHS Constitution. However, the NHS constitution itself is not set out in primary legislation and in this respect we believe the Patient Rights (Scotland) Bill has the potential to effect change in a more substantive way.

15. Discussions on the Bill have been informed by the context of the Human Rights Act (1998), the European Convention of Human Rights (ECHR) and Article 12 of the UN’s International Covenant of Economic, Social and Cultural Rights, which says that “the States Parties to the present Covenant recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. Scottish Government strategic aims and objectives are already in line with the progressive nature of Article 12, and some of the conditions necessary to achieve this progressive right are actually outwith health care. In order to take this forward within health care settings it is believed that setting out health care principles in the schedule to the Bill and the planned implementation work will help to ensure that everyone in Scotland is able to access health care services in a way that takes into account their individual needs.

16. Development of the Bill included the best way to ensure that patient responsibilities were also considered, and the right of NHS staff to be treated with dignity and respect. There are often complex reasons why a patient cannot or does not fulfil their responsibilities, and patients should always receive the highest possible standard of health care; the Bill does not seek to change that, but the Scottish Government was keen to ensure that consideration is given to developing patients’ understanding of their role in their own treatment as well as the rights of others. When rights are being met, it’s also key to remember that organisations meet these in the context of aiming to provide for many others, so resource and capacity constraints need to be factored in, as well as what is proportionate in each individual case.

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\(^2\) The Quality Strategy aspires to create high quality person-centred, clinically effective and safe healthcare service that is world-leading in approach. It will be published in 2010.

\(^3\) Better Together is Scotland's Patient Experience Programme. It supports Health Boards, frontline staff and patients in driving forward service improvement through the systematic collection and use of patient experience information. The programme also helps best practice to be shared between different services.
POLICY OBJECTIVES

Rights and Principles

17. There are existing rights for patients and expectations on them but these are articulated in disparate ways and are not always known or understood by patients or by staff. The Scottish Government wants to be in a position where:

- patients recognise their rights and have independent support and advice available to ensure these are met;
- patients work in partnership with staff to support their own health, where this is possible;
- staff fully recognise that patients have rights and feel comfortable with patients articulating them; and
- patients recognise and accept that they have responsibilities on them to support their own health and in their use of the health care system.

18. The Scottish Government is keen to ensure that the Bill provides an underpinning to an increased focus on person-centred, safe and effective treatment, to mutuality, and to a partnership between the NHS and the people of Scotland. The approach taken in the Bill seeks to avoid duplication of existing legislation, although some respondents to the consultation wanted some of the existing rights pertinent to health care reiterated in the Bill. It is anticipated that a greater emphasis on a patient’s individual needs and working in partnership with patients will contribute over the long term to improved patient experience and increased patient satisfaction and participation in health care, as well as a greater sense of ownership of the NHS for everyone in Scotland.

19. The Bill provides that the healthcare received should meet certain criteria that cover patient focus, optimum benefit, patient participation, and information and support. These are underpinned by a schedule of health care principles on patient focus, quality care and treatment, participation, communication, information, complaints, and avoidance of waste. The Bill also has provisions on a right to make complaints, raise concerns, and give feedback, and on patient advice and support and Patient Rights Officers. It also establishes a treatment time guarantee for eligible patients.

20. The patient-focus principles in the schedule cover the patient’s needs and regard to their abilities, characteristics and circumstances, dignity and respect, privacy and confidentiality, care and compassion, and the availability of support necessary to receive or access health care.

21. Patient rights are upheld when people are treated with dignity and respect, their privacy and confidentiality are upheld appropriately and the diversity of their individual needs, abilities and circumstances is met. The Scottish Government knows the importance of care and compassion to patients and so there is a principle on this, which also helps to emphasise one of the key attributes of health care staff. Care and compassion are vital elements of the health care experience and can have a direct impact on outcomes for patients.

22. Patients may require different types of support in order to access health care and that is why there is a principle on availability of support necessary to receive or access health care. Health Boards are already expected to provide access to non-clinical third party support such as
translation, interpreting and communication support (TICS) services through their standard resource allocation and the NHS publicly commits to arrange interpreting help if it can. The Scottish Government is providing additional funding to aid the development of TICS services, to support this principle and also support the principles on communication and participation. It was also clear from the consultation that people were concerned that some patients would need the extra support that advocacy services can provide to help ensure that their rights under the Bill could be realised. In order to help delivery of the patient focus principle of access to support, and because there is a provision about directing patients to support such as advocacy, the Scottish Government is putting additional funding into the provision of advocacy. Like the additional funding for TICS, this supports not just the patient-focused principle but also the principles on participation and communication.

23. The Bill legislates for support in other ways also. The Patient Advice and Support Service and the Patient Rights Officers will support patients in their dealings with the NHS and in other matters affecting their health. See below paragraphs 41-45 for more detail on this provision.

24. The quality care and treatment principle in the schedule covers regard to the importance of providing the optimum benefit to the patient’s health and wellbeing, consideration of the range of options, and health care based on current recognised clinical guidance.

25. The Scottish Government recognises that all treatment carries a level of inherent risk and that any treatment undertaken should aim to provide optimum benefit to the patient’s health and wellbeing and be based on clinical need, taking into account the health board’s duty, under the National Health Service (Scotland) Act 1978, to deliver health care to the population of its area as a whole. Guidance from the General Medical Council states that doctors should discuss with patients their condition and treatment options; care and treatment that are intended to help patients are fundamental to clinical practice and regulated healthcare professionals are expected to follow their statutory professional regulators’ codes of conduct, performance and ethics (these invariably include requirements relating to serving the interests of service users). The quality care and treatment principle will help to provide added status for quality as well as quantity of care.

26. The principle on participation aims to take forward patient participation in their own health care. Health care professionals aim to work in partnership with patients at all times, making sure that patients understand their health care needs and participate in decisions about what care is planned for them; better health outcomes are achieved when patients are fully informed partners in decisions about their treatment and care. This is underpinned in the Bill.

27. To facilitate participation in care and treatment, health care professionals need to ensure that a patient receives information in a way that he or she can understand. Research notes that tailoring information to patients’ needs and characteristics is important. Tailoring information might include providing translation, interpreting or communication support (TICS) services. As noted earlier, because an increase in demand for TICS services as a result of the provisions in the Bill is anticipated, the Scottish Government is providing additional funding to support the development of TICS throughout NHS Scotland. In addition, NHS 24 is taking forward

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planning for further development of the website healthinmylanguage, which offers translated information about health and health services in Scotland.

28. Key to participation is that staff and health care practitioners are reciprocally treated with dignity and respect by patients. The Scottish Government acknowledges the difficulties in legislating for this and has decided to take it forward with a principle whereby Health Boards encourage patients to treat staff with dignity and respect. This is allied to the patient focused principle on patients being treated with dignity and respect; together, these two principles are meant to contribute to building mutual trust, understanding and respect between patients and healthcare staff.

29. The Scottish Government believes that improving patient participation and appropriate communication will lead, over time, to patients having a better understanding of their health care and treatment and being better able to manage their health condition. It is also believed that it will improve individual’s experience of the health service; from Scottish Public Services Ombudsman’s reports on complaints it is known that communication is a concern. Through the work on the Quality Strategy and through the underpinning provided by the Bill, the Scottish Government would expect to see a positive change in such data over time and, it is anticipated, an eventual reduction of complaints relating to communication. Implementation of the Bill should also contribute to more effective and appropriate communication through a proposed staff training element on patient rights, and through public awareness raising.

30. The Scottish Government anticipates that the Bill’s measures and its implementation could lead over time to a reduction in waste of resources in the provision of health care. More emphasis on patient focus and greater partnership between patients and staff should help to ensure that the communication and timing of appointments is more suitable to the requirements of the patient so that patients are able to attend appointments or to cancel in advance if they are unable to attend. In addition, if staff are aware in advance that a patient cannot make an appointment, then resources can be employed more efficiently. The implementation measures will include a focus on patient responsibilities and subsequent more efficient use of health care resources.

The Treatment Time Guarantee (TTG)

31. The consultation proposals referred to the waiting time guarantee; this is now known as the treatment time guarantee (TTG) in the Bill. The Scottish Government is keen to reduce, as much as possible, periods of waiting and anxiety for patients by providing them with a treatment time guarantee, to remove risk of unacceptably long waits following diagnosis, as well as reducing the amount of time that might be spent in pain from the condition.

32. Waiting for admission to hospital for an operation can be a time of anxiety, worry and stress for patients, it is therefore important that the patient is fully aware of what the waiting time will be and has assurance that it will be delivered. This is why the TTG is a key part of the Bill. The Scottish Government intends that this TTG will be set at a maximum wait of 12 weeks from agreement to treatment to the commencement of that treatment, for eligible patients.

33. The 12 weeks maximum length of the waiting time is in primary legislation. The TTG will apply to planned and elective care, delivered on an inpatient or day case basis; details will
be specified in secondary legislation. Placing these in secondary legislation will make it easier to alter categories in response to progress on waiting times and treatment times.

34. Health Boards will be expected to deliver the TTG where it applies, as it will be a legal obligation. Health Boards will be supported in their efforts to meet the TTG through the current support mechanisms on meeting waiting times as provided by the Scottish Government.

35. The Bill and secondary legislation will set out the measures the Scottish Ministers expect Health Boards to take in order to meet the TTG; Health Boards will be expected to take into account clinical need and best value principles in deciding which options to use. Where a patient’s TTG is not met, Health Boards will be expected to ensure that the patient is provided with an explanation for the delay, information about the Patient Advice and Support Service (see below paragraphs 41-45) and the complaints process. The patient should also be given confirmation that they will begin treatment at the next available opportunity, taking into account clinical priority and availability; this may involve using other Health Boards and other providers. The emphasis is on how the situation will be rectified and the treatment delivered; there is no financial penalty for the Health Board nor financial compensation for the patient should the patient’s TTG not be met.

36. There will be a small number of services excluded from the TTG, to be in secondary legislation. These are explored below:

- Assisted conception: this is covered by separate guidance and standards, however, the Scottish Government is aware that there is inequity in access to this service and it is the intention to work towards introducing a maximum waiting time. An Expert Group is to be formed to advise on all aspects of assisted conception treatment.

- Obstetrics: it would not be logical to apply a maximum 12 week waiting time to the process of birth and delivery.

- Complementary and alternative medicines, including homeopathy, provided on the NHS: these are made available on the NHS on the basis of local priorities and clinical judgement. By their nature, these services are likely to be in addition to the diagnosis and clinical care which a patient receives and will not be the primary basis of a referral for diagnosis and treatment.

- Organ/tissue transplants: these procedures are dependent on organ/tissue availability.

- Direct access services: patients do not wait for direct access services. These services mainly relate to diagnostic tests, for example, x-rays. A GP can send a patient directly to get an x-ray at the direct access service and there would be no wait to access this service. This enables the GP to ascertain whether they are able to treat the patient’s condition or if the patient needs to be referred to a hospital consultant for treatment.
• Diagnostic tests: targets for these are part of the whole treatment journey under the Scottish Government’s 18 weeks referral to treatment target\(^5\).

• Treatments undertaken in a hospital outpatient department: many outpatient treatments will be undertaken at the outpatient consultation and will have only a short wait. These treatments will not only include minor surgical procedures but also include the prescription of medicine. This will be covered by the 18 weeks referral to treatment target.

• Certain designated national specialist services (scoliosis): the Scottish Government is keen to ensure that there is no perverse impact on patient care because of the TTG. Certain designated national specialist services are delivered by very few clinicians and the timing of planned/elective treatment can be dependent on availability of these staff. The Scottish Government does not want a patient to be offered a treatment only on the basis that it can be delivered within the TTG where a longer wait for a particular designated national specialist service would be more appropriate. For this reason it is intended to exclude the designated national specialist service for scoliosis and for this to be regularly reviewed, since treatments can move out of this category over time.

• Services on the Department of Health’s specialised service definitions list where no equivalent clinical services are offered in Scotland: for similar reasons as for certain designated national specialist services, it is intended to exclude services on the Department of Health’s specialist service definitions list where no equivalent clinical services are offered in Scotland. As health care in Scotland and in England are devolved, it cannot be ensured that the NHS in England delivers Scotland’s treatment time guarantee. Where it is most appropriate that the patient receive a treatment outwith Scotland, the Scottish Government would not wish them to receive a less appropriate treatment in order to meet the TTG.

• Alcohol and drug misuse services: there is already a new HEAT target\(^6\) for drug treatment waiting times which is that by March 2013, 90% of clients will wait no longer than 3 weeks from referral received to appropriate drug treatment that supports their recovery. Waiting times appropriate to alcohol treatment will be defined and incorporated into a target covering both drugs and alcohol by April 2011. To include alcohol and drug misuse services within the TTG could result in perverse outcomes, where services focus on getting all clients treated within 12 weeks for legal purposes, but as a result do not achieve the 3 week target.

37. Some services delivered on an inpatient basis, for example, assessments, where the person is an inpatient, are not covered by the proposed planned/elective definition of the TTG.

38. From the consultation it was clear that a number of stakeholders were concerned about access to mental health services and the coverage of the TTG to these. Through secondary legislation, the Scottish Government intends that the TTG will apply to planned and elective care

\(^5\) The referral to treatment target is the Scottish Government commitment to deliver by the end of December 2011 an 18 weeks whole journey waiting times target from referral to start of treatment.

\(^6\) HEAT Targets are the Cabinet Secretary’s key operational targets and performance measures for NHSScotland and describe the contribution that the NHS makes towards meeting the Scottish Government’s purpose and outcomes.
delivered on an inpatient or day case basis; where people are not already receiving treatment for a mental illness, access to mental health services is generally on an unplanned basis, often in the context of crisis, and that is almost exclusively the case for admissions on an inpatient basis, (whether on a voluntary or compulsory basis). For those patients who are unplanned admissions, it would not be appropriate to have a maximum waiting time of 12 weeks. Care/treatment delivered on an outpatient or day patient basis is primarily about ongoing care or programmes of care for those who already have access to treatment, rather than the one-off elective focus of the treatment time guarantee. There are some aspects of child and adolescent mental health services that may take place on a planned basis, in particular admissions to inpatient care, and those would be covered by the TTG and associated secondary legislation.

Advice and support, Patient Rights Officers, and the Right to Make Complaints

39. Research on patients and carers’ experiences of the NHS complaints system has informed the development of the Bill. A number of the research recommendations can be taken forward without the need for legislation but it was decided that there needed to be an explicit ‘right to make complaints’ to try and address the concern that many patients have about even raising an issue or making a complaint; it was also thought that some issues with the complaints processes, including the link up with independent advice and support, could be improved in order to address some of the issues raised.

40. Many people feel vulnerable when they interact with the health service. The Scottish Government intends to build on the current support provision, which includes independent advice and support services, advocacy and translation, interpreting and communication support services, to help ensure that people who need it have access to the appropriate support to help them to access their rights.

41. The Bill provides for an advice and support service, to be called the Patient Advice and Support Service and to be staffed by Patient Rights Officers, to support patients in the realisation of their rights and to raise awareness of their responsibilities, and to support patients if they need assistance to take forward a complaint. In the consultation, some respondents were keen for this service to be independent of Health Boards whilst others were not; some respondents also thought that this role could be effectively delivered by advocacy services. We think there is a role for both the advice and support service and for advocacy. There is a Bill provision on making people aware of or directing to advocacy and the Scottish Government is making further funding available to support provision of advocacy. As many patients value the arms length nature of the current advice and support service, the Bill notes that the Patient Advice and Support Service is not to be provided by a Health Board, Special Health Board or the NHS’s Common Services Agency (which will be securing the provision of the advice and support service).

42. An evaluation of the existing Independent Advice and Support Service (IASS) suggests that IASS is accessed mainly by people on a comparatively low income, living on their own, a high proportion of who have mental or physical health problems. Analysis of case studies and user experiences also suggests that IASS provides a valuable resource of support for people who

may be vulnerable.\textsuperscript{9} We also know that where an IASS worker becomes involved in a complaint, that in over half of cases the complaint is resolved or no further action is taken. Although the figures could not establish to what extent IASS performs a preventative role, tackling issues early enough so that they don’t need to become the subject of more formal procedures,\textsuperscript{10} it might be speculated that this is the case.

43. The current Independent Advice and Support Service assists people in taking forward complaints about NHS services, provides information and advice about NHS service provision and procedures, advises people on what they can expect from the NHS and provides general information and advice to assist patients. The new PASS will build on this. It will promote an awareness and understanding of patient rights and responsibilities, provide advice and support in relation to local resolution if things go wrong and signpost people to advocacy or other sources of advice and support. Health Boards will be expected to publicise advice and support services, under the right to make complaints provision. It is intended that the NHS Common Services Agency will be required to secure the provision of a patient advice and support service, to enable greater consistency in the provision across Scotland. Through contract specification, the new service will be required to provide an annual report on its activities to Health Boards.

44. There will be at least one Patient Rights Officer (PRO) per Health Board (although these may not be full time), based on an assessment of need undertaken by individual Health Boards. The PRO will not be limited to supporting patients only from their own geographical health board but will also support patients in their dealings with Special Health Boards or Health Boards outwith their own region, where treatment has taken place in another Board area or where the patient finds it easier to meet with a PRO in another Board area.

45. The PASS and its PROs will:
\begin{itemize}
  \item promote an understanding of patient rights and responsibilities,
  \item provide advice and support for patients,
  \item explain options available when, for example, giving feedback or making a complaint,
  \item make people aware of and direct them to advocacy and other sources of support, where appropriate.
\end{itemize}

Complaints

46. Some consultation respondents flagged up unsatisfactory experiences of the complaints system and that people may not always be satisfied with the resolution of a complaint or the way a complaint is handled. There were also concerns about the length of time medical negligence claims can take, and the adversarial nature of the process. It is important to note that where there is a medical negligence claim or some form of criminality this is taken forward separately from the NHS Complaints process in accordance with relevant protocols, rules and procedures; the Patient Rights (Scotland) Bill does not deal with such claims.

47. The Scottish Government is working to address these issues through a number of avenues, including legislating for the PASS and the PROs, and establishing a group to consider

\textsuperscript{9} Ibid. p51
\textsuperscript{10} Ibid. p50
and report on a system of no-fault compensation (this latter action is outwith the Bill). It is anticipated that the proposals to provide enhanced independent support to patients going through the complaints process and the measures to enhance patient participation will encourage improvements in the ways in which complaints are dealt with. These are also underpinned through a principle in the schedule to the Bill that issues of concern are dealt with reasonably, promptly and according to proper procedures.

48. The Bill also provides for a specific right to make complaints. The aim is to improve patients’ awareness of their right to lodge a formal complaint and also to help ensure that patients have a better understanding of how their complaint will be dealt with. The Bill repeals the Hospital Complaints Procedure Act 1985 which placed a duty on health authorities in England and Wales and Health Boards in Scotland to establish a complaints procedure for hospital patients. This will be replaced with the measures outlined in the Bill and with further measures in secondary legislation. The Bill also legislates for the handling and monitoring of complaints and how these can be used to improve health services. It is intended that when a patient makes a complaint they should be informed also of the advice and support available to them.

49. Through secondary legislation and directions, the Scottish Government will set out clearer monitoring procedures and feedback mechanisms, to assist in using complaints to improve the health service, and will amend timescales to respond to complainants with the result of an investigation. From the Making It Better research on the complaints process, it was apparent that differences between hospital complaints processes and primary care complaints processes may be confusing for complainants, and that there was some concern about the capacity to properly investigate a complaint within the shorter timescale in primary care complaints processes.

Protections and limitations

50. There has been concern that the Bill might be ‘a charter for lawyers’ or encourage ‘a lawyer by every bedside’. In the consultation responses it was clear that people did not want the NHS in Scotland to be crippled by compensation claims at the expense of front line services.

51. The Bill does not establish individual rights for individual patients (e.g. access to a particular treatment). The rights set out in the Bill are also not enforceable by legal action; this means that patients or their representatives would not be able to seek redress through the legal system (including claiming compensation) if they considered that their rights as set out in the Bill had not been met. This is because, as noted above, we do not want the NHS in Scotland, and its services, to be crippled by compensation claims as a result of the Patient Rights (Scotland) Bill. The option of pursuing a declaratory judicial review will still be available. Any rights which patients have under any other legislation or rule of law (for example a right of action to claim damages for personal injury) are not affected.

ALTERNATIVE APPROACHES

52. It would be possible to achieve some of the aims of the Bill through other means, such as directions or regulations under the National Health Service (Scotland) Act 1978. However, this option would not offer the opportunity to give prominence to patient rights through legislating for them in primary legislation; it would also not give the opportunity to provide a right to make
This document relates to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

complaints and establish advice and support, such as the Patient Rights Officers, in primary legislation. The Scottish Government believes that legislating for these will help to level out the balance of power between health care staff and patients.

53. The consultation proposals raised the issue of a scheme of no-fault compensation and the Scottish Government response to the consultation analysis noted respondents’ concerns. A group has been established to consider the introduction of a no-fault compensation scheme for injuries as a result of medical treatment; it will report in October 2010 and is outwith the Patient Rights (Scotland) Bill.

See http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/No-faultCompensation

EVALUATION AND MONITORING

54. The Scottish Government intends to monitor compliance with patient rights legislation through a number of existing or soon to be established measures outwith the Bill. These include the Participation Standard, which Health Boards in Scotland will have to meet from April 2010 to show that they are involving the people who use their services. This Standard focuses on three key areas: Patient Focus, Public Involvement, and Corporate Governance of Participation.

55. Better Together: Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focused services by Health Boards, which reflect the principles raised in the Bill. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so.

56. In addition, as part of the work developing the Quality Strategy for NHS Scotland, a range of measures are being explored that will demonstrate improvements in the delivery of patient focused care, including the possibility of using a patient-reported outcome measures (PROMS)-based approach to do this. PROMS gives an insight into the way patients perceive their health and the impact that treatments or adjustments to lifestyle have on their quality of life.

57. It is intended that the contract specification for the PASS, which will be drawn up by the Common Services Agency, will include details of how the service will be monitored and the statistical information that Health Boards should receive from the service, which will include equality monitoring. Currently, the Scottish Health Council has a role to monitor the IASS and it is envisaged that this role will continue in regard to PASS.

EFFECTS ON EQUAL OPPORTUNITIES

58. The Patient Rights (Scotland) Bill will have a positive effect on equal opportunities. An Equality Impact Assessment has been carried out and is published on the Scottish Government website at http://www.scotland.gov.uk/Topics/People/Equality/18507/EQIASearch. The Scottish Government has considered any unintended effects created by the Bill, and has taken steps to mitigate and eliminate these, including by providing additional targeted resources to, for example, advocacy and translation, interpreting and communication support, and by considering how the eventual implementation and communication of the rights set out in the Bill will be undertaken.
59. The Bill will provide an excellent opportunity to promote equality of opportunity. The Bill aims to underpin a patient-focused NHS, in which individual needs are considered and where patients feel that they have a say in their own treatment, and that their wishes are listened to and respected. The Bill will contribute to building a mutual NHS, in which patients are affirmed as partners in their care, where possible, and help to ensure that all those who work for NHSScotland respect the expertise of patients and their carers and improve the ways in which they communicate with and involve them in the decisions that affect them.

60. A training programme for staff on the rights of patients is being planned. Training and awareness raising will include equality issues across all equality strands, and it is envisaged that this will particularly emphasise to staff the importance of access and communication issues.

61. As described in paragraph 22, it is proposed to provide additional funding to NHS Health Scotland to support the development of TICS. This will have a positive effect on equal opportunities and will help to enable people to access services more easily, leading to patients who need these services being communicated with in an appropriate manner that allows them to be partners in their own care and to understand their rights and responsibilities.

62. Providing additional funding to support advocacy services’ provision will also help to enable more people who cannot uphold their rights on their own to be supported when using the health service, or when making a complaint. The Patient Advice and Support Service, Patient Rights Officers and the complaints process will also promote equality of opportunity by providing support and advice to people who may not otherwise be able to, or know how to, raise a complaint or issue about the health service.

HUMAN RIGHTS

63. As discussed above, the Bill takes a principles-based approach to patient rights, and has been developed and constructed to take account of the Human Rights Act (1998) and the European Charter on Human Rights. Consideration has also been given to Article 12 of the International Covenant on Economic, Social and Cultural Rights.

ISLAND COMMUNITIES

64. The Patient Rights (Scotland) Bill will apply to all communities across Scotland, including island communities. Placing emphasis on responding to individual needs and circumstances will help to ensure that the needs of island populations are taken into account when accessing health services.

65. The treatment time guarantee (TTG) includes provision that if the TTG cannot be met within 12 weeks, then an option is for the patient to be treated in another health board area. This has the advantage that patients in island or rural communities will receive the service that they are entitled to, although potentially this could mean being away from home for treatment. If this is unavoidable, the patient should be made aware of this as early as possible. Where a patient has to travel for their TTG, appropriate transport arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board. As part of the implementation of the Bill, the Scottish Government is reviewing guidance on this issue so that patients in island or rural areas are not disadvantaged.
This document relates to the Patient Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

66. The Patient Advice and Support Service (PASS) will operate in each health board area, including those covering island communities. Patients and their supporters will be able to use the PASS service that is most convenient for them, even if they were treated by different Health Board, or a Special Health Board. The aim is to make the service as accessible as possible for patients, including those in island communities.

LOCAL GOVERNMENT

67. As the services proposed and the changes introduced by the Bill relate to NHS services and will be implemented by Health Boards, the Bill will have minimal impact on local government. Officials met with representatives from COSLA to explore any impact on local government and COSLA agreed that the impact would be minimal.

SUSTAINABLE DEVELOPMENT AND ENVIRONMENTAL CONCERNS

68. The Bill will have no negative impact on sustainable development, and will have a strong positive effect on the health and wellbeing of the people of Scotland, by helping to make health care services more accessible and more responsive to individual needs.

69. The environmental impact of the Bill has been considered, and the Scottish Government considers the policies within the Bill as a qualifying plan within the meaning of section 5(4) of the Environmental Assessment (Scotland) Act 2005. However, it is considered that the Bill is likely to have minimal effect in relation to the environment and, as such, exempt for the purposes of section 7 of the 2005 Act. A pre-screening report has been completed, which confirmed that the Bill will have minimal or no impact on the environment and consequently that a full Strategic Environmental Assessment did not need to be undertaken. The pre-screening report will be published on the Scottish Government website at:

http://www.scotland.gov.uk/Topics/Environment/SustainableDevelopment/14587/Register
DELEGATED POWERS MEMORANDUM

PURPOSE

1. This memorandum has been prepared by the Scottish Executive in accordance with Rule 9.4A of the Parliament’s Standing Orders, in relation to the Patient Rights (Scotland) Bill. It describes the purpose of each of the subordinate legislation provisions in the Bill and outlines the reasons for seeking the proposed powers. This memorandum should be read in conjunction with the Explanatory Notes and Policy Memorandum for the Bill.

2. The contents of this Memorandum are entirely the responsibility of the Scottish Government and have not been endorsed by the Scottish Parliament.

OUTLINE OF BILL PROVISIONS

3. The Bill is divided into 22 sections and 1 schedule. These address 4 key aspects of health care provision:

Rights and Principles (sections 1-5)

4. The Bill sets out the manner in which health care will be delivered and is underpinned by a schedule of Health Care Principles. Each relevant NHS body is duty bound to have regard to these Principles when performing its functions. The Bill also introduces the right of patients to make complaints, raise concerns or give feedback about the health care they have received.

The treatment time guarantee (sections 6-10)

5. The Bill provides for a treatment time guarantee and specifies the measures a Health Board must take if it fails to meet the treatment time guarantee for an eligible patient. Patient eligibility and the treatments and services excluded from the guarantee will be set out in regulations.

Complaints and patient feedback (sections 11-13)

6. The Bill ensures that relevant NHS bodies and their service providers have adequate arrangements in place to handle complaints or feedback received from patients. This includes
publicising the complaints process, advertising the details of the advice and support available to patients and monitoring any complaints received.

Support (sections 14-17)

7. The Bill will legislate for an independent patient advice and support service (PASS), with a staff of patient rights officers. The PASS and its staff will promote awareness of patient rights and responsibilities, provide advice and support to those wishing to make a complaint, raise concerns or give feedback and provide information and advice on the health service.

Rationale for subordinate legislation

8. The Government has had regard, when deciding where and how provision should be set out in subordinate legislation rather than on the face of the Bill, to:
   - the need to strike the right balance between the importance of the issue and providing flexibility to respond to changing circumstances;
   - the need to make proper use of valuable Parliamentary time; and
   - the need to anticipate the unexpected, which might otherwise frustrate the purpose of the provision in primary legislation approved by the Parliament.

9. The delegated powers provisions are listed below, with a short explanation of what each power allows, why the power has been taken in the Bill and why the selected form of Parliamentary procedure has been considered appropriate. Powers that are referred to here as being exercisable by regulations or orders are made by statutory instrument.

Delegated powers

Section 1(4) – (Patient Rights) - Power to modify subsection (2) following consultation with appropriate parties

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: affirmative resolution of the Scottish Parliament

Provision

10. The provision in section 1(4) gives Scottish Ministers the power by order to modify the provisions in section 1(2) as regards the manner in which health care is delivered to patients. Prior to making an order, Scottish Ministers must consult with such persons as they consider appropriate.

Reason for taking power

11. Section 1(2) sets out the manner in which health care is to be delivered. Read together with section 1(1), it establishes that it is the right of every person that the health care received is patient focused; that it is to have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing; that it allows and encourages patients to participate as fully as
This document relates to the Patients Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

possible in decisions about their health care; and that information and support is provided to patients to enable their participation.

12. Scottish Ministers may wish to review the manner in which health care is delivered to take account of changing patient expectations. Any review and subsequent amendments will be taken forward in close consultation with relevant stakeholders with the aim of strengthening and developing the delivery of health care services to reflect patient needs.

Choice of procedure

13. Section 1(4) gives Scottish Ministers the power to modify how health care is delivered and could significantly alter the right set out at 1(1). It is therefore considered that the higher level of scrutiny afforded by affirmative procedure is appropriate.

Section 4(2) – (Health Care Principles) - Power to modify the health care principles following consultation with appropriate parties

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: affirmative resolution of the Scottish Parliament

Provision

14. This provision allows Scottish Ministers to modify the Health Care Principles set out in the schedule, following consultation with such persons as they consider appropriate.

Reason for taking power

15. The general rights set out in section 1(2) are underpinned by a schedule of Health Care Principles where each relevant health care body must have regard to in performing their functions.

16. The Health Care Principles relate to patient focused care; quality care and treatment; patient participation; communication; complaints; and waste. They set out to achieve best practice in health care provision and provide guidance to health care practitioners and staff.

17. The provision in 4(2) recognises that Scottish Ministers may wish to review the Health Care Principles to take account of changing patient expectations. The power to amend the schedule allows the Principles to be expanded or modified to address other aspects of health care provision over time and ensure greater consistency in how health care is delivered across the NHS in Scotland. Any review and subsequent amendments will be taken forward in close consultation with health service providers, voluntary organisations, representative groups and the public.

Choice of procedure

18. Given that the use of this power will likely be made in conjunction with Parliamentary agreement to change section 1(2), it is felt that an equal level of scrutiny is required for the provision at 4(2) as that at 1(4). The Health Care Principles are a fundamental element of the
This document relates to the Patients Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

Bill and each relevant NHS body is duty bound to have regard to these to support the delivery of the right set out in 1(1). Therefore, it is considered that affirmative resolution procedure is appropriate.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

Provision

19. Section 7(1) provides that the Scottish Ministers must, by regulations make further provision about the treatment time guarantee. Section 7(2) provides that the regulations must set out the descriptions of patients which are eligible for the treatment time guarantee and how the waiting time is to be calculated.

Reason for taking power

20. The Bill provides for a treatment time guarantee which will provide eligible patients with the right to receive an agreed treatment within 12 weeks from agreement to treatment, to the start of that treatment. It is considered, however, that it is more appropriate for the details of how that guarantee will operate and be delivered to be provided in secondary, rather than primary, legislation, given the level of detail which will be provided, and the fact that a measure of flexibility is required to amend these details in response to different circumstances both now and in the future.

Choice of procedure

21. Scottish Ministers will have a duty to make regulations on those matters central to the operation of the guarantee. These regulations will address matters of detail as to the operation of the treatment time guarantee, together with administrative and procedural matters which are technical in nature. Therefore, given the detailed nature of these provisions and the need for flexibility in implementing the treatment time guarantee within the framework of the Bill, it is considered that negative resolution procedure is appropriate.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

Provision

22. Section 7(3) gives power to Scottish Ministers to specify, by regulations, the treatments and services which will not be covered by the treatment time guarantee, the action a Health Board must take to ensure it complies with the treatment time guarantee, the circumstances in
This document relates to the Patients Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

which the maximum waiting time for a patient can be recalculated or extended, or when the responsibility for a treatment time guarantee may transfer to a different Health Board, and the information that a Health Board is to provide to patients about the treatment time guarantee.

Reason for taking power

23. The current intention is that the treatment time guarantee will not apply to certain treatments and services, which will be listed in regulations. Specifying the exclusions in secondary legislation will ensure flexibility to respond to progress on treatment and waiting times which may mean that certain treatments and services which are initially excluded become included in the treatment time guarantee in the future.

Choice of procedure

24. Similarly to section 7(1), the regulations will address further matters of detail as to the operation of the treatment time guarantee, as well as administrative and technical matters and it would not be an effective use of Parliament’s time to make this subject to the affirmative procedure. The provisions allow Regulations to implement further details of the treatment time guarantee within the framework of the Bill and, given the need for flexibility in doing this, it is considered that negative resolution procedure is appropriate.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

Provision

25. This provision gives Scottish Ministers the power to change the maximum waiting time of 12 weeks to a different time period, and allow the maximum waiting time to be different for different categories of treatment or service.

Reason for taking power

26. This provision allows the Scottish Ministers flexibility to amend the length of the maximum waiting period to respond to changing circumstances, for example health care providers may become able to provide certain treatments in less than 12 weeks.

Choice of procedure

27. It is considered that the negative procedure provides an appropriate level of scrutiny for this power, given the limited nature of the enabling power and the need for flexibility if changes are required to respond to changing circumstances regarding treatment times. Any modification to the maximum waiting time will be administrative in nature, and this procedure is considered an appropriate balance between speed and flexibility on the one hand, and the need for scrutiny of a provision of this nature.
Section 11(4) – (Complaints and other feedback) - Power to ensure adequate arrangements are in place to deal with complaints

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

Provision

28. Section 11(3)(a)(ii) and (4)(a) provides that the Scottish Ministers may make regulations about the arrangements which relevant NHS bodies and their service providers must have in place to handle complaints.

Reason for taking power

29. The Bill imposes a duty on Scottish Ministers to ensure that each Health Board, Special Health Board and the Common Services Agency has a suitable complaints process, publicises how complaints are to be made and handled and makes patients aware of the advice and support available to them when they make a complaint. This provision gives Scottish Ministers the power to make provision about the arrangements required including those which service providers should have in place for dealing with complaints.

30. Section 11(4)(a) gives Scottish Ministers power to make regulations providing for the arrangements mentioned in section 11(1) and (2) and the matters described in 11(3) regarding complaints procedures.

31. Section 11(3)(a)(ii) read together with 11(4)(a), allows Scottish Ministers to specify in regulations who else can make a complaint other than the patient or someone on their behalf. This could include a parent or guardian of a child, a relative of someone who has died and any other person who is affected, or likely to be affected by the action, omission or decision of the NHS body which is the subject of the complaint. As there are complex issues surrounding patient confidentiality and qualification of ‘next of kin’, it is considered appropriate to address this in secondary legislation rather than on the face of the Bill.

Choice of procedure

32. Any regulations made under the provision at 11(4) will be concerned with matters of detail rather than principle. In order to achieve the correct balance between Parliamentary scrutiny and flexibility, negative procedure is considered appropriate.
This document relates to the Patients Rights (Scotland) Bill (SP Bill 42) as introduced in the Scottish Parliament on 17 March 2010

Section 14(2) – (Patient Advice and Support Service: Establishment and Funding) – Establishment and funding of the Patient Advice and Support Service

**Power conferred on:** Scottish Ministers  
**Power exercisable by:** orders made by statutory instrument  
**Parliamentary procedure:** negative resolution of the Scottish Parliament

**Provision**

33. Section 14(2) inserts a new section 10ZA into the National Health Service (Scotland) Act 1978. This section requires the Common Services Agency to secure the provision of the patient advice and support service in relation to each “relevant body”. Section 10ZA(6) provides that a “relevant body” is a Health Board and such other body as the Scottish Ministers may by order specify.

**Reason for taking power**

34. The Bill provides for the establishment of a Patient Advice and Support Service which will replace and enhance the current Independent Advice and Support Service (IASS). It is intended that the NHS’s Common Services Agency will be required to secure a package of Patient Advice and Support Services (PASS), to enable greater consistency in the provision across Scotland.

35. It is intended that each territorial Health Board will have a PASS. If a patient has an issue with a Special Health Board, then they would consult the PASS as provided by the territorial Health Board that is most convenient for them. However, Scottish Ministers wish to have the flexibility to expand the provision of the service in the future to allow a Special Health Board, such as the National Waiting Times Centre, to also have its own PASS.

**Choice of procedure**

36. The decision to include other bodies into the requirement to provide a PASS is not considered contentious. Negative resolution procedure is therefore considered appropriate. It should be noted that as these orders will be made in terms of powers in the National Health Service (Scotland) Act 1978, they will be subject to the provisions of section 105(1), (2), (6) and (7) of that Act.

Section 15(6) – (Patient Advice and Support Service) – Further provision about the Patient Advice and Support Service

**Power conferred on:** Scottish Ministers  
**Power exercisable by:** regulations made by statutory instrument  
**Parliamentary procedure:** negative resolution of the Scottish Parliament

**Provision**

37. This provision allows Scottish Ministers to make further provisions about the patient advice and support service.
Reason for taking power

38. The functions of the PASS include promoting awareness and understanding of patient rights and responsibilities, providing advice and support in relation to local resolution if things go wrong and signposting people to advocacy or other sources of advice and support. The provision at 15(6) allows Scottish Ministers to expand these functions to include other relevant issues.

39. Section 15(2) requires that the PASS reports on its activities. The provision at 15(6) also allows Scottish Ministers to specify in regulations further details about this requirement such as timing, method and format of the report.

Choice of procedure

40. Given that such regulations will be almost entirely administrative and procedural in nature, it is submitted that negative resolution procedure is appropriate. It would not be a good use of parliamentary time to make this power subject to affirmative procedure.

Section 20(1) – Ancillary provision

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: affirmative or negative resolution of the Scottish Parliament

Provision

41. This provision allows Scottish Ministers to make subordinate legislation to make provisions which are required for the full implementation of the Bill.

Reason for taking power

42. The new procedures introduced by the Bill may give rise to the need for ancillary provisions. Scottish Ministers may need to make such provision by order to support the full implementation of the Bill. This provision empowers Scottish Ministers to make provisions concerning any incidental, supplemental, consequential, transitional, transitory or saving matters where this is thought to be necessary or expedient.

43. Without these powers to make ancillary provision, it might be necessary to return to Parliament, through subsequent primary legislation, to deal with a matter which is clearly within the scope and policy intentions of the original Bill. It would not be an effective use of Parliament’s time, or the Scottish Government’s resources to deal with such matters through primary legislation. They are best addressed through subordinate legislation.

Choice of procedure

44. In terms of section 21(3), these orders are in general made subject to negative resolution procedure but an exception is made where the order adds to, replaces or omits any part of the text of an Act. In that case, in terms of section 21(2)(b), affirmative resolution procedure applies. This approach on procedure is in line with the approach taken in most Bills and there are not considered to be any special factors justifying a different approach in this case.
Section 22(3) – (Short Title and Commencement)

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: no procedure

Provision

45. Section 22(3) provides for all sections of the enacted Bill (other than sections 20, 21 and 22) to come into force on such a day as the Scottish Ministers appoint by order.

Reason for taking this power

46. This is a standard commencement by order power. As usual with commencement orders, no provision is made for laying the order in Parliament as the power is to commence provisions which the Parliament has already scrutinised, together with any consequential or transitory arrangements.

Choice of procedure

47. Whilst the order will not be subject to Parliamentary procedure as such, the Subordinate Legislation Committee will, in terms of its remit, have the opportunity to consider the order.
Mr Douglas Wands
Clerk
Health and Sport Committee
The Scottish Parliament
Edinburgh
EH99 1SP

Our ref:  F2929427
23 April 2010

Dear Mr Wands

PATIENT RIGHTS (SCOTLAND) BILL

I would like to draw the Health and Sport Committee’s attention to a small inaccuracy in the Financial Memorandum which accompanies the Patient Rights (Scotland) Bill. In the table between paragraphs 64 and 65, the column for 2010-11 shows costs of £34,000 for the scoping study and £60,000 for communications and awareness raising. The figures were transposed in error: the table should show that the scoping study will cost £60,000 and that communications and awareness raising will cost £34,000. The overall figure of £94,000 remains the same. The table at Annex A is unaffected.

I apologise for any inconvenience caused by this error. Please do not hesitate to contact me if you require further information.

Yours sincerely

Lauren Murdoch
Patient Rights Bill Team Manager

Copy to:
James Johnston, Scottish Parliament Finance Committee Clerk
# Health and Sport Committee

## 9th Report, 2010 (Session 3)

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Health and Sport Committee

Remit and membership

Remit:

To consider and report on (a) health policy and the NHS in Scotland and other matters falling within the responsibility of the Cabinet Secretary for Health and Wellbeing and (b) matters relating to sport falling within the responsibility of the Minister for Public Health and Sport.

Membership:

Helen Eadie
Ross Finnie (Deputy Convener)
Christine Grahame (Convener)
Rhoda Grant
Michael Matheson
Ian McKee
Mary Scanlon
Dr Richard Simpson

Committee Clerking Team:

Clerk to the Committee
Douglas Wands

Senior Assistant Clerk
Douglas Thornton

Assistant Clerk
Seán Wixted

Committee Assistant
Andrew Howlett
INTRODUCTION

Procedure

1. The Patient Rights (Scotland) Bill (“the Bill”) was introduced by Nicola Sturgeon MSP, Deputy First Minister and Cabinet Secretary for Health and Wellbeing (“the Cabinet Secretary”), on 17 March 2010. The Bill\(^1\) is accompanied by Explanatory Notes (SP Bill 42–EN), which include a Financial Memorandum, and a Policy Memorandum (SP Bill 42-PM), as required by the Parliament’s Standing Orders. The Health and Sport Committee was subsequently designated lead committee on the Bill. Under Rule 9.6 of the Parliament’s Standing Orders, it is for the lead committee to report to the Parliament on the general principles of the Bill.

Purpose of the Bill

2. The principle policy intention of this Bill is to clarify and support the existing rights of patients within the Scottish health service. The measures in the Bill are as follows—

- To set out the rights of patients receiving health care from the NHS in Scotland;
- To introduce a guarantee for eligible patients to start to receive medical treatment within 12 weeks of the treatment being agreed (“the treatment time guarantee”); and
- To provide for the rights of patients to make complaints regarding treatment, as well as to provide feedback on their treatment by the NHS, through the provision of a new patient advice and support service. This service, which is to be provided by the Common Services Agency of NHS

\(^1\) Patient Rights (Scotland) Bill. Available at: http://www.scottish.parliament.uk/s3/bills/42-PatientRights/b42s3-introd.pdf
Scotland, will include the establishment of Patient Rights Officer(s) in each of NHS Scotland’s 14 health board areas.

Scottish Government consultation

3. The Scottish Government undertook a public consultation on its proposals to introduce specific legislation on patients’ rights between September 2008 and January 2009. The consultation set out the background on patient rights, entitlements and responsibilities and sought responses in eight specific areas, namely: access; respect; safety; communication; information; participation; privacy; and independent support and redress. The consultation also considered the introduction of a 12 week waiting time guarantee (as part of access issues) and a possible no-fault compensation scheme (as part of independent support and redress issues). The Government received 230 written submissions in response to its consultation document.2

4. In addition, an external company was contracted to organise and facilitate national events and focus groups, and analyse the consultation responses. 102 people attended the national events and 68 people participated in the focus groups. Health Boards and Public Partnership Forums also organised events on the Bill consultation.3

Committee consideration

5. The Committee would like to record its thanks to those who gave evidence to, or otherwise participated in, its inquiry into the general principles of the Bill.

Formal evidence

6. The Committee issued a call for written evidence on 25 March 2010, with a closing date of 13 May 2010. 41 written submissions were received in response to the call for evidence. The Committee subsequently agreed the following programme of oral evidence sessions—

8 September 2010

Lauren Murdoch, Patient Rights Bill Team Leader, Fiona Montgomery, Head of Patient Support and Participation Division, Alastair Pringle, Head of Patient Focus and Equalities, Margaret Duncan, Waiting Times Policy Lead, and Kathleen Preston, Health and Community Care Solicitor, Legal Directorate, Scottish Government;


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2 Patient Rights (Scotland) Bill, Policy Memorandum, paragraphs 4-11. Available at: http://www.scottish.parliament.uk/s3/bills/42-PatientRights/b42s3-introd-pm.pdf

3 Policy Memorandum, paragraphs 4-11.
29 September 2010
Jim Elder-Woodward, Board Member, Inclusion Scotland; Shelley Gray, Director of Policy and Campaigns, Long Term Conditions Alliance Scotland; Carolyn Roberts, Head of Policy and Campaigns, SAMH; Delia Henry, Director, RNID Scotland; Mhairi Thurston, Lecturer in Counselling, University of Abertay, and Allen Thurston, Reader in Education, University of York, RNIB Scotland;

Dr Sally Winning, Deputy Chair BMA Scotland; Theresa Fyffe, Director, RCN Scotland; Dr Bill Mathewson, Deputy Chair (Policy), Royal College of General Practitioners Scotland and John Gallacher, Secretary, Health Committee, UNISON;

Hilary Patrick, Vice-convener of the Mental Health and Disability sub-committee, and Katie Hay, Law Reform Officer, Law Society of Scotland.

6 October 2010
Jacqueline Richardson, Patient Focus and Relations Manager, NHS Forth Valley PFPI Steering Group and Melanie Hornett, Nurse Director, NHS Lothian;

Nicola Sturgeon MSP, Cabinet Secretary for Health and Wellbeing, Lauren Murdoch, Patient Rights Bill Team Leader, Scottish Government.

7. Extracts from the minutes of all meetings at which the Bill was considered are attached at Annexe A. Where written submissions were made in support of oral evidence, they are reproduced, together with the extracts from the Official Report of each of the relevant meetings, at Annexe B. All other written submissions are included at Annexe C.

Reports from other committees
8. The Financial Memorandum was scrutinised by the Finance Committee, which sought written and oral evidence from interested organisations, followed by oral evidence from the Scottish Government Bill team, and then reported to the Health and Sport Committee. The report is attached at Annexe D. The provisions within the Bill for making subordinate legislation were considered by the Subordinate Legislation Committee. Its report to the Health and Sport Committee is attached at Annexe E. These reports are discussed in detail later in this report.
PATIENT RIGHTS AND HEALTH CARE PRINCIPLES

Policy intention

Introduction

9. The Policy Memorandum which accompanies the Bill states that the aim of the Government is to make Scotland “a world leader in person-centred health care, to improve patient experience and support people in participation in their health care.” The Policy Memorandum states that “the health care that patients receive should meet certain criteria, according to a set of health care principles.”

Patient rights set out in the Bill

10. Section 1 of the Bill sets out a series of patient rights. Health care is to—

   a) be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs;

   b) have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing;

   c) allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing;

   d) have regard to the importance of providing such information and support as is necessary to enable the patient to participate in accordance with paragraph (c) and in relation to any related processes.

11. The Bill also provides that patients have the right to make complaints, raise concerns and give feedback about the health care they have received.

12. These rights are qualified by section 2 of the Bill, which sets out other matters which must be taken into account in interpreting the rights of a patient. The Explanatory Notes to the Bill state that the rights of an individual patient should be balanced with the effect on the rights of other patients in receiving healthcare and should take into account the resources available; should be subject to the exercise of clinical judgement and the effective and efficient use of health service organisation and resources.

13. The Bill does not place a specific duty on NHS Scotland to comply with these rights. Instead, it requires the NHS to “have regard to” a set of principles when performing its functions. NHS bodies will also have to consider and take account of any related guidance. The principles are set out in the Schedule to the Bill and

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4 Policy Memorandum, paragraph 3.
5 Policy Memorandum, paragraph 2.
6 Patient Rights (Scotland) Bill, section 1.
Health and Sport Committee, 9th Report, 2010 (Session 3)

are broken down into categories: patient focus; quality care and treatment; patient participation; communication; complaints and other matters.\(^8\)

14. Section 3 of the Bill places a duty on a “relevant NHS Body” to have regard to those rights and principles when delivering healthcare to patients. Under the Bill, relevant bodies are defined as Health Boards, Special Health Boards and the Common Services Agency of NHS Scotland. The duty of having regard to those rights and principles also extends to any person with whom a relevant NHS body enters into a contract, agreement or arrangement to provide health care, in so far as those rights and principles are relevant to the service being provided. Therefore, contractors delivering services, such as GP practices or cleaning and catering services in a hospital, will be covered by the Bill in so far as those services are covered by the provisions of the Bill.\(^9\)

Use of primary legislation to promote patient rights

15. The central theme to emerge from the Committee’s evidence taking on the Bill was a debate over the decision of the Scottish Government to use primary legislation as a vehicle to promote and strengthen patient rights.

16. The Government acknowledged in the Policy Memorandum that, in response to its consultation on patient rights, a concern raised by respondents was that legislation was unnecessary. However, the Government stated its belief that “patient rights are extremely important and that they should be given the prominence and priority that primary legislation affords.”\(^10\)

17. The Policy Memorandum also highlighted alternative methods adopted by other governments in promoting patient rights within their jurisdictions, such as the Australian Charter of Healthcare Rights (2008) and the NHS Constitution in England (2009). However, the Scottish Government argued that the Patient Rights (Scotland) Bill has the potential to “affect change in a more substantive way” than the NHS Constitution in England.\(^11\)

18. The merit of introducing primary legislation, as a means of promoting patient rights was raised in evidence with Scottish Government officials. Reference was made to The NHS and You,\(^12\) a publication of Health Rights Information Scotland. This publication draws together information on the rights of patients in Scotland, covering issues such as levels of service in the NHS; clinical standards; targets; patient communication and confidentiality, and systems for making complaints.

19. Asked about the added benefit which a Bill would create for patients, over and above such publications, Scottish Government officials stated that

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\(^9\) Explanatory Notes, paragraph 12.

\(^10\) Policy Memorandum, paragraph 9.

\(^11\) Policy Memorandum, paragraph 14.

Publications such as *The NHS and You* had “no legal status”, whereas primary legislation would. Officials continued—

“As a matter of law, that publication, in itself, has no legal effect. Where it restates the law that is found elsewhere, it is simply information; where it outlines expectations, it is not really a statement of the law but just some factual information. Of course, if the Patient Rights (Scotland) Bill were enacted by the Parliament, it would become primary legislation and the law of Scotland. Therefore, it would be part of our statutory base and would be a statement of the law. The rights that are contained in the bill will become law if it is enacted.”

*What constitutes a right?*

20. A central theme that emerged from the evidence received by the Committee centred on the definition of ‘rights’. In many respects this goes to the heart of the Bill, and the debate on whether the promotion of patient rights requires primary legislation in order to be effective. Another key aspect surrounding the definition of a ‘right’ is the question of how patients can enforce their rights, and the sanctions which apply in the event of a failure by the health service to uphold and deliver those rights?

21. A major aspect of the debate was the legal status which the Bill affords to patient rights and, whether the Bill actually adds any real meaningful value to those rights. Many of the witnesses who gave evidence to the Committee drew attention to section 18 of the Bill, which provides that nothing in the Bill gives rise to any legal claim for which a person could seek redress through the courts (e.g. liability or right to seek damages; right of action for specific implement; right of action for interdict or a right of action for suspension).

22. However, there was near unanimous consensus that the legislation should avoid establishing a ‘lawyer’s charter’ which might encourage people to take legal action against the NHS, as the first option, when they feel their rights have been infringed. Against this backdrop, the question remains as to whether it is wise to seek to promote certain rights by way of primary legislation and, if so, what are the consequences, real and perceived, for the NHS?

23. The definition of a ‘right’ is a complex issue which goes beyond the consideration of the general principles of this Bill. However, in the context of the rights and principles set out in the Bill, perhaps the description which seems most suitable, in the context of the Bill, is that given by the Scottish Association for Mental Health ("SAMH") in their written evidence to the Committee. In considering the issues surrounding the proposed 12 week treatment time guarantee, and the use of HEAT targets within the NHS, SAMH stated—

“HEAT targets are a core set of objectives, targets and measures set for the NHS over a three year period. The Patient Rights (Scotland) Bill, in contrast,

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is about the fundamental rights of patients; which are not of a fleeting or transitory nature."\textsuperscript{15}

24. SAMH went on to point out that the strength of the Bill lay in the fact that it draws together a set of patient rights and health care principles, which could serve as the foundation of a patient-centred NHS.\textsuperscript{16}

25. The issues of whether the Bill addresses ‘rights’ in the legal sense was commented on by other witnesses. Age Scotland stated—

“There is no doubt that laying out the rights and healthcare principles of patients in legislation is helpful in as much as it provides in one place a full list of patient rights as decided by the will of Parliament. However, as is stressed in the Bill and its accompanying documents, it is not intended to provide recourse to compensation or litigation where those rights are not met. In this context it is questionable whether they are in fact ‘rights’, although we would suspect that some cases where patients rights as described in the Bill are not met could fall foul of human rights law or other existing legislation." \textsuperscript{17}

26. The question of seeking to set out rights in primary legislation, and the potential consequences of such legislation, was a point stressed to the Committee by the Law Society of Scotland. In its written evidence it stated that “the Society’s biggest concern is that the Bill contains valuable principles and guarantees but does not contain the necessary provisions to make them enforceable.”\textsuperscript{18}

27. During the debate on the question of patient rights, and how they might be defined, several witnesses expressed concerns over the possibility that the Bill may have unintended consequences for the way in which patient rights are viewed and understood, both by patients and by professionals working in the health service.

28. These concerns centred on the fact that the Bill does not include all of the rights which a patient currently has. There was general agreement amongst witnesses that trying to include a comprehensive list of all patient rights in a single piece of primary legislation would be very challenging. Therefore, those rights which are clearly specified in the Bill may, inadvertently, assume a level of importance in the eyes of patients and health care professionals, over and above those rights not specifically set out in the Bill. This, it was feared, may lead to the perceived development of a hierarchy, where some rights could be seen to be more important than others.

29. The Law Society of Scotland also viewed this as a real concern. During evidence Hillary Patrick commented—

\textsuperscript{15}SAMH. Written submission to the Health and Sport Committee.  
\textsuperscript{16}SAMH. Written submission to the Health and Sport Committee.  
\textsuperscript{17}Age Scotland. Written submission to the Health and Sport Committee.  
\textsuperscript{18}Law Society of Scotland. Written submission to the Health and Sport Committee.
“I believe strongly that that is the case....people will take the view that the rights for which the bill provides are their only rights”

30. Commenting on this concern, the Scottish Public Services Ombudsman stated that there was a “danger” that people may come to see their rights in relation to healthcare “as being confined to the rights set out in the Bill.”

31. Consumer Focus Scotland believed that the Bill would strengthen and support the idea that patients have rights, by giving them recognition in the eyes of the law. However, it expressed caution in relation to the fact that the Bill does not make it entirely clear that patients have other rights in relation to their healthcare. Therefore, the rights of patients should not be defined solely in terms of those rights expressed in the Bill.

32. Other witnesses also echoed this concern. In their written submission to the Committee, the Scottish Disability Equality Forum stated—

“We are aware that most of the rights and principles contained in the Bill are drawn from existing legislation. The purpose of this Bill (to some extent) is to pull existing rights together in order to increase public and NHS awareness. We fully support this objective. However, the concern amongst our members is how this legislation will be any different from the laws which originally set out these rights.”

Support for the aims of the Bill

33. Patient representative organisations who gave evidence to the Committee voiced support for the Bill, in its aim of seeking to rebalance the relationship between patients and healthcare professionals, by promoting a culture of mutuality within the NHS.

34. Jim Elder-Woodward of Inclusion Scotland, speaking about the importance of developing and promoting a culture of mutuality, highlighted the “paternalism of professional bodies” in the NHS. Mutuality, he stated, could only truly exist when patients are empowered by the necessary legislation to engage with the NHS on an equal basis—

“I think that having a right gives the patient a resource so that they can come to the table on a mutual basis....if we are to work on the basis of mutuality, each person around the table needs to bring a resource with them. For patients, the resource will be the Patient Rights (Scotland) Bill.”

35. Shelly Gray of the Long Term Conditions Alliance Scotland supported this view—

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21 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
22 Scottish Equality Disability Forum. Written submission to the Health and Sport Committee.
“If the bill prompts work to embed patient rights throughout the NHS—the Government has talked about increasing advocacy services and introducing a programme of training for NHS staff as a result of the bill—and to embed a culture of rights in the NHS, that would be of major value.”

36. The Rarer Cancers Forum welcomed the introduction of the Bill and expressed the view that it could become “a powerful mechanism for improving the quality of services and bolstering the confidence of patients and the public in the NHS in Scotland.”

37. The British Psychological Society expressed the belief that the Bill would “allow for increased patient participation and partnership” in the decision making process relating to a patient’s healthcare.

38. Diabetes UK Scotland pointed to a survey which demonstrated that the right which their members most valued was for healthcare to be “patient-focused” and, provided the “optimum benefit to the patient.” It went to state that people with diabetes “value respect and mutuality as cornerstones of care.”

39. The need for a shift towards a culture of greater mutuality was acknowledged and supported by NHS Lothian. It stated that the Bill would provide an “excellent opportunity” for the Government to lead in developing mutuality with the NHS.

40. Allen Thurston of RNIB Scotland expanded on the need for a culture of mutuality in the health service in Scotland. Referring to the continuing difficulty many blind people experience when communicating with the health service, for example, not being able to receive written correspondence regarding their treatment in a format accessible to them, he stated—

“Despite the regulatory and professional conduct standards of the bodies in question, despite the laws that have been introduced and despite the fact that this has been a persistent problem for a long time, nothing has changed. Perhaps the bill is required to change practice.”

Rights not contained in the Bill

41. Perhaps inevitably, the inclusion of certain rights in the Bill led several organisations to highlight concerns over rights which are not specified in the Bill, but which many witnesses felt needed to be included.

42. The Law Society of Scotland identified “about 17 rights that patients already have under law, under statute, under common law or under national health service practice” which are not set out in the Bill.

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25 Rarer Cancers Forum. Written submission to the Health and Sport Committee.
26 British Psychological Society. Written submission to the Health and Sport Committee.
27 Diabetes UK Scotland. Written submission to the Health and Sport Committee.
28 NHS Lothian. Written submission to the Health and Sport Committee.
30 Law Society of Scotland. Written submission to the Health and Sport Committee, 1 October 2010.
43. In supplementary written evidence, the Law Society of Scotland set out some of those rights which it believed were missing from the Bill—

- Right to access medical records;
- Medical reports issued for insurance purposes;
- Right to advocacy services (for mental health service users);
- Right to appoint welfare attorney / make advance directive;
- Right to life (e.g. treatment rationing);
- To a GP;
- To a second opinion;
- Access to Scottish Public Services Ombudsman;
- Health professionals must show due care;
- Guidance from government about treatments should be given due consideration (judicial review available).

44. The Society also reiterated its concern that even if the Bill fulfils the policy intention envisaged by the Government, namely to send out a strong message that patients have rights—

“….it does not give a full enough picture of what those rights are. The numerous other rights conferred on patients both under statute and common law run the risk of being overlooked or forgotten if people assume that the Patient Rights (Scotland) Bill is where to go for a comprehensive list of their rights.”

45. Breast Cancer Care stated in their submission that healthcare should be based on “clinical and patient-specific need that excludes discrimination on the grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age.”

46. The General Medical Council highlighted that fact that the “fundamental existing legal right of patients to refuse treatment” did not appear to have been included in the Bill. It stated that this existing right “extends beyond just being encouraged to participate fully in decisions relating to health and well being, as is proposed in the Bill.” It also highlighted the fact that the Bill did not seem to recognise the distinction between patients with capacity, who have a legal right to consent to or refuse treatment, and patients who lack that capacity.

31 Law Society of Scotland. Written submission to the Health and Sport Committee, 1 October 2010.
32 Breast Cancer Care. Written submission to the Health and Sport Committee.
33 General Medical Council. Written submission to the Health and Sport Committee.
47. In oral evidence to the Committee, the Scottish Public Services Ombudsman commented that “there is a danger that people might see their rights as being confined to the rights that are set out in the bill.”

48. Liz Macdonald of Consumer Focus Scotland, set out what she saw as the important aspect of promoting patient rights—

“The bill is valid in so far as it says that patients have rights, and I would like something to be added to the bill that says that not all the rights that patients have are in the bill: the bill is simply flagging up the importance of patient rights.”

The enforceability of rights

49. Section 18 of the Bill makes provision for important protections and limitations on the rights set out in the Bill.

50. Subsection (1) provides that the Bill does not prejudice the exercise of clinical judgement; the effective and efficient use of the health service organisation or resources or any relevant legislation or rule of law.

51. Subsection (2)(a) provides that the rights set out in the Bill are not of a nature that will impose any liability on any person to pay damages. This means that a patient could not claim damages from a Health Board for an alleged failure to deliver health care in the manner set out in the Bill.

52. Subsection 2(b), (c) and (d) provide that no person could enforce the rights set out in the Bill by an action for specific implement, interdict or suspension. This does not, however, alter or affect a person’s rights under any other law, for example a right to claim damages in the case of medical negligence, because of the provisions of section 18(1)(c).

53. The Policy Memorandum explains that the Scottish Government took this decision in response to concerns that the Bill might be ‘a charter for lawyers’ or ‘encourage a lawyer by every bedside’ which might lead the “NHS in Scotland to be crippled by compensation claims at the expense of front line services.”

54. Several of the witnesses who gave evidence to the Committee questioned the effectiveness of a Bill aimed at enhancing patient rights, which, in their view, greatly restricts the means by which those rights could be enforced. Some witnesses expressed a view that a right which is not enforceable in law cannot be considered to be a ‘right’ in the common understanding of the term.

55. The British Medical Association ("BMA") commented in its evidence to the Committee that many of the principles set out in the Bill are already covered by

36 Explanatory Notes, paragraph 45.
37 Explanatory Notes, paragraph 46.
38 Explanatory Notes, paragraph 47.
39 Policy Memorandum, paragraph 50.
various professional codes of conduct and existing legislation, for example the Human Rights Act and Data Protection Act. While the BMA felt that these rights and principles were “commendable”, it stated that the only possible benefit of setting them out in primary legislation would be to provide for “a new process of redress for patients who believed that these principles have not been met.”

56. The Scottish Disability Equality Forum referred to a call from some of its members, for more clarity around the rights and principles set out in the Bill, and what they would actually mean in practice. They stated—

“If it is to avoid disillusionment and disenfranchisement the NHS and Scottish Government must consider how they can show the rights and principles contained in the Bill are being respected, that they are meaningful and that there has been some improvement – particularly if they are not enforceable by individuals.”

57. The Law Society of Scotland stated that, while the Bill contains valuable principles and guarantees for patients, the biggest concern is that the Bill “does not contain the necessary provisions to make them enforceable.” In oral evidence to the Committee, Hillary Patrick confirmed that a patient could still seek a statement from the courts, known as a declarator, to the effect that a health board was in breach of legislation and was, therefore, acting illegally. However, in her view, the provisions of the Bill were not “meaningful.”

58. A note of caution was expressed by the Scottish Health Council about raising the expectations of patients if the Bill is unable to deliver on them—

“the rights and principles outlined in the Bill are sound and reflect matters which are of obvious importance to patients. We are conscious however, that the language of ‘rights’ can be powerful and may create expectations about entitlement and enforceability that will not be met in practice.”

59. The General Medical Council echoed this view when it referred to the “danger in passing legislation that is not clear or enforceable”, as opposed to increasing the focus on person centred care. This, the General Medical Council warned, may lead to a position where “clinicians and others may be led to feel that person centred care is less of a priority.” It went on to state that the Bill may lead to confusion “as there are existing obligations on doctors which are enforceable” including those set out in General Medical Council guidance.

Alternatives to primary legislation
60. While many patient representative groups supported the use of legislation to enforce and promote patient rights, witnesses representing health professionals questioned whether primary legislation was the most appropriate means of delivering on this aspiration.

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40 British Medical Association Scotland. Written submission to the Health and Sport Committee.
41 Scottish Disability Equality Forum. Written submission to the Health and Sport Committee.
42 Law Society of Scotland. Written submission to the Health and Sport Committee.
44 Scottish Health Council. Written submission to the Health and Sport Committee.
45 General Medical Council. Written submission to the Health and Sport Committee.
61. The BMA stated in its written evidence that in response to the Scottish Government’s consultation process it had questioned the need for legislation on patient rights and that it remained “unconvinced of the purpose of legislating in this area.” Instead, the BMA believed that many of the rights and principles set out in the Bill “are more suited to a patients’ charter style approach, particularly since there are no rights to legal recourse set out in this Bill.”

62. Consumer Focus Scotland reflected this concern when it stated that it was “not essential to have legislation” in relation to patient rights. Referring to the right of patients to make a complaint under the Bill, it stated that, “putting this right into legislation does not really add anything to the rights which patients already have, and we question what is achieved by doing this.”

63. The Royal College of Nursing (“RCN”) endorsed the health care principles set out in the Bill but believed they did not require to be placed in primary legislation. While welcoming the commitment of the Scottish Government to strengthen patient rights, it considered that primary legislation about patients’ rights “will not have the desired effect on patients’ experience” and that it remained “unconvinced that legislation is more useful than a review of how rights and responsibilities are promoted and implemented”, within the health service.

64. In their written evidence to the Committee, Roche Products Ltd welcomed the rights set out in the Bill but stated that—

“we believe that [the rights in the Bill] suffer from vagueness, and would suggest that more specific rights are set out in the Bill. The NHS Constitution for England sets out a number of clear patient rights - including legal rights to treatment with NICE-approved medicines - and this could be a useful template for the enshrinement of similar legal rights in Scotland.”

65. The Royal College of General Practitioners stated in their evidence that although its members felt that the objectives of the Bill had merit, “enforcing them as statutory legislation would be perceived as unnecessarily bureaucratic” and that legal costs would prove extremely high for the healthcare system.

66. In his written submission the Scottish Public Service Ombudsman pointed out that, with the exception of the treatment time guarantee, the Bill—

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46 British Medical Association Scotland. Written submission to the Health and Sport Committee.
47 British Medical Association Scotland. Written submission to the Health and Sport Committee.
48 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
50 Royal College of Nursing Scotland. Written submission to the Health and Sport Committee.
51 Roche Products Ltd. Written submission to the Health and Sport Committee.
52 Royal College of General Practitioners. Written submission to the Health and Sport Committee.
“….does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist. The notion of enshrining these rights and principles within primary legislation carries the risk of an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS.”

Response from the Scottish Government

67. The Cabinet Secretary responded directly to the question of whether primary legislation is required to enhance patient rights in Scotland—

“This Government, previous Governments and future Governments have done and will do many things by means other than primary legislation. That is right and proper, but some measures are of such import that they should be in primary legislation. Their being in primary legislation raises their importance and meaning as a matter of fact and law, as well as through the message that it sends. The clarifying of, and the giving of status to, certain key rights that patients have that are highly pertinent to their relationship to the health service falls into that category.”

68. Responding to questions regarding the lack of enforceability provisions in the Bill, the Cabinet Secretary defended the decision to restrict legal action in pursuance of the rights set out in the Bill. This decision, she stated, was based on the desire of the Scottish Government to ensure that a litigious culture was not encouraged to develop around the health service in Scotland.

69. The Cabinet Secretary went on to state that witnesses who opposed the creation of a litigious culture, with respect to patient rights, did not necessarily oppose the use of primary legislation to promote those rights—

“….some who have given oral evidence to the committee, interpret it differently: they do not want additional rights for patients to go to court, but nevertheless agree that putting patients’ rights in primary legislation is very important for effecting the change about which I am talking. Therefore, we cannot say that somebody saying that they do not want the proverbial lawyer by the bedside translates in all cases into meaning that they do not want the rights in primary legislation. It is interesting that those who tend to focus on the lack of enforceability also say that they do not want the lawyer by the bedside.”

70. Addressing the specific point of whether the Scottish Government had considered options other than primary legislation as a means of delivering enhanced patient rights, the Cabinet Secretary replied—

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53 Scottish Public Services Ombudsman. Written submission to the Health and Sport Committee.
“We did look carefully at the NHS Constitution and the legal underpinning for that in England. We also considered practice in Australia and other countries. We are not alone in giving a legal underpinning to patient rights; it is an international trend and I happen to think that it is important. We decided that we want a set of rights in primary legislation that are about the manner in which patients could expect to be treated rather than about specific individual rights.”57

71. In relation to those rights not set out in the Bill, the Cabinet Secretary stated that the Government had decided that it did not wish to “repeat a plethora of existing individual rights” in the Bill and that “the bill should be about the manner in which patients are treated rather than their specific rights”. She reiterated the point that “the Bill will not affect any existing rights” which patients in Scotland have at present.58

72. The Cabinet Secretary also explained that the reason the Government had opted to set out certain patient rights in primary legislation was the belief it held that this was the most appropriate means of ensuring a change to the “culture and dynamics of the patient relationship and levelling the playing field” within the health service. She also remarked—

“I have read carefully some views that the bill should contain something that shows that other rights are given elsewhere. I will listen to all that and make a judgment on it. Of course, it is open to anyone to suggest that particular provisions should be added to the bill.”59

73. Asked whether she believed that the aims of the Bill could be achieved by setting out rights in a single document and publishing that by direction under the powers granted by the National Health Service (Scotland) Act 1978, the Cabinet Secretary replied—

“I can do many things under the 1978 act. If you ask whether what you propose would be an equally good or better way of achieving not just the immediate change but the longer-term culture change that I want to bring about, the answer is no—that would not be as desirable.”60

Conclusion

74. From the written and oral evidence received by the Committee it is clear that there is overwhelming support for the rights and principles which the Bill sets out to enshrine. There is a general acceptance of the need to ensure that the rights of patients are respected and clearly understood, both by patients themselves, and those who support them in their care, such as family and friends, and by the wide range of health care professionals who are directly, or indirectly, involved in the treatment and care of patients.

60 Scottish Parliament Health and Sport Committee, Official Report, 6 October 2010, Col 3576.
75. Furthermore, it is clear from the evidence received by the Committee that the present framework for the promotion and communication of patient rights is not consistent and therefore, not as effective as it should be, and that improvements need to be made.

76. The Committee considers that the principal debate arising from scrutiny of the Bill centres on whether primary legislation is the most appropriate method of seeking to ensure the effective delivery of patient rights within the NHS in Scotland. The Committee has considered carefully the arguments in favour of setting out specific patient rights in statute. However, the Committee also noted evidence from a number of witnesses that there may be negative consequences from so doing.

77. The Committee welcomes, and shares, the commitment of the Scottish Government to promote the rights of patients and to foster a patient-centred culture within NHS Scotland, and recognises that patient user groups want greater clarity about their rights.

78. The Committee also supports the desire of the Scottish Government to avoid creating a ‘charter for lawyers’ resulting in an increase in compensation claims and litigation against the NHS.

79. The Committee considers that there is an inherent contradiction between, on the one hand, setting out patient rights in primary legislation giving the impression of enforceable rights and, on the other, making express provision in the Bill to limit the legal enforceability of these rights. In our view, there is a risk that the Bill may raise unrealistic expectations amongst patients regarding their rights due to the limitations on legal enforcement under section 18 of the Bill. Should the general principles of the Bill be agreed to, the Committee considers that a remedy such as alternative dispute resolution should be explored further at Stage 2.

80. The creation of a non-litigious remedy may not require primary legislation. Given that there was no support for a ‘charter for lawyers’, some Members therefore question whether the Bill is the most appropriate vehicle to achieve the Government’s objective.

81. The Committee also acknowledges the concerns expressed that the rights and principles set out in the Bill, may be perceived as the only rights which patients have, or to which NHS bodies in Scotland need have regard.

82. Some Members of the Committee believe the Government’s objective would be more effectively achieved by bringing up to date a revised and comprehensive patient rights charter. This should be in plain English, enshrining the healthcare principles set out in the Schedule to the Bill, all of the rights available to patients (existing rights, new rights provided for in the Bill, including an alternative dispute resolution mechanism), to be published by the Cabinet Secretary using the powers of direction under the NHS (Scotland) Act 1978.
TREATMENT TIME GUARANTEE

Background

83. Section 6 of the Bill introduces a statutory 12 week treatment time guarantee for patients. The objective of this guarantee is to ensure that a patient waits no more than a maximum of 12 weeks from the time a course of treatment for a medical condition is agreed with their clinician/doctor, to the point at which that treatment commences. The guarantee itself is intended to operate within the overall 18 week referral to treatment time target which is currently operated within NHS Scotland.  

84. The guarantee is subject, however, to several conditions and exemptions. The Policy Memorandum states that the guarantee is intended to apply only to “eligible patients” who are undergoing “planned and elective care, delivered on an inpatient or day case basis.” The Government intends to set out the detail of the treatment time guarantee, including the detailed description of an “eligible patient” in secondary legislation under the Bill.  

85. The Policy Memorandum explains that there will be a small number of services excluded from the treatment time guarantee. A list of these excluded services is provided—

- assisted conception;
- obstetrics;
- complementary and alternative medicines;
- organ transplants;
- direct access services (e.g. direct access X-rays);
- diagnostic tests;
- outpatient treatments;
- certain national specialist services (scoliosis);
- specialist services delivered in England used by Scottish patients, and
- alcohol and drug misuse services.  

86. Under the terms of section 6, a health board must take “all reasonably practicable steps” to ensure that it complies with the treatment time guarantee. If treatment for an eligible patient breaches the 12 week treatment time guarantee, then section 8 provides that the health board must “make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity”; “provide an explanation to the patient as to why the treatment did not start within the maximum waiting time”; and give the patient details of the advice provided.
and support services available to them, as well as, information on how to complain. 64

87. Section 8 also specifies that a health board must not give priority to the start of any treatment where this would be “detrimental to another patient with a greater clinical need for treatment”.

88. In addition, the provisions of section 18 of the Bill apply to the treatment time guarantee, meaning that, in the case of a breach, there is no financial penalty for the health board and no financial compensation will be payable to the patient. 65 Section 18 also provides that the treatment time guarantee is not enforceable by legal action.

The need for a treatment time guarantee

89. The Committee received evidence which questioned the need for a new statutory treatment time guarantee. A view was expressed that with improvements to waiting times across NHS Scotland in the last few years, and the fact that most patient treatment now complies with the existing 18 week referral to treatment time target, the 12 week treatment time guarantee might not be required. Despite these concerns, some witnesses expressed strong support for the establishment of the treatment time guarantee feeling that, on the whole, it could have a positive effect for patient care. 66

90. In its evidence to the Committee, Consumer Focus Scotland questioned the wisdom of establishing the treatment time guarantee. They said—

“It seems curious that this one kind of treatment is singled out in this way, by making the treatment time guarantee statutory. But what is given on the one hand, an apparent “right” to treatment within 12 weeks, is taken away with the other, when section 18 makes it clear that this right is not enforceable.” 67

91. Several patient representative groups welcomed the establishment of the treatment time guarantee. Breast Cancer Care stated that it believed the guarantee would be a “progressive step towards ensuring every patient will receive a minimum standard of care” and that the guarantee would “go some way in alleviating the anxiety many patients face when waiting for treatment for a particular health condition.” 68

92. The Royal National Institute for the Deaf Scotland (“RNID Scotland”), the Royal National Institute for the Blind Scotland (“RNIB Scotland”) and National Deaf Children Scotland (“NDCS”) made a joint written submission to the Committee. In the submission, RNID Scotland strongly welcomed the proposals in the Bill for the treatment time guarantee. It submitted that any provision which would lead to a

64 Patient Rights (Scotland) Bill, section 8.
65 Policy Memorandum, paragraph 35.
66 NHS Highland; Royal National Institute for the Deaf; Royal National Institute for the Blind; National Deaf Children Scotland; Royal College of General Practitioners; Royal College of Physicians Edinburgh. Written submissions to the Health and Sport Committee.
67 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
68 Breast Cancer Care. Written submission to the Health and Sport Committee.
decrease in the period between when a patient is referred to audiology services, to the time when they have a hearing aid fitted, would add to the quality of life of many people with a hearing impairment. However, RNID Scotland called for “a commitment from the Scottish Government that while audiology is included in the 18 week waiting time guarantee from referral to treatment by 2011, it will also be included in the 12 week treatment time guarantee.” In the same submission, NDCS stated—

“even a maximum wait of 18 weeks is too long for deaf children. There are 38 weeks in a school year. Eighteen weeks is the equivalent of almost half a year’s education.”

93. This concern about inclusion of particular forms of treatment was shared more widely by witnesses who felt that establishing a principle where the treatment time guarantee would apply to some forms of treatment, but not others, was potentially discriminatory. Many witnesses who supported the establishment of the treatment time guarantee felt that it should be applied more generally across NHS services.

94. The Chartered Society of Physiotherapy Scotland stated that there are approximately 28,000 people in Scotland in need of physiotherapy, and the waiting times for physiotherapy treatment varied from health board to health board area. It continued—

“… in this context, the rights of patients must be matched against the capacity of services and the available resource. In the case of physiotherapy provision, and against the backdrop of increasing efficiency savings, the legislation offers only limited scope for service improvement.”

95. Long Term Conditions Alliance Scotland pointed to the fact that timely medical treatment is essential for patients suffering from long term conditions. However, in relation to the treatment time guarantee it felt that—

“… this right must also apply to follow-up appointments and ongoing care. If these rights and guarantees only apply to a person’s first appointment there is a risk that people with long term conditions who require ongoing health services will be pushed to the back of the queue.”

96. NHS Lothian referred to the fact that, going forward, more forms of treatment which are currently delivered on an in-patient/day case basis and would therefore, currently be subject to the treatment time guarantee, may be delivered on an outpatient basis. In light of this fact, they believed that “there may be a case for

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71 Chartered Society of Physiotherapy Scotland. Written submission to the Health and Sport Committee.
72 Long Term Conditions Alliance Scotland. Written submission to the Health and Sport Committee.
extending the potential remit of the treatment time guarantee to all treatments in due course.”

**Potential impact of the treatment time guarantee**

97. There was substantial debate on the question of how the treatment time guarantee would operate in practice, and the potential impact it will have on the quality, efficiency and effectiveness of patient treatment.

**Potential distortion of clinical priorities**

98. One area of concern regarding the operation of the treatment time guarantee was the potential it may have to skew the delivery of treatment to patients. Some witnesses expressed the view that, while the Bill would require that clinical priority should always take precedence, there may be unintended consequences as health boards strive to meet targets.

99. In their written evidence to the Committee, the BMA stated that it did not believe that a guarantee relating to any treatment times for patients should be set out in primary legislation—

“The widespread use of centrally imposed treatment time targets has many unintended consequences, distorts clinical priorities and harms patients. All centrally-set targets have the potential to distort clinical care. Any objective which encourages clinicians to take actions which are potentially not in the patient’s best clinical interests is unhelpful.”

100. This concern was also reflected by the RCN. In its written evidence it cautioned against the potential unintended consequences of setting NHS targets, such as the 12 week treatment time guarantee, in primary legislation. This, it felt, could “create perverse incentives for gaming”, where health boards might encourage clinicians to manipulate waiting lists so as to prioritise the treatment of new patients in their caseloads, over other patients who may require review or follow-up, in order to ensure that a 12 week treatment time guarantee could be met.

101. Referring to ways in which a health board might seek to ensure that it complied with the legal requirements of the Bill, Hillary Patrick of the Law Society of Scotland stated—

“If I were a health board legal officer, I would say, “Please don’t agree the treatment until you know that it can be delivered within the 12 weeks.” I would advise the board to make noises that the treatment would be a good thing and to say that it will get back to the patient. Unless I am missing something, that seems to me to be an easy way of avoiding the impact of the legislation.”

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73 NHS Lothian. Written submission to the Health and Sport Committee.
74 British Medical Association Scotland. Written submission to the Health and Sport Committee.
75 Royal College of Nursing Scotland. Written submission to the Health and Sport Committee.
102. Responding to the concerns raised on the possible skewing effect of treatment targets, Melanie Hornett of NHS Lothian acknowledged that this was an issue that may often concern patients and clinical staff alike. However, she sought to reassure the Committee that health boards are committed to ensuring that targets do not interfere with the clinical priorities of patient treatment. 77

Exemptions from the treatment time guarantee

103. One of the main issues of concern for some witnesses centred on the services and treatments which would be exempted from the guarantee. In particular, several witnesses were anxious that the guarantee should apply to areas such as diagnostic tests, certain treatment carried out on an outpatient/primary care basis, and access to mental health and cognitive behavioural therapy treatment.

104. SAMH stated in its submission to the Committee that it was “extremely disappointing that mental health has been largely excluded from the treatment time guarantee.” This, SAMH felt, was a major weakness in the Bill. While recognising that most of the mental health needs faced by patients are of an ongoing nature, which cannot readily be addressed by one-off interventions, SAMH took the view that “this fact alone should not preclude mental health from inclusion in TTGs.” It went on to state—

“TTG applies from the time of agreement to treatment to the actual commencement of that treatment. It is, therefore, irrelevant how long a particular course of mental health treatment may last as the focus is on the time to commencement of treatment, and not the completion of it.”78

105. While supporting the principle of a treatment time guarantee, the Law Society of Scotland considered that it should include psychological services, “including talking treatments”, for which there are, the Society pointed out, “long waiting lists at present, particularly in some areas of Scotland.”79

106. During oral evidence to the Committee the Society went on to voice more general concerns regarding the potential discriminatory nature of the treatment time guarantee, Hillary Patrick of the Society stated—

“Cognitive behavioural therapy is a good example...why could a planned intervention like that not fall within the treatment time guarantee? Is it because it is not being given to an in-patient, and if not, why not? Why is that not discriminatory? Why are adults with mental health issues not being given those rights? It appears to be slightly discriminatory.”80

107. Carolyn Roberts of SAMH referred to the possible implications of human rights legislation on the implementation of the treatment time guarantee. She acknowledged that the Scottish Government, in the Policy Memorandum to the Bill, recognised the importance of ensuring that the requirements of international

78 SAMH. Written submission to the Health and Sport Committee.
79 Law Society of Scotland. Written submission to the Health and Sport Committee.
human rights law are met in respect of the provision of health services in Scotland. However, referring to Article 12 of the International Covenant on Economic, Social and Cultural Rights, which stated that ‘it is the right of everyone to enjoy the highest attainable standard of physical and mental health’, she stated that SAMH was—

“….concerned that the bill perpetuates what started with the 18-week guarantee—most mental health services are excluded from it.”

**Monitoring of primary care services**

108. One final issue raised in relation to the operation of the treatment time guarantee was how a health board might ensure that the guarantee was being met in relation to those eligible services which are delivered via primary care (e.g. in a GP practice). In response, NHS Lothian stated—

“As yet there is no such mechanism….one of our concerns about the bill is that it focuses on acute in-patient elective care and does not cover the huge area that you have described or the area of mental health. NHS Lothian has its own mental health targets, for example, and is managing to deliver them in line with the current targets for other forms of care. Such a mechanism could be put in place, but we have yet to try it with primary care.”

**Response from the Scottish Government**

109. Responding to the issues raised about the scope of the treatment time guarantee, the Cabinet Secretary sought to clarify the application of the 12 week treatment time guarantee in relation to the existing 18 week referral to treatment time target. She stated—

“When we move to a referral-to-treatment target, because that is a whole-journey waiting time target it requires to have tolerances attached to it, given that sometimes diagnosis takes longer than 18 weeks. The 12-week treatment time guarantee ensures that if, for argument’s sake, it takes 18 weeks to diagnose a condition, the patient will have the backstop of the 12-week treatment time guarantee, rather than be left hanging because they are already outside the 18 weeks, fall into one of the tolerance areas and therefore have no guarantee of how long treatment will take. I think that it is important to see the 12-week guarantee within the overall context of the 18-week referral-to-treatment target. There is a hard target and guarantee in the bill: once someone is diagnosed, they will be treated within 12 weeks.”

110. The Cabinet Secretary continued—

“I was very clear that the treatment time guarantee is about in-patient, elective treatment. Any treatment that is not provided on that basis is not covered by the treatment time guarantee. I have explained why we think that a treatment time guarantee is important within the context of the 18-week referral-to-treatment target. Of course, other treatments that are not required

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on an in-patient basis are still covered by the 18-week referral-to-treatment target." 84

111. Addressing the specific issue of mental health/cognitive behavioural therapy treatment, in relation to the treatment time guarantee, the Cabinet Secretary acknowledged the problems associated with waiting times for these services. However, she stated that the Scottish Government is committed to reducing waiting times in areas such as mental health and physiotherapy to the level where they can be included within the 18 week referral to treatment target. She also acknowledged that, in relation to some of these treatments, a specific in-patient treatment time guarantee may be required “to take account of what can be the unintended consequences of a whole-journey waiting time target.” 85

112. In supplementary written evidence, the Scottish Government stated that “patients with mental health needs are not excluded in the Patient Rights (Scotland) Bill; the Bill applies to all patients.” 86 Commenting on the “misconception” that mental health treatments are excluded from the 12 week treatment time guarantee, the Scottish Government stated—

"With reference to comments made on the exclusion of cognitive behavioural therapy (CBT), this is not specifically excluded from the TTG. However, where a service is not delivered as planned or elective care on an inpatient or day-case basis, it will not be covered by the eligibility criteria for the TTG: this is the same for all services. It is my understanding that CBT is not usually delivered in this way. (Some aspects of child and adolescent mental health services are delivered as planned or elective care on an inpatient or day case basis and these were therefore given in the Policy Memorandum as an example of a mental health service covered by the eligibility criteria)." 87

113. Responding to the concerns raised in relation to the possible distorting effect which the treatment time guarantee might have on the delivery of services based on clinical needs, the Cabinet Secretary stated—

“I am often asked whether targets skew clinical priorities; I am sure that the same question was put to previous Governments. Targets are intended not to skew clinical priorities but to ensure that patients are treated timeously; everyone recognises that point. Ultimately, decisions about treatment should be clinical decisions. Section 8(3)(a) seeks to make that clear, although I take the point that the same provision should be included elsewhere in the bill." 88

114. In supplementary written evidence to the Committee, the Scottish Government responded to questions raised with witnesses regarding section 18 of the Bill. This focused on limiting the legal actions which can be pursued by a patient for failure by a health board to meet the 12 week treatment time guarantee. Concern was expressed that if the guarantee is to be seen as part of the 18 week referral to treatment target, this may have implications for the rights of patients to

86 Scottish Government. Letter from the Head of the Bill Team dated 21 October 2010.
87 Scottish Government. Letter from the Head of the Bill Team dated 21 October 2010.
pursue legal action for failure to meet that target. The Scottish Government responded—

“In relation to the treatment time guarantee (TTG), on 29 September questions were raised about whether the prohibition in the Bill that would affect legal action in respect of failure to meet the 12 week TTG would compromise the right to take legal action in respect of the 18 week referral-to-treatment target. I can confirm that the current waiting time targets are not legal rights, but targets which are set and measured by the Scottish Government. Patients do not, therefore, have any legal basis for going to court if these rights are not met. The inclusion of the 12 week treatment time guarantee does not therefore remove any rights in this respect.”

Conclusion

115. The Committee acknowledges that treatment time targets can play a role in driving down waiting times for patients in Scotland.

116. The principal question which the Committee had to consider regarding the proposed 12 week treatment time guarantee was whether a statutory target of this type is required.

117. There are diverging views among Committee members about the value of a new statutory target.

118. The Committee noted the unequivocal statement by the Cabinet Secretary that the 12 week Treatment Time Guarantee only applies to elective in-patient treatment. The continuing change in delivery from in-patient treatment to day care to out-patient treatment and even primary care, has the potential to make for confusion rather than clarity, since any given procedure may be delivered in different settings for different patients in different health board areas.

119. Some Members consider that the treatment time guarantee will be beneficial to patients by providing reassurance about the maximum time they may have to wait for treatment following diagnosis.

120. Other Members consider that the proposed guarantee would add little to the existing 18 week referral to treatment target and are concerned by evidence that a new target could have unintended consequences including the potential for distortion of clinical priorities. In addition, these Members question the value of a statutory “guarantee” which cannot be enforced.

121. The Committee acknowledges that most procedures initiated and completed within primary care are likely to comply with the 18 weeks referral to treatment target and it would, therefore, be unnecessarily bureaucratic to monitor this. We recommend that compliance with the 18 weeks referral to treatment target should be reported in the annual report of a GP practice.

89 Scottish Government. Letter from the Head of the Bill Team dated 21 October 2010.
122. The Committee also noted the concerns raised about the proposed exclusion of a number of services from the treatment time guarantee, most notably mental health services. While the Committee accepts that it would be illogical to set targets for the treatment of patients accessing mental health services in response to a crisis, it is disappointed that access to services such as cognitive behavioural therapy are deemed to be outside the scope of the 12 week guarantee and existing treatment targets.

**PATIENT COMPLAINTS AND FEEDBACK**

**Background**

123. Section 11 of the Bill provides that that Scottish Ministers must ensure that each Health Board, Special Health Board and the Common Services Agency of NHS Scotland has: a suitable complaints process; publicises this process; tells the complainant about the advice and support available to patients; publicises the advice and support available; and monitors complaints. Subsection (2) provides that those bodies must also ensure that anyone providing a health service on its behalf (such as GPs) must have suitable complaints processes in place to identify any areas of concern.91

124. Section 12 of the Bill provides for health boards, special health boards and the Common Services Agency of NHS Scotland to encourage patients to raise concerns or give feedback on healthcare, and that patients can give feedback to a Patient Rights Officers, or to the relevant body. Patient Rights Officers will also be required to ensure that the feedback provided to them by patients is passed on to the relevant body.92

**Evidence received by the Committee**

125. Many patient representative groups who provided written and oral evidence to the Committee stressed the importance of an accessible, effective complaints and feedback system for patients. Many also pointed to the need for any system to be seen by patients as independent of NHS structures so as to ensure trust in the system.

126. There was also a clear distinction drawn between the way patients viewed a system where feedback on their treatment and experiences with the health service could be made, and that of a formal complaints system to address their concerns and grievances.

127. Some witnesses raised concerns about the reluctance of patients to make complaints in relation to their treatment while other patient groups stressed the fact that many people place more importance on an effective feedback system, where their views can be recognised and valued by the health service, as opposed to a system for dealing with formal complaints and grievances.

128. Organisations such as the British Heart Foundation Scotland and Chest, Heart and Stroke Scotland welcomed the renewed focus within the Bill on

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91 Explanatory Notes, paragraphs 24-29.
92 Explanatory Notes, paragraph 30.
recognising the views and concerns of patients as a central part of the way in which the health service should function. The British Heart Foundation supported the need for patients to be actively encouraged to provide feedback on their experience of treatment.93

129. Chest, Heart and Stroke Scotland highlighted the dilemma many patients face if they wish to make a complaint while they are receiving medical treatment. In its experience many patients often refrain from making complaints due to the concern that this may result in repercussions which could impact on the care they receive. Chest, Heart and Stroke Scotland stressed the need for the feedback and complaints system to be “supportive in encouraging patient feedback at all stages in their care pathway, putting the emphasis on NHS boards to seek feedback from the patients so that it becomes more the ‘norm’ and does not appear from the patient’s perspective to be something to be scared of.”94

130. NHS Forth Valley Patient Focus and Public Involvement (PFPI) Steering Group formed a focus group with other patient representative organisations to consider the provisions of the Bill. In evidence to the Committee, feedback from the focus group was that—

“… the Bill focused too much on complaining formally rather than on sharing experience and giving feedback. It was felt that the language is negative and gives an impression of an adversarial culture rather than one which supports local resolution at the point of the ‘complaint’. There were comments that this may lead to staff being defensive and perpetuate a culture of complaining and litigation. There was discussion about the numbers of people who do not complain about their care or treatment even when they are unhappy about the service they have received. Although the group agreed that having the right to complain within the Bill may make it easier for some, it was felt unlikely that it would increase the engagement of seldom heard groups. There was also concern about the ability to challenge habitual complainers and about managing peoples’ expectations.”95

131. RNID Scotland informed the Committee that, while a significant proportion of deaf/hearing impaired patients experienced difficulties accessing health services, their research shows that nearly a quarter take no action to address this with the health service. Some of the reasons for this being that patients did not like to complain; did not have enough time or were too ill or tired to complain; while others felt it was useless to complain as they felt it would not improve the situation.

132. Research conducted by RNIB Scotland indicates that many blind and partially sighted people are “very reticent about making complaints, as they do not feel they want to cause any problems and are unaware of how the processes may work.”96

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93 British Heart Foundation. Written submission to the Health and Sport Committee.
94 Chest, Heart and Stroke Scotland. Written submission to the Health and Sport Committee.
95 NHS Forth Valley PFPI Steering Group. Written submission to the Health and Sport Committee.
133. Medical and professional bodies expressed similar views to those of patient groups – that an emphasis on developing a positive culture on feedback and engagement amongst health care professionals, NHS employees and patients would be a more effective method of delivering the change required. The Royal College of General Practitioners stated that health care staff should be encouraged to view patient complaints not as threat, but as a learning opportunity.97

134. Citizens Advice Scotland expressed a concern that the Bill does not explicitly place a duty on the NHS to provide feedback to patients who have submitted complaints, commented on their experiences, or raised concerns about NHS services.98 It stated—

“We are concerned that the NHS is not under any obligation to proactively provide information to patients on the progress of complaints and concerns raised. In addition, there is no obligation on the NHS to provide this information to the Patient Advice and Support Service either when the service has assisted the patient in filing complaints, concerns or comments.”99

135. Consumer Focus Scotland supported the imposition of a duty on NHS bodies to publicise how complaints can be made and how they will be handled. They expressed caution, however, about the potential for this duty to lead to duplication in the production of information about complaints by boards as Health Rights Information Scotland currently produced approved information for all boards, and with NHS inform, provide easy access to information for members of the public. It felt that it would be important that the current infrastructure is supported and built on by NHS bodies, so as to avoid developing a “new cottage industry of information production.”100

136. The Scottish Human Rights Commission referred to the need for a human rights based approach to the development of a complaints and feedback system. They highlighted the system recently developed by The State Hospital, Carstairs as a best practice example of this—

“… the experience documented in the Commission’s independent evaluation of the human rights based approach adopted by The State Hospital suggests that it is important, in order to ensure the sustainability of a human rights based approach, that the rights of everyone involved are taken into account – patients, staff, carers, families and others – as parts of a common framework of rights, duties and shared responsibilities.”101

137. NHS Lothian cited the work it had undertaken in developing an efficient and responsive complaints and feedback system—

97 Royal College of General Practitioners. Written submission to the Health and Sport Committee.
98 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
99 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
100 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
101 Scottish Human Rights Commission. Written submission to the Health and Sport Committee.
“NHS Lothian will be implementing systematic fast, frequent feedback from patients to improve quality of care. ... Our modernised complaints function will have single point access where enquiries, comments and other requests for information by phone and web will be centralised. This new Hub will have ‘feeds’ from our website and be supported by call centre type technology. Giving patients and the public access to expert advisers in our system, who are able to instantly connect with services, advise on rights and solve problems is the benchmark standard NHS Lothian is aiming to achieve.”

138. Commenting on the additional value which the Bill might provide, the Scottish Public Services Ombudsman stated that, in relation to the work of his organisation, the Bill would not change the way in which patient complaints are considered at present. He stated that, as the Bill “contains no new rights” for patients, the only difference may be that once the Bill had been enacted, he may make reference to the Act when publishing a report or a decision on a complaint case. Referring to the provisions for a patient complaints system, he stated that the Bill may make the complaints process “more bureaucratic” for patients.

139. Responding to a question regarding the value the Bill might add to the work of his organisation, the Scottish Public Services Ombudsman said—

“It might impact on how the providers of the service across the NHS think about how they go about things. However, there is no new route by which rights can be pursued, which means that someone who had a complaint about the NHS and wanted to take it to the ombudsman would be in the same position that they are in at the moment, were the bill to be passed.”

140. The Law Society of Scotland commented on the potential effect the Bill may have, in a legal sense, for the rights of patients. Referring to the complaint provisions within the Bill, Hillary Patrick of the Law Society of Scotland stated that—

“The bill will not weaken the general law, but what will it add to it other than information about changing the complaints system? Law is not needed to do that; the NHS has its own complaints system. The question for the committee is: what is the benefit of enshrining such a system in legislation? I remain to be convinced that the bill will add anything.”

Response from the Scottish Government

141. Responding to questions on the system of complaints and feedback for patients, the Cabinet Secretary confirmed that patients currently have a right to make a complaint about their care or treatment by the health service. However, this right is not set out in primary legislation. By establishing a ‘statutory right’ for patients to make a complaint, the Cabinet Secretary argued that the Bill will go

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102 NHS Lothian. Written submission to the Health and Sport Committee.
103 Scottish Parliament Health and Sport Committee, Official Report, 8 September 2010, Col 3265.
some way to addressing some of the issues expressed in evidence, about the reluctance of patients to make a complaint about the NHS or its staff.\textsuperscript{107}

142. Furthermore, in her view, the more important aspect of the provisions of the Bill would be the statutory duty which would be placed on health boards to deal with, monitor and report on patient complaints, as well as the duty to seek improvements to patient care in response to complaints.\textsuperscript{108}

Conclusion

143. The Committee believes that the development of a more open and accessible system of patient feedback within the NHS is to be encouraged. Such a system can have a beneficial impact both for patients and health care staff by allowing patient concerns to be addressed before they reach the point of escalating to a formal complaint. The Committee notes, in particular, the system currently operated by The State Hospital, Carstairs which received praise from the Scottish Human Rights Commission as an example of best practice.

144. The Committee acknowledges that many people feel vulnerable when they interact with the health service, particularly when they feel the need to raise a concern or make a complaint. It is, therefore, vital that the NHS puts in place appropriate arrangements to handle such matters in a sensitive and supportive manner.

145. However, the Committee is not clear what practical difference the provisions of the Bill will make for patients who wish to give feedback, raise concerns or complain about the health care they have received. Patients already have a “right to complain” and the provisions of the Bill will not alter that right in any way.

THE PATIENT ADVICE AND SUPPORT SERVICE

Background

146. Section 14 of the Bill amends the 1978 Act by inserting a new section 10ZA. This section will require the Common Services Agency of NHS Scotland to secure the provision of a patient advice and support service (“PASS”) for each health board in Scotland. The Scottish Ministers will be able to extend the remit of the PASS to any other body that they may specify in secondary legislation. The Common Services Agency will be required to procure the PASS, on a contractual basis, from a provider, or providers. The PASS may be supplied by more than one provider, however, a health board, a special health board or the Common Services Agency itself, will be restricted from providing the PASS.\textsuperscript{109}

\textsuperscript{109} Explanatory Notes, paragraphs 34-35.
Policy objective

147. The Policy Memorandum stated that the objective of establishing the PASS is “to support patients in the realisation of their rights and to raise awareness of their responsibilities, and to support patients if they need assistance to take forward a complaint”. The PASS will be staffed by Patient Rights Officers (“PROs”), who will provide the advice and support service to patients. The Policy Memorandum also noted the opposing view of respondents to the Government’s consultation as to whether such a service should, or should not, be independent of health boards. Some respondents expressed the view that an advice and support service could be provided by patient advocacy services, rather than by establishing a new service. In an effort to address these suggestions, the Bill provides for Patient Rights Officers to be able to make patients aware of, or direct them to, advocacy services. The Government is making further funding available to advocacy services to support this provision.  

The Independent Advice and Support Service

148. Currently, information and advice is provided to patients via the Independent Advice and Support Service (“IASS”). Each health board area in Scotland contracts for the current IASS, which is provided by the Citizens Advice Bureaux (“CABx”) in Scotland.

149. In their written evidence to the Committee, Citizens Advice Scotland, the representative body for the 83 CABx across Scotland, outlined how the IASS works—

“IASS is a part of the CAB service in Scotland. Funded by local NHS boards, IASS offers advice and support to all NHS users and their families in relation to any concerns and complaints they may have regarding care received from the NHS. The service also provides general advice and has a holistic outlook to supporting its clients, as patients’ health concerns are frequently interlinked with other issues they are experiencing such as debt or employment issues which can have a significant impact on people’s health and well being.”

150. Much of the written and oral evidence received by the Committee highlighted the important role of an independent service which can advise and support patients in relation to their healthcare needs. While there was much regard for the work of the IASS today, several witnesses acknowledged the need to make improvements to the current service.

151. The benefits of the current IASS system, with its access it to the full range of services provided by the CABx, was also noted by patients. NHS Forth Valley Patient Focus and Public Involvement (PFPI) Steering Group reported that—

“... as IASS sits in citizens advice bureaux, our patient panel members feel strongly that it is almost a one-stop shop, such that people who have

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110 Policy Memorandum, paragraph 41.
111 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
concerns about not only their health care but their housing or other benefits can go to one point of contact and be signposted quickly.”\textsuperscript{112}

152. In its written submission, Citizens Advice Scotland referred to independent research which demonstrated that the provision of information and advice on issues such as welfare benefits, debt management, housing and employment, can have a very beneficial effect on the general health of individuals, as it can assist in reducing levels of anxiety and stress and help to foster a sense of personal control over their situation. This, in turn, Citizens Advice Scotland stated, can reduce the need for prescriptions such as anti-depressants, reduce the number of visits that they make to a GPs and other health professionals.\textsuperscript{113}

153. Referring to feedback from a sample of users of the current IASS, Citizens Advice Scotland reported that the service was “highly valued” by users, particularly given the “holistic advice and information provided” by the IASS. Citizens Advice Scotland strongly recommend that any new patient advice service build on the work of the IASS by ensuring it “continues with the provision and delivery of general information, advice and support service to patients, their families and carers”\textsuperscript{114} Citizens Advice Scotland also highlighted some of the difficulties which have been experienced since the IASS was first established.

154. In oral evidence Citizens Advice Scotland pointed out that, in the past year, some health boards have cut the level of funding they provide to support the IASS.\textsuperscript{115} In supplementary written evidence to the Committee, Citizens Advice Scotland detailed the health board funding extensions for the provision of the IASS from financial year 2009-10 to the current financial year. This showed that in 11 out of 14 health board areas, funding for the IASS remained at a standstill, or had been reduced. The largest reduction was proposed by NHS Tayside, which plans to reduce its funding for the IASS by 33.4% from 2009-10 levels. However, Citizens Advice Scotland acknowledged that the funding reduction had been agreed after negotiations between Tayside Health Board and the local Citizens Advice Bureaux which provide the IASS.\textsuperscript{116}

155. Commenting on the variation in the levels of funding provided by boards, as well as variations in the levels of services offered to patients across various board areas, Citizens Advice Scotland stated that the—

“….current set-up for the independent advice and support service is inconsistent in different health boards because of how it was funded and the way in which its structure was set up. We would welcome more consistency.”\textsuperscript{117}

\textsuperscript{113}Citizens Advice Scotland. Written submission to the Health and Sport Committee.  
\textsuperscript{114}Citizens Advice Scotland. Written submission to the Health and Sport Committee.  
\textsuperscript{115}Citizens Advice Scotland. Written submission to the Health and Sport Committee.  
\textsuperscript{116}Citizens Advice Scotland. Written submission to the Health and Sport Committee, 20 October 2010.  
156. Responding to questions on the level of cooperation by health boards with the current IASS system, and the importance of a strong relationship between them and the new PASS service, Citizens Advice Scotland commented—

“Yes, that has been a problem. IASS is starting to make a difference in some health boards where it has been established for longest. The first health board came on board four years ago. There, relationships between the NHS complaints officers and the IASS workers are extremely good, to the point that the complaints officers were phoning me up to ask for leaflets to distribute. In other areas, people from within the NHS who have come across IASS through other routes might or might not contact me. People are saying that they have not got enough work, so they are not marketing that service. I think that that is partly because they have poor relationships with the NHS board, which does not see the value of the service.”

157. Citizens Advice Scotland pointed to the need for more proactive marketing of the IASS by NHS boards, so as to ensure patients were aware of its existence and made used its services.

The need for a new Patient Advice and Support Service

158. As with other aspects of the Bill, some of the evidence received by the Committee questioned whether primary legislation is required in relation to the establishment of a new patient advice and support service. In its written evidence the BMA stated that—

“It is difficult to see why provision for this service and the Patient Rights Officers should be necessary in primary legislation, particularly with all the ensuing cost and bureaucracy to change the legislation, particularly when the existing service appears to be functioning relatively well.”

159. Commenting on the role of the proposed PASS, and the need to retain the best element of the current IASS system in any new patient advice service, Suzanne Dyer highlighted some of the benefits the current IASS service provides, given its location within the CABx structure—

“I am able to advise people on benefits to do with illness, such as disability living allowance or attendance allowance. There are people who are more expert on other benefits in our office. I would sit with the patient while the other person came in, to ensure that the patient got a person-centred approach and dealt with the same person right the way through their care.”

160. Highlighting what they considered to be a benefit of the proposals in the Bill, the Chartered Society of Physiotherapy Scotland welcomed the establishment of the PASS and stated that the—

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120 British Medical Association Scotland. Written submission to the Health and Sport Committee.
121 Scottish Parliament Health and Sport Committee, Official Report, 8 September 2010, Col 3261.
“creation of a central independent service is likely to change culture, by providing a reference of information beyond that available from the service provider. This may increase patient awareness and expectations, and access the complaints process when things go wrong.”

161. Consumer Focus Scotland referred to the work of Health Rights Information Scotland (“HRIS”), which is a joint initiative between Consumer Focus Scotland and the Scottish Government, and has responsibility for producing and providing information to patients on their rights.

162. Highlighting the role of HRIS, Consumer Focus Scotland noted that, under the provisions of the Bill, only the PASS service will be empowered to provide information to patients. As PASS will be independent of the NHS and will, in the opinion of Consumer Focus Scotland, most likely, not be located on NHS premises where patients would normally look to access information (i.e. hospitals and GP surgeries), this may give rise to a gap in the provision of information to patients.

163. Consumer Focus Scotland also expressed dismay at the prospect that the role of HRIS may not continue under the new system. By way of addressing this potential deficiency, Consumer Focus Scotland recommended that—

“….the model established by HRIS for central production of information for use throughout the NHS is one which should be built on and continued. It provides a source of key information for the new NHS inform service, and we would urge the Scottish Government to ensure that the role and functions of HRIS will be preserved in the future.”

164. Citizens Advice Scotland echoed concerns regarding potential gaps which may be created as a result of the establishment of the PASS. While commenting on issues relating to the patient feedback and complaint process, Citizens Advice Scotland recommended that a duty be placed on the NHS to provide feedback, both directly to patients and to the PASS when that service is involved in supporting a patient. This would have the advantage of allowing the PASS to monitor the NHS’s response to the complaints and comments it receives, and measure the impact that the PASS has had on any improvements made to the services provided by the NHS.

165. The Scottish Public Services Ombudsman expressed a view that, as the Bill provides no new route by which rights or complaints could be pursued, the establishment of the PASS would make no difference to the way in which a patient would approach the Ombudsman—

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122 Chartered Society of Physiotherapy Scotland. Written submission to the Health and Sport Committee.
123 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
124 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
125 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
“It is important to remember that the PASS and PRO set-up that is proposed in the bill is building on the strong base that IASS has put in place. Therefore, we are talking about a possible improvement rather than anything new.” \(^{126}\)

166. NHS Lothian raised concerns regarding the establishment of a new patient advice service. It suggested that an alternative to the creation of the PASS could be for health boards to commission community health and voluntary organisations to deliver such a service via local service level agreements. \(^{127}\)

167. A similar model of patient advice service was referred to by Diabetes UK Scotland. In its evidence to the Committee it suggested the development of—

“….a community development model, prioritising the skilling up of groups and communities of patients and healthcare staff, could offer a more effective basis of any new service, whether based within the health service or, possibly, in the voluntary sector. This section of the Bill needs in-depth investigation and consideration with a particular focus on the balance of compliance, advocacy, advice and information and how these are best delivered.” \(^{128}\)

*The costs of establishing the PASS*

168. The total recurring costs for the establishment and operation of the PASS and the PROs is estimated by the Scottish Government to be £2,081,000 per annum. The Financial Memorandum explains that Health Board funding for the IASS was estimated to be £831,000 in 2009/10. In addition £134,000 was provided by the Scottish Government to Citizens Advice Scotland for central support functions. The Financial Memorandum states that this money would be redirected to the new service. A further £116,000 will be provided from the Healthcare Policy and Strategy Directorate budget and £1 million of new recurring funding will be provided for the PASS and PROs. \(^{129}\)

169. NHS Lothian expressed concerns regarding the costs of establishing the new PASS service, and the impact those costs may have on boards. Referring to the strategies and activities they have undertaken in relation to providing information and engaging with patients, carers and the general public in the Lothian board area, they stated—

“NHS Lothian through various strategies wants to build on these activities, yet the proposal would see a significant sum of money allocated to a third party. While an independent service may be important, the replacement of an existing much lower cost independent service (IASS) should be questioned.” \(^{130}\)

170. Commenting on the funding structure for the PASS, Scottish Government officials stated—

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\(^{127}\) NHS Lothian. Written submission to the Health and Sport Committee.

\(^{128}\) Diabetes UK Scotland. Written submission to the Health and Sport Committee.

\(^{129}\) Financial Memorandum, paragraphs 108-111.

\(^{130}\) NHS Lothian. Written submission to the Health and Sport Committee.
“Currently, health boards pay for the independent advice and support service. We have said that we expect that contribution to continue and that we will pay the additional money from central Government funds. We think that the final bill for the PASS service will be £2 million.”

171. Others, such as the Royal College of Physicians of Edinburgh, also expressed concerns regarding the establishment costs of the PASS. While supporting the establishment of an “independent” patient advice service, the College sought a reassurance that the costs of the new service will be “proportionate given the public sector pressures.”

Patient Rights Officers

Background

172. As part of the establishment of the PASS, section 15 of the Bill would also create the role of Patient Rights Officer (“PRO”). PROs will be responsible for delivering PASS services to the public. Section 15 also outlines the services that the PASS will provide to patients, and members of the public. Sections 16 and 17 of the Bill set out the duties of PROs and establish duties on the relevant NHS bodies, the PASS and PROs to share relevant information.

The role of the Patient Rights Officers

173. The role of a PRO will be to carry out the functions of the PASS in supporting patients in the realisation of their rights, awareness amongst patients of their responsibilities, as well as supporting patients if they need assistance to take forward a complaint. PROs will also be able to raise awareness of advocacy services and direct patients to such services if required.

174. The Financial Memorandum stated that the total funding provision for the PASS is expected to provide between 60 – 85 full time equivalent PROs. Furthermore, there will be at least one PRO per health board area, although this may not be on a full time basis, depending on an assessment of needs undertaken by individual health boards. PROs will not be limited to supporting patients only from their own geographical board area, they also be required to support patients in their dealings with special health boards or health boards outwith their own region, where treatment has taken place in another health board area or where the patient finds it easier to meet with a PRO in another board area.

175. In oral evidence to the Committee, Scottish Government officials expanded on the specific responsibilities PROs will have as part of their job role. This “will include promoting an understanding of rights and responsibilities for both patients and staff” in the NHS, as well as “helping to clarify both existing patient rights and those that the bill will introduce”. Officials continued—

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132 Royal College of Physicians of Edinburgh. Written submission to the Health and Sport Committee.
133 Explanatory Notes, pages 6-7.
134 Policy Memorandum, paragraph 40.
135 Financial Memorandum, paragraph 114.
136 Financial Memorandum, paragraph 107.
“Patient rights officers will be there to provide advice and support for patients in relation to local resolution and mediation if things go wrong, and to provide an objective and independent insight into health services and areas for improvement, working with health boards. They will also be able to signpost to advocacy services where appropriate, and to provide an independent source of advice and information to boards to support the development of advocacy plans.”

176. Much of the written and oral evidence received by the Committee centred on issues such as the number of PROs who would be in post across Scotland; their role, in terms of supporting and advising patients; whether they will play a largely ‘signposting’ function, or, whether they should undertake advocacy on behalf of patients. Concerns were also expressed as to how the PROs, and the wider PASS structure, would interact and engage with health boards, health care staff, patients and their carers/families and, the wider voluntary sector.

177. Although supportive of the creation of the role of the PRO, Citizens Advice Scotland, expressed concern that PROs would be unlikely to be able to assist users with all of their support needs—

“Patient Rights Officers are unlikely to be able to assist users with all of their information and advice needs. Users may, for example, require assistance with claiming welfare benefits or managing complex debt. IASS is built onto the existing information, advice and support structure available through the CAB service and at the moment, users can be referred to in-house specialists where relevant. It is important that PASS continues to make similar provisions available to users.”

178. Consumer Focus Scotland expressed the view that all hospitals and Community Health Partnerships should be required to have a dedicated PRO as part of any new system. While recognising the benefits to patients of having access to an advice and support service which is independent of the NHS, Consumer Focus Scotland also felt there would be merit in PROs being employed by the health service, as key members of NHS teams. This, it was submitted, would have the advantage of providing a highly visible and responsive service “for all patients, carers and members of the public” which could handle patients’ concerns at an early stage, and resolve issues and concerns informally and quickly, before they become more formal complaints.

179. During their oral evidence to the Committee, Consumer Focus Scotland expanded on this—

“…we have argued that there is some value in attaching the fairly strong title of patient rights officer to the people in the NHS who are currently described as patient liaison officers or complaints officers. Having them as a more visible and accessible presence in NHS premises would be useful, and would

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138 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
139 Consumer Focus Scotland. Written submission to the Health and Sport Committee.
mean that issues could be dealt with when they arose, which would avoid them becoming complaints or going anywhere near litigation.\textsuperscript{140}

180. The Scottish Public Services Ombudsman expressed some caution regarding the establishment of a new system of PROs, and the potential negative effects, at least in the short term, for public confidence in the independence of the system—

“As I read the bill, PROs are designed for signposting. My worry about PROs and, to an extent, PASS stems from my experience in setting up the Police Complaints Commissioner for Scotland. For about the first six months, the first question that 80 per cent of callers to that commission asked was, “Are you, or have you ever been, a police officer?” In positioning PROs and PASS, we will have to be careful that, although they are funded by health boards and Government, they are capable of giving independent free advice.”\textsuperscript{141}

\textbf{Patient advocacy}

181. In oral evidence Scottish Government officials confirmed that the PASS, and PROs would work to ‘signpost’ mediation and advocacy functions to patients, but not deliver them directly. They stated—

“An advocate stands beside someone to help them to negotiate systems. It is complex for a patient even to understand what is available. The independent patient advice and support service and the patient rights officer will work with an individual to help them to identify the best possible mechanism for them....the role of PASS is not to undertake that work, but to understand someone’s issue and to signpost them, or introduce them, to the appropriate mechanism, be that mediation or advocacy.”\textsuperscript{142}

182. Several patient representative organisations stressed the need for an advocacy system for patients. Inclusion Scotland considered that PROs and the PASS “cannot operate effectively without the development of parallel advocacy services for disabled people.”\textsuperscript{143}

183. Long Term Conditions Alliance Scotland stated that, in order for the PASS and PROs to help make patient rights a reality, greater clarification will be required on how the new service would interact with the various voluntary organisations that provide information, support and advocacy services to patients. Long Term Conditions Alliance Scotland recommended that PROs should have a specific responsibility for directing people to support organisations, relevant to their personal health needs, such as voluntary organisations dealing with specific medical conditions.\textsuperscript{144}

\textsuperscript{143} Inclusion Scotland. Written submission to the Health and Sport Committee.
\textsuperscript{144} Long Term Conditions Alliance Scotland. Written submission to the Health and Sport Committee.
184. The need for greater clarity regarding the role of PROs, in relation to patient advocacy, was also commented on by the Scottish Public Services Ombudsman, who stated—

“While we welcome the inclusion of signposting to advocacy in the Bill we believe that there is a need for clarification on the difference between the roles of the Patient Rights Officer and of Independent Advocacy. The SIAA [Scottish Independent Advocacy Service] occasionally encounters some confusion from certain agencies and some people about what Independent Advocacy is and is not. We believe that without such clarification this confusion will continue. It will be important, when drawing up the service specification for the Patient Advice and Support Service, that this distinction is clearly made.”

Training and education
185. The RCN expressed concern about the extent to which PROs would have the training, skill and experience to—

“….direct patients to the full range of legal remedies available to them in the light of a breach of any of their rights, including the rights under the Bill.”

186. Citizens Advice Scotland highlighted the experience it had gained from operation of the IASS system and of the importance of ensuring that NHS staff and health care professionals utilise the educational, training and awareness-raising opportunities provided by NHS Education for Scotland regarding the work of PASS and the role of PROs.

187. SAMH stressed the need for PROs to receive dedicated mental health awareness training so as to ensure they have a comprehensive understanding of the needs of people with mental health problems, and know how to communicate effectively with mental health service users, especially in times of distress. SAMH argued that it was vital for PROs to—

“….feel comfortable in dealing with all patients’ or carers’ queries, and know how to respond to them appropriately.”

Response of the Scottish Government
188. During her evidence to the Committee, the Cabinet Secretary stated that the decision of the Scottish Government to place a patient advice and support service on a statutory basis, was designed to address many of the concerns which had been expressed, regarding the variations and inconsistencies in the current Independent Advice and Support Service. The central objective of this decision is to place a statutory duty on health boards, relating to the delivery and funding of a

145 Scottish Public Services Ombudsman. Written submission to the Health and Sport Committee.
146 Royal College of Nursing Scotland. Written submission to the Health and Sport Committee.
147 Citizens Advice Scotland. Written submission to the Health and Sport Committee.
148 SAMH. Written submission to the Health and Sport Committee.
patient advice and support service so that, even if they wished to, health boards
could not make cuts to this service as a way of saving costs.¹⁴⁹

189. The Cabinet Secretary argued that by establishing a statutory duty on all
health boards to contract for the provision of the PASS, that this would ensure that
a patient advice and support service is embedded as a core element of the NHS in
Scotland. As a result, any future decisions on changes to the role and functions of
a patient advice and support service will require to be taken in the context of
changes to a “core service” of the NHS and would, therefore, most likely require
further primary legislation.¹⁵⁰

190. The Cabinet Secretary accepted the views expressed by various witnesses,
regarding the benefit which the current IASS system provides to patients, by virtue
of its delivery by CABx, and the holistic advice and support that can be offered to
patients as a result. When asked if she would consider ensuring that the
contractual basis for the provision of the new patient advice and support service
would seek to retain access to such a holistic advice service for patients, she
stated—

“I am happy to consider that. This is only stage 1. The committee will know,
from its consideration of previous bills, that I take on board all the
suggestions that it makes. I am not sure what might be possible under
procurement rules, so I do not want to give a definitive yes or no answer.
However, as with all the suggestions that the committee makes, I am more
than happy to consider that suggestion.”¹⁵¹

Conclusion

191. The Committee notes the evidence it has received regarding the provision
and operation of the current IASS. While recognising the variations which currently
exist in the provision of the service across differing health boards areas, we
believe the IASS provides an important advice and support service for patients.

192. The Committee welcomes the commitment of the Scottish Government to
build upon and improve the present service by addressing the contractual and
funding problems which have arisen in relation to the IASS. We are concerned,
however, with the approach the Government has taken, by proposing the
establishment of the new Patient Advice and Support Service.

193. The current structure of the IASS has delivered some important advantages
for patients, one of which is the ‘one stop shop’ for advice and support that
Citizens Advice Bureaux can provide to users of the IASS. The Committee
therefore welcomes the commitment of the Cabinet Secretary to consider ways of
ensuring that the ‘one stop shop’ approach is retained as part of any new
contractual provision for an advice and support service.

194. However, the Committee also considers that the role of the PASS, and
PROs, are not sufficiently clearly defined in the Bill as introduced. The Bill

specifies that the role of a PRO will be to act as a “signpost” for patients, assisting them with feedback, providing them with advice and supporting them in making complaints. However, PROs will be prevented from carrying out any advocacy role on behalf of patients. We fail to see how this will be an improvement on the current service provided by the IASS.

195. The Committee considers that a central element in the success of any new advice and support service will be patient confidence in its role and remit. For this reason, the Committee believes that it is essential that the service be independent, and, crucially, seen to be independent from the NHS.

196. The Committee recognises the current variations in the funding and delivery of the IASS and welcomes the commitment of the Scottish Government to address these issues. However, the Committee questions the need to establish an entirely new Patient Advice and Support Service as a means of achieving improvements. In our view, a more effective and efficient approach could be to build on the current IASS structure by developing it through a new national contract. Such an approach would retain the best elements of the present system whilst addressing the concerns regarding the inconsistencies in the level of service and funding between health board areas.

FINANCIAL IMPLICATIONS OF THE BILL

Background

197. As required by Rule 9.3.2 of the Parliament’s Standing Orders, the Bill was on introduction accompanied by a Financial Memorandum. The Financial Memorandum should set out the best estimates of the administrative, compliance and other costs to which the provisions of the Bill would give rise, best estimates of the timescales over which such costs would be expected to arise, and an indication of the margins of uncertainty in such estimates. The Financial Memorandum must distinguish separately such costs as would fall upon (a) the Scottish Administration; (b) local authorities; and (c) other bodies, individuals and businesses.

198. The Standing Orders also require the lead committee to consider and report on the Financial Memorandum of the Bill and, in preparing its report, to take into account any views submitted to it by the Finance Committee.

199. The Finance Committee considers all financial memorandums accompanying a bill on introduction. In relation to the Bill, the Finance Committee agreed to seek written evidence from affected organisations, to take subsequently oral evidence from the Scottish Government Bill team and then to produce a report to the Health and Sport Committee in advance of its evidence sessions with the Minister and the Cabinet Secretary. The Finance Committee’s report is attached at Annexe D.

Summary of costs outlined in the Financial Memorandum

200. The Financial Memorandum sets out the costs associated with the Bill under three headings—

- principles in provision of services;
- the treatment time guarantee; and
- support and recourse.

201. The report from the Finance Committee followed this structure.

Principles in provision of services

Staff education and training

202. The Finance Committee noted that the significant costs arising from this area of the Bill are non-recurring costs of £800,000 in 2011-12 and 2012-13 in relation to staff education and development.¹⁵³

203. In its submission to the Finance Committee, NHS Education for Scotland highlighted concerns that NHS boards will have additional resource implications as a result of this area of the Bill.¹⁵⁴ In addition, NHS Lothian argued that a significant proportion of the funding should be directed to boards because models of education delivery should be local, relevant and accessible to frontline staff.¹⁵⁵ NHS 24 said that the amount suggested within the FM for staff training would only cover the development of training programmes and it fails to acknowledge the additional hours boards are required to cover to give staff the time required for training.¹⁵⁶

204. The Finance Committee raised these issues in an oral evidence session with the Scottish Government Bill team. In response to concerns raised regarding additional resourcing costs, the Bill team said that the Government was “fairly confident that the costings are accurate” and that training would be built into existing programmes. In relation to the comments from health boards about potential additional costs due to the requirement to provide cover for staff while on training, the Bill team replied that as training would be incorporated into pre-registration training, induction training, other training, “rather than taking some people out every day to do a whole day away from their normal duties.”¹⁵⁷

The treatment time guarantee

205. The Financial Memorandum states that the Scottish Government does not anticipate any direct financial costs in relation to the 12 week treatment time guarantee. The treatment time guarantee sits within the overall 18 weeks referral

¹⁵³ Financial Memorandum, paragraphs 62 and 64.
¹⁵⁴ NHS Education for Scotland. Written submission to the Finance Committee.
¹⁵⁵ NHS Lothian. Written submission to the Finance Committee.
¹⁵⁶ NHS 24. Written submission to the Finance Committee.
to treatment target, which is the whole patient journey maximum waiting time from
general practitioner referral to commencement of treatment.\textsuperscript{158}

206. The money provided to health boards to deliver the 18 week referral-to-
treatment time target was originally £270m over 3 years (up until financial year
2010-11). However, this was reduced by £20m to £70m for 2009-10 and 2010-11.
As the 12 week treatment time guarantee is intended to operate within the 18
week referral-to-treatment time target, no additional money is provided to health
boards.\textsuperscript{159}

207. In written submissions to the Finance Committee, some health boards
referred to the £20 million per annum reduction. In 2009-10, to meet targets, NHS
Ayrshire and Arran stated that it had had to invest an extra £3.7 million of its
general allocation to supplement funding from the Scottish Government. It
estimated the additional funding required for 2010-11 to be approximately £4
million.\textsuperscript{160}

208. In its written evidence to the Health and Sport Committee, the BMA
expressed the view that, in a period of constraint in public sector funding, the 12
week treatment time guarantee was “likely to be unaffordable” and it did not
believe that the guarantee could not be justified “in this financial climate.”\textsuperscript{161}

209. In oral evidence to the Finance Committee, the Bill team confirmed that the
treatment time guarantee was “inextricably linked to the 18-week referral to
treatment target” and stated that—

   “Money that is going towards meeting that 18-week target, as well as the
   waiting times, will be covered through recurring funding.”\textsuperscript{162}

210. The Finance Committee reported that the Bill team had acknowledged that
problems exist at individual boards where extra capacity may be required. The Bill
team confirmed that—

   “…the £70 million has not yet been allocated. We are in discussions with
   boards on the appropriate allocations.”\textsuperscript{163}

Support and recourse

\textit{Patient Rights Officers and the Patient Advice and Support Service}

211. The Finance Committee reported that the most substantial costs arise from
this area of the Bill, including £831,000 being redirected from the current IASS to
supplement an additional £1,250,000 of new funding from the Scottish
Administration. This funding is to support the PASS and the introduction of
PROs.\textsuperscript{164}

\textsuperscript{158} Financial Memorandum, paragraphs 80-81.
\textsuperscript{159} Financial Memorandum, paragraph 84.
\textsuperscript{160} NHS Ayrshire and Arran. Written submission to the Finance Committee.
\textsuperscript{161} British Medical Association Scotland. Written submission to the Health and Sport Committee.
\textsuperscript{164} Financial Memorandum, paragraph 104.
212. In a written submission to the Finance Committee, NHS Lothian argued that this was a considerable level of funding and expense for a service which is in large part currently delivered by boards who may continue to do so.\textsuperscript{165}

213. In its written submission to the Health and Sport Committee, Citizens Advice Scotland also warned of the potential for higher service costs arising from the establishment of a new system. Citizens Advice Scotland argued given that a considerable amount of work which would be carried out by PROs could be “very effectively dealt with by local CAB advisers”. This would have the advantage of creating economies of scale and cost savings which, Citizens Advice Scotland suggested, would not be present if the service were to be delivered solely by PROs.\textsuperscript{166}

214. The Finance Committee also reported that there appear to be inconsistencies in the Bill documents in relation to the number of PROs the Bill would create. The Policy Memorandum states 40 – 50 while the Financial Memorandum states 65 – 80. During oral evidence with the Bill team, the Finance Committee asked for an explanation of this difference. The Bill team responded—

“The 40 to 50 would be the additional ones, with the additional central funding. There are already 30 or so independent advice and support service workers. The 40 to 50 are the additional workers that we could provide with the £1.25 million from central funding.”\textsuperscript{167}

215. The Finance Committee acknowledged the clarification from the Scottish Government, but expressed concern that different figures were provided in the two documents, and that an additional explanation may have been helpful.

Advocacy

216. The Finance Committee reported that the Financial Memorandum shows that the Scottish Government will provide a non-recurring £500,000 in 2010-11 to allow health boards to assess the provisions for advocacy services required in their area. The Scottish Government will then provide £500,000 per annum of recurring new money from 2011-12 to support advocacy services.\textsuperscript{168}

217. In written evidence to the Finance Committee, health boards had explained that they may need to provide more services than the £500,000 would fund.\textsuperscript{169} In response to this the Bill team stated that the £500,000 allocated to boards in 2010-11 is to assess what the current situation is across each board and whether there are any gaps, and that—

“The money will then go towards addressing these gaps, which might not be the same across all boards.”\textsuperscript{170}

\begin{footnotesize}
\textsuperscript{165} NHS Lothian. Written submission to the Finance Committee.
\textsuperscript{166} Citizens Advice Scotland. Written submission to the Health and Sport Committee.
\textsuperscript{168} Financial Memorandum, paragraph 119.
\textsuperscript{169} NHS Orkney. Written submission to the Finance Committee.
\end{footnotesize}
Translation, Interpreting and Communication Support

218. The Financial Memorandum explains that PROs will direct patients to relevant support services. It is anticipated that one of the main services patients will be directed to is Translation, Interpreting and Communication Support (TICS). The Scottish Government is providing additional funding of £250,000 per annum of nonrecurring funds from 2010-2011 to 2012-2013 to NHS Scotland.171

219. In its written submission to the Finance Committee, NHS Lothian said—

“…there needs to be an accurate costing of the implementation implications for NHS Boards. NHS Boards will continue to deliver the bulk of a “patient rights service” but with no new money to assist them. The only financial support is to national organisations. For example, the requirements for interpretation, translation and communication support cannot be underestimated. Yet there is no funding for NHS Boards to meet this increasing need, which is extremely necessary to address not only in respect of informed consent and good person – centred care, but also the legal duties under Equality and Human Rights legislation.”172

220. During the evidence session the Bill team agreed that this was a valid point and said—

“Over the next year, a bit of work will be done with health boards to look at how we co-ordinate and ensure better efficiency and effectiveness in the translation of materials centrally.”173

General issues

221. The Finance Committee noted that, overall, the new money being allocated is £784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13 as a result of this Bill.174 In light of the likely reductions in future budgets, the Finance Committee questioned whether funds would definitely be available. The Bill team stated—

“We do not know what the spending review will provide, but the best that we can say at the moment is that these figures are what we are working to. As with all things, as we work our way through, we will look to see whether we can get the same outcomes for slightly less or get better value for money elsewhere.”175

Conclusion

222. The Committee notes the report of the Finance Committee and the evidence it received on the Financial Memorandum to the Bill. The Committee considers that the costs associated with the Bill are significant, especially so when public finances are under serious pressure. Given the

171 Financial Memorandum, paragraph 128.
172 NHS Lothian. Written submission to the Finance Committee.
174 Financial Memorandum, paragraph 58.
concerns raised by NHS boards, Citizens Advice Scotland and other organisations regarding the financial implications of the Bill, the Committee is uncertain whether the projected costs are accurate and reliable. The Committee therefore invites the Scottish Government to respond to the financial issues raised during Stage 1 scrutiny in order to provide reassurance that the projected costs of the Bill will not escalate following its enactment.
SUBORDINATE LEGISLATION

Background

223. Under Rule 9.6.2 of Standing Orders, where a Bill contains provisions conferring powers to make subordinate legislation, the Subordinate Legislation Committee (“SLC”) must consider and report to the lead committee on those provisions. The SLC may also consider and report to the lead committee on any provision in such a Bill conferring other delegated powers.

224. The SLC’s report is attached at Annexe E. In it, the SLC reported that it considered each of the delegated powers provisions in the Bill and that it determined that it did not need to draw the attention of the Parliament to the delegated powers in the following sections: 1(4), 4(2), 11(4)(a), 14(2), 15(6), 20(1) and 22(3). The SLC considered that it did not need to draw the attention of the Parliament to the powers of direction in sections: 5(3), 9(2), 11(4)(b), 12(5) and 14(2). Its report commented on other delegated powers provisions in the Bill and, where the SLC remained unsatisfied after further explanation from the Scottish Government, its comments are summarised below.

Report of the Subordinate Legislation Committee

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

225. The power under section 7(1) relates to the descriptions of patients which are eligible for the guarantee and to how the waiting time is to be calculated. The exercise of the power will determine which patients will or will not be eligible to benefit from the guarantee. These are not specified on the face of the Bill, nor are criteria specified on the basis of which the descriptions of eligible patients are to be determined.

226. The SLC considered that the description of patients who are eligible (or, by default, not eligible) for the guarantee is fundamental to that guarantee, which is itself a central provision in the Bill. The SLC appreciated that flexibility may be required to allow for amendment of how the guarantee should apply, in response to different circumstances now and in the future. However, the SLC considered that a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible or of criteria on the basis of which such descriptions are to be determined. The SLC acknowledged that this is ultimately a policy issue for consideration by the Committee and is content to refer this matter to it for further consideration.

227. Similarly, the SLC considered that the method of calculation of the waiting time may also be of significance. While at first sight this may appear to be an administrative matter, the exclusion of certain circumstances from the calculation could considerably extend the practical effect of the guarantee.

228. Given the significance of the guarantee, and the significance and effect on the operation of the guarantee of the designation of eligible patients and the
calculation of the waiting time, the SLC considered that affirmative rather than negative procedure would be more appropriate.

229. The SLC drew to the attention of the Committee its view that the power to exclude patients from eligibility for the treatment time guarantee is significant. In its view, a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible which could be amended or of criteria on the basis of which such descriptions are to be determined.

230. The SLC recommended that the power in section 7(1) be subject to affirmative rather than negative procedure because of the significance of the guarantee and the significance and effect on the operation of that guarantee of designation of eligible patients and the method of calculating the waiting time.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

231. Regulations made in exercise of this power may address matters of detail relating to the operation of the guarantee or be of an administrative or technical nature. However, regulations made under this power may also exclude specified treatments and services from the guarantee. The SLC considered that the exclusion of specified treatments and services from the guarantee was an important decision in which the Parliament may wish to play an active role. The SLC therefore asked the Scottish Government to consider whether affirmative procedure would be more appropriate.

232. The SLC acknowledged that treatments and services may be changing all the time and that flexibility will be required to respond to progress on waiting times and on specific treatments and services. However, the SLC did not agree with the statement in the Scottish Government response that this is largely an issue of a medical and technical nature. The SLC was of the view that the exclusion of specified treatments and services from the guarantee is an important issue of significance to patients and to the public generally (as potential patients) and that accordingly affirmative rather than negative procedure is more appropriate.

233. The SLC recommended that this power be subject to affirmative, rather than negative procedure because of the significance, through the exercise of the power, of the exclusion of specified treatments and services from the guarantee.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

234. The practical effect of this power is to enable the Scottish Ministers to change the maximum waiting time of 12 weeks set out in section 10 to a different time period and to allow the maximum waiting time to be different for different categories of treatment or service. The SLC accepted that maximum waiting times may have to be altered from time to time and in respect of particular treatments and services and that flexibility in this respect will be required. However, the SLC was concerned at the width of the power in that it allows the maximum waiting time to be extended (as well as reduced) and no limit is set on how far the maximum waiting time may be extended. The SLC considered that this could have a significant impact on the nature of the guarantee and on the extent of the right
afforded by sections 1(1) and 6(1). The SLC was also concerned at the choice of negative procedure, given that the maximum waiting time is a central policy issue, and sought clarification on the choice of negative rather than affirmative procedure.

235. The SLC did not consider that the first element of the Scottish Government’s response, on its own, adequately addressed the SLC’s concerns with respect to the nature and width of the power. However, the SLC was pleased to note the Scottish Government’s commitment, in the second element of its response, to consider further whether an amendment should be brought forward to apply draft affirmative procedure. An amendment to this effect would address the SLC’s concerns with respect to this power since it would provide an enhanced role for the Parliament in determining any alteration of the maximum waiting time.

236. The SLC recommended that the power should be made subject to affirmative procedure given the significant impact the exercise of the power may have on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The SLC noted the Scottish Government’s commitment to consider further whether an amendment should be brought forward to apply draft affirmative procedure.

Section 9(3) – suspension of the treatment time guarantee

237. Section 9(3) provides that the Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such periods as they consider necessary. The SLC acknowledged that it may be necessary or otherwise appropriate to suspend the guarantee in exceptional circumstances, but it was not clear to the SLC why subordinate legislation could not or should not be used for this purpose given the significance of the matter on the rights conferred by the Bill. It was also not clear to the SLC whether the suspension of the guarantee would be specific (in the sense that it would apply to a specified health board or to a specified hospital) or whether it would be of general application.

238. The SLC accepted that the Scottish Government would intend to suspend the treatment time guarantee only in exceptional circumstances. Section 9(3) makes clear that it is only in exceptional circumstances that the power may be exercised. However, the SLC noted that emergency subordinate legislation is used to address exceptional circumstances in other contexts e.g. the making of prohibition orders with respect to the use of food on public health grounds. The SLC was particularly concerned by the use of directions to suspend the guarantee given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The SLC is accordingly not satisfied from the Scottish Government’s response that directions are appropriate for this purpose.

239. The SLC noted that the suspension of the treatment time guarantee could be specific (in the sense that it would apply to a specified health board or health boards or to a specified hospital or hospitals) or could be of general application, and that the position as to when powers of direction may be used is made clear by section 21(5).
240. The SLC was satisfied that the position as to when powers of direction may be used is made clear in the Bill.

241. However, the SLC was not satisfied that directions are appropriate for the purpose of suspending the treatment time guarantee in exceptional circumstances given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The SLC recommended that the power under section 9(3) should be expressed as a power to make subordinate legislation. If it is necessary for policy reasons to be able to bring that legislation into force immediately subject to subsequent endorsement by Parliament for it to continue in force, then it is possible to provide for such procedure.

Conclusion

242. The Committee endorses the findings and recommendations of the Subordinate Legislation Committee.

EQUALITIES

Equality Impact Assessment

243. The Scottish Government prepared an equality impact assessment for the Bill, which the Committee found clear and helpful. The Committee supports the adoption by the Scottish Government of this approach for assessing the potential equality impact of legislation.

244. The Committee notes from the equality impact assessment that the Bill would have an impact on anyone who accesses NHS services in Scotland. The Bill itself relates to patients, but the equality impact assessment acknowledges that it may have consequences for others such as carers, family and friends of patients.

245. The Committee welcomes the commitment given by the Scottish Government in the equality impact assessment that it will continue to monitor the potential impacts on equality groups as the Bill progresses through the parliamentary stages by considering evidence presented by equality groups, and by continuing to engage with key equality stakeholders, and will consider any changes accordingly.

OVERALL CONCLUSION

246. The Committee is unanimous in its support for the commitment of the Scottish Government to place patients at the centre of the NHS in Scotland. We recognise the commitment of the Cabinet Secretary, NHS staff and patient support groups in seeking to bring about a real shift within the NHS in order to develop a genuine culture of mutuality between patients and health care professionals.

247. Central to achieving this objective is the clear and effective promotion of the rights and responsibilities of patients in Scotland. While the active engagement of NHS staff and patient support groups will be vital for this, the Committee believes that the Scottish Government must assume the lead role in developing a clearly articulated vision for a patient-focused health
service. The question before the Committee is whether the Patient Rights (Scotland) Bill will help to meet this objective?

248. The Committee is divided on the appropriateness of using primary legislation as a vehicle to promote patient rights in Scotland. Some Members feel that the Bill has the potential to offer a renewed focus on patient rights, including a new treatment time guarantee and an enhanced patient advice and support service. These Members consider that the Bill will provide the necessary impetus to help overcome any organisational or cultural obstacles to change which may exist within NHS Scotland.

249. However, a majority of the Committee is not persuaded by the evidence which has been advanced to date, that primary legislation is the most appropriate means of promoting patient rights. As an alternative, some Members of the Committee recommend that the Scottish Government seeks to publish a revised and comprehensive patient rights charter. Such a charter could be enforced by the Cabinet Secretary using the existing legal powers available to her under the provisions of the National Health Service (Scotland) Act 1978.

250. Some Members consider that the Bill, as introduced, will not contribute significantly to the goal of achieving a patient-focused health service and, contrary to the Government’s policy intentions, may potentially cause confusion regarding the legal rights of patients.

251. Consequently, the Committee is unable to make a recommendation to the Parliament on the general principles of the Patient Rights (Scotland) Bill.
ANNEXE A: EXTRACTS FROM THE MINUTES

23rd Meeting, 2010 (Session 3)

Wednesday 8 September 2010

Patient Rights (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—

Lauren Murdoch, Patient Rights Bill Team Leader, Fiona Montgomery, Head of Patient Support and Participation Division, Alastair Pringle, Head of Patient Focus and Equalities, Margaret Duncan, Waiting Times Policy Lead, and Kathleen Preston, Health and Community Care Solicitor, Legal Directorate, Scottish Government;

Christine Lang, Independent Advice and Support Service (IASS) Development Worker, and Suzanne Dyer, Independent Advice and Support Service (IASS) case worker, Peebles CAB, Citizens Advice Scotland;

Liz Macdonald, Senior Policy Officer, Consumer Focus Scotland;

Jim Martin, Scottish Public Services Ombudsman.

27th Meeting, 2010 (Session 3)

Wednesday 29 September 2010

Patient Rights (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—

Hilary Patrick, Vice-convener of the Mental Health and Disability sub-committee, and Katie Hay, Law Reform Officer, Law Society of Scotland;

Dr Sally Winning, Deputy Chair, British Medical Association Scotland;

Theresa Fyffe, Director, Royal College of Nursing Scotland;

Dr Bill Mathewson, Deputy Chair (Policy), RCGP Scotland;

John Gallacher, Secretary, Health Committee, UNISON;

Shelley Gray, Director of Policy and Campaigns, Long Term Conditions Alliance Scotland;

Carolyn Roberts, Head of Policy and Campaigns, SAMH;

Delia Henry, Director, RNID Scotland;

Mhairi Thurston, Lecturer in Counselling, University of Abertay, and Allen Thurston, Reader in Education, University of York, RNIB Scotland;
Jim Elder-Woodward, Board Member, Inclusion Scotland.

29th Meeting, 2010 (Session 3)

Wednesday 6 October 2010

Patient Rights (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—

Jacqueline Richardson, Patient Focus and Relations Manager, NHS Forth Valley PFPI Steering Group;

Melanie Hornett, Nurse Director, NHS Lothian;

Nicola Sturgeon MSP, Cabinet Secretary for Health and Wellbeing, Lauren Murdoch, Patient Rights Bill Team Leader, and Kathleen Preston, Health and Community Care Solicitor, Legal Directorate, Scottish Government.

Patient Rights (Scotland) Bill (in private): The Committee considered issues to be covered in its forthcoming Stage 1 report.

30th Meeting, 2010 (Session 3)

Wednesday 27 October 2010

Patient Rights (Scotland) Bill (in private): The Committee considered a draft Stage 1 report and agreed to consider a revised draft, in private, at its next meeting.

31st Meeting, 2010 (Session 3)

Tuesday 2 November 2010

Patient Rights (Scotland) Bill (in private): The Committee considered a revised draft Stage 1 report. Various changes were agreed and the Committee agreed to consider a further revised draft at its next meeting.

32nd Meeting, 2010 (Session 3)

Wednesday 3 November 2010

Patient Rights (Scotland) Bill (in private): The Committee considered a revised draft Stage 1 report. Subject to a number of changes, the report was agreed to.
ANNEXE B: ORAL EVIDENCE AND ASSOCIATED WRITTEN EVIDENCE

23rd Meeting 2010 (Session 3), 8 September 2010

Written Evidence
- Scottish Government
- Citizens Advice Scotland
- Consumer Focus Scotland
- Scottish Public Services Ombudsman
- Regulatory Impact Assessment
- Equality Impact Assessment

Oral Evidence
- Scottish Government
- Citizens Advice Scotland
- Consumer Focus Scotland
- Scottish Public Services Ombudsman

Supplementary Written Evidence
- Scottish Government
- Citizens Advice Scotland

27th Meeting 2010 (Session 3), 29 September 2010

Written Evidence
- Law Society of Scotland
- British Medical Association Scotland
- Royal College of Nursing Scotland
- Royal College of General Practitioners Scotland
- Inclusion Scotland
- Long Term Conditions Alliance Scotland
- SAMH
- Joint submission from the RNID, RNIB and NDCS
- Age Scotland
- General Medical Council
- UNISON Scotland

Oral Evidence
- Law Society of Scotland
- British Medical Association Scotland
- Royal College of Nursing Scotland
- Royal College of General Practitioners Scotland
- Inclusion Scotland
- Long Term Conditions Alliance Scotland
- SAMH
- RNID
- RNIB
- UNISON Scotland
Supplementary Written Evidence
Law Society of Scotland

29th Meeting 2010 (Session 3), 6 October 2010

Written Evidence
  NHS Forth Valley
  NHS Lothian

Oral Evidence
  NHS Forth Valley
  NHS Lothian
  Cabinet Secretary for Health and Wellbeing

Supplementary Written Evidence
  NHS Lothian
  Cabinet Secretary for Health and Wellbeing
Patient Rights (Scotland) Bill

Cover Note from the Scottish Government

The Patient Rights Bill is a key opportunity to place patients at the heart of the NHS in Scotland. The Bill does this by legislating for: rights for patients about the way in which healthcare is received, support through a Patient Advice and Support Service with its Patient Rights Officers, for a right for patients to raise concerns and complaints, and for a treatment time guarantee to give eligible patients surety about length of wait for agreed treatment. The Bill is about the way in which healthcare is received rather than rights to specific treatments or services.

We know that the vast majority of patient encounters are good – the Government wants this to be the case for every patient, every time and considers that the Bill contributes to this, whilst respecting the duties of Health Boards to all patients. There are also provisions to ensure that clinical judgement remains key and, because this Bill is about delivery, the Government has included provisions against the Bill being used to sue the NHS – we know from debate that Members were concerned about the potential for the Bill to create ‘a lawyer by every bedside’.

The Bill contributes to the patient focused aspect of the Quality Strategy’s person-centred work. In tune with the Strategy, the Bill is about ensuring that every individual contact between a patient and a member of NHS staff is the best that it can be.

The Bill contains provisions for healthcare principles, to which providers of health care should have regard. These mean that when a patient receives healthcare, it should be patient focused, it should have regard to the importance of providing the optimum benefit, it should allow for the patient’s participation in decisions, and it should provide appropriate information and support to allow them to do so. We believe that codes of conduct, governance standards and professional regulations offer avenues to deal with potential breaches of the rights and principles. The implementation planning for the Bill, including staff training, will include embedding a patient focused approach at all levels.

The technical and administrative detail of the Bill will be in secondary legislation and directions, supported with guidance and public information. Scottish Government officials are continuing to work with relevant stakeholders to consider how the Bill will be implemented in practical terms, to aid the drafting of regulations, directions and information. The Government aims to share early drafts of secondary legislation with the committee at stage 2, which would then be more fully consulted on at a later stage, but in attached information sheets we have outlined the general areas that we anticipate these will cover. These are for information only and may be subject to change.

In summary, the aim is to reinforce a mutual NHS which respects the rights of both patients and staff. This Bill gives an opportunity to give prominence, through primary legislation, to the quality of care and to patients as the centre of the NHS.
Annexe A

Patient Rights (Scotland) Bill – Directions - Health Care Principles

The Scottish Government may issue Directions on the practical application of the Health Care Principles of the Patient Rights (Scotland) Bill, in accordance with Section 5 (3) of the Patient Rights (Scotland) Bill.

It is anticipated that the Directions will cover these broad aims:
- Awareness raising
- Patient focus
- Quality care and treatment
- Patient participation

Awareness raising – publicising of the Principles to patients and staff.

Patient Focus – to arrange appropriate support in advance where possible, and to communicate this to relevant staff. The support that is available for patients and how to request it should be publicised; types of support might include advocacy or communication support.

Quality Care and Treatment – that current clinical guidelines and standards are followed when delivering medical care; that care governance standards are implemented at all levels; to take action to ensure the delivery of patient focused, safe and effective care.

Patient Participation – measures to take in order that patients understand the information that is given to them; that all staff receive training in communication skills and that staff are aware of how to access support services for patients to enable participation and to promote these options to patients.
Patient Rights (Scotland) Bill – Regulations and directions – Treatment Time Guarantee

The Scottish Government will issue regulations and direct Health Boards on the Treatment Time Guarantee, in accordance with Section 7(1) to (3) and Section 9(2) and (3) of the Patient Rights (Scotland) Bill.

As outlined in the Policy Memorandum to the Bill, it is intended that the treatment time guarantee will apply to patients receiving planned, elective treatment on an inpatient or day case basis. This will be much simpler than giving very long lists of included treatments. The Policy Memorandum also outlined proposed exclusions, and why, and the Government is continuing to consider these. A limited number of excluded treatments to the treatment time guarantee will be set out in the Regulations.

It’s likely that methods for calculation of the waiting time will be modelled on the calculations and circumstances currently used in waiting times’ targets (New Ways of Defining Waiting Times) to ensure that there is consistency of use and understanding across health boards. The method of calculation will be set out in the Regulations. These regulations will be technical and administrative in nature. The Government also proposes that Boards should make it clear to patients how their waiting time is calculated.

The Government proposes that regulations on what Boards should do to comply with the Guarantee and which Board has responsibility for individual patients should cover such issues as monitoring the treatment time guarantee, arranging for provision of treatment with appropriate alternative providers (such as the National Waiting Times Centre) and in what circumstances responsibility for the patient should transfer to another provider.

The Government may issue guidance to assist boards in the administration of the treatment time guarantee. This could include giving worked examples of situations.

The Bill also allows for Ministers to direct a Board to take specific action. These may be actions that all Boards should do or there may be circumstances where Ministers direct specific Boards to take specific actions. This would be dependent on the issues. Ministers may also direct that the treatment time guarantee should be suspended in exceptional circumstances. Currently, the Government doesn’t propose to specify what those circumstances will be since their exceptional nature means that they are difficult to predict: that includes how the NHS may be affected by them and whether it would be necessary to suspend the treatment time guarantee.
The Patient Rights (Scotland) Bill - The Patient Advice and Support Service (PASS)

The Scottish Government may issue Regulations about the Patient Advice and Support Service, in particular about the service it is to provide, in accordance with Section 15(6) of the Patient Rights (Scotland) Bill. The Government is considering what should be set out in Regulations and what will be set out in the contract specification between the NHS’s Common Services Agency and PASS. The information below therefore sets out how it is anticipated the PASS will operate.

Who can use Patient Advice and Support Service (PASS) – that the service is available to patients, carers, users of NHS services and members of the public (including children).

Geographic coverage – that the service is to be accessible across Scotland including to those living in remote and rural areas.

Cost – that the PASS will be provided free at the point of delivery.

Function of PASS – the Patient Rights (Scotland) Bill states that PASS will help patients and members of the public raise concerns, make a complaint or raise feedback about their healthcare. PASS will also make patients and members of the public aware of their rights and responsibilities when using the NHS. The PASS will not give legal or clinical advice on healthcare issues, investigate complaints, assist with complaints about private healthcare services (except where these have been purchased by the NHS but are provided by an independent sector organisation) or support a patient/ carer/ relative to attend a Fatal Accident Inquiry.

Patient Rights Officers (PRO) – there must be at least one PRO per health Board and they will provide support and advice to any member of the public (see ‘Who can use PASS’) regardless of which Health Board they reside in or are receiving care in.

Staff Training – that PROs should be suitably trained in order to carry out their functions effectively, that training should take account of the needs of the service users and the support and advice they might require e.g. mental health, gender, sexual orientation, and long-term care.

Monitoring and Evaluation – that there will be monitoring and evaluation of the PASS.

Reporting to Health Boards – that the PASS will report on its activities.

Role of responsible bodies – that Health Boards and service providers will make service users aware of the PASS.
Annexe D

Patient Rights (Scotland) Bill - Complaints and Feedback

The Scottish Government may issue Regulations and Directions relating to the arrangements for dealing with complaints and feedback, in accordance with Sections 11(4) and 12(5) of the Patient Rights (Scotland) Bill. The Directions on Complaints and Patient Feedback may be combined into one document as this will avoid duplication given they are closely related.

The Government anticipates that the following issues will be covered:

- who can make a complaint and how a complaint should be acknowledged and investigated
- what’s excluded from the NHS complaints process
- the method of communication between the Health Board and the complainant
- the information which must be given to a complainant such as details of the Patient Advice and Support Service
- the time period for making a complaint and timescales for responding to complainants
- monitoring and reporting of complaints and feedback and reviewing these
- publicising the NHS Complaints Procedure
- encouraging patients to raise concerns or give feedback on healthcare they have received.
- staff training
- how Health Boards should publicise the various advice and support available to service users
- learning from complaints

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010
Patient Rights (Scotland) Bill

Citizens Advice Scotland

1. Summary of key points

2. Introduction

3. Concerns and recommendations:
   - Complaints (section 11)
   - Patient Feedback (section 12)
   - Patient Advice and Support Service:
     Establishment and Funding (section 14)
   - Patient Advice and Support Service (section 15)
   - Patient Rights Officers (section 16)
   - Duties to Share Information (section 17)
   - Conclusion Explanatory Notes

Summary

4. Citizen Advice Scotland (CAS) welcomes the ethos and health care principles that underpin the Patient Rights (Scotland) Bill. However, we have specific concerns with some of the main provisions of the Bill.

5. CAS supports the following features of the Bill:
   - The introduction of the Patient Advice and Support Service (PASS);
   - The creation of the post of Patient Rights Officer;
   - The introduction of the right to make complaints and provide feedback;
   - The commitment to providing patients with details on the support and advice available to them and information on how they can make complaints (section 1, clause 8, part 2c);
   - The commitment to ensuring that those making a complaint are given details of the advice and support available to them, that the details of this advice and support is publicised, and that complaints should be monitored (section 1, clause 11, part 3).

6. CAS has concerns regarding:
   - The lack of obligation on the NHS to provide feedback on submitted complaints;
   - The lack of detail provided on the role and structure of the Patient Advice and Support Service and the Patient Rights Officers;
• The lack of clarity on whether and how the service standards set by the Independent Advice and Support Service (IASS) will be undertaken and maintained by PASS;

• Patient Rights Officers covering level one and two complaints about the NHS (see appendix).*

7. Although the Bill will improve patient rights in Scotland, we are concerned that the NHS is not under any obligation to proactively provide information to patients on the progress of complaints and concerns raised. In addition, there is no obligation on the NHS to provide this information to the Patient Advice and Support Service either when the service has assisted the patient in filing complaints, concerns or comments.

8. There is also a lack of clarity on how the new advice and complaints service will affect the holistic support and advice work currently being carried out by the Independent Advice and Support Service.

Introduction

9. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland’s network of 83 Citizens Advice Bureau (CAB) offices. These bureaux deliver free, impartial and confidential frontline advice services through more than 200 service points across the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.

10. In 2008/09, the Scottish CAB service dealt with just under one million client issues resulting in 2,677 enquiries handled by bureaux across Scotland each day of the year. The sorts of issues dealt with by bureaux include welfare benefits, housing, debt, consumer and employment. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities.

11. Last year the CAB service in Scotland dealt with over 29,000 sickness benefit issues and 59,260 disability benefit issues. In this period the service also dealt with a total of 324,800 debt issues, 257,444 benefit issues, 86,897 housing issues and 74,017 employment related issues accounting for 76% of all client issues.

12. The Independent Advice and Support Service (IASS) is a part of the CAB service in Scotland. Funded by local NHS boards, IASS offers advice and support to all NHS users and their families in relation to any concerns and complaints they may have regarding care received from the NHS. The service also provides general advice and has a holistic outlook to supporting its clients, as patients’ health concerns are frequently interlinked with other issues they are experiencing such as debt or employment issues which can have a significant impact on people’s health and well being.¹

¹ Greater Glasgow and Clyde Citizens Advice bureaux report assisting with 1154 issues through the IASS service in 2008/09.
13. CAS welcomes the Patient Rights (Scotland) Bill, although we have serious concerns about the following:

- NHS feedback following submission of a complaint;
- The role and structure of the Patient Advice and Support Service (PASS);
- The role of Patient Rights Officers;
- The lack of provision for independent evaluation of PASS and the outcomes that it produces.

Concerns and Recommendations

Section 11: Complaints

14. CAS is concerned that the Bill does not explicitly include a requirement for the NHS to provide feedback to patients who have submitted a complaint, commented on their experiences of the NHS, or raised concerns about its services.

15. We recommend the inclusion of a requirement for the NHS to provide feedback both directly to patients and to the Patient Advice and Support Service (PASS) when it has been involved in supporting a patient. This would allow PASS to monitor the NHS’s response to the complaints and comments it receives, and measure the impact that PASS has had on any improvements made to the services provided by the NHS.

Section 12: Patient Feedback

Please note that the concerns and recommendations we outlined above in relation to section 11 of the Bill also apply to this section.

16. While CAS welcomes the establishment of PASS, which builds effectively on the work already being carried out by IASS, we have some concerns about how this service may operate.

17. The precise role and possible structure of PASS is unclear, as provision on both a local health board basis and national basis are mentioned in the Bill, associated explanatory notes and memoranda.

More clarity is also required on how Patient Rights Officers would be managed by PASS, both in health board areas and across Scotland.

18. It is essential that the service is impartial, independent and confidential. Based on our experiences with IASS, we therefore consider that the service will need to have in place the following elements:
• Reliable, quality assured, current and comprehensive information sources;

• Effective training and support for staff;

• Independent quality control systems and clear criteria against which its management, administration, service provision, advice and information provision can be measured and reported on;

• Clear systems for collecting performance information and statistics for reporting to the NHS, the Scottish Government, the Scottish Health Council, with this information made available in the public domain;

• Delivery structures that ensure consistent service provision across the whole of Scotland (avoiding any postcode lottery or variation in standards) and that ensure local access to support wherever possible;

• Systems to ensure that the service is well publicised.

19. The establishment and maintenance of a central support service to cover the whole of Scotland will be crucial to the effective delivery of PASS. IASS’s experience to date indicates that central provision is required to:

• Gather, collate and report on statistics and other data in relation to the performance of the service on both a health board and Scotland-wide basis. Without a central resource, consistency of reporting will be lost and it will not be possible to gather data for national stakeholders with which to measure, benchmark and compare performance;

• Provide standardised training programmes to ensure that all Patient Rights Officers have the appropriate knowledge, skills and competencies;

• Provide social policy information in terms of trends, patterns, and issues raised by users of the service for use by the NHS and others in policy development;

• Market the service consistently across the whole of Scotland to potential users, NHS staff, agencies who are likely to refer patients, and to the general public.

Section 14: Patient Advice and Support Service: Establishment and Funding

Please note that the concerns and recommendations we outlined above in relation to section 12 of the Bill also apply to this section.
20. CAS strongly recommends that PASS continues with the provision and delivery of general information, advice and support service to patients, their families and carers as currently provided by IASS. Feedback from a sample of IASS users suggests that the holistic advice and information provided by this service is highly valued. Furthermore, Aberdeen University published a report a few years ago outlining the positive impact bureaux outreach services had on patients and their families in Aberdeen.²

21. Independent research evidence³ clearly demonstrates that the provision of information and advice about, for example, welfare benefits, debt, housing and employment assists people in the following ways:

- It reduces anxiety and stress and helps users to feel more in control of their situation;
- This in turn reduces the need for prescriptions such as antidepressants, required by some patients to help them cope, and reduces the number of visits that they make to GPs and other health professionals;
- It can help people to move out of health care accommodation and back to their homes by assisting them to access both the support services and adaptations to their homes that they need in order to do so.

22. It will be important that the budget for PASS includes costs relating to marketing, training, performance reporting and provision of information.

Section 15: Patient Advice and Support Service (PASS)

Please see our comments on section 14 (above).

23. IASS is currently delivered by bureaux across Scotland. General advice and information on welfare benefits, debt, employment, housing, relationships and access to health services is delivered alongside information and advice on level one and level two complaints about the NHS. The Bill suggests that all such work would be carried out by paid Patient Rights Officers. We are concerned that this will result in:

- Loss of integration of complaints and patient rights associated work with a broader, more holistic service which caters to users’ social and economic needs as well as their NHS-related ones;

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² Farmer, Jane and Lucy Kennedy, ‘CAB outreach services evaluation: A report on the impact of Citizens Advice Bureau outreach services at Aberdeen Royal Infirmary and Banff and Buchan on client health and professional workload’ by Jane Farmer and Lucy Kennedy, University of Aberdeen, Department of Management Studies, May 2001.

• Reduced access to the service, particularly in remote and rural areas. At present, NHS users can access IASS through over 200 outlets across Scotland and they can be referred for specialist help by an IASS caseworker from any one of these locations. Any immediate or urgent concerns can be dealt with on the spot, prior to a referral being made;

• Higher service costs. A considerable amount of the work assigned by the Bill to Patient Rights Officers could actually be very effectively dealt with by local CAB advisers. This would create economies of scale and cost savings that would not be present if the service were to be delivered solely by Patient Rights Officers, as outlined in the Bill;

• Patient Rights Officers are unlikely to be able to assist users with all of their information and advice needs. Users may, for example, require assistance with claiming welfare benefits or managing complex debt. IASS is built onto the existing information, advice and support structure available through the CAB service and at the moment, users can be referred to in-house specialists where relevant. It is important that PASS continues to make similar provisions available to users.

24. CAS agrees that it is important for patients to take responsibility for their own health and well-being. We recommend that PASS plays a role in assisting and educating patients through the provision of health information; assistance to access, interpret and effectively use health information; and referrals to appropriate support services.

25. We also recommend that an independent evaluation of PASS be carried out annually.

Section 16: Patient Rights Officers

Please see our comments on section 15 (above).

Section 17: Duties to share information

26. While CAS broadly welcomes these provisions, we feel that this section of the Bill could be strengthened through the following:

• Placing an obligation on the NHS to market PASS effectively;

• Placing an obligation on the NHS to provide feedback to patients and, where relevant, to PASS about changes or improvements made as a result of the feedback, comments or complaints made by NHS users.
Conclusion:

27. CAS supports the principles of the Patient Rights (Scotland) Bill, ensuring that patients are able to exercise their rights and are aware of their responsibilities. We also welcome the creation of PASS and the new role of Patient Rights Officers.

28. We are, however, concerned that PASS may fail to provide the holistic service that is available to patients currently through IASS. If this element of service provision is omitted from the new structure, the efficiency and cost effectiveness that would have resulted from its use for level one and two complaints will be lost.

29. Consequently, we recommend that the structure and role played by PASS and Patient Rights Officers be clarified and that adequate provisions be made to ensure patient well being and the success of the service.

EXPLANATORY NOTES:

30. We strongly support the provision of education, training and awareness-raising about PASS and the role of Patient Rights Officers through NHS Education for Scotland (NES). Experience of delivering IASS has demonstrated the importance of this in ensuring take up of the support service.

Alizeh Hussain
Social Policy Officer (Parliamentary)
Citizens Advice Scotland
10 May 2010
Patient Rights (Scotland) Bill

Consumer Focus Scotland

Introduction

Consumer Focus Scotland started work on 1 October 2008. Consumer Focus Scotland was formed through the merger of three organisations – the Scottish Consumer Council, energywatch Scotland, and Postwatch Scotland.

Consumer Focus Scotland works to secure a fair deal for consumers in both private markets and public services, by promoting fairer markets, greater value for money, and improved customer service. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors’ clients, public transport users, or shoppers in a supermarket.

We have a commitment to work on behalf of vulnerable consumers, particularly in the energy and post sectors, and a duty to work on issues of sustainable development.

General comments

Consumer Focus Scotland welcomes the opportunity to provide written evidence on the Patient Rights (Scotland) Bill to the Health and Sport Committee of the Scottish Parliament. We have a keen interest in this area because Health Rights Information Scotland, a joint initiative between the Scottish Government and Consumer Focus Scotland, is based in our offices.

The project already aims to raise people’s awareness of their existing rights as patients, and works closely with NHS boards to make sure good quality, accessible and consistent information is available in healthcare settings throughout Scotland. Consumer Focus Scotland responded to the consultation on the proposal for a Bill1 and we reiterate some of our comments in this evidence.

The Committee is seeking evidence in four areas:

- The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

- The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

- The complaints and patient feedback system set out in the Bill1 (Section 11)

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1 Consumer Focus Scotland, Consultation on a patients’ rights bill for users of the NHS in Scotland, January 2009.
The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

1 Patient rights and health care principles

Patient rights
Consumer Focus Scotland starts from the position that patients in Scotland already have rights in relation to the healthcare they receive. These rights go well beyond those mentioned in or created by the Bill. For example, patients have rights:

- created by other pieces of legislation, like the right to see their health records, to be registered with a GP, or not to be discriminated against
- created by the common law, for example the right to refuse medical treatment
- based on government policy or on service standards, for example the right to expect to receive treatment within current waiting times targets.

We believe that the Patient Rights (Scotland) Bill can strengthen and support the idea that patients have rights, by giving patients “rights recognition in the eyes of the law. However, we would express caution in relation to four main points:

- it is not made entirely clear in the Bill that patients have other rights in relation to their healthcare;
- the rights of patients should not therefore be defined solely in terms of the rights of patients under the Bill, as is done in section 15(4);
- the important thing about rights is not that people have them, but that they are able to make them a reality. The way patient rights are made a reality is at least as important as the fact that some of the rights are set out in a Bill;
- the provisos contained in section 2(2) reflect the reality that in health care settings rights are not absolute, but depend on the resources available, and the needs of other patients.

Making rights a reality requires various actions:

- clear communication of the key message that people have rights in relation to their healthcare;
- easy access to information about what their rights are and what this means in practice;

• easy access to sources of support and advice.

While Health Rights Information Scotland (HRIS) already provides a variety of information about people’s rights\(^2\), the Bill provides an opportunity to restate patients’ rights in a way which reflects the broad range of legal rights and legitimate expectations which they have, and which includes the specific commitments made in the Bill. Information needs to be provided at different levels of detail for different circumstances, and to support the key message of the Bill there will be a need for communication, focusing on a simple statement that people do have rights in relation to their healthcare. Consideration will need to be given as to whom the communication is intended to reach, and the most effective and relevant way to do this.

Our experience, through HRIS, of the way information is made available to patients suggests that even when good quality information exists, it is not always easy for patients to get that information. We consider that the Bill would be strengthened by placing a duty on NHS boards to ensure that information about patients’ rights is made available to patients when they need it.

In the Bill, it is only the patient advice and support service which is given the responsibility for providing information and advice to patients. But this service will be independent of the NHS, and most likely not located on NHS premises, so there is a danger that there will still be a gap in the provision of information to patients in the settings where they are most likely to look for it, i.e. places like their GP surgery, hospital waiting rooms etc. Placing a duty on NHS boards to provide information and advice would be a useful addition to the Bill.

**Healthcare principles**

These principles are set out in a schedule to the Bill. They deal with the way a person should be treated by the NHS rather than what they are entitled to from it. While they do, in general, reflect the things which matter to patients about how they are treated, we have some specific comments.

1 *Anything done in relation to the patient takes into account the patient’s needs.* We would prefer it if this included the words “and preferences”, to show that decisions include patients wherever possible.

6. *The patient’s abilities, characteristics and circumstances are considered.* This could be read as suggesting that it is acceptable to discriminate between people on the grounds of, for example, their characteristics. While it is correct that services should consider and take account of these things, they should not then use these as a basis for refusing or changing a service. This needs to be made clear.

\(^2\) see [www.hris.org.uk](http://www.hris.org.uk)
7. *Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.*

“Regard is had” sounds rather weak. This should be strengthened, for example by saying “consideration must always be given to ...”

8. *The range of options available in the patient’s case is considered.*

This is quite vague, and does not state who will consider them, or whether they will be discussed with the patient. We would suggest this should be strengthened to say “Where there are different options for the care or treatment of a patient, these should all be considered and discussed with the patient, family or carers.”

10. *Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing.*

We consider that patients should not be forced to participate in decisions if they do not want to, and would prefer if this was worded to say “Patients participate as fully as they want to in decisions ...etc”.

16. *Waste of resources in the provision of health care is avoided.*

This does not sit well in a list of principles about the way patient care should be provided. We would suggest that this is removed.

2 **Treatment time guarantee**

The treatment time guarantee which is included in the Bill relates only to treatment in a hospital as an in-patient or day case (where an overnight stay is not required). There are many other target times for particular kinds of treatment in different settings which are unaffected by the Bill. It seems curious that this one kind of treatment is singled out in this way, by making the treatment time guarantee statutory.

But what is given on the one hand, an apparent “right” to treatment within 12 weeks, is taken away with the other, when section 18 makes it clear that this right is not enforceable. Where a health board has not complied with the guarantee, it is required by section 8 to make arrangements to ensure the treatment starts as soon as possible, to explain to the patient why treatment has not started, and to provide information about advice and support and how to make a complaint. Section 18 explicitly states that nothing in the Act gives rise to any liability to pay damages, or to any right to take action to enforce the “right” to treatment.

We do not believe that including this treatment time guarantee in the Bill gives patients any more protection than is currently offered by the national waiting times targets, and is potentially confusing to patients who may think they have rights, but which they are unable to enforce in any way.

3 **Complaints and patient feedback**

The Bill claims to introduce a new right to complain. But in practice people already have a right to complain, even if the right is not an enforceable legal
right. NHS healthcare providers are already required by policy and guidance to implement the NHS complaints procedure, to publicise this and even encourage patients, their families and carers to use it, as one of the ways in which useful feedback can be obtained on the basis of which services can be improved. Health Rights Information Scotland already refers to people having a right to complain in the information it provides.

Putting this right into legislation does not really add anything to the rights which patients already have, and we question what is achieved by doing this. As with other aspects of the Bill, the important thing is what helps to make rights real for people. What helps or supports people to make a complaint? What would encourage people to give feedback, good or bad, on the service they have received?

The things which can help are good information about how to do these things, and easy access to people who can advise or help them. As with other aspects of the Bill, these things cannot be created by legislation, although they can be supported by legislation, for example section 11(3)(b) and (c) which require NHS bodies to publicise how complaints can be made and how they will be handled, and give patients advice and support about how to make a complaint.

We would like to see provision in the Bill for complaints to be handled through mediation where possible. It is in the interests of both patients and NHS bodies that disputes are resolved as early as possible, and the Bill provides an opportunity to encourage the use of mediation in relation to NHS complaints where appropriate. While provision for the use of mediation might be made through regulations under section 11(4), putting this on the face of the Bill would help to raise awareness and use of mediation.

This would fit with the approach taken in other recent legislation, such as the Education (Additional Support for Learning) (Scotland) Act 2004, which places a duty on education authorities to make arrangements to provide independent mediation services to resolve disputes between parents or young people and the authority, and the Legal Profession and Legal Aid (Scotland) Act 2007, which gives power to the Scottish Legal Complaints Commission to mediate in complaints about legal practitioners. The Fit-for-Purpose Complaints System Action Group also recommended in its final report that mediation should be used where appropriate in complaints handling in public services in Scotland. ³

While we support the imposition of a duty on NHS bodies to publicise how complaints are made and handled, there is a danger that they may interpret this as a requirement to produce more information themselves about complaints. With HRIS already producing quality approved information for all boards, and with NHS inform providing easy access to information for members of the public, it is important that this supportive infrastructure is

³ Fit-for-Purpose Complaints System Action Group: Report to Ministers, July 2008
supported and built on by NHS bodies, and that the legislation does not provoke a new cottage industry of information production.

4 Patient advice and support service and the role of Patient Rights Officers

The Bill proposes the establishment of a new patient advice and support service (PASS). Unlike the current service, known as the Independent Advice and Support Service (IASS), the new service will be established on a national basis, rather than each NHS board contracting with a local provider. As with IASS, the service cannot be provided by a health service body, and must be independent. The service will be staffed by Patient Rights Officers.

While Consumer Focus Scotland welcomes the proposed introduction of Patient Rights Officers, we believe that they would be more effective at intervening in situations before they escalate into becoming complaints if they were located in healthcare settings. We have previously argued that every hospital and every Community Health Partnership should be required to have a Patient Rights Officer. While we understand the desirability of patients having access to sources of independent advice and support, we consider that there are also reasons for having patient rights officers employed by the NHS working as key members of NHS teams. They would:

- provide a highly visible, responsive service for all patients, carers and members of the public
- provide information and advice about health and health services
- handle patients’ concerns early, and resolve issues and concerns informally and quickly, before they become complaints
- provide information on the NHS complaints procedure and how to give feedback
- refer patients to sources of independent advice and support, for example CAB services, advocacy services, or other patient support groups
- provide feedback to hospitals, CHPs and NHS boards about aspects of patient experience, complaints and information provision
- act as a gateway for patient focus and public involvement activity.

An evaluation of the Patient Advice and Liaison Service (PALS) in England⁴, which is an in-house service, showed that the service had:

- improved the patient experience
- led to improvements in services
- filtered and/or enabled complaints.

⁴ University of the West of England, Developing the patient advice and liaison service2006
Functions of the PASS

Section 15 sets out the role and functions of the Patient Advice and Support Service. In section 15(4) it is stated for the purposes of the functions set out in subsection (2),

\[
a \text{reference to the rights of patients is a reference to the rights of patients under this Act.}
\]

This would mean that the PASS service would not be able to promote an awareness and understanding of other rights which people have as patients in the NHS. We believe that this subsection is an error which needs to be corrected.

Patient Rights Officers are described as “providing information and advice” about various things. We think it is essential to emphasise that it is not the role of PASS or the PROs to produce information, but to make available information produced primarily by other people, and in particular the quality assured information which will be available through NHS inform.

Equally, we think it is important that there is a duty on NHS bodies themselves to provide the kind of information described in section 16 (a), and that NHS bodies should not be able to claim that this is the job of an external independent body.

5 Explanatory notes

We welcome the recognition in the explanatory notes to the Bill that HRIS will be supporting the Bill by producing new information about health rights for members of the public. This will be one of the most important ways in which people’s rights can be made a reality.

However, we are dismayed by the suggestion that the role of HRIS in the production of core national information about rights and responsibilities, NHS services, and how to use those services may not be a continuing one. We believe that the model established by HRIS for central production of information for use throughout the NHS is one which should be built on and continued. It provides a source of key information for the new NHS inform service, and we would urge the Scottish Government to ensure that the role and functions of HRIS will be preserved in the future.

Sarah O’Neill
Head of Policy Solicitor
Consumer Focus Scotland
6 May 2010

Patient Rights (Scotland) Bill
Scottish Public Services Ombudsman

Introduction
Thank you for requesting written evidence to inform the Health and Sport Committee’s consideration of the Patient Rights (Scotland) Bill (the Bill) at Stage 1.

The Scottish Public Services Ombudsman (SPSO) provides a ‘one-stop-shop’ for members of the public making complaints about organisations providing public services in Scotland. This includes complaints about the National Health Service (NHS).

The SPSO's experience of dealing with complaints from members of the public about the NHS provides us with a unique perspective on the delivery of health services in Scotland and the concerns of service users.

The notion that patients have rights in relation to their health care is at the heart of the work we do in securing justice for individuals who experience a problem with the NHS. This submission draws on this experience to comment on the proposals in the Bill.

The patient rights and health care principles
We consider that the rights and healthcare principles included in the Bill reflect current good practice in healthcare delivery. With the exception of the treatment time guarantee, the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist.

The notion of enshrining these rights and principles within primary legislation carries the risk of an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS. The use of formal, adversarial and potentially expensive procedures in this context would be unhelpful. In this respect, we note that the important protections and limitations set out in Section 18 should ensure that this does not occur in practice.

Although the SPSO's investigation reports into health complaints usually do not refer to rights as such, it is implicit that – where maladministration or service failure have been identified – a patient’s right to a high standard of service will not have been met. Recurrent themes that have emerged in our work include: the lack of dignity with which patients are sometimes treated; failures in communication with patients; and poor care for elderly patients.

The Annex to this submission contains case summaries taken from the SPSO’s Commentaries, which may provide some useful illustrative examples of our work on NHS complaints and a helpful context for the Committee’s consideration of the rights and principles outlined in the Bill.
While we recognise that the vast majority of interactions between members of the public and the NHS in Scotland are successful, we welcome any measures which will help to ensure that patients are treated fairly and that issues such as those noted above and in the Annex are avoided. While the provision of statutory rights is unlikely to achieve this in itself, it may provide a useful addition to current initiatives to assure and enhance the quality of health services provided to members of the public.

It should be noted that, although the patient rights being proposed in the Bill do not give rise to any additional legal remedies (as noted in Section 18, Sub-Section 2), members of the public will be able to bring complaints to the SPSO alleging a breach of those rights. While the SPSO is not empowered to determine legal rights and obligations, we are able to investigate whether due regard has been given to any legislative provisions (as failure to do so may constitute maladministration). Consequently, we will be able to uphold complaints where due regard has not been given to the provisions in the Bill.

In publicising the patient rights contained in the Bill, care should be taken to make clear that such rights are generally not absolute but must be balanced with the rights of others and considered in the particular circumstances of the individual concerned. This is recognised in Section 2, Sub-Section 2 of the Bill and it would be helpful if these provisions were clearly highlighted to patients to avoid the provision of statutory rights leading to unrealistic expectations regarding rights and entitlements.

The 12 week treatment time guarantee
The SPSO frequently considers complaints about delay in the provision of health services and we are aware that this can be a particular source of frustration and dissatisfaction for members of the public. Providing clarity around the timescale between a treatment being agreed by a member of the public and the treatment commencing is likely to be helpful. Members of the public with health problems, who will naturally be anxious about their conditions, are likely to benefit from the increased certainty afforded by the proposed guarantee.

The complaint and feedback system
The landscape of public sector complaints handling has recently been reviewed and proposals are currently being considered by the Scottish Parliament for the SPSO to take on the role of supporting the design and development of good practice in public sector complaints handling. A key aspect of this role will be the standardisation of practice across the public sector and ensuring that complaints systems are designed to ensure and support learning from complaints.

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The Bill’s provisions with regard to complaints and, in particular, the emphasis on monitoring complaints and informal feedback to secure service improvements, aligns with the proposed extension to the SPSO’s remit. In light of this, in preparing and issuing the regulations and directions referred to Section 11, Sub-Section 4, it is hoped Scottish Ministers will work closely with the SPSO to ensure that the NHS complaints system reflects best practice and achieves coherence within the broader, simplified public sector complaints handling landscape.

Provisions to support more informal feedback are likely to be welcomed by members of the public who may not wish to complain formally, but who may nonetheless have valuable feedback to provide. Indeed, recent research has highlighted that there are many reasons why patients might not wish to complain and noted that the current system of receiving complaints could do more to capture and act on feedback.3

Concerns about complaints handling often form a secondary aspect of the complaints the SPSO receives and it may be helpful for the Committee to have an indication of the sorts of issues we have identified in this area and the recommendations we have made to Health Boards. In the last few years, we have made recommendations that NHS providers should:

- reflect on their complaints policy, review their complaints protocol and discuss how to respond to complaints from non-patients;
- ensure that information is obtained from the staff involved in a case to allow complaints to be investigated appropriately and all issues raised in complaints are addressed;
- remind staff dealing with complaints of the need to have regard to the NHS complaints procedure timescales;
- remind staff of their obligations to manage complaints in line with the NHS complaints procedure and take action to ensure that information about the NHS complaints procedure which is held locally in hospitals and clinics is up to date;
- review their complaints handling procedure to ensure that complainants are given direct answers to reasonable direct questions, that individual circumstances, distress and stated preferences are reasonably taken into account when suggesting meetings with correspondents and complainants, that it is made clear to correspondents how to set in motion the complaints procedure and that avoidable errors are reasonably eliminated, taking into account the individual circumstances of a complaint;

• consider how NHS Scotland’s publication: ‘Can I help you? Learning from comments complaints and suggestions’ should be taken into account when making decisions on complaint time limits;

• ensure that guidance to complaint handling staff emphasises the need for full disclosure of relevant information;

• when responding to complaints, take into account the need to provide as full information as possible, particularly where interviews have been held with staff;

• undertake a full review of the operation of their complaints process and the relationship of this to clinical governance, as a matter of urgency; and

• urgently establish a complaints procedure in line with the standards set out by the NHS complaints procedure.

While it is not possible to conclude that there are systemic problems in NHS complaints handling from the evidence of individual complaints, these do indicate that the standard of complaints handling in the NHS can be variable and occasionally poor. The provisions in the Bill do not address the above issues in detail, but it may be helpful for any guidance that is subsequently issued to pick up on some of the issues identified in the course of the SPSO’s investigations.

**Patient advice and support service**

The introduction of the Independent Advice and Support Service (IASS) in March 2006 was welcomed and supported by SPSO, in recognition of the fact that complaints about healthcare often require a level of independent support and advice additional to that required in other areas of the public sector. Recent research has shown that IASS has helped to support patients’ in complaining about the NHS.  

The Bill’s proposals to increase the level of support currently being provided is likely to help patients feel more able to raise their concerns about the NHS. While the introduction of the new Patient Advice and Support Service (PASS) may lead to a rise in the number of complaints received by Health Boards, the new Patient Rights Officers should also help to ensure that complaints are properly directed and resolved more quickly.

Jim Martin
Scottish Public Services Ombudsman
7 May 2010

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Annex

SPSO Case Summaries

Diagnosis; follow-up care; communication; complaint handling
A Medical Practice, Greater Glasgow and Clyde NHS Board (200801102)
After she was diagnosed with diabetes, Ms C raised a number of concerns about her GP Practice (the Practice)'s handling of the diagnosis and aftercare. I upheld all her complaints as I found that the Practice had not followed recognised procedures in reaching a diagnosis, or in their complaint handling. I also found that they had not arranged appropriate follow-up for Ms C, and that their communication with her about the diagnosis and test results was inadequate. I recommended that the Practice put in place protocols to ensure that diabetes is in future diagnosed in line with recognised practices, and that newly diagnosed diabetics receive appropriate follow-up care. I also recommended that the Practice take steps to ensure that in future they deal with complaints in line with the NHS complaints procedure and asked them to apologise in writing to Ms C for the failings identified in my report.

Clinical treatment; complaint handling; policy/administration
A Dental Surgery (200802819)
Mr C complained that his Dental Practice did not provide him with appropriate treatment, and that when he complained they acted unprofessionally and unhelpfully. I upheld both his complaints as I found that information about Mr C’s treatment was not adequately recorded or protected within the practice; details of his clinical treatment were missing; there was no complaints procedure in place, and the NHS complaints procedure was not followed. I recommended that the Practice urgently establish a complaints procedure and implement policies to record and protect all clinical information in future; that they ensure staff understand these; that they identify and retrieve the missing information about Mr C’s treatment; and that they apologise to Mr C for the failures identified and for their poor handling of his complaint.

Delay in diagnosis; clinical treatment; policy/administration; communication
Greater Glasgow and Clyde NHS Board (200802662)
Mrs C was unhappy with the care and treatment that her daughter (Miss A) received when she attended hospital with back pain. Miss A was treated for a chest infection and referred for physiotherapy, but was later diagnosed with a spinal infection. Mrs C complained that the infection was not diagnosed earlier. Miss A was also provided with which meant she could not be operated on. Mrs C was also concerned that surgical treatment could not be carried out, as Miss A had been provided with an anti-coagulant medicine because of a history of DVT (deep vein thrombosis). I upheld the complaint about delay in diagnosis and recommended that the Board apologise to Miss A for this and review their process for identifying and acting upon warning indicators in patients. I also recommended that they ensure that officers handling complaints accurately reflect in their responses information provided by clinicians. I did not uphold the complaint about medication, as I found that...
treatment was appropriate and surgery would not have been the normal treatment for a spinal infection.

Care of the elderly; clinical treatment; communication; record-keeping
Lothian NHS Board (200901408)
Mr C was unhappy with the care provided to his late wife (Mrs C) by the Board. Mrs C had multiple health problems, including dementia. When her health began to deteriorate after a fall she attended a hospital Accident and Emergency unit. She was admitted to the hospital, but was transferred to a second hospital the following day. She was given a course of antibiotics, some of which she refused. No assessment was made of Mrs C’s ability to make that decision, and the antibiotics were subsequently discontinued. Mrs C's condition continued to deteriorate and she died in the second hospital just over a week later. I upheld all Mr C’s complaints as I found that the Board had not provided appropriate treatment or antibiotics, nor had they communicated effectively with Mr C about his wife’s condition or treatment, especially given that Mrs C herself did not seem to be competent to refuse treatment. I made a number of recommendations, including reviews of policy and procedures, and the provision of guidance and information to staff, all of which can be read in full in my report. I also recommended that the Board apologise to Mr C for the failings identified in my report.

Clinical treatment; communication; policy/administration
Tayside NHS Board (200802400)
Miss C suffered from myotonic dystrophy. She also had learning difficulties. She died in hospital after minor surgery on her parotid gland. Her father (Mr C) complained about the care provided to Miss C before and after surgery. He said that she was not properly assessed by a consultant anaesthetist before her operation and that her post-operative care and treatment was inadequate. He was also unhappy about the way in which staff communicated with the family. I upheld all of Mr C’s complaints as I found that there had been significant failings by staff, especially given Miss C’s learning difficulties. I made a number of detailed recommendations about the Board’s arrangements, policies and procedures, particularly in relation to people with learning difficulties, and these are described in full in my report. I also recommended that the Board provide an explicit, unambiguous and meaningful apology to Miss C's family for all the failings identified in this report, detailing the steps they have put into place to ensure that a similar occurrence is not repeated.
REGULATORY IMPACT ASSESSMENT

1. Title of proposal
   Patient Rights (Scotland) Bill

2. Purpose and intended effect
   Objects
   1. The Bill is intended to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland. It will facilitate a truly mutual NHS which respects the rights of both patients and staff and embeds partnership working to enable the NHS in Scotland to become a world leader in person-centred health care.

   2. The Patient Rights (Scotland) Bill will provide that the health care that patients receive should meet certain criteria, according to a set of health care principles. The Bill will legislate for a patient advice and support service, for a treatment time guarantee, and will establish a right to make complaints and give feedback. The Scottish Government wants to develop a clear, shared understanding between health services and the people they serve of the expectations and entitlements of patients and of responsibilities when using health services. As we take forward implementation of the Bill, we will set out patients’ rights and responsibilities in relation to their own health care.

   3. As a result of the Bill, patients will be more aware of the rights they have and they will be better able to exercise those rights. Implementation will encourage the notion that as owners of the NHS, patients have responsibilities. This will contribute to a mutual ethos for the NHS, where people are partners in their care with staff. Ultimately, this will contribute to the Government’s purpose and its strategic objectives, especially around improving health outcomes and tackling health inequalities.

   4. For the purposes of this assessment the Bill has been divided into four areas:

      - Rights and Principles
      - The treatment time guarantee
      - Support
      - Right to make complaints

   Rights and Principles

   5. The Bill establishes that it is the right of every patient that the health care they receive is patient-focused, has regard to providing the optimum benefit to the patient’s health and wellbeing, allows for patient participation as fully as possible, allows for information and support and allows for concerns or complaints to be raised. This is underpinned by a schedule of health care principles which health care providers will have a duty to have regard to when delivering NHS services.
The Treatment Time Guarantee

6. This will provide eligible patients with a guarantee of treatment within 12 weeks from agreement to treatment to the start of that treatment.

7. Through Regulations and Directions we intend to set out eligibility criteria for the treatment time guarantee and the limited number of services that are excluded; these are explored in the Policy Memorandum.

Support
(Patient Advice and Support Service, Patient Rights Officers)

8. The Bill will legislate for a Patient Advice and Support Service (PASS), with a staff of Patient Rights Officers (PROs). The intention is to place a duty on the Common Services Agency (NHS National Services Scotland) to secure this nationally.

Right to make a complaint

9. The Bill will establish a right to make complaints about health services. It will also revoke and restate existing legislation to strengthen the complaints process. It will also legislate for encouraging feedback.

10. People who wish to complain about a primary care issue have a choice to complain direct to the primary care provider or to the Health Board. In secondary legislation we intend to amend timescales to respond to complainants with the result of an investigation. We intend that Health Boards should ensure that primary care services they contract report in a consistent manner on complaints received.

Background

11. A Patients Rights Bill and a Waiting Time Guarantee were manifesto commitments. In the Better Health, Better Care Action Plan (December 2007) the Scottish Government committed to a public consultation on the possible content of a Patients’ Rights Bill as part of the Scottish Government’s commitment to a mutual NHS.

Rationale for government intervention

12. While there are currently in place existing rights for patients and expectations on them, these are articulated in disparate ways and are not always known nor well understood by patients or by staff. We want to be in a position where: patients recognise their rights and have independent support and advice available to ensure these are met; patients work in partnership with staff to support their own health rather than being passive recipients of care, where this is possible; staff fully recognise that patients have rights and feel comfortable with patients articulating them; and patients recognise and accept that they have responsibilities on them to support their own health and in their use of the health care system.

13. The treatment time guarantee will provide clarity and certainty to eligible patients about what they can expect in terms of waiting time (for planned or elective...
care delivered on an inpatient or day case basis) and will place a duty on Health Boards to ensure that the treatment time guarantee is met.

14. In terms of the wider strategic context, the Bill should contribute to improved health outcomes through:

- Placing patients at the centre of the NHS
- Setting out in a clearer way what patients can expect from the NHS
- Introducing a treatment time guarantee.

15. The Patient Rights Bill also contributes to the Scottish Government’s Strategic Objective of a Healthier Scotland and contributes to the following National Outcomes:

- We live longer, healthier lives
- Our public services are high quality, continually improving, efficient and responsive to local people’s needs.

16. It will also contribute to meeting the targets set by the following National Indicators and Targets:

- Improve people’s perceptions of the quality of public services delivered
- Improve the quality of the healthcare experience
- Achieve annual milestones for reducing inpatient or day case waiting times, culminating in delivery of an 18 week referral to treatment time from December 2011.

Consultation

17. Within government:
There has been ongoing consultation with Scottish Government officials, particularly in the Health Directorates, on the principles, provisions and structure of the Bill. There has also been close collaboration with the Scottish Government Legal Department and the Office for the Scottish Parliamentary Counsel. This process is ongoing.

18. Public consultation:
A public consultation on a Patients’ Rights Bill for users of the NHS in Scotland took place from September 2008 until January 2009. The Scottish Government sought to ensure that the consultation documents were widely circulated, hard copies were sent out where required, in addition to the document being available online, and there was an easier read version of the consultation document available.

19. An external company was used to set up eight focus groups as well as two national events. Funding was also offered to NHS Boards to hold local consultation events. Officials working on the Patient Rights Bill attended and spoke at a number of these local meetings, as well as the two national events. It is estimated that approximately 800 people attended meetings on the Patient Rights Bill.

20. The response to the consultation included 230 written submissions and the findings from the meetings and focus groups. These were analysed and reported on by the external company that set up the focus groups and the two national events, as well as being considered by Scottish Government officials.
21. The following documents were published on 17 June 2009:
   • Consultation Analysis Report: http://www.scotland.gov.uk/Publications/2009/06/10131759/0
   • Research Findings: http://www.scotland.gov.uk/Publications/2009/06/10131718/0
   • Scottish Government Response to the Consultation Analysis Report: http://www.scotland.gov.uk/Publications/2009/06/17113955/0


23. Ongoing stakeholder engagement:
   Since the consultation closed the Scottish Government has continued to engage with stakeholders on the development of the Patient Rights Bill. It has been an agenda item at a number of NHS staff/Scottish Government meetings and officials have spoken on the Bill and answered questions. Officials have also proactively arranged meetings, including with professional organisations, community health partnerships, NHS staff, and the third sector, to inform the development of the Bill. This process is ongoing.

Options

Option 1 - Do nothing

24. With this option there would be no treatment time guarantee for eligible patients (planned or elective care as an inpatient or day case). The opportunity to facilitate a mutual NHS in Scotland, where patients and NHS staff would work together in partnership and patients would be involved in decisions about their care and treatment, would be lost. Patient Rights Officers would not be available to support patients.

25. This option represents the baseline against which other options will be assessed. The costs and benefits of this option are therefore zero.
Option 2 - Deliver a Patient Rights Bill

26. This Bill will facilitate partnership working in NHS Scotland between patients and staff. It will facilitate improving patients’ health and health experiences by letting them know what they can expect from the NHS and, in turn, what the NHS expects from them. It will also help to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland and it will legislate for a treatment time guarantee.

27. The Bill will give patients the right to make complaints and will legislate for a Patient Advice and Support Service (PASS), with a staff of Patient Rights Officers to provide support and assistance to patients in finding out about and exercising their rights.

Costs and benefits

28. It should be noted that the benefits described in the following pages do not represent direct financial gains to NHS Scotland. Rather, they are an expression of the benefits of the Bill in monetary terms. The Bill also has significant social and health benefits, which are described below, but which are not easily quantifiable in monetary terms.

29. A full and detailed methodology for this Regulatory Impact Assessment can be found at Annex A.

Rights and Principles

Benefits

30. This part of the Bill sets out rights and principles in the delivery and receipt of health care. It aims to encourage a partnership between patients and staff. By increasing patients’ involvement in health care provision, confidence in the NHS, and understanding of their rights and responsibilities, broad impacts are foreseen. Some of these impacts it has been possible to assess quantitatively, while other benefits are social in nature, or are more difficult to quantify.

31. The overall monetary benefits associated with Rights and Principles are estimated at between £0.19 million and £1.9 million, as shown in the table below.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
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<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
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<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
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<tr>
<td>Sub-total</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
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32. Detailed methodology and discussion behind the calculation of the costs and benefits associated with Rights and Principles (where this has been worked out quantitatively) can be found at Annex A.
33. The Scottish Government anticipates 6 broad impacts:

- **A potential reduction in the number of missed appointments.** This will arise through two channels. Firstly, more patient focus and greater partnership between patients and staff should ensure that the timing of appointments is more suitable to the requirements of the patients. This will make attending appointments less costly to patients in terms of opportunity costs; secondly, a greater partnership and understanding of their responsibilities by patients should result in patients making greater effort to attend appointments. Both these effects should result in an increase in attendances.

- **A more efficient use of health resources.** Greater partnership and understanding of their responsibilities should also mean that patients are more likely to notify the appropriate health bodies when they know in advance that they will be unable to attend a scheduled appointment. Patients will also have a greater incentive to cancel appointments as they will know that the official measurement of time spent waiting could revert to zero should they miss an appointment without cancelling in advance, and so they could risk incurring longer wait times, where this applies. These factors should result in a reduction in the number of missed appointments through the formal cancellation of appointments that would otherwise have been missed. Knowing about these cancellations in advance will allow health services to reorganise their resources to provide better care to patients.

- **An improvement in the respect and dignity between staff and patients.** We anticipate that making patients feel more involved in the healthcare process, and giving them a clearer understanding of the rights of staff, may result in staff being treated with more respect by patients.

- **Greater emphasis on the patient as an individual.** We anticipate that the greater emphasis on a patient’s individual needs, combined with working in partnership with patients, will contribute over the long term to improved patient experience and increased patient satisfaction and participation in their own health care, as well as a greater sense of ownership of the NHS for everyone in Scotland.

- **Greater emphasis on appropriate communication and information.** We have developed rights and principles on areas such as communication and participation. Research tells us, for example, that tailoring information to patients’ needs and characteristics is important. For example, this might include focusing on patient requirements from information gathered from the patient, rather than from clinician expectation of what is important. We anticipate that this could lead to long term gains to patients’ confidence and a better experience for those living with long term conditions.

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3 For example, in patient-clinician interactions, there is evidence that the sharing of the patient’s actual experience, as well as knowledge of their social circumstances may contribute to a more successful
Sub-total of benefits

34. The overall monetary benefits associated with Rights and Principles are estimated at between £0.19 million and £1.9 million (see Annex A for further detail). In addition to these monetary benefits there is also the benefit of more efficient use of resources, greater emphasis on the patient as an individual and greater emphasis on appropriate communication and information. These benefits have not been assessed quantitatively. Nevertheless, we might speculate that an underpinning through the Bill of improved patient participation and appropriate communication could lead over time to an increase in a better understanding of health care and treatment, better self-care and a reduction of complaints in this area, leading to a reduced burden on services and potential cost savings, as well as the social benefits to the patient and the NHS in Scotland.

Costs:

35. The costs for the general framework of rights and responsibilities relate to the education of staff and patients on the rights in the Bill as well as public information awareness raising. The costs for these activities are:

Table 2 - Staff education and development costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning and specification*</td>
<td>-</td>
<td>Commissioning and development of educational resources</td>
<td>800,000</td>
<td>Completion, implementation and evaluation of educational resources</td>
<td>800,000</td>
</tr>
<tr>
<td>Scoping study</td>
<td>60,000</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Communications and awareness raising</td>
<td>34,000</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sub-total</td>
<td>94,000</td>
<td>Sub-total</td>
<td>800,000</td>
<td>Sub-total</td>
<td>800,000</td>
</tr>
</tbody>
</table>

* A cost of £25,000 for Planning and Specification is incurred in 2009-10.

Table 3 - Public awareness raising costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation with stakeholder organisations</td>
<td>2,500</td>
<td>Production &amp; Dissemination of public information</td>
<td>60,000</td>
<td>Dissemination of public information &amp; review of information</td>
<td>10,000</td>
</tr>
<tr>
<td>Draft &amp; test public information</td>
<td>15,500</td>
<td>Training for Patient Rights Officers</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sub-total</td>
<td>18,000</td>
<td>Sub-total</td>
<td>60,000</td>
<td>Sub-total</td>
<td>10,000</td>
</tr>
</tbody>
</table>

36. For staff education and development, costs are lower in the first year as this represents a lead-in period, with full costs being incurred in the following years.

Costs and benefits – Treatment Time Guarantee

Benefits
37. This part of the Bill will provide eligible patients with a 12 weeks treatment time guarantee (TTG) from agreement to treatment to the start of treatment. It is intended that eligibility and exclusions will be dealt with in secondary legislation. We expect the TTG to cover approximately half a million patients a year. Detailed methodology and discussion behind the calculation of the costs and benefits of the impacts (where this has been worked out quantitatively) can be found at Annex A. Two main impacts expected are:

- **Reduced waiting times.** Eligible patients currently waiting more than 12 weeks will directly benefit from receiving treatment within the new guaranteed timescale; and
- **Reduced uncertainty.** Patients will have greater certainty regarding how long they will need to wait to receive treatment.

Sub-total of benefits
The overall benefits associated with the treatment time guarantee in the Bill are therefore estimated at between £1.01 million and £5.345 million, as shown in the table below. It should be noted that these do not represent financial gains to NHS Scotland. Rather, they are an expression of the benefits to patients of the treatment time guarantee in monetary terms.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£1.01 million</strong></td>
<td><strong>£5.345 million</strong></td>
</tr>
</tbody>
</table>

Costs
38. The introduction of the treatment time guarantee will not introduce an additional financial cost on Scottish Government budgets, as it is to be funded by NHS boards through existing monies.

39. It is difficult to directly assess the costs to NHS Boards of earlier treatment. In an attempt to approximate for these costs, an assumption has been made that bringing forward treatment will increase the costs to the boards of treating patients waiting in excess of the 12 weeks by between 10%-20%. Due to the small number of patients waiting more than this period, the costs involved are small, with the high cost estimate at less than £150,000 per year across Scotland. The costs are shown in the table below, on the basis that there are approximately 325 patients currently waiting longer than 12 weeks affected by the treatment time guarantee at an average cost of £2,000 each.
Table 5 - Costs associated with the treatment time guarantee (2008-09 prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bringing forward treatments</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£71,500</strong></td>
<td><strong>£143,000</strong></td>
</tr>
</tbody>
</table>

**Costs and benefits – Support and Right to make Complaints**

**Benefits**

40. This section of the Bill covers the Patient Advice and Support Service and Patient Rights Officers.

41. The Bill will legislate for a Patient Advice and Support Service (PASS), to be staffed by Patient Rights Officers (PROs). Health Boards will also be obliged to inform patients about the support they can receive from the Patient Advice and Support Service, and PROs will have a duty to signpost patients to further sources of support where appropriate, such as advocacy services, to ensure that those who need it have the appropriate support to access their rights.

42. We anticipate that there will be social benefits to legislating for an advice and support service, and we can speculate that over time, there may also be some cost savings and reduction in administrative burden on health services involved, if, for example, an effective advice and support service leads to a reduction in complaints.

Table 6 - Benefits associated with Support

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS.</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>N/A</strong></td>
<td><strong>N/A</strong></td>
</tr>
</tbody>
</table>
Costs:
43. Support for patients will be provided through improvements to a number of means of patient support, which support the principles in the Bill. Costs are shown below.

Table 7 - Costs associated with Support (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>National procurement of Patient Advice and Support Service</td>
<td>-</td>
<td>Patient Advice and Support Service (New SG funding)</td>
<td>1,116,000</td>
<td>Patient Advice and Support Service (New SG funding)</td>
<td>1,116,000</td>
</tr>
<tr>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
</tr>
<tr>
<td>Investment in development of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
</tr>
<tr>
<td>Sub-total</td>
<td>750,000</td>
<td>Sub-total</td>
<td>1,866,000</td>
<td>Sub-total</td>
<td>1,866,000</td>
</tr>
</tbody>
</table>

44. Further details on the costs associated with the Patient Advice and Support Service and Translating, Interpreting and Communication Support Services are provided in Annex A.

45. The Bill will establish a right to make complaints. It will revoke and restate existing legislation to strengthen the complaints processes. It will legislate for a principle of feedback. Through secondary legislation and directions, we aim to amend the collection, quality and overview of information to address concerns raised elsewhere about patient complaints/feedback and the use of that information.

46. Establishing greater understanding of a patient’s right to complain may increase the number of complaints; however, a greater patient focus and involvement in the health care process could increase patient satisfaction and reduce the number of complaints.
Small/Micro Firms Impact Test

47. It is not expected that the proposals in the Patient Rights Bill will have a direct or immediate impact on small or micro businesses. However, in the long-term, the proposed treatment time guarantee may result in some positive impact on all businesses, as employees who are absent from work due to illness may be treated earlier as a result of the treatment time guarantee and will therefore be able to return to the workplace earlier.

48. Although the use of private sector health care will be an option available to Health Boards to ensure the treatment time guarantee is met, its use is expected to be minimal. There may also be some members of the public in Scotland who currently make use of health care in the private sector for inpatient and day case treatments, who choose to use the NHS instead because of the treatment time guarantee and other measures within the Bill which are intended to improve the services provided by the NHS. However, it is expected that this will be minimal since most people who use private sector health care in Scotland do so because medical insurance is provided as part of their employment package.

Legal Aid Impact Test

49. We sought to look into whether there would be some impact on legal aid if, as a result of an improved complaints system and better support, more people complain which could lead to an increase in the absolute number that are then taken forward as medical negligence cases. It is important to note, however, that medical negligence cases are usually separate from complaints and an increase in pressure on the legal aid budget would be largely dependent on an increase in medical negligence itself.

“Test Run” of business forms

50. Currently there is no intention to introduce new forms as a direct result of the Patient Rights Bill.

Competition Assessment

51. It is unlikely that the Patient Rights Bill will have an impact on competition. See Annex B.
Enforcement, sanctions and monitoring

52. The aim is to introduce legislation in 2010. Delivery will be undertaken by NHS Boards, although certain aspects will be taken forward by the Scottish Government and third party organisations.

53. Compliance with patient rights legislation will be monitored through a number of existing or soon to be established measures outwith the Bill. These include the Participation Standard, which NHS Boards in Scotland will have to meet from April 2010 to show that they are involving the people who use their services. This Standard focuses on three key areas: Patient Focus; Public Involvement; and Corporate Governance of Participation.

54. Better Together: Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focussed services by Health Boards, which reflect the principles raised in the Bill. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so.

55. As part of the Scottish Government’s work developing the Quality Strategy for NHS Scotland, a range of measures are being explored that will demonstrate improvements in the delivery of patient focused care; these include the possibility of using a Patient-reported outcome measures (PROMS)-based approach.

56. It is intended that the contract specification for the Patient Advice and Support Service, which will be drawn up by the Common Services Agency, will include details of how the service will be monitored and the statistical information that NHS Boards should receive from the service, which will include equality monitoring. Currently, the Scottish Health Council has a role to monitor the existing Independent Advice and Support Service and it is envisaged that this role will continue for PASS.

57. It will be the responsibility of Health Boards to ensure and monitor the delivery of the 12 weeks treatment time guarantee. There is no financial penalty should a breach of the treatment time guarantee occur, rather the emphasis is on how the situation will be rectified. Health Boards are obliged to ensure that the patient is provided with an explanation for the delay, information about the Patient Advice and Support Service and the complaints process and confirmation that they will begin treatment at the next available opportunity. The Scottish Government also monitors Boards’ delivery of waiting times standards and targets. This will also apply to the treatment time guarantee.
Implementation and delivery plan

Implementation

58. The intention is that Scottish Ministers will issue guidance to Health Boards setting out the details of implementation of the Bill. The Bill will provide that Health Boards have a duty to follow this guidance.

59. An implementation plan is being developed for the Bill as introduced to Parliament; the plan will cover staff training, patient and public awareness, the advice and support service and Patient Rights Officers, advocacy funding and funding for translation, interpreting and communication to support patients.

Post-implementation review

60. The effects that the Bill has on patients’ experiences of the NHS will be monitored, for example through Better Together: Scotland’s Patient Experience Programme.

61. The effects of the Bill will also be monitored through the “Participation Standard”, which NHS Boards in Scotland will have to meet from April 2011 to show that they are involving the people who use their services.

62. Waiting times will be monitored to ensure that NHS Boards are complying with the treatment time guarantee for inpatients and day cases, see the Enforcement section, above.

Summary and recommendation

63. The results of the Patient Rights Bill Cost-Benefit appraisal are summarised below. The high and low ‘net benefits’ figures have been calculated using the high benefits against the low costs, and the low benefits against the high costs respectively; they therefore represent ‘best case’ and ‘worst case’ scenarios respectively. The ‘benefits: costs ratio’ shows the return on each £1 spent. For more detailed analysis and methodology behind these conclusions, please see Annex A.

64. It is clear that there are significant benefits associated with the Bill. However, in the ‘worst case’ scenario, the monetized net benefits are negative. This must be weighed against the significant positive social benefits associated with the Bill, which cannot be estimated in monetary terms. These provisions will not only improve patient experience of the NHS in Scotland, but will contribute to improved health in Scotland overall, as well as lead to more efficient use of resources and the improved quality of the health care experience and better support for patients.

65. Furthermore, a relatively conservative ten year period has been used for the appraisal. As costs are incurred upfront whilst benefits accrue over time, if a longer time period were to be used for the appraisal, the scale of net benefits would become increasingly large.

66. Table 8 shows the total costs and benefits over a ten year period. Again, it should be noted that these are not primarily financial impacts to NHS Scotland but overall social costs and benefits expressed in monetary terms. These have been adjusted over time using the methodology set out in Annex A. As is consistent with HM Treasury’s The Green Book, more importance has been attached to costs and benefits occurred in the short term.
Table 8 - Summary of costs and benefits over the appraisal period of ten years (discounted 2008-09 prices)

<table>
<thead>
<tr>
<th></th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£1,225,000</td>
<td>£12,254,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£1,691,000</td>
<td>£1,691,000</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£10,129,000</td>
<td>£50,643,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£479,000</td>
<td>£958,000</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Costs</td>
<td>£12,737,000</td>
<td>£12,737,000</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£11,354,000</td>
<td>£62,896,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£14,907,000</td>
<td>£15,386,000</td>
</tr>
<tr>
<td>Net Benefits</td>
<td>-£4,032,000</td>
<td>£47,989,000</td>
</tr>
<tr>
<td>Benefits: costs ratio</td>
<td>0.7</td>
<td>4.2</td>
</tr>
</tbody>
</table>

67. As has been discussed in this assessment, the impacts of the Patient Rights Bill (Scotland) remain uncertain. This is natural given the innovative nature of the Bill, which makes drawing lessons from other health services, either in the UK or the rest of the world, difficult.

68. The approach to assessing benefits has, therefore, erred on the side of caution. Nonetheless, despite this cautious approach, the benefits assessed for the Bill are significant, at up to £7.3 million per year (see table 12, Annex A), and a present value of £62,896,000 over the ten year appraisal period. In addition to these monetary benefits, there are equally significant non-monetary benefits such as the improved health care experience for patients. These benefits need to be viewed in the context of the numbers benefitting, with more than 400,000 patients covered by the treatment time guarantee and all patients benefitting from the rights set out in the Bill. It should be noted that these do not represent financial gains to NHS Scotland; rather, they are an expression of the benefits to patients of the Bill in monetary terms.

69. The costs of the Bill will take several years to be fully incurred, as new staff are trained and support services such as the Patient Advice and Support Service further bedded in. They are expected to amount to a present value of £15,386,000 over the appraisal period. This figure needs to be viewed in the context of the health budget, approximately £11.3 billion per year.
70. Overall, the net impact of the Bill is uncertain. The analysis indicates that the monetized elements of the Bill provide net benefits with a range of £-4,032,000 to £47,989,000. Given this range, it is highly likely that the Bill will deliver significant positive benefits, particularly when the non-monetized benefits, such as the improved patient experience, are considered. In order for the overall impact of the Bill to be positive in the worst case scenario, the social and health benefits to the people of Scotland would have to be valued at approximately 10 pence per year by each person in Scotland, which is again highly likely.

71. It is therefore recommended that a Patient Rights Bill, as set out in option 2, be delivered in Scotland.

Declaration and publication
72. I have read the Regulatory Impact Assessment and I am satisfied that the benefits justify the costs.
ANNEX A
COST AND BENEFITS ANALYSIS - DETAILED METHODOLOGY

1. This annex sets out in detail the methodology behind the calculation of the costs and benefits of the impacts, both direct and indirect, of the Patient Rights (Scotland) Bill.

2. It is important to note that the Patient Rights (Scotland) Bill introduces a significant change to the NHS in Scotland reinforcing and strengthening the Scottish Government's commitment to place patients at the centre of the NHS in Scotland as part of facilitating a truly mutual NHS. It represents a new concept in the delivery of health services, not just in the UK, but to a degree in the world as a whole. Very few countries have introduced such an approach, although many are now considering it. Due to differences in the rights covered by those countries that have introduced Patient Rights legislation and the Scottish Bill it is difficult to infer from elsewhere the potential impacts that may occur in Scotland. It must therefore be recognised that any discussion of the benefits, and indeed costs, of the Patient Rights (Scotland) Bill takes place in an environment of uncertainty. It is inappropriate to attempt to produce spuriously accurate predictions of any future costs and benefits, and the figures presented here reflect this inherent uncertainty.

3. All monetary figures presented below are in 2008-09 prices unless otherwise stated. Where costs and benefits have been converted between years, HM Treasury’s GDP deflator has been used to adjust for differences in prices between years. Benefits relating to health or which are income-contingent have been grown by 2% per year in real terms, in line with standard practice in health appraisal. Healthcare costs have been grown in real terms in line with the Personal Social Services Research Unit (PSSRU) hospital and community services pay and price index.

Benefits

Option 1 – Do Nothing

4. This option represents the baseline against which other options will be assessed. The benefits of this option are therefore zero.

Option 2 – Introduction of the Patient Rights (Scotland) Bill

5. For the purposes of this assessment the Bill has been divided into four areas:

- Rights and Principles
- The Treatment Time Guarantee
- Support
- Right to make complaints

The benefits of each part are assessed below.

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4 Department of Health (2004), Policy Appraisal and Health
5 PSSRU (2008), Unit costs of health and social care 2008.
Rights and Principles

- A potential reduction in the number of missed appointments.
- A more efficient use of health resources.
- Improvements in the respect and dignity between staff and patients.

Reduction in the number of missed appointments

6. Currently there is no central collection of data on the number of missed appointments in NHS Scotland as a whole. The area for which official data is available relates to outpatients. Outpatient data is reported in SMR00\(^6\), and has recently been summarised in a useful form in a Scottish Parliamentary Question\(^7\). This gives a figure of 162,285 missed first patient appointments in the financial year 2008-09. Other unofficial data sources come from surveys undertaken by other bodies; for example, a survey by the BBC\(^8\) in 2005 suggested that approximately one million GP appointments and half a million nurses appointments were missed in Scotland in that year. According the BBC article, the British Medical Council estimated this to have a cost of £21 million. Since the level of missed appointments in the outpatients data has remained broadly constant over this time, it may be reasonable to assume that the level of missed GP and nurse appointments has also been maintained, although there is no evidence to inform this issue.

7. Due to difficulties in establishing any change in missed GP and nurse appointments since 2005, in establishing whether there is any double counting between the missed nurse appointments and the missed outpatient appointments, and in verifying the costs assigned by the British Medical Council, only the figures relating to the outpatients have been used in the estimate produced below. The figures presented below are therefore a relatively conservative estimate of the overall benefit to NHS Scotland as a whole.

8. The average cost of an outpatient appointment in 2008/09 was £112\(^9\). Assuming that there is no relationship between the type of appointments which are missed and the cost of the appointment, this suggests that a 1% reduction in the number of missed outpatient appointments would deliver benefits of £180,000 per year; a 10% reduction would deliver benefits of £1.8 million per year. Although a 10% reduction may be viewed as somewhat optimistic, given that data limitations have resulted in the exclusion of considering missed appointments in other healthcare services such as GP practices and inpatients appoints, the figure of £1.8 million is likely a reasonable estimate of the benefit of fewer missed appointments in NHS Scotland as a whole.

9. Consideration also needs to be given to the potential benefits in future years. Although the percentage rate of missed outpatient appointments has declined slightly over the past decade, the numbers of missed appointments has been increasing as the overall number of cases increases. It is reasonable to assume that the overall number of missed appointments will continue to increase. For the purposes of the assessment, the number of missed appointments has been assumed to increase in

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\(^6\) Scottish Morbidity Record 00

\(^7\) Scottish Parliament written answer, 14 September 2009, S3W-26533

\(^8\) http://news.bbc.co.uk/1/hi/scotland/4178590.stm, accessed 10\(^{th}\) November 2009

\(^9\) Scottish Health Services Costs (Cost Book) 2008-09 – Executive Summary
line with patient numbers. Activity data for the past five years\textsuperscript{10} suggest that patient numbers have been increasing in total by approximately 0.8\% a year. Adjusting for expected patient numbers and costs in 2010/11, the expected benefits from fewer missed appointments have been estimated at £0.19 million and £1.9 million per year. The cost of each missed appointment is assumed to remain constant in real terms, which is a conservative assumption as potential cost savings are being measured.

**More efficient use of resources**

10. Calculation of the benefits of the more efficient use of resources due to advanced knowledge of cancellations is challenging as it is difficult to predict what each individual hospital or care provider would choose to divert these resources to, which will be determined by the clinical needs of the current patients. It will also depend on how much notice is given and therefore the impact on other patients. One possible approach would be to assume that the alternative tasks undertaken would be at least as valuable as the cancelled appointment, otherwise the resources would have been devoted to this alternative to begin with. There are several drawbacks with this approach. Firstly, it assumes that healthcare resources are perfectly substitutable between different specialities, which is unlikely to be the case; secondly, it assumes that resources are allocated purely on a clinical basis, which again is unlikely to be the case as other constraints, such as the availability of staff or facilities, performance targets, and financial concerns will all be considerations; finally, the approach risks double counting the benefits associated with reduced numbers of missed appointments, as it is again based on the cost of the appointment which was missed.

11. As no satisfactory method could be derived for valuing these benefits, they have not been included in the assessment of monetary costs and benefits; however, they are still relevant to the assessment of the Bill’s overall worth.

**Improvements in the respect and dignity between staff and patients**

12. We consider that an increased awareness of patients’ rights and responsibilities will bring an improvement in the respect and dignity afforded by both patients and staff. At the extreme end of lack of respect, assaults on staff can occur.

13. Records on the number of NHS Scotland staff who are assaulted are not held centrally, but are maintained by the local NHS Board. UNISON Scotland performs an annual survey of the Boards as part of their annual report on violent assaults on public sector staff. The most recent report\textsuperscript{11} provides data for 2008-09. Only eleven of the fourteen territorial NHS Boards submitted data, so it therefore contains a conservative estimate of the total number of assaults, especially since not all assaults may be formally recorded.

14. The Home Office has produced a measure of the economic and social costs of crime\textsuperscript{12}, which assigns costs to fifteen different categories of crime. The UNISON report does not disaggregate the assaults into these categories, and since not all assaults on public sector staff are reported to the police it is unlikely that they would be recorded in a manner which allows them to be easily compared to the Home Office categories. As such, a degree of judgement has had to be applied in converting the

\textsuperscript{10} Costs Book 2008/09, and estimated patient contacts from Practice Team Information, ISD Scotland.

\textsuperscript{11} UNISON (2009), Violent assaults on public service staff in Scotland: follow up survey 2009.

\textsuperscript{12} Home Office (2005), The economic and social costs of crime against individuals and households, Home Office Online Report 30/05.
number of assaults to a usable format. The average values for broad categories of assaults have been taken from the Home Office report, ‘violence against the person’ at £10,407 per crime and ‘common assault’ at £1,440; these figures are in 2003-04 values and prices. It has been assumed that 50% of assaults fall into each category; although the evidence base is weak in this area this is supported by some evidence from (the then) Greater Glasgow board which suggested that the two were of equal proportion\(^{13}\). This implies an average cost per assault of £5,924. These costs cover the fear of crime, physical and emotional costs resulting from the crime itself, and health and justice costs. Individual elements of each of these components could be criticized when it comes to applying them in a health care setting; for example, as stated above, many staff assaults are not reported to the police, so police costs may not be a relevant concern; also, since the assaults occur within a health care environment, overall health care costs may be lower, as costs such as ambulance callouts may be avoided. In counter to these criticisms, it can be argued that although not all staff assaults are reported to the police, they are still formally reported within the NHS, and so there are administration costs associated with such assaults; furthermore, if only a proportion of assaults are being reported to the police, it may well be that these assaults are the more serious ones, and so the police costs for dealing with them may be higher than average; as regards health care costs of crime, it is arguably unethical for society to assign a lower cost of crimes to assaults against health care workers than against other members of society merely because they may occur within a health care environment; finally, due to the incidence of assaults on frontline hospital staff, it may be that healthcare workers suffer from a greater anticipatory fear of crime. Taking these arguments collectively, the values from the Home Office report have been left unadjusted.

15. The Home Office report gives values for 2003-04. These have been converted to 2008-09 prices using the GDP deflator series published by HM Treasury\(^{14}\); the values have been further uplifted to 2008-09 values by 2% a year under an assumption that the costs will increase in line with real income, which is a standard assumption in the valuation of road accidents\(^{15}\) and health benefits\(^{16}\).

16. Again, due to uncertainty over the impact of the Bill, a range of potential benefits is used. Here, the uncertainty reflects not only the impact of the Bill but also the valuation of the impact. The benefits of reducing assaults by between 1% and 10% are estimated at £1 million to £5 million per year. Although the 10% figure may appear high, it needs to be remembered that it is applied to an incomplete measure of the total number of assaults.

17. The values shown here use the number of assaults that occurred in 2008-09 as the basis for calculations. The relevant measure for the assessment is the expected number of assaults that would occur in the years once the Bill has been introduced. This can be estimated by looking at the recent trends in assaults on public sector staff. The UNISON data\(^{17}\) indicates that overall assaults in health have remained unchanged over the last seven years, but this masks significant variations, with a sharp increase up to a peak of 2006-07 followed by a sharp decrease to the latest

\(^{13}\) NSH Greater Glasgow (2005), Staff News, Issue 16
\(^{14}\) GDP deflator as published 29\(^{th}\) September 2009.
\(^{15}\) See Department for Transport, WebTAG, Unit 3.4.
\(^{16}\) Department of Health (2004), op cit.
This recent decline is supported by the latest NHS Scotland Staff Survey\textsuperscript{18}, which indicates that the number of staff experiencing a violent or aggressive incident had declined by 10\% since 2006. A decline in the number of assaults by 2010-11, when the Bill comes into force, might therefore be expected.

18. Given the recent evidence of a downward trend in the number of assaults, a 5\% a year reduction has been assumed as the baseline for the analysis. This is slightly lower than the 10\% a year decline in the two years since 2006-07, for the following reasons. Firstly, although health assaults have been declining, this is from a very high level, and such dramatic reductions may well not be maintained. Secondly, the decline in assaults on health staff goes against the general trend suggested by the UNISON data of increasing assaults on public sector staff. Since the drivers of the numbers of assaults are not well understood, it is difficult to be sure that the numbers of assaults in health will continue to go against this trend. Finally, some of the decline in assaults may have been caused by legislation and campaigns to reduce assaults on staff; since the Patient Rights Bill will support these campaigns by improving patients’ understanding of their responsibilities toward staff, it would be inappropriate to include these impacts in the baseline, as it would underestimate the benefits associated with the Bill.

19. Adjusting for the expected decline in the numbers of assaults, therefore, the benefits from reduced assaults in 2010-11 has been calculated at between £1.0 million and £4.8 million. It should be noted that these are socio-economic welfare impacts and do not represent potential financial costs borne by the NHS.

20. Due to the difficulty in establishing a baseline for assaults in NHS Scotland, and in establishing a direct causal link between the Bill and numbers of assaults, these figures are not included in the overall benefits of the Bill. They should therefore be viewed as illustrative of the potential benefits should the Bill in fact result in such a reduction.

Sub-total of benefits
21. The overall monetary benefits associated with Rights and Principles are therefore estimated at between £0.19 million and £1.9 million, as shown in the table below. In addition to these monetary benefits there is also the benefit of more efficient use of resources, which has not been assessed quantitatively.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Reduced number of assaults</td>
<td>Not included</td>
<td>Not included</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£0.19 million</strong></td>
<td><strong>£1.9 million</strong></td>
</tr>
</tbody>
</table>

\textsuperscript{18} NHSScotland (2008), \textit{Staff opinion survey 2008}
Treatment Time Guarantee

22. This part of the Bill will provide eligible patients with the right to a 12 week treatment time guarantee from agreement to treatment to the start of treatment. Although there will be exclusions, it is still expected to benefit around half a million patients a year. Two main impacts are expected:

- **Reduced waiting times.** Patients currently waiting more than 12 weeks will directly benefit from receiving treatment within the new guaranteed timescale; and
- **Reduced uncertainty.** Patients, regardless of the amount of time they may have spent waiting, will have greater certainty regarding how long they will need to wait to receive treatment.

Reduced waiting times

23. Current waiting times for inpatients and day cases are published by the Information Services Division (ISD) of NHS Scotland, on a quarterly basis. This provides overall waiting times for all specialities (excluding obstetrics and mental health); waiting times for specific specialities are not available. The most recent data\(^\text{19}\) indicate that only 1% of inpatients and day cases were waiting more than 12 weeks, and only 0.1% waits longer than 15 weeks. The data suggest that there are in the region of 18,000 patient days spent waiting longer than the 12 weeks target per quarter; however, this covers total inpatients and day cases, whilst only 400,000 of the approximately 1.5 million of these patients will be affected; the 18,000 number can therefore be scaled down, leaving approximately 5,000 patient days.

24. One approach to the valuation of reduced waiting times would be to argue that reducing waiting times represents a bringing forward of future consumption to the present. This is a concept typically dealt with in economics using a discount rate. The standard discount rate applied in UK government appraisals is 3.5% per year, which equates to approximately 0.1% per week. This suggests that a treatment received after 12 weeks is approximately 0.2% more valuable than one received after 15 weeks. Using an average value of an inpatient and day case treatment of approximately £2,000\(^\text{20}\) as the shadow price to measure the value of the treatment to the patient, this suggests an annual benefit of approximately £15,000 per year. If a higher discount rate were used, under the assumption that people are willing to pay more to bring forward medical treatment than consumption of an average good, then a higher estimate could be derived, for example £30,000.

25. This discount rate, however, contains various elements which are arguably not relevant over such short timescales. As well as pure time preference, the discount rate also includes catastrophe risk (the risk that a catastrophic event may occur, such as death, that means that there would be no opportunity or benefit from receiving the treatment in the future), and an adjustment to take into account the fact that society

\(^{19}\) Quarter ending September 2009
\(^{20}\) Costs Book 2008-09, R042X, R040X, and R040LSX. Long stay inpatient costs have been excluded from the analysis as they are typically mental health services the majority of which are unlikely to be covered by the eligibility criteria of the TTG in the Bill and secondary legislation. Average costs data in the Costs Book is not easily broken down to eliminate particular specialities, therefore the average cost for inpatients and day cases used include some specialities such as obstetrics which will be excluded in secondary legislation. Inspection of the data, however, indicates that these specialities have costs which are similar to or below the average cost, and therefore their inclusion will not affect the conclusions of the analysis.
will be wealthier in the future. Neither of these is likely to be as important over a very short timescale, which would suggest that a lower discount rate, perhaps 1%-2%, would be more appropriate. These rates would produce a range of benefits between £4,000 and £8,000 per year.

26. An alternative approach would be to directly elicit patients’ willingness to pay for reductions in waiting time. This can be done primarily through two methods, either revealed preferences, where patients’ willingness to pay for reduced waiting time is observed in a market, or through stated preferences, where preferences are elicited directly through questionnaires or similar techniques.

27. Revealed preference techniques are difficult to employ within a healthcare setting, as in most western countries healthcare is not provided in a market but is instead provided by the state. A notable exception is America, where there is a sizeable private market; however, there is little research specifically into how waiting times may affect insurance premiums. An alternative approach, similar to that adopted by the Department of Health for the valuation of providing personal care at home, might be to view waiting times as a form of uncertainty, and therefore use insurance premia themselves as a measurement of willingness to pay to reduce this uncertainty. The total payment for certainty is approximately 20%\(^{21}\) of overall health insurance costs; health care costs themselves represent the remaining 80%, and therefore the payment for certainty is approximately 25% of total healthcare costs. This approach has its drawbacks, however, as it covers all forms of uncertainty rather than those relating specifically to waiting times; the 25% figure would therefore very much represent an upper bound on the potential benefits. By focussing on uncertainty as a proxy, it also risks double-counting the benefits associated with reducing uncertainty itself.

28. Stated preference techniques also have drawbacks, as they are dependant upon the quality of the sample and measurement technique, and within a field such as health, which is relatively complicated and emotive, respondents may have difficulty in providing useful responses. The results of such studies need to be treated with a degree of caution, therefore, but still are useful. A study of Canadian, Danish, and Spanish patients\(^{22}\) suggests that total wait costs can be between 10%-25% of overall treatment costs. This is for costs presented in 1991 US prices. Converting to current prices, adjusting for real income growth and differences in waiting times, and using the latest Scottish costs, this would be between 3% to 11%. An earlier study by Propper\(^{23}\) suggested a value at the lower end of this range, at 5%, whilst another study by Johanessen \textit{et al.}\(^{24}\) suggested a higher value, at between 19% and 22%.

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\(^{21}\) Department of Health, (November 2009), \textit{Impact Assessment of Personal Care at Home Bill}.


29. Due to the wide range of results presented above, and a desire to take a cautious approach to the estimation of benefits, a range of 3% to 15% of healthcare costs has been taken as a proxy for the total cost of waiting. This suggests a cost per day of waiting of between approximately £1.90 and £9.50, which, applied to the total number of days waiting in excess of 12 weeks, suggests a benefit of approximately £10,000 to £45,000 per year. Due to the theoretical shortcomings of the discounting approach discussed above, and to maintain consistency with the calculation of benefits associated with reduced uncertainty, these figures are the preferred measure of the benefits associated with reduced waiting time.

30. One possible consequence of introducing the treatment time guarantee is that some patients with a low clinical need may experience an increase in waiting times if patients who would otherwise have been waiting more than 12 weeks are prioritised ahead of them. This impact is difficult to assess quantitatively. Firstly, it may be that no patients suffer in this manner, as depending on how health services adjust their treatment provision it may be possible that the cost is borne solely by healthcare providers rather than shared with patients; secondly, it is increasingly accepted that the context in which people receive information is extremely important. Therefore it is possible that, for example, a patient who would have received an offer of an eight week waiting time before the Bill would still consider themselves better off after the Bill even if their waiting time were increased to nine weeks. This is because previously they would have had no frame of reference for their waiting time, whilst after the introduction of the 12 week treatment time guarantee, patients will inevitably judge their offer of a wait time against this guarantee to some degree. Since these relativities affect people’s assessment of benefit, it may be that the knowledge that the offer of the nine week waiting time is three weeks less than the maximum they could have waited will confer a benefit great enough to offset the disutility associated with having their wait time increased from eight to nine weeks. Due to the uncertainty of this impact, therefore, it has not been quantitatively assessed.

Reduced uncertainty

31. It is generally accepted that people prefer certain outcomes to uncertain ones, particularly where stakes are high. Providing greater certainty in the provision of health care can therefore be expected to provide benefits in the form of a better patient experience. These benefits will accrue to all patients affected by the 12 weeks treatment time guarantee.

32. The reduction in uncertainty can be viewed as resulting from the narrowing of the variability of a patient’s expected wait time. This can be proxied in a simple sense by assuming that all patients that currently wait more than 12 weeks for their treatment now wait between 9 and 12 weeks (wait time statistics are collected on the basis of three week bands). This results in a narrowing of the distribution of wait times and a reduction in the variance of wait times by approximately 4%. If the wait time of patients currently waiting fewer than 12 weeks is also affected, then depending on whether they are currently waiting more or less than the mean wait, this figure could either be increased or decreased. Due to the level of uncertainty of this impact, it has been assumed to be neutral.

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25 This is known as the ‘framing effect’, which was first set out in Tversky, A. & Kahneman, D., (1981), The framing of decisions and the psychology of choice, *Science*, 211, pp. 453-458.
33. The simplest way to value this 4% reduction in wait variability is to treat it as if it were a reduction in mean wait time. Very little evidence exists within the health field as to the relative valuation of variability and mean wait times. In other fields, evidence suggests that in some circumstances reductions in the variability of time can be more important than mean time reductions, with a ratio of the value of variability to mean of up to three. The only health paper which has been found to address this area is that of Propper, which suggests a value for this ratio close to or slightly below one. Due to the lack of a better evidence base a value of one has been assumed. As such, the two have been treated as the same with uncertainty captured through the range applied in the valuation of wait time.

34. Applying the same ranges as discussed above for the valuation of reductions in wait time to the 4% reduction in the variability of wait time suggest benefits of between £1 million and £5.3 million.

**Sub-total of benefits**

The overall benefits associated with the treatment time guarantee are therefore estimated at between £1.01 million and £5.345 million, as shown in the table below.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£1.01 million</strong></td>
<td><strong>£5.345 million</strong></td>
</tr>
</tbody>
</table>

**Support and the Right to make complaints**

35. This covers Patient Advice and Support Service, Patient Rights Officers, and the right to make complaints.

36. The Bill will establish for the first time a right to make complaints. It will also revoke and restate existing legislation to strengthen the complaints processes. It will also legislate for encouraging feedback. It will signal to Health Boards the importance of this right to make a complaint and how information gathered through the complaints and feedback processes can aid in a continuous loop of improvement.

37. In terms of the wider strategic context, the Bill should contribute to improved health outcomes through placing patients at the centre of the NHS supporting the delivery of safe, high quality health care and setting out in a clearer way what patients can expect from the NHS and what their responsibilities are. This should improve the quality of the healthcare experience and the public's perception of it. Due to difficulties in measuring these factors, they have not been assessed quantitatively.

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26 See, for example, Department for Transport, WebTAG Unit 3.5.7.
27 Op. cit
Sub-total of benefits

Table 11 - Benefits associated with Support

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS.</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Sub-total</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Overall benefits

38. The overall benefits associated with the Bill are shown in the table below. Due to the uncertainty associated with each of these impacts, a central estimate is not presented, as this would attach spurious accuracy to a particular point estimate. The monetary benefits of the Bill are therefore estimated at between £1.2 million and £7.3 million per year, with additional non-monetary benefits relating to the more efficient use of resources and the improved quality of the healthcare experience.

Table 12 - Summary of benefits associated with the Bill

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Reduced number of assaults</td>
<td>Not included</td>
<td>Not included</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>£1.2 million</td>
<td>£7.3 million</td>
</tr>
</tbody>
</table>

39. For consistency with the Financial Memorandum, all figures below are given in outturn prices unless otherwise stated.
Costs

Option 1 – Do Nothing

40. This option represents the baseline against which other options will be assessed. The costs of this option are therefore zero. Failure to adopt change would, however, result in a lack of integration between the strategic vision for NHS Scotland and the delivery of healthcare services.

Option 2 – Introduction of the Patient Right (Scotland) Bill

Rights and Principles

41. This part of the Bill sets out the rights and responsibilities of both NHS staff and patients. The costs will therefore relate to the education of staff and patients as well as public information awareness raising. The costs for these activities are shown below.

Table 13 - Staff education and development costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11 Costs</th>
<th>2011-12 Activity</th>
<th>Costs</th>
<th>2012 - 13 Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning and specification*</td>
<td></td>
<td>Commissioning and development of educational resources</td>
<td>800,000</td>
<td>Completion, implementation and evaluation of educational resources</td>
<td>800,000</td>
</tr>
<tr>
<td>Scoping study</td>
<td>60,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications and awareness raising</td>
<td>34,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>94,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* A cost of £25,000 for Planning and Specification is incurred in 2009-10.

Table 14 - Public awareness raising costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11 Costs</th>
<th>2011-12 Activity</th>
<th>Costs</th>
<th>2012 - 13 Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation with stakeholder organisations</td>
<td>2,500</td>
<td>Production &amp; Dissemination of public information</td>
<td>60,000</td>
<td>Dissemination of public information and review of information</td>
<td>10,000</td>
</tr>
<tr>
<td>Draft &amp; test public information</td>
<td>15,500</td>
<td>Training for Patient Rights Officers</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sub-total</td>
<td>18,000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sub-total | 60,000       |                 |       |                   | 10,000 |
The Treatment Time Guarantee

42. The introduction of the treatment time guarantee will not introduce an additional financial cost on Scottish Government budgets, as it is to be funded by NHS boards through existing monies for the 18 weeks Referral to Treatment Target.

43. It is difficult to directly assess the costs to NHS Boards of earlier treatment. In an attempt to approximate for these costs, an assumption has been made that bringing forward treatment will increase the costs to the boards of treating patients waiting in excess of the 12 weeks by between 10%-20%. Due to the small number of patients waiting more than this period, the costs involved are small, with the high cost estimate at less than £150,000 per year. The costs are shown in the table below, on the basis that there are approximately 325 patients currently waiting longer than 12 weeks affected by the waiting time guarantee at an average cost of £2,000 each.

Table 15 - Costs associated with the treatment time guarantee

<table>
<thead>
<tr>
<th>Activity</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bringing forward treatments</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
<tr>
<td>Sub-total</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
</tbody>
</table>

Support

44. Support for patients will be provided through the Patient Advice and Support Service, which will build on the current Independent Advice and Support Service. This will be supported with additional staff and other resources, and funding to other forms of support, the costs of which are shown below.

Table 16 - Costs associated with Support (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11 Costs</th>
<th>2011-12 Activity and Costs</th>
<th>2012 - 13 Activity and Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>National procurement of Patient Advice and Support Service</td>
<td>-</td>
<td>Patient Advice and Support Service 1,116,000 (New SG funding)</td>
<td>Patient Advice and Support Service 1,116,000 (New SG funding)</td>
</tr>
<tr>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services 250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services 250,000</td>
</tr>
<tr>
<td>Investment in development of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services 500,000</td>
<td>Investment in provision of advocacy services 500,000</td>
</tr>
<tr>
<td>Sub-total</td>
<td>750,000</td>
<td>Sub-total 1,866,000</td>
<td>Sub-total 1,866,000</td>
</tr>
</tbody>
</table>
45. It is anticipated that the Patient Rights Bill will lead to an increased demand for translation, interpreting and communication support (TICS). In light of this, the Scottish Government will provide funding of £750,000 over 3 years 2010 to 2013 to support the development of TICS services. This will be provided to NHS Health Scotland to provide support, resources and guidance materials; research on needs, procurement and service standard work; community engagement and marketing; communication events, and extended partnership work across NHSScotland.

46. Note that the £1,116,000 funding for the Patient Advice and Support Service includes £116,000 redirected from the Healthcare Policy and Strategy Directorate budget; however, it excludes funds which are already spent on patient advice and support, either by NHS Boards or the Scottish Government, as these do not represent additional expenditure in the area.

Cost-Benefit Appraisal

47. The benefits and costs outlined above can be expected to accrue over time. They therefore need to be analysed over a number of years to come to a complete assessment of the net benefits to society. This appraisal has been carried out in line with HM Treasury’s The Green Book, which sets out the procedures to be followed in government appraisals. The primary feature is that costs and benefits in the future should be discounted to represent society’s preference for receiving goods and services now rather than later.

48. The total net benefits of the Bill are therefore calculated as:

\[
\text{Net Present Value (NPV)} = \sum_{t} \frac{\text{Benefits}_t - \text{Costs}_t}{(1+r)^t}
\]

That is, the net benefits and costs of year \( t \), adjusted by the discount rate for year \( t \), \((1+r)^t\), summed over all years in the appraisal period. The standard discount rate of 3.5% has been used, with 2010/11 taken as the base year. A 10 year period has been used to measure costs and benefits.
Profile of costs and benefits

49. It is reasonable to assume that not all of the benefits associated with the Bill will be realised immediately. The following assumptions have been used to profile the benefits over time:

Costs and benefits associated with Rights and Principles and Support

50. The benefits associated with Rights and Principles and Support will rely upon support infrastructure that will take time to achieve complete penetration of public awareness. The expected profile of the benefits is set out below:

Table 17 - Profile of benefits associated with Rights and Principles and Support

<table>
<thead>
<tr>
<th>Year</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>Zero benefits – this year sees investment in support infrastructure in preparation for delivery;</td>
</tr>
<tr>
<td>2011-12</td>
<td>25% of expected benefits</td>
</tr>
<tr>
<td>2012-13</td>
<td>50% of expected benefits</td>
</tr>
<tr>
<td>2013-14</td>
<td>75% of expected benefits</td>
</tr>
<tr>
<td>2014-15 and onwards</td>
<td>100% of expected benefits</td>
</tr>
</tbody>
</table>

51. Once the delivery of these elements has begun therefore, in 2011/12, it is expected that benefits will be fully realised within four years.

52. The costs for these sections of the Bill follow the profiles set out in the Costs section above. They are assumed to remain constant in real terms beyond 2012/13.

Costs and benefits associated with the treatment time guarantee

53. The 12 week waiting time target is expected to be achieved by 31\textsuperscript{st} March 2010; therefore, the costs and benefits for this part of the Bill are expected to accrue immediately in 2010/11. It is expected that as waiting lists are brought down, the long term costs of meeting the target will decline, as more efficient systems are developed and put in place.

Table 18 - Profile of costs and benefits associated with the treatment time guarantee

<table>
<thead>
<tr>
<th>Year</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>100% expected benefits – 100% expected initial costs</td>
</tr>
<tr>
<td>2011-12</td>
<td>100% expected benefits – 90% expected initial costs</td>
</tr>
<tr>
<td>2012-13</td>
<td>100% expected benefits – 80% expected initial costs</td>
</tr>
<tr>
<td>2013-14</td>
<td>100% expected benefits – 70% expected initial costs</td>
</tr>
<tr>
<td>2014-15</td>
<td>100% expected benefits – 60% expected initial costs</td>
</tr>
<tr>
<td>2015-16 and onwards:</td>
<td>100% expected benefits – 50% expected initial costs</td>
</tr>
</tbody>
</table>

Benefits have been grown in line with real incomes and costs have been grown in line with real medical service costs and patient numbers.
Appraisal results

54. The appraisal results are summarised below. The high and low ‘net benefits’ figures have been calculated using the high benefits against the low costs, and the low benefits against the high costs respectively; they therefore represent ‘best case’ and ‘worst case’ scenarios respectively. The ‘benefits: costs ratio’ shows the return on each £1 spent.

55. It is clear that there are significant benefits associated with the Bill. However, in the ‘worst case’ scenario, the monetized net benefits are negative. This must be weighed against the significant positive benefits associated with the Bill, in particular relating to Support which cannot be estimated in monetary terms. Furthermore, a relatively conservative ten year period has been used for the appraisal. As costs are incurred upfront whilst benefits accrue over time, if a longer time period were to be used for appraisal, the scale of net benefits would become increasingly large.

Table 19 – Summary of costs and benefits over the appraisal period of ten years (discounted 2008/09 prices)

<table>
<thead>
<tr>
<th></th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£1,225,000</td>
<td>£12,254,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£1,691,000</td>
<td>£1,691,000</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£10,129,000</td>
<td>£50,643,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£479,000</td>
<td>£958,000</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Costs</td>
<td>£12,737,000</td>
<td>£12,737,000</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£11,354,000</td>
<td>£62,896,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£14,907,000</td>
<td>£15,386,000</td>
</tr>
<tr>
<td>Net Benefits</td>
<td>-£4,032,000</td>
<td>£47,989,000</td>
</tr>
<tr>
<td>Benefits: costs ratio</td>
<td>0.7</td>
<td>4.2</td>
</tr>
</tbody>
</table>

56. Note that, for the Rights and Principles and Support and Recourse elements of the Bill, only a central cost range has been provided. This is because these costs are based on the forecast costs of service provision and there is no evidence base with which to suggest upper or lower values. In line with HM Treasury Green Book guidance on appraisal, this uncertainty has been addressed through sensitivity guidance.

57. The range of potential monetary net benefits is therefore between -£4,032,000 and £47,989,000. Although due to lack of certainty it is not possible to provide a central estimate of net benefits, it is clearly very likely that they are significantly positive, even before non-monetary benefits are included.


**Sensitivity analysis**

58. Standard sensitivity analysis has been carried out to investigate how much costs would have to increase to eliminate the monetary benefits identified above. In the best case scenario, costs would have to rise by in excess of 300% in order for the monetized benefits of the Bill to be eliminated.

**Summary and conclusions**

59. As has been discussed throughout this assessment, the impacts of the Patient Rights (Scotland) Bill remain uncertain. This is natural given the innovative nature of the Bill, which makes drawing lessons from other health services, either in the UK or the rest of the world, difficult.

60. The approach to assessing benefits has, therefore, erred on the side of caution. Nonetheless, despite this cautious approach, the benefits assessed for the Bill are significant, at up to £7.3 million per year (see table 12), and a present value of £62,896,000 over the ten year appraisal period. In addition to these monetary benefits, there are equally significant non-monetary benefits such as the potentially improved health care experience for patients. These benefits need to be viewed in the context of the numbers benefitting, with more than 400,000 patients covered by the treatment time guarantee and all patients benefitting from the rights set out in the Bill.

61. The costs of the Bill will take several years to be fully incurred, as new staff are trained and services such as the enhanced Patient Advice and Support Service are bedded in. They are expected to amount to a present value of £15,386,000 over the appraisal period. This figure needs to be viewed in the context of the health budget, approximately £11.3 billion per year.

62. Overall, the net impact of the Bill is uncertain. The analysis indicates that the monetized elements of the Bill provide net benefits with a range of -£4,032,000 to £47,989,000. Given this range, it is highly likely that the Bill will deliver significant positive benefits, particularly when the non-monetized social and health benefits, such as the improved patient experience, are considered. In order for the overall impact of the Bill to be positive in the worst case scenario, these benefits would have to be valued at approximately 10 pence per year by each person in Scotland, which is highly likely.
ANNEX B
COMPETITION ASSESSMENT

The Office of Fair Trading has formal guidance for conducting competition assessments, as set out in Completing competition assessments in Impact Assessments: Guideline for policy makers (August 2007). This sets out four areas where the impact of the Bill should be considered. That is, would the Bill:

- Directly limit the number or range of suppliers?
- Indirectly limit the number or range of suppliers?
- Limit the ability of suppliers to compete?
- Reduce suppliers’ incentives to compete vigorously?

The impact of the Bill in these areas is considered below.

**Would the Bill directly limit the number or range of suppliers?**
No. The supply of healthcare services, which are provided by NHS Scotland, will be unaffected.

**Would the Bill indirectly limit the number or range of suppliers?**
No. The supply of healthcare services by NHS Scotland is determined by clinical need, and will therefore not be indirectly affected.

**Would the Bill limit the ability of suppliers to compete?**
No. NHS Scotland is provided by the public sector and does not make use of internal markets to encourage competition between suppliers.

**Would the Bill reduce suppliers’ incentives to compete vigorously?**
No. NHS Scotland is provided by the public sector and does not make use of internal markets to encourage competition between suppliers.

**Conclusion**
Having answered ‘no’ to the for questions in the Office of Fair Trading Guidance, it can be stated that the Bill is unlikely to raise any competition concerns.
Equality Impact Assessment - Patient Rights (Scotland) Bill

What is the purpose of the proposed policy (or changes to be made to the policy)?

The Patient Rights (Scotland) Bill will provide that the health care which patients receive should meet certain criteria, according to a set of health care principles. We also intend to legislate for a patient advice and support service and Patients Rights Officers, to legislate for a treatment time guarantee, and establish a right to make complaints and give feedback about healthcare.

Who is affected by the policy or who is intended to benefit from the proposed policy and how?

The Patient Rights Bill will have an impact on anyone who accesses NHS services in Scotland. The Bill itself relates to patients, but it may have consequences for others such as carers, family and friends of patients. The Bill is relevant to primary, secondary and tertiary health care services.

NHS staff will also be affected by this policy, in the way in which they interact with patients, in terms of the way in which complaints are dealt with and administered and in terms of fulfilling the treatment time guarantee.

The Bill will also affect third party organisations that will have the opportunity to bid for the contract to provide the Patient Advice and Support Service, and Patient Rights Officers.

How have you, or will you, put the policy into practice, and who is or will be delivering it?

The aim is to introduce secondary legislation by way of regulations and directions.

Delivery will be undertaken by NHS Boards, primary care service providers and third parties.

Aspects will be taken forward by the Scottish Government.

How does the policy fit into our wider or related policy initiatives?

The Patient Rights Bill fits in with the Scottish Government's Strategic Objective of a Healthier Scotland and contributes to the following National Outcomes:

- We lead longer, healthier lives
- Our public services are high quality, continually improving, efficient and responsive to local people's needs.

It will also contribute to meeting the targets set by the following National Indicators and Targets:
- Improve the quality of the health care experience
- Achieve annual milestones for reducing inpatient or day case waiting times, culminating in delivery of an 18 week referral to treatment time from December 2011.

The following policy initiatives are also relevant:
Quality Strategy
Better Health, Better Care;
Better Together: Scotland’s Patient Experience Programme;
Equally Well, the Report of the Ministerial Taskforce on Health Inequalities.

The Patient Rights Bill relates to the rights of a person in terms of his/her receipt of NHS care. Therefore the provisions in the Bill are in addition to other legislation relating to equality, such as the Disability Discrimination Act or the Race Relations Act, as well as the body of human rights law.

Disability

Evidence
20% of people in Scotland have a disability according to the definition of the Disability Discrimination Act 1995 (Office for National Statistics – Census Results – 2001). This definition covers a wide range of impairment types and conditions and as such it is important to recognise that disabled people are not a homogenous group and will have a wide range of needs and experiences. For example, someone who is a wheelchair user is likely to have very different needs to someone who is a Deaf British Sign Language (BSL) user, or someone who has mental health problems.

It is estimated that 730,000 adults in Scotland have hearing loss, of whom 533,000 would benefit from NHS hearing services. (Public Health Institute of Scotland - NHS Audiology Review in Scotland - 2003). The number of profoundly Deaf people using British Sign Language in Scotland is estimated at between 4,000 and 6,000. (Scottish Association of Sign Language Interpreters – Creating Linguistic Access for Deaf and Deafblind People: A Strategy for Scotland – 2002)

In 2008, the number of people registered blind or partially sighted in Scotland was 35,900 of which approximately 2,700 were deafblind. (Scotland's Chief Statistician - Registered Blind and Partially Sighted Persons - 2008)

It is estimated that there are 120,000 people with learning disabilities in Scotland. There is evidence that people with learning disabilities have a higher number of and more complex health needs than the rest of the population, as well as higher levels of unmet health needs and different causes of death than non-learning disabled people. (Scottish Government - Scottish Ministers’ Duty Report: Health and Wellbeing - 2008)
There are no precise figures for the number of people with mental health problems in Scotland. The Scottish Health Survey suggests that those with a “high score” on the General Health Questionnaire in relation to mental health amounted to some 13% of men aged between 16-64 and 17% of women. (Scottish Government - *Scottish Ministers’ Duty Report: Health and Wellbeing* - 2008). There is also evidence to show that Deaf people are 4 times more likely to experience mental health problems than hearing people, and are also less likely to be able to access appropriate services. (Scottish Council on Deafness, *Making the Case: Specialist Mental Health Services for Deaf People in Scotland*, 2008. P.6).

There is a complex relationship between disability and ill-health, but it is important not to conflate the two. Disabled people may experience ill-health or benefit from measures promoting good health in the same way as anyone else in the population. (Scottish Government - *Report of the Disability Working Group* - 2006)

In terms of health, Social Focus on Disability 2004 reports that 50% of adults with a long term illness or disability rated their health as “not good” over the past 5 years, compared with 5% of non-disabled adults. Correspondingly, 33% of adults with a long term illness or disability visited their GP more than 10 times in the last year, compared with 5% of non-disabled adults.

Disabled people are more likely to be living in poverty than non-disabled people, and in turn, individuals in low income households are more likely to report poor health. (Cabinet Office 2004 and Prime Minister’s Strategy Unit 2005 – information taken from Scottish Government - *Scottish Ministers’ Duty Report Health and Wellbeing* - 2008) As such, a survey conducted by MORI in 2003 found that 90% of disabled people had used the health service in the past 3 months, which is significantly higher than the general population.

However, a survey by NOP for the Disability Rights Commission in 2003 showed that 24% of disabled people mentioned difficulties in the course of an appointment or visit to the hospital and 18% in accessing a dentist.

**Consultation**

As part of the consultation process for the Patient Rights Bill a focus group for disabled people was organised by the Glasgow Centre for Inclusive Living and took place on 6 January 2009. The group consisted of people with a range of impairment types. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus group described examples of times when access to certain services was restricted for disabled people (e.g. screening equipment) because of their impairment, and the question was raised as to whether patients should accept this lesser service.
The group also felt that it was important that hospitals and health care premises were accessible, and this is very important in ensuring that disabled people are able to fulfil their responsibilities and, for example, don’t miss an appointment because they are unable to access the hospital building.

It was also suggested the Patient Rights Bill should be extended to embrace all health care, meaning local authority social care as well as NHS health care.

Written Consultation Responses:

The Scottish Government received many written responses from organisations representing disabled people, including: Scottish Council on Deafness/Hearing Concern LINK, Deafblind Scotland, Scottish Association for Mental Health, RNID Scotland, Scottish Disability Equality Forum, Deaf Action, Inclusion Scotland, Depression Alliance, Epilepsy Scotland, HIV Scotland, Scottish Consortium on Learning Disabilities/Enable, PAMIS, Scottish Central Branch of the National Federation of the Blind.

There was broad support from disability organisations with the proposals in the consultation and with the aims of the Patient Rights Bill. However, there were some specific concerns and issues raised about the impact of the Bill on disabled people.

Some of the main points raised by consultation respondents were:

Waiting Times Guarantee

Waiting time guarantees should apply to mental health services too.

The waiting time guarantee might be difficult to implement for deaf people due to the lack of interpreters and communication support workers in Scotland.

A maximum wait of 18 weeks is too long for paediatric audiology. 18 weeks is almost half of the school year, having little or no hearing for half of the school year will have serious implications for a child’s education and progress and place deaf children at a disadvantage.

Steps to fulfil the waiting times guarantee such as sending patients to another area, to a private facility or abroad may be more difficult for disabled people than for non-disabled people due to the reliance on carers and support workers, and it may also be more difficult in terms of transport and access to the support networks at place in their home area. If disabled people would rather wait for treatment than go elsewhere, they should not be penalised for this.
Access and Communication

Access to services, including physical access to premises and equipment as well as access to appropriate communication support and information, was a significant issue raised by many consultation respondents.

Respondents raised the issue that disabled people need information in a suitable format, and to be communicated with in an appropriate way, otherwise they will be unable to make informed decisions about their treatment or care.

It was felt that contract staff, such as cleaners or catering staff, who have patient contact, should be adequately trained in disability equality and should be subject to the Patient Rights Bill.

Patient Responsibility

Some impairments, such as mental health problems, autism and learning disabilities, may make it difficult for the patient to behave in an appropriate manner, and they should not be denied their rights simply because they are unable to fulfil their responsibilities.

There is concern around disabled patients taking responsibility for their own care and enforcing their rights, either because they are unable to or because they do not understand their rights and responsibilities, or because they cannot communicate with health care staff. For example, deaf patients cannot take responsibility for their own care/take medication etc unless the advice is provided in an accessible format that can be accessed when they need to.

Complaints, Advice and Support, Advocacy

There was strong support for advocacy from a range of respondents and it was felt that advocacy is necessary in order for disabled people to enforce their rights and to gain equal access to the complaints system. It was suggested that the groups that advocacy would particularly help are deaf people, people with learning disabilities and people with mental health problems. Respondents felt that advocacy services should be readily available and patients should be signposted to them by NHS staff. It was also felt that there is geographic inequality of access to advocacy services.

It is important that there should be good access both to the first stage of the complaints process and to the Ombudsman.

Deaf patients should be able to feedback/complain in writing via email or SMS. Deaf people generally find it very difficult to complain, partly because of low awareness of the complaints process and also because they find it difficult to access due to communication barriers.
Other Issues

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Patient Rights Bill, for example, concerns about physical premises and equipment being inaccessible and lack of transport to access appointments. Obtaining adequate nutrition was also an issue brought up by many respondents, not only in terms of people with profound impairments, but also for people who were unable to cut up their own food, or for people with sensory impairments.

Many of these additional issues are also already addressed by existing legislation, such as the Disability Discrimination Act (1995) and other strategies that the Scottish Government has in place, such as the National Integrated Programme for Improving Nutritional Care, which was set up in 2008 with the aim of improving and enhancing the nutritional care of people in hospital and tackling associated issues in relation to patients who are nutritionally vulnerable. In addition, we believe that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and as such, will contribute to addressing some of these issues.

Impact

Evidence shows that disabled people are likely to access health care more frequently than non-disabled people, and that they can experience problems when doing so. Results from the consultation also suggest that disabled people can face significant problems in accessing health care, often due to access and communication issues.

As such, the Patient Rights (Scotland) Bill will have a positive impact on disabled people as it will set out in legislation principles and rights that must be taken into account by health care workers and contract staff (e.g. cleaners, catering staff). This will be accompanied by a staff training programme to ensure staff are aware of the rights of patients and carers, with the aim of improving communication with disabled people and making staff more aware of a range of accessibility issues.

It is anticipated that the Patient Rights Bill will lead to an increased demand for translating, interpretation and communication support (TICS). In light of this, the Scottish Government will provide funding of £750,000 over 3 years 2010 to 2013 to support the development of TICS services. This will be provided to NHS Health Scotland to provide support, resources and guidance materials; research on needs, procurement and service standard work; community engagement and marketing; communication events, and extended partnership work across NHSScotland. Investing in the TICS infrastructure will help to ensure that all patients are aware of their rights, and are communicated with in an appropriate manner.

The Scottish Government will also take reasonable measures to ensure that any information and publicity undertaken about the Bill will be accessible to disabled people.
Advocacy

One concern raised by many consultation respondents is that the Bill does not include a right to advocacy and that without support and help, many disabled people, especially those with learning disabilities and mental health problems, will find it difficult to enforce their rights, with the result that the Bill does not have the positive effect envisaged. Consequently, it is proposed that the Bill will place a duty on Patient Rights Officers to signpost people to advocacy services where appropriate. As a result of consideration of the potential impact across a range of equality groups, we have decided to allocate £1.5 million over 3 years 2010-13 to support advocacy services to help those who need assistance in upholding their rights access appropriate support.

Treatment Time Guarantee

Some consultation respondents were concerned about the position of mental health services and the proposed treatment time guarantee. The treatment time guarantee will apply to mental health services, where they are delivered as planned and elective care on an inpatient or day case basis. This is likely to have the greatest impact in terms of child and adolescent mental health services.

The majority of mental health services are emergency admissions whether on a voluntary basis or not (rather than planned or elective care). For those patients who are emergency admissions, it would not be appropriate to have a maximum waiting time of 12 weeks. Care/treatment delivered on an outpatient or day patient (as opposed to day case) basis is primarily about ongoing care or programmes of care, rather than the one-off elective focus of the treatment time guarantee.

Another area to consider is around treatment time targets for paediatric audiology. It has been suggested by consultation respondents that 12 or 18 weeks is too long for a child to wait before being treated by audiology services. 12 weeks is just over one third of the school year, and it is suggested that to be without hearing for that length of time would have a detrimental impact on a child’s educational progress and attainment. However, although audiology services (adult or children) have previously not been covered by any waiting time standards, the Scottish Government announced on 27 October 2007, that audiology services would be covered by the 18 weeks referral to treatment target (RTT) which is due to be delivered by the end of 2011. This means that the Scottish Government has expanded the cohort of patients who will be covered by the treatment time guarantee, bringing patients with hearing difficulties within waiting time targets. Both the 18 weeks RTT and the proposed 12 week treatment time guarantee are maximum waits and it is expected that most patients will be seen quicker than these. Within these waiting times it is for the consultant to decide the patient’s clinical priority taking account of the individual’s particular needs.
A further issue raised was that if a patient’s home Health Board could not meet the treatment time guarantee, and they were offered an appointment in another Health Board area, there was concern raised that some patients (including disabled patients) would find it harder than others to go for treatment outwith their home Health Board. There was concern that these groups could be penalised if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason. Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision making process. Where a patient has to travel, appropriate transport and accommodation arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board. Moreover, the Scottish Government is keen to ensure that once the Bill becomes law, Health Boards must monitor the delivery and impact of the treatment time guarantee and collect information to aid in the assessment of any differential impact on patients according to the equality strands.

It is expected that Health Boards will specify a requirement to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Health Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is disadvantaged.

It was also brought up by consultation respondents that D/deaf people and others who require the support of an interpreter to access health care may not be able to get their treatment within the maximum 12 weeks because of lack of British Sign Language (BSL)/English interpreters. The Scottish Government is clear that Health Boards should ensure that any additional support requirements are put in place before the patient is admitted to hospital and this should not in any way impact on the treatment time guarantee.

However, the Scottish Government is very aware of the barriers and problems some deaf people face in terms of accessing health services and having their needs met. We have been working for some time to improve the collection, transfer and use of information on patients’ communication needs and requirements across the NHS.

In addition, the Scottish Government is providing £750,000 of additional money over 3 years 2010-13 to support the development of the Translation, Interpreting and Communication Service (TICS), which will help to ensure that interpreters and communication support workers are available, although we acknowledge that there is a shortage of British Sign Language (BSL)/English interpreters in Scotland. To help address this problem, the Scottish Government, in conjunction with the British Sign Language and Linguistic Access Working Group (BSL&LAWG) is currently providing funding to train additional BSL interpreters and to develop the infrastructure and strategic direction of BSL/English interpreter training pathways in Scotland.
Patient Responsibility

One further area where it was felt that the Bill could have an adverse impact on disabled people was in terms of patient responsibility, where many consultation respondents pointed out that some disabled people will be unable to take responsibility for their own health care or medication because of their impairment, or because information has not been given to them in an appropriate way. There was concern that disabled people could be penalised or be denied their rights if they did not discharge their responsibilities. The Scottish Government notes that the rights of any individual are subject also to meeting the rights of others (this is similar to the concept of qualified rights in the European Convention of Human Rights). The aim of this is also to address concerns about staff-patient interactions and to allow a Health Board’s responsibility to the individual to be balanced against the Health Board’s responsibility to all the patients in its area. However, the Scottish Government is clear that even if a patient cannot or does not fulfil their responsibilities, they will still receive the highest possible standard of health care.

Complaints

Some disabled people, especially deaf people, find it hard to complain because of inaccessible systems and processes, or because they are not aware of the process, and there was concern that disabled people would therefore not benefit from having a right to make complaints. Currently, NHS bodies in Scotland must ensure that their services recognise and respond sensitively to the individual needs, background and circumstances of peoples’ lives and in doing so must comply with the terms of existing equalities legislation. This requirement extends to local arrangements for handling complaints. As such, staff involved in the implementation of the NHS Complaints Procedure should use the Equality and Diversity Impact Assessment Toolkit to ensure that their local arrangements fully meet the needs of potentially disadvantaged individuals or groups: this includes ensuring ready access to translation and interpreting services, including those for people with sensory impairment, and the provision of appropriate independent support and advocacy services for all who need it.

In addition to what is already in place (described above), the Bill proposes the provision of a Patient Advice and Support Service (PASS), including Patient Rights Officers, who can help and support patients when making a complaint and signpost to further support and advocacy services. It is recognised that PASS and the complaints system must be accessible to all and that Patient Rights Officers will also need to be accessible and responsive to the individual needs, background and circumstances of people's lives.
Age

Evidence
Scotland’s population is ageing, and life expectancy for men and women is expected to increase by around 6 years by 2031, by which time the number of men and women over 75 is expected to be 1.75 times the current level. In the 10 years from 1998 to 2008, the ageing of the population was reflected in the number of children under 16 reducing by 9%, and the number of people aged 75 and over increasing by 13%. (The Registrar General’s Annual Review of Scotland’s Population - 2009)

The age profile of Scotland’s population will continue to change over the coming decades. The number of people of pensionable age is projected to rise by around 31%, from 0.98 million in 2006 to 1.29 million in 2031, which equates to approximately 20% of the population.

In 2006, approximately 25% of Scotland’s population was recorded as being less than 19 years old. (Office for National Statistics – Census Results – 2001).

The proportion of people with a long-term illness or disability increases with age: 13% of people aged 70 years and over have both a long-term illness and disability compared to 2% of 30-39 year olds. (Scottish Executive - The Scottish Health Survey 2003. Volume 2: Adults - 2005)

As such, an ageing population tends to increase the demand for health care, although its effects are being offset to some extent by the fact that older people are, on average, healthier than they have ever been. The main impact of the age profile will be on the type of demand for services since older people have a higher incidence of chronic disease and on average a greater number of long term conditions. (Scottish Government - Better Health, Better Care: Action Plan - 2007)

However, we also know that both younger and older people experience barriers in accessing health care. (NHS – Fair for All Age and Health Guidance – 2007)

Mental Health problems are an issue in both younger and older age groups. Almost 15% of people over 65 report living with major depression which disrupts their lives, and more than 700,000 people have dementia. For young men (15-34) the main cause of death is suicide, and this is 6 times higher for gay and bi-sexual men. (NHS – Fair for All Age and Health Guidance – 2007)

Sexual health problems are also increasing among younger people. For example, the incidence of sexually transmitted infections (STIs) for females is highest for those aged 20 to 24 years (37% of all female diagnoses). The incidence of STIs for males is also highest for those aged 20 to 24 years (37% of all male diagnoses). Between 2000 and 2005, the most marked increase in incidence of STIs occurred for both men and women aged between 15 to 19 years and 20 to 24 years. (Scottish Government - High Level Summary of Equality Statistics: Key Trends for Scotland – 2006)
Consultation

As part of the consultation process for a Patient Rights Bill a children and young people's focus group was organised by Callander Youth Project. It was held on 25 November 2008. There were eleven participants, (six females and five males) with an age range between 11-17 years.

Another group focusing on age (and gender) took place in Dumfries on 27 November 2008. This group consisted of ten people (five women and five men) with an age range from 20s to 60s. Both focus groups were facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus groups agreed with the main principles of the consultation, and the young people’s group raised some specific issues:

Some young people felt that they were sometimes given less favourable treatment because of their circumstances, saying that young people should be treated with respect and that health care services should not treat older people better. Young people also felt that the way in which they are communicated with is important.

Written Consultation Responses:

Several written responses were also received from organisations involved with this community, including Scotland’s Commissioner for Children and Young People, Action for Sick Children (Scotland), Children in Scotland, Help the Aged in Scotland, Alzheimer’s Scotland, British Geriatrics Society, and Better Government for Older People in South Lanarkshire.

The responses were in broad agreement with the proposals in the consultation, but there were some specific points relevant to older and younger people that were raised.

Older People

Information needs to be communicated in a way patients can understand, especially patients with Alzheimer’s or dementia. The availability of advocates for people in this position should be encouraged.

Consideration needs to be given to people with Alzheimer’s or dementia who may not behave appropriately because of their condition. It is important that they are given dignity and respect, and that their care and treatment does not suffer. Also, the ability of patients with dementia to comply with advice on medication and treatment and to raise concerns about the safety of their care will depend on them being enabled to do so by carers, home care staff and advocates.
Older people may not be in a position to take responsibility for their own care and are less likely to be able to travel to other Health Board areas for treatment. This needs to be taken into account in planning their care and treatment, and ensuring this is on an equitable basis.

Younger People

There is a lack of particular mention of children and young people in the consultation. Children and young people need specific support to access health care services and they should be specifically mentioned in the Bill so that health care staff are aware that the Bill also applies to children and young people.

Health services need to recognise that teenagers and young adults may also have special needs, and that the transition between children’s and adult services can be in itself a disruption, while at the same time are facing the changes of adolescence and stressful periods at school.

Children and young people would benefit from the support of advocacy services.

Children are not always able to discharge their responsibilities independently of their parents.

Other Concerns

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Patient Rights Bill, such as access to transport for older patients, the right to food and adequate nutrition and transitions for teenagers between children and adult services. The Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients’ individual needs are taken into consideration and respected, and will contribute to addressing these issues.

Impact

The Patient Rights Bill will have a positive impact on older and younger people, as it will set out clearly in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers such as cleaning staff, and will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues. The Scottish Government is clear that the rights set out in the Bill relate to everyone, including children and young people. The Bill will not supersede existing legislation on children’s rights, and we will endeavour to ensure that we encourage health care providers to be aware of these and to communicate with children in a manner appropriate to their level of understanding and capability.
A further positive impact on young people is that mental health services are included in the 12 week treatment time guarantee where they are delivered as planned and elective care on an inpatient or day case basis. This is likely to have greatest impact in respect of child and adolescent services which make greater use of planned admissions than other mental health service areas where services tend to be accessed quickly in the context of crisis.

One concern raised by consultation respondents is that the Bill does not include a right to advocacy, and that without support and help, some older and younger people, especially those with dementia, will find it difficult to enforce their rights with the result that the Bill does not have the positive effect envisaged. As such, it is proposed that the Bill will place a duty on Patient Rights Officers to signpost people to advocacy services where appropriate. As a result of consideration of the potential impact across a range of equality groups, the Scottish Government will allocate £1.5 million over 3 years to support the development of advocacy services, to ensure those who need assistance in upholding their rights can access appropriate support.

In addition, if a patient’s home Health Board could not meet the 12 week Treatment Time Guarantee, and they were offered an appointment in another Health Board area, there was concern raised by consultation respondents that some patients (including older people) would find it harder than others to go for treatment outwith their home Health Board. There was concern that these groups could suffer if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason. Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision-making process. Where a patient has to travel, appropriate transport arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board.

The Scottish Government expects Health Boards to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is disadvantaged.

Consultation respondents also pointed out that some older people, particularly those with dementia, will be unable to take responsibility for their own health care or medication. There was concern that patients could be penalised if they did not discharge their responsibilities. The Scottish Government notes that the rights of any individual are subject also to meeting the rights of others (this is similar to the concept of qualified rights in the European Convention of Human Rights). The aim of this is also to address concerns about staff-patient interactions and to allow a Board’s responsibility to the individual to be balanced against the Board’s responsibility to all the patients in its area. However, we are clear that even if a patient cannot or does not fulfil their responsibilities, they will still receive the highest possible standard of health care.
Race

Evidence

According to the 2001 Census, the size of the ethnic minority population was 2 per cent of the total population of Scotland showing an increase from 1.3 per cent in 1991. Scotland's ethnic minority populations are considerably younger than the general population: 57% are aged under 30 compared with 36% of the white group.

However, this figure is likely to have increased, especially in the Greater Glasgow area, as asylum seekers were not included in the census figures, and the number of migrant workers has increased since 2001. (Scottish Government/National Resource Centre for Ethnic Minority Health – *Equal Services?* - 2005).

According to an analysis of the 2001 Census, Chinese people are the group that have the highest proportion of people who assess themselves as having good or fairly good health (96%). This is closely followed by people in the "Other Ethnic" group and by Africans with 95% of people reporting good or fairly good health. In contrast, 90% of White Scottish people and only 86% of White Irish people reported good or fairly good health. (Scottish Government – *Analysis of Ethnicity in the 2001 Census: Summary Report* – 2004)

As of January 2009, there are an estimated number of 1,590 Gypsy/Travellers living in Scotland, although it is difficult to obtain accurate counts, due to the mobile lifestyle of this community. Studies of Gypsies/Travellers, such as the 2004 health study of Gypsies/Travellers by Sheffield University and the 2009 Accommodation Needs Assessment of Gypsies/Travellers in Grampian both point to a lower life expectancy and high incidences of chronic ailments among this population.

A Health Scotland working group has recently produced a report paper and from the available evidence we know that health outcomes for Gypsy/Travellers differ for a variety of reasons including:

- access to health services may be affected by: a limited understanding of services; cultural or attitudinal barriers; practical barriers e.g. traveller communities facing difficulties in registering with a GP; the need for key health care messages to be communicated in a culturally sensitive way;
- cultural factors such as diet or attitudes towards exercise;
- mental health - many studies have focussed on the impact of difference, disadvantage or isolation on mental health and the lack of a culturally sensitive response or a lack of understanding of health care providers to respond appropriately to need. (Health Scotland - *Health in our Multi-Ethnic Scotland - Future Research Priorities* - 2009)

Significant inequalities are observed in people from ethnic minorities in both incidence and mortality from Scotland's biggest killers (cancer, stroke and coronary heart disease). For example, South Asian men have a 45% higher incidence of heart attack and South Asian women have an 80% higher incidence, compared with the rest of the Scottish population. (Scottish Public Health Observatory - Cited in *Scottish Government Race Equality Scheme 2008-11* - 2008)
Consultation

As part of the consultation process for the Patient Rights Bill, a minority ethnic communities focus group was organised by BEMIS (Black and Ethnic Minority Infrastructure in Scotland) and was held on 3 December 2008, in Glasgow. There were nine participants representing Jewish, Asian (4), Eastern European/Roma, Gypsy Travellers, Arab and Persian communities. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Members of the focus group felt strongly that there should be increased training on cultural differences for all health practitioners. Group members also raised the issue of access to appropriate food and some felt that hospitals should put the necessary arrangements in place to allow food to be brought in from home.

A member of the Gypsy-Traveller community said that the biggest concern for this community is access to services and especially accessing a GP.

There appeared to be concerns around respecting different cultural needs and wishes. Special dietary requirements, in particular, appeared to be poorly catered for in hospitals e.g. Kosher and Halal. Other examples given were women who did not want to see a male doctor, and circumcision not being carried out at the required age (according to religious vows) because of waiting lists. These things were thought to be simple yet important.

The group felt that information is often communicated in words that are too complicated for many people to understand. This could be because of language barriers or educational barriers. All verbal and written communication should be in plain English. How information is communicated to the community is also important, with participants suggesting that it is not enough to simply translate information into different languages.

Written Consultation:

Written responses were also received from organisations involved with this community, including Chinese Community Development Partnership, BEMIS (Black and Ethnic Minority Infrastructure in Scotland) and Amina Muslim Women’s Resource Centre.

Consultation responses were broadly supportive of the Bill, although there are still some concerns as to how people from ethnic minority backgrounds are treated in the NHS and how culturally sensitive services are.

Comments included:

Patients should be told that they have the right to ask for an interpreter. Healthcare Staff should be aware that if they send letters and appointments out in English, they might need to be translated by a family member, potentially breaching patient confidentiality.
Health services should not assume that family members will interpret at appointments etc. When an interpreter is provided, staff should check the interpreter is not known to the patient.

It should be recognised that patients can only comply with advice on medication and treatment if their rights to communication and access have been upheld.

Other Concerns

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Bill, such as access to food that is culturally appropriate. There is already significant work underway on these issues outwith the Bill. For example, the Scottish Government has published a National Catering and Nutritional Specifications for Food and Fluid Provision in Hospitals in Scotland, which is part of an overall programme of work to improve the nutritional care of patients in Scottish hospitals. The document has a section dedicated to special and personal diets, including information about Halal diets. There is an expectation that where special diets are required, they will be provided.

More generally, the Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and will contribute to addressing these issues.

Impact

Communication

From the evidence gathered, and our consultation work, we know that people from minority ethnic backgrounds often experience difficulties in accessing services that are culturally sensitive and may also experience problems understanding advice or information given to them, due to language barriers. Therefore, as for the other equality strands, the Patient Rights Bill will have a positive impact on the experiences of people from minority ethnic backgrounds when using health services, as it will set out in legislation principles and rights that must be taken into account by health care workers and contract staff (e.g. cleaners, catering staff). This will be accompanied by a training programme to make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and make staff more aware of a range of accessibility issues, which will include cultural awareness and race equality.

In addition, the Scottish Government is providing £750,000 of additional money over 3 years 2010-13 to support the development of the Translation, Interpreting and Communication Service (TICS), which will help to ensure that interpreters and communication support workers are available and that all patients are communicated with in an appropriate manner.

The Scottish Government will also take reasonable measures to ensure that any information and publicity undertaken about the Bill takes into account language needs and cultural issues.
Treatment Time Guarantee

In terms of concerns raised by consultation respondents about waiting times for religious circumcision, all circumcision, whether undertaken for religious or medical reasons is included in the 12 week treatment time guarantee. This means that patients will not have to wait longer than 12 weeks for treatment from the date they agree the treatment with the consultant. The exception to this is where the patient is under 6 months old. In Scotland, doctors agree that circumcision should always be carried out under a general anaesthetic, and as there are clinical concerns about performing general anaesthesia on children under 6 months of age, the procedure will not be performed until the child is at least 6 months old. The operation will usually be carried out as soon as it is safe for the child, at the optimum ages of between 6 and 12 months old.

Gender

Evidence
Data from the 2001 Census shows that 48.05 % of the population are male, and 51.95% are female.

The Scottish Health Survey 2003 said that overall, women were more likely than men to have consulted a GP in the past two weeks (20% vs. 16%) but the reverse was true among those aged 65 and over. Over a third of men and women had visited hospital as an outpatient during the previous 12 months; 9% of men and 13% of women had been admitted as inpatients.

The survey also showed that 42% of men and 54% of women aged 16 and over were taking at least one prescription medication (excluding contraceptives) and the use of medication increased with age. One in five women aged 16-54 were using contraceptive medication.

Inequalities due to some aspects of diversity are well understood. For example coronary heart disease admission rates in Scotland among men are nearly double those of women, and on average, men develop heart disease 10 years earlier than women. (Equally Well: Report of the Ministerial Task Force on Health Inequalities - Volume 2 - 2008) However, women are 2.7 % more likely than men to develop an auto-immune disease such as diabetes. (Fair for All - Improving Gender Equality Practice in NHS Scotland – 2008)

Mental health problems affect more women than men. Specifically, women experience higher rates of depressive disorders than men. However, men are more likely to complete suicide and experience earlier onset of schizophrenia with poorer clinical outcomes than women.
Evidence suggests that the cultural constructions of masculinity can have a negative effect on health, and may contribute to the reluctance of men to access health services or seek help for problems at an early stage for fear of appearing ‘weak’. Research suggests this may make men more likely to self-medicate with drink and drugs than accept they have a mental health problem etc. (Equally Well: Report of the Ministerial Task Force on Health Inequalities - Volume 2 - 2008)

Gender is also has a significant influence on the NHS workforce which is disproportionately female. Data from NHS Workforce statistics 2008 shows that 77.9% of the total NHS workforce (including GPs and dentists) in Scotland is female

Consultation

As part of the consultation process for a Patient Rights Bill a group focusing on gender (and age) took place in Dumfries on 27 November 2008. The group consisted of five male participants and five female with an age range from 20s to 60s. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus group broadly agreed with the rights as laid out in the consultation and felt that the rights around information, communication and participation were closely linked.

Written Consultation:

Written responses were also received from organisations involved with women or with issues that primarily affect women, including Scottish Federation of University Women, the Scottish Women’s Convention, Glasgow South Soroptimists, National Childbirth Trust and the Family Planning Association. There were no responses from any organisations specifically representing only men, although some of the organisations mentioned here deal with both men and women.

Responses were positive and in favour of the principles outlined in the consultation, although there were some concerns about the impact on women.

One consultation respondent was concerned that women need to access abortion and emergency contraception well before the 12 week waiting time guarantee. They suggested that the maximum waiting time for abortion services recommended by the Royal College of Obstetricians and Gynaecologists (3 weeks) should be incorporated as a right in the Bill.

Women are more likely to have caring responsibilities than men, and therefore may not be able to take up treatment in another Board area as a result. It is important that women are not penalised for this or put back to the start of the waiting list.
Impact

We know that men and women can have different attitudes towards health and health care, and that this can affect the way they access health care services, and their health outcomes. As with other equality groups, the Patient Rights Bill will benefit both men and women, as it will set out in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers, such as cleaning or catering staff. This will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues.

As we know that the majority of the NHS workforce is female, making patients more aware of their responsibilities in terms of treating staff with dignity and respect is likely to have a greater impact on women than on men. However, male staff will also benefit.

Treatment Time Guarantee

Similarly to concerns raised by disabled people and older people, there was concern that as women tend to have more caring responsibilities than men, they could be adversely affected by the treatment time guarantee, in that they may be less able to travel outwith their own Health Board area for treatment. There was concern that these groups could be penalised if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason.

Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision making process. Where a patient has to travel, appropriate transport and accommodation arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board. Moreover, we will seek to ensure that Health Boards monitor the delivery and impact of the treatment time guarantee and collect information to aid in the assessment of any differential impact on patients according to the equalities strands.

We expect that Health Boards will specify a requirement to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Health Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is being disadvantaged.

It was suggested by a consultation respondent that the 12 weeks treatment time guarantee was not appropriate in the context of abortion and emergency contraception services, and that the Bill should contain a right to an abortion within 3 weeks, as per the current guidance from the Royal College of Obstetricians and Gynaecologists (RCOG).
However, the RCOG guidelines have already been adopted in Scotland, and are a Key Clinical Indicator for the Sexual Health Strategy and an NHS Quality Improvement Scotland standard. Therefore women are already able to access abortions within the RCOG recommended waiting time.

As emergency contraception is not an inpatient or day case treatment in that the patient does not need to be admitted to hospital, this is therefore not included in the treatment time guarantee. In Scotland, systems are already in place to allow access to emergency contraception within 72 hours through GP surgeries, pharmacies, sexual health and family planning services.

Lesbian, Gay, Bisexual and Transgender (LGBT)

Evidence

There are no precise figures as to how many lesbian, gay, bisexual and transgender (LGBT) people live in Scotland. According to Stonewall Scotland, there are around 300,000 gay people in Scotland which equates to 6% of the population. Scottish Public Health Observatory figures record that around 5% of men and women report ever having had a same sex partner. It is generally accepted that LGBT people make up 5 to 7% of the population of Scotland. (Cited in Scottish Government - Challenging Prejudice: Changing Attitudes towards Lesbian, Gay, Bisexual and Transgender People in Scotland – 2008)

The NHS Inclusion Project found in 2003 that 25% of LGBT people in Scotland had experienced inappropriate health advice or treatment due to their sexual orientation or gender identity and that this can have a negative effect on self esteem, leading to mental and physical ill-health.

Stonewall's report, Towards a Healthier LGBT Scotland (2003) found that: "Low self-esteem, anxiety and depression are common experiences for many LGBT people. These in turn can be linked to other health concerns including higher than average rates of suicide and self-harm, and homelessness, often associated with prostitution and academic underachievement, is also linked." A health needs assessment of young LGB people in Glasgow found rates of self harm of 29% among men and 65% among women; this is compared to rates of around 10% for the general population.

According to the report of the LGBT Hearts and Minds Agenda Group, LGBT people are also at greater risk from poorer sexual health as they fear ‘coming out’ and lack appropriate and inclusive education. It is also well documented that LGBT people are more likely to drink, smoke and use illegal substances than the general population. (Scottish Government – Challenging Prejudice: Changing Attitudes towards Lesbian, Gay, Bisexual and Transgender People in Scotland – 2008)
Discriminatory attitudes, low disclosure rates of sexual orientation and the limited knowledge of service providers result in LGB people using health services less than the general population. Those transgender people who do access services tend to use them more due to ongoing health care needs. International surveys show that LGBT people are likely to access health care services after specific problems arise, and present later in an illness when it is potentially more difficult to treat. A lack of targeted health promotion and poor information on the risk of certain conditions can lead to reduced screening for LGBT people on a range of issues (NHS Scotland – Towards a Healthier LGBT Scotland – 2003)

Transgender people reported very positive experiences of using sexual health services, but were least satisfied with NHS24 and mental health services. This related to fears of how unfamiliar medical professionals would react to disclosure of transgender status (NHS24) and lack of understanding and knowledge about transgender issues by general psychiatrists, leading to inappropriate treatment and long delays in accessing assessment by an experienced gender specialist. (Scottish Transgender Alliance – Transgender Experiences in Scotland Research Summary – 2008)

Consultation

As part of the consultation process for a Patient Rights Bill a focus group for lesbian, gay, bisexual & transgender (LGBT) people took place in Edinburgh on 2 December 2008. There were eight participants who were recruited from both the LGBT Centre for Health and Wellbeing and the Equality Network’s contact lists. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Participants were broadly in favour of the rights outlined in the consultation, and some specific points raised were:

- Some participants felt that there should be explicit mention of gender reassignment, gender identity or gender expression in the consultation document, because there is a big problem with how transgender people are treated by hospital staff.
- Concern was expressed about privacy and confidentiality of medical records, and staff who did not need to know finding out someone’s sexual orientation or gender identity.
Written Consultation:

Organisations in this community did not submit any written responses to the consultation, although 2 LGBT organisations were emailed specifically to draw the consultation to their attention. This indicates that the consultation may not have been promoted enough to these communities, or through the right outlets, or there may be other barriers to response within the LGBT sector. It may be that LGBT communities did not feel the consultation had any relevance for them, despite all we know about LGBT access to health and the problems and barriers that many experience. It may also be that organisations within the LGBT sector are less well resourced than some other equality groups, and don’t have the capacity to respond within the timeframes. These are issues that require further consideration for any further consultation and engagement work undertaken on the Patient Rights Bill, and also during the parliamentary stages.

Consultation Post-Introduction

As a result of not receiving any written consultations from organisations representing the LGBT sector, Scottish Government officials met with 2 LGBT organisations (Equality Network and Scottish Transgender Alliance) post-introduction of the Bill to Parliament. The main points raised were:

- There should be specific mention of equality in the primary legislation, for example, like the equality clause in the Housing Act (Scotland) 2001.
- However, it is difficult to enforce or regulate equality
- When the Common Services Agency (CSA) procures the Patient Advice and Support Service (PASS), need to ensure that they pass on the equality duties they are subject to in the procurement process and contract.
- The contract for PASS should include a clause on equality training.
- Patient Rights Officers should have specific training on transgender issues, as there is a historical exclusion of this group of people.
- There should be a clause in the secondary legislation that specifically includes transgender people, as there is a fear they will be excluded unless explicitly included.
- Transgender people are concerned that although not the SG current intention, gender reassignment surgery will end up being tucked into the groups excluded from the TTG. For example, at the moment the procedures are excluded from the 18 weeks Referral to Treatment Target, because the procedures have been included in the Aesthetic Referral Protocol. The transgender community disagree with this categorisation and see these procedures as part of the treatment for a medically recognised condition (gender dysphoria) rather than as a cosmetic procedure. Transgender people are already experiencing considerable difficulty accessing surgery in Scotland and are concerned that the introduction of the TTG will not help this issue.
Impact

We know that LGBT people often face barriers to accessing health services, and often report receiving inappropriate treatment and services. Therefore, similarly to other equality strands, the Patient Rights Bill will have a positive impact on LGBT people, as it will set out in legislation principles and rights that must be taken into account by healthcare workers and staff contracted by healthcare providers such as cleaning or catering staff. This will be accompanied by a staff training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues, including LGBT equality.

The Scottish Government’s discussions with LGBT organisations indicate that as described above, the Patient Rights (Scotland) Bill should have a positive impact on LGBT people. However, there are also some potentially less positive impacts, particularly for the transgender community.

General Principles

It was suggested that there should be an equality clause in the primary legislation of the Bill. Currently, equal opportunities is reserved to the UK Government, therefore the Scottish Government has limited scope to introduce equality issues into primary legislation. However, one of the principles focuses of the Bill is to provide more support to patients when they receive healthcare, and to ensure that the healthcare received takes into account the individual needs of the patient, which the Scottish Government believes will help to make the health service more equitable and accessible. It is the Scottish Government’s intention that there will be more specific mention of equality issues in the secondary legislation to the Bill.

It was also suggested that there should be specific mention in secondary legislation that transgender people are included in the Bill. The Scottish Government is clear that the rights set out in the Bill relate to everyone, including transgender people. The Scottish Government will endeavour to ensure that it encourages health care providers to be aware of the needs of transgender people and that training on transgender and other equality issues will be part of the staff training packages attached to the Bill.

Treatment Time Guarantee

In the post-introduction consultation, the issue of treatments for gender dysphoria being excluded from the Treatment Time Guarantee (TTG) was raised. The Scottish Government is clear that the TTG will apply to treatments that are planned and elective, and delivered on an inpatient or day case basis. There will be a very small number of exclusions, which will not include procedures or treatments likely to be used to treat gender dysphoria. The TTG will start once an eligible patient and the consultant have agreed to the specific treatment. This does not affect the current procedures in place for psychological assessment and reflection which must take place before surgical or other interventions take place.
Patient Advice and Support Service and Patient Rights Officers

It was suggested when speaking to LGBT groups that when the Common Services Agency (CSA) procures the Patient Advice and Support Service (PASS), they need to ensure that they pass on the equality duties they are subject to in the procurement process and contract, and that the contract for PASS should include a clause on equality training. It was also suggested that because transgender people are a historically excluded group, that Patient Rights Officers should have specific training on transgender issues.

The needs of all equality groups will be considered in the design, development and delivery of the PASS service and the Scottish Government will expect the provider of the PASS to ensure that its employees undergo equalities training.

Training for NHS staff will be provided through NES. NES are undertaking to develop both generic person-centred approaches to training, as well as work to develop educational resources to enable staff to support particular client (patient) groups. There are particular client groups which are likely to experience barriers to accessing their rights and participating fully in their healthcare and this includes transgender people. Targeted educational materials to support these vulnerable groups will be required to help staff address their individual needs.

It is recognised that PASS must be accessible to all and that Patient Rights Officers will also need to be accessible and responsive to the individual needs, background and circumstances of people’s lives.
Religion and Belief

Evidence

According to the 2001 Census, more than six out of ten people said that their religion was Christian (65%). After Christianity, Islam was the most common faith with 426,000 people in Scotland describing their religion as Muslim. This is followed by people from other religions (27,000), Buddhists (6800), Sikhs (66,000), Jews (6400) and Hindus (5600). These groups each accounted for less than 1% of the Scottish population. Added together these groups accounted for less than 2% of the overall population.

This group is likely to face some of the same issues as minority ethnic people when accessing health care, such as lack of cultural knowledge, support and language barriers.

Research has shown that religious involvement is associated with positive mental health outcomes. A growing number of studies also emphasise the importance of spiritual beliefs and the value of support from faith communities for people with mental health problems. Other studies have found a resistance to spiritual issues within mental health services, where religious beliefs are sometimes interpreted as symptoms of illness. (NeLH in collaboration with Mentality - Models of Mental Health Promotion – 2004)

Some patients find that their religious or spiritual beliefs help them cope better with their illness. Because of this, religious beliefs often influence medical decisions, especially those made when illness is serious or terminal. Many patients would like physicians to address their spiritual needs and to support them in this area. Furthermore, a growing research database indicates that in the majority of cases, religious beliefs and practices are related to better health and quality of life. (NHS Scotland Fair for All – Religion and Belief Matter – 2007)

Consultation

As part of the consultation process for a Patient Rights Bill a religion and belief focus group took place at Central Mosque, Glasgow, on 1 December 2008 and was organised by the Scottish Inter Faith Council. There were twelve participants and the religious faiths and beliefs represented were; Baha'i, Buddhist, Christian (Catholic and Protestant), Hindu, Humanist, Islam Jain, Jehovah's Witnesses, Jewish, Mormon, Pagan and Sikh. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Some of the issues raised were lack of understanding by staff of religious and faith beliefs and there was also discussion about the degree to which patients could be expected to disclose their religious beliefs to staff. Focus group members also said it could depend on how ill someone was, as to whether or not they would let staff know about their religious beliefs or needs. The group also acknowledged that there would be circumstances when clinical need would have to take priority over religious needs.
**Written Consultation:**

Several written responses were also received from organisations involved with this community, including Scottish Churches Committee on Healthcare Chaplaincy, Amina - Muslim Women's Resource and the Catholic Bishops' Conference Scotland.

Respondents were broadly in agreement with the consultation proposals; some of the comments raised included:

The right to dignity and respect can only be upheld if NHS staff respect the culture and beliefs of the patient.

Muslims want to be treated by a member of staff of the same sex, and this should be respected and should not be optional.

Muslims’ faith may be an integral part of their palliative care, and this should be understood and supported.

Muslim women want to be examined by female staff only, and need hospital clothes that respect their modesty. They also need to be accommodated in female only wards when in hospital.

Concerns about timely access to religious circumcision for babies.

**Other Concerns**

There were also other concerns and issues raised by consultation respondents, like the availability of appropriate meals, such as Halal. However, there is already significant work underway to address these issues outwith the Bill. For example, the Scottish Government has published a National Catering and Nutritional Specifications for Food and Fluid Provision in Hospitals in Scotland, which is part of an overall programme of work to improve the nutritional care of patients in Scottish hospitals. The document has a section dedicated to special and personal diets, including information about Halal diets. There is an expectation that where special diets are required they will be provided.

In addition, the Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and will contribute to addressing these issues.
Impact

From the evidence collected and our consultation work, we know that having a religious belief may be beneficial in terms of coping with illness, but that people with religious beliefs often find that services are not sensitive to their spiritual needs. In terms of the Patient Rights (Scotland) Bill, again there will be a positive impact on this group, as the Bill aims to promote a culture of dignity and respect, and will set out in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers such as cleaning and catering staff. This will be accompanied by a staff training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues, including awareness of and sensitivity to religious beliefs and practices.

Treatment Time Guarantee

In terms of concerns about waiting times for religious circumcision, all circumcision, whether undertaken for religious or medical reasons is included in the 12 week treatment time guarantee. This means that patients will not have to wait longer than 12 weeks for treatment from the date they agree the treatment with the consultant. The exception to this is where the patient is under 6 months old. In Scotland, doctors agree that circumcision should always be carried out under a general anaesthetic, and as there are clinical concerns about performing general anaesthesia on children under 6 months of age, the circumcision will not be performed until the child is at least 6 months old. The operation will usually be carried out as soon as it is safe for the child, at the optimum ages of between 6 and 12 months old.
**Overall Conclusions**

**Changes to Policy?**

Detail on changes we have made to the Bill, is set out in the analysis of adverse impacts and solutions for overcoming these for relevant equality groups at Step 4 of this EQIA.

The Scottish Government has considered in detail any negative or unintended effects created by the Bill, and has taken steps to mitigate and eliminate these, including by providing additional targeted resources, and by considering how the eventual implementation and communication of the rights set out in the Bill will be undertaken. The Scottish Government will continue to monitor the potential impacts on equality groups as the Bill progresses through the parliamentary stages by considering evidence presented by equality groups, and by continuing to engage with key equality stakeholders, and will consider any changes accordingly.

**Promoting Good Relations**

The Patient Rights Bill will provide an excellent opportunity to promote equality of opportunity and good relations across and between different equality groups. The Bill aims to contribute to a patient-focused NHS, in which individual needs are considered and where patients feel that they have a say in their own treatment, and that their wishes are listened to and respected. The Bill will contribute to building a mutual NHS, in which patients and the public are affirmed as partners rather than recipients of care, and will help to ensure that all those who work for NHSScotland respect the expertise of patients and their carers and improve the way in which they communicate and involve patients in the decisions that affect them.

The Bill will set out in legislation principles and rights that should be taken into account by health care workers and will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of equality issues. Training and awareness raising will include equality issues across all strands, and we envisage that this will particularly emphasise to staff the importance of access and communication issues.

Another way in which the Bill will have an impact on promoting equality of opportunity is in terms of the additional funding we will provide to support the development of the Translation, Interpreting and Communication Service (TICS). This will help to enable people to access services more easily, and to be communicated with in an appropriate manner that allows them to be partners in the own care and to understand their rights and responsibilities.

The Patient Advice and Support Service, Patient Rights Officers and the complaints process will also promote equality of opportunity by providing support and advice to people who may not otherwise be able to or know how to raise a complaint or issue about the health service.
Providing additional funding to support advocacy services will also help to promote equality of opportunity by enabling more people who cannot uphold their rights on their own to be supported when using the health service, or when making a complaint.

**Is a Further Impact Assessment Needed?**

There is sufficient evidence of the interaction between equality groups and access to and experiences of health care services to be able to undertake a meaningful EQIA. The Scottish Government has also consulted extensively as part of the Bill consultation, and has met separately with organisations representing equality groups, particularly with those representing disabled people. There will be further engagement with people and organisations from across the equality strands as part of the ongoing parliamentary process, and we will reflect on any issues identified in the EQIA.

One group with which there has been the least engagement is lesbian, gay, bisexual and transgender (LGBT) people and organisations, although there was a focus group with LGBT people as part of the Bill consultation process. The Scottish Government believes that the Bill will have a positive impact on LGBT people, but is aware that there will need to be further engagement as the Bill enters the parliamentary stages which we will reflect in the EQIA.

**Update** – Since the Bill was introduced to the Scottish Parliament, the Scottish Government has met with Equality Network and Scottish Transgender Alliance, both organisations representing the LGBT community in Scotland, to discuss the Bill and its implications for LGBT people. The groups were generally positive about the potential of the Bill to have a constructive impact on the way that health care is provided to LGBT people, but concerned about how the Bill would be enforced. For a fuller discussion of the issues raised, please see the LGBT section of this EQIA (above).

**Monitoring**

The Scottish Government will be monitoring the impact of the Patient Rights Bill through a number of avenues. One of the ways in which compliance with patient rights legislation will be monitored is through the “Participation Standard”, which NHS Boards in Scotland will have to meet from April 2010 to show that they are involving the people who use their services. The Participation Standard consolidates existing standards, guidance and practice statements into a more structured and cohesive framework, focusing on three key areas: Patient Focus; Public Involvement; and Corporate Governance of Participation. Each key area is supported by a wide range of criteria against which Health Boards must demonstrate the actions they have taken.
Better Together: Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focussed services by health boards, which reflect the principles raised in the Bill. Better Together will use an evidence-based approach, including surveys, focus groups and the collection of patient stories, to find out about patients’ experiences of their care in the NHS. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so. Further work will be undertaken with those who may find it difficult to complete surveys for communication, impairment or other reasons.

Furthermore, as part of the government’s work developing the proposed Quality Strategy for NHS Scotland, we have committed to exploring a range of measures that will demonstrate improvements in the delivery of patient-focused care. We are investigating the possibility of using a Patient-reported outcome measures (PROMS) based approach to do this.

In terms of the Patient Advice and Support Service (PASS), the contract specification which will be drawn up by the Common Services Agency will include details of how the service will be monitored and the statistical information that Health Boards should receive from the service, which will include equality monitoring. Currently the Scottish Health Council has a role to monitor the existing Independent Advice and Support Service, and it is envisaged that this role will continue for PASS.
Patient Rights (Scotland) Bill:
Stage 1

10:02

The Convener: Item 3 is our first oral evidence session on the Patient Rights (Scotland) Bill. Two panels of witnesses will give evidence today, the first of which consists of officials from the Scottish Government's bill team. I welcome Lauren Murdoch, bill team leader; Fiona Montgomery, head of patient support and participation division; Alastair Pringle, head of patient focus and equalities; Margaret Duncan, waiting times policy lead; and Kathleen Preston, health and community care solicitor, who is from the Scottish Government legal directorate.

As we have a series of extremely helpful cover notes from the bill team, as well as a regulatory impact assessment and an equality impact assessment, as part of our papers for the meeting, I do not think that the committee requires any opening statement. We are under time pressure today, so we will move straight to questions.

Helen Eadie (Dunfermline East) (Lab): I would like to ask the bill team a question about the evidence that we have received. A number of submissions questioned the concept of providing rights with no sanctions in the event that those rights are not met. Some organisations—in particular, Age Scotland—went as far as to question whether they could be considered as legal rights at all. I invite the bill team to respond to that.

Fiona Montgomery (Scottish Government Healthcare Policy and Strategy Directorate): The Government feels that patient rights are extremely important. One reason for having a bill is that we want to put patients at the heart of the NHS, and we think that having rights in primary legislation gives them the priority and prominence that they require.

In an early debate that was held on the bill, members in the Parliament made it clear to us that they did not want a lawyers' charter around the bill, so we have tried hard to develop a bill that will give people rights but which will not take it to the next stage, which could result in there being a lawyer by every bedside, with people suing any time they think that their rights have not been met.

Helen Eadie: I hear what is being said, but I will make my own mind up on that issue and so will everybody else.

The rights in the bill will not be legally enforceable, but a patient could still seek a declaratory judicial review. People may or may not know that that is a pronouncement that an individual or a body has a specific right or duty. It is a useful remedy when the petitioner wants to establish that a particular right exists or that a particular status applies when that has been doubted or denied. The judicial review usually has various other legal remedies available alongside declarators, but in this case other remedies—damages, specific implement, interdict and suspension—would be removed by section 18. Therefore, not only does the bill not introduce any new sanctions, it removes sanctions. This is one of those worrying situations in which patients are, in effect, having rights removed.

The Convener: A lawyer here was about to answer the question, but I remembered that, as I am in the chair, I must not answer it.

Kathleen Preston (Scottish Government Legal Directorate): Perhaps I could answer it.

The bill will not remove any rights that patients have under the existing law. At the moment, patients have the right to seek judicial review in certain circumstances when there was a question about the legality of a decision or the process by which it had been arrived at. That is a general principle that applies to decisions of public bodies and that will not change.

What we are saying in the bill is that there will not be a right to claim the remedies that we have excluded—for example, damages—for any alleged breach of the rights that are set out in the bill, so the rights that are in the bill will not in themselves give rise to a set of legal remedies. That is the Government's position.

Helen Eadie: Convener, I am grateful for that answer and I have no more questions, but I do not think that the witness really answered the point that section 18 in fact removes the legal remedies.

The Convener: You are right. I think that Ross Finnie is on the same trail.

Ross Finnie (West of Scotland) (LD): Yes, I would like to pursue the issue a little, if I may.

I make it clear at the outset that I do not contest the importance of patient rights. I do not contest the need for the patient rights that currently exist to be brought together and codified in a more easily understandable way, but I have concerns about the legal import, because the committee is after all being asked to consider a parliamentary bill, which will become law, and I think that we are entitled to ask why we are doing that.

I have two documents in front of me. One you will instantly recognise as the Patient Rights (Scotland) Bill. I hope that you will also recognise the other, as it is "The NHS and You", which is the currently available publication by the health rights
Ross Finnie: No—I am sorry, but I must interrupt you. My question is very simple. From the perspective of the ordinary citizen, what would be the difference in law between the status of the bill, were it to become law, and the status of the HRIS document?

Kathleen Preston: You have said that the bill would be unenforceable, but my colleagues would disagree with that, as I would.

Ross Finnie: The Law Society of Scotland has said that it would be unenforceable.

Kathleen Preston: The Law Society is entitled to its view, but the Government’s position is that the bill will specify in primary legislation rights that patients will have. The treatment time guarantee—

Ross Finnie: I know what it will specify, but how will it be enforced? What power in the bill makes it enforceable?

Kathleen Preston: Within the bill there is a set of remedies that would be available to patients. My colleagues will be able to expand on that. The policy is that the new rights will not lead to court actions by individual patients. No doubt, my colleagues can give you more information on that policy. That does not mean that the rights will not be legal rights.

Ross Finnie: With respect, I did not say that. I did not say that they would not be legal rights; I said that I would have no opportunity to enforce them. They would be legal rights—fine, but that would not affect me one jot. They would be no different from what is stated in the HRIS document. I even have rights of judicial review according to that document.

Kathleen Preston: Those rights will not be removed, but there will be a statutory right to complain and a statutory treatment time guarantee. Those rights will be matters of law. Health boards, as a matter of law, will be obliged...
to comply with the provisions of the act. However, it is not the policy that individual patients will be able to sue in court for individual remedies for alleged breach of these rights. I think that that is probably as far as I can go.

10:15

The Convener: I think that the cabinet secretary might have to answer other parts—

Ross Finnie: It is a matter of law—

The Convener: I heard the law bit.

Ross Finnie: I accept that we are getting terribly close to a policy issue rather than a legal issue. However, the 1978 act gives wide powers to the cabinet secretary—obviously, it refers to the secretary of state—in terms of the establishment of health boards, the amount of care that is to be provided and the right of the cabinet secretary to do such things as will ensure the procurement of those services. I am not entirely clear about what is new different, as a matter of law. The things that are contained in the HRIS document might not have the force of law in the sense of being part of primary statute, but they have all been made by the utterances either of a secretary of state or a cabinet secretary under the powers that those individuals have under the 1978 act. I am not sure what difference will be made by our having a non-enforceable series of regulations.

Kathleen Preston: I can only respond to that on the legal side; other responses would be for others to give. The legal answer to your question is that, as I said earlier, the bill will set out those provisions in primary legislation and Parliament will have decided on the content of the bill and the rights in the bill. As you have correctly identified, ministers have wide powers under the 1978 act. However, those are powers of the Executive that ministers must exercise as they see fit, within the provisions of the law. They are powers that are being exercised by the Government. However, the provisions and rights in the bill are rights that are set out in primary legislation, as sanctioned by Parliament.

That is probably about as far as I can go in that explanation.

The Convener: I think that we have clarity now that nothing in the bill is enforceable in a court of law.

Kathleen Preston: That is correct, other than the normal judicial review—

The Convener: However, if there were an action for damages for medical negligence and it rested on a failure to obtemper the waiting time between agreement on treatment and start of treatment, could this be relied on as persuasive?

Kathleen Preston: I think that, in answering that, I might be straying into giving legal advice to the committee, which is, of course, not within my remit. I should make it clear that nothing in the bill will affect any existing rights of patients to sue for medical negligence.

The Convener: But it might be persuasive. I am not asking you to give a definitive answer, but is it something that could be relied on by solicitors, who might say to their clients, "You weren't treated within 12 weeks; you had to wait 20 weeks, and that was a substantive factor in the deterioration in your health"?

Kathleen Preston: I think that it would be wrong for me to speculate on the arguments that my colleagues might or might not make.

Dr Simpson: Like Helen Eadie, I am concerned about the rights that people will ultimately have. Section 18(2) states:

"Nothing in this Act gives rise to—

(a) any liability to pay damages,

(b) any right of action for specific implement,

(c) any right of action for interdict,

(d) any right of action for suspension."

I want to be clear about this. If I want to claim a right under the bill, whether it is a new right or not, and I want compensation, I cannot claim for damages even if I am suing on the ground that failure to provide me with my right was negligent; nor can I claim for specific implement, interdict or suspension.

Kathleen Preston: Yes. The intention is that if the only ground of claim is an alleged breach of one of the rights in the bill, that in itself will not give rise to any of those remedies. However, if someone has suffered personal injury as a result of some fault or negligence on the part of someone in the health service, that is not within the terms of the bill and is not affected by the provisions of the bill.

Dr Simpson: The point that Ross Finnie was trying to make was about what the ordinary punter is to understand by the bill. All members deal with complaints about the health service, although not daily, I am glad to say, because there are not that many complaints relative to the turnover in the health service. Are you saying that, when we advise our constituents, we will have to decide whether their complaints fall within or outside the scope of the bill? Will we have to consider which bit of someone's complaint is related to the bill and is therefore unenforceable and which bit might be enforceable and can be pursued? It seems to me that the bill is complicating and not simplifying things for ordinary members of the public.
The Convener: Ms Preston, let me give you a break. I know that you are perfectly capable of responding and I am not undermining you in any way, but perhaps the other witnesses want to pitch in.

Fiona Montgomery: The bill is the first part of the exercise; there will be regulations, directions, guidance and information for the public. People will not have to decide whether their complaint is in or out just by looking at the legislation; there will be more guidance and advice. That is why the bill provides for patient rights officers, who will help people to make their way through the system.

Rhoda Grant (Highlands and Islands) (Lab): I—

The Convener: Hang on a minute, Rhoda. May I let Mary Scanlon in? She has been waiting patiently to come in after Richard Simpson asked his B-list supplementary question.

Mary Scanlon (Highlands and Islands) (Con): Like other members, I am struggling to understand why the bill is necessary. The sceptics are not just round this table. Consumer Focus Scotland said:

“Consumer Focus Scotland starts from the position that patients in Scotland already have rights in relation to the healthcare they receive. These rights go well beyond those mentioned in or created by the Bill.”

I found the evidence from Consumer Focus quite persuasive.

We also heard from the Scottish Public Services Ombudsman, who works well with health boards on complaints—I have always found his office to be exceptionally helpful when I have been dealing with complaints from constituents. The SPSO set out a list of recommendations that he has made to NHS boards and said:

“The provisions in the Bill do not address the above issues in detail”.

Like members, Consumer Focus and the SPSO seem to be striving to find a justification for the bill. The complaints system that we have is good and, in the areas in which it is not so good, it is improving by the day. Will the witnesses respond to the evidence from those organisations, from which we will hear later this morning?

Fiona Montgomery: The SPSO said elsewhere in his submission that the bill “confirms and makes explicit rights”, which may be “a useful addition to current initiatives to assure and enhance the quality of health services”—

Mary Scanlon: Sorry, but the point is—

The Convener: Excuse me, Mary, hang on a second, please.

Mary Scanlon: I asked a question. I did not ask the witness to quote from another part of the submission. I asked her to respond to the point that I raised.

The Convener: Before the witness does that, I ask members to let witnesses conclude what they have to say. Members might not be happy about what is being said, but let the witnesses conclude and then challenge, just so that the Official Report of the meeting is not broken up with interruptions.

Mary Scanlon: I just want an answer to the question.

The Convener: Ms Montgomery, will you finish your answer, after which Mary Scanlon can come in and challenge?

Fiona Montgomery: Okay. As I said, there are existing legal rights. For example, people can see their health records. Some things are out there already. There are also what we could call expectations, rather than legal rights. However, we have found that people still have difficulty exercising those rights, which is one reason why we are moving forward. We want mutually beneficial relationships. As all the health interactions go on, we want patients to be active participants in them, so that they have a shared understanding that leads to better health outcomes, because people will be better informed.

We have been making progress on complaints. We commissioned a report a couple of years ago to find out about barriers to making a complaint, which found that many people have issues with the health service but do not raise them for a variety of reasons. We have been working hard to bring that into what we might call the bill package—some issues will be dealt with in regulations, directions, guidance and so on. Although we believe that the health service complaints process is a good one among the public service complaints processes, we still think that there are issues for patients in using it. If we give people a legal right to complain, they might feel that they can exercise it more than they have done, as there has been a barrier in the past.

The Convener: Now is your moment, Mary. I was always going to let you back in.

Mary Scanlon: Thank you.

I am speaking on behalf of the Scottish Public Services Ombudsman, who is in a good position to make these points. His submission states:

“With the exception of the treatment time guarantee, the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist.”

Given that we are arguing about the law, I point out, if I may, that the SPSO goes on to state:
"The notion of enshrining these rights and principles within primary legislation carries the risk of an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS."

I do not see that as a positive way forward, or that it will help patients in any way. I ask for a response to that.

**Fiona Montgomery:** Throughout the process, including the consultation, we have said clearly that the bill is not about creating a new set of rights for people. There are one or two new rights, such as the treatment-time guarantee and a legal right to complain, but we are bringing together a range of things, some of which, as Ross Finnie said, were in “The NHS and You”, and which were expectations in the past.

**Ross Finnie:** I am sorry to witter on about this—

**The Convener:** You never witter, Ross.

**Ross Finnie:** What exactly do you mean by the phrase “legal right to complain”? You have used the phrase two or three times now. Can you please point out to me which section in the bill gives people a legal right to complain?

**Kathleen Preston:** Perhaps I can answer that. Section 1(3) states:

“It is the right of every patient to make complaints and otherwise raise concerns and give feedback about health care received.”

**Helen Eadie:** But there are no sanctions.

**The Convener:** Go on, Ross.

**Ross Finnie:** Is that a new right?

**Kathleen Preston:** It will be the first time that the right has been set out in primary legislation.

**Ross Finnie:** So the rights that are referred to in the document to which I referred earlier should have had a health warning saying, “We’re telling you in this patient rights information leaflet that you have a right to complain but, actually, you don’t”? Is that what we are saying?

**Kathleen Preston:** No, that is not what I am saying.

**Ross Finnie:** So we already have the right—it is not a new right.

**Kathleen Preston:** I am saying that it will be the first time that the right has been put on the statute book in primary legislation.

10:30

**Ross Finnie:** Will you help us out and explain the difference? Previously, I was told that I have a right to complain; it is set out in the pamphlet, “The NHS and You” and, indeed, in every pamphlet published by every health board. What is the difference between the rights that have been conveyed to me in those pamphlets and this new legal right? What difference will that make to me as an ordinary citizen?

**Kathleen Preston:** As I said, the difference is that the new legal right will be set out in primary legislation. The consequences of having in the Patient Rights (Scotland) Bill the right to complain are set out in further sections of the bill that deal with complaints procedures, on which my colleagues are able to expand.

**The Convener:** May I clarify something? You are saying that a patient will not have more or less of a right than they already have; you are simply putting that right into a document that is like a road map. It says, “Here are the things that already exist for you, but we have put them here so you can find them more easily”, including in future guidance and subordinate legislation. Is that your point?

**Kathleen Preston:** All that I can say about the right to complain is that the policy is to put the right in primary legislation.

**The Convener:** We are on to policy matters now. I do not want to stray into that area because it is not your territory—it would be unfair to go into the Government’s policy.

**Helen Eadie:** It is not about a lack of accuracy. The bill will remove one of the sanctions under section 18—the path to judicial review. Patients do not have any rights if they do not have sanctions.

**The Convener:** I do not think that you can remove judicial review per se, but I do not want to give legal advice from the chair.

**Helen Eadie:** It is in the Scottish Parliament information centre briefing; it does not come from me.

**The Convener:** I sometimes have issues with SPICe, but I am not going to deal with its briefings at the moment, although I hasten to add before I offend some of the personnel that I do not refer to the briefing that has been mentioned by Helen Eadie. I have already offended many people including cricketers of the world and God knows who.

I want to move on.

**Rhoda Grant:** My question is about the treatment time guarantee in the bill. We have a current waiting time guarantee delivered by the ministers. My understanding is that if the NHS is in breach of your waiting time guarantee as it currently stands, you can use that fact in a court of law if you suffer detriment. Going by the answers to other committee members’ questions, to have a treatment time guarantee in the bill appears to be a retrograde step because it would remove a
patient’s right to legal redress if there were a breach.

Kathleen Preston: I cannot express an opinion on what the position is if the existing waiting time targets are breached. I am afraid that I cannot comment.

The Convener: We accept that we are not here to seek counsel’s opinion from you.

Rhoda Grant: Currently, nothing prohibits a member of the public from going to the courts if their waiting time guarantee has not been met and they have suffered detriment. It is clear in the bill, however, that if your treatment time guarantee is not met you cannot do that. It seems to me that the treatment time guarantee and the waiting time guarantee are one and the same thing.

The Convener: Perhaps we should raise with the minister that conflict about removing rights or not. I think that members will agree that we have exhausted the topic with the witnesses who are present. However, it is certainly a concern that we should raise with the cabinet secretary and her ministerial team when they appear before us.

What is Rhoda Grant’s next question?

Rhoda Grant: My next question is about the patient advice and support service, which I understand will take over in part the role of the independent advice and support service. Does every health board area currently have an independent advice and support service?

The Convener: Are there any other volunteers to answer that question? You do not get a cup of tea if you do not answer a question—you will be out of the tea brigade. Some of you are too comfortable sitting there.

Fiona Montgomery: Every health board has an independent advice and support service, although they all started at different times. We have asked boards to extend those contracts until the end of March 2011.

Rhoda Grant: Other than being a national body, how will the new service differ from what is already in place?

Fiona Montgomery: One of the main differences is that the service will be nationally consistent. Because each board has had a different contract, some of the contracts differ slightly in respect of access to and availability of the service. One of the main changes will be that the service will be consistent under one contract. That does not necessarily mean that there will be one provider—there may be an umbrella of providers—but there will certainly be one contract.

The other difference is that patient rights officers will have a slightly wider remit. Alastair Pringle may want to say something about that.
provision. The service will be able both to provide elements of broader holistic advice and information, and to signpost to other existing sources.

Rhoda Grant: That seems to be a retrograde step, from the patient’s perspective. We should look at the service that is available to people. Instead of meeting one person who will deal with all of their concerns and worries, people will have to meet one person who will deal with their health service complaints. That person may be able to advise them on other issues, but they will have to find someone else who can help them to deal with those issues. By definition, patients are people who are not feeling well and may be at their lowest. They need help and support almost immediately and do not need to have to go rooting around, speaking to different people and making appointments.

The new service will cost in excess of £3 million per annum. It seems to me that there would be a way of changing the contracting arrangements to a national contract rather than several local contracts, which would surely have a cost saving as you would be contracting once rather than several times. There could be an opportunity to amend the system, deal with the problems that exist, save money and ensure that the service to the patient is not affected in any detrimental way.

Alastair Pringle: Much of what will be in the patient advice and support service is still being developed as part of the national service specification. That is being done by building on the evaluation of the independent advice and support service and working in partnership with health boards and others. Some of the detail of what will be in the PASS has still to be developed.

I acknowledge Rhoda Grant’s comments about a national contract being able to save money. One issue from the evaluation was that a lot of patients are not aware of the service and that there are not necessarily enough staff available for patients. The key aim of the independent patient advice and support service is to offer advice and support to patients individually, so any increase in funding is directly aimed at being able to offer greater accessibility and quality of service.

I reiterate the points that we do not want to duplicate the existing good practice but that the independent patient advice and support service will use sources of advice, such as NHS inform and Citizens Advice Scotland, and draw on their information. Both provide holistic health and wellbeing information, and none of the sources sits in isolation from the others. The Scottish Government believes that the system is building on what exists rather than isolating it or taking a retrograde step.

Rhoda Grant: It just seems to me that the service is another layer that someone has to deal with. Although I understand and commend the wish to improve and develop the service, I cannot help but think that there is an easier and more holistic way of doing it than by setting up a new bureaucracy with the costs and so on that are involved. However, that is a policy issue, so I should not be asking about it.

The Convener: In the impact assessment, you talk about legal aid and the impact on the legal advice and assistance system. I note that PASS will assist patients to make a complaint or raise feedback about the health care system, so do you think that it could save money for the advice and assistance part of legal aid?

Fiona Montgomery: Those are obviously difficult things to quantify, but we definitely think that helping people to get through the first part of the process—which includes complaints, feedback and possibly disciplinary or negligence cases—will make a difference to how cases go forward. I am not saying that we will reduce the number of complaints, but we are interested in getting early resolution for people on issues that have arisen. We hope that the patient rights officers will be able to help with that.

Complaints and feedback are obviously important to boards in learning and improving services, so we want to get that information, and to resolve issues, as quickly as possible.

The Convener: I appreciate that you will not give legal advice to people on whether they have remedies and so on, as that would not be the role of PASS. I am just interested to see whether, once PASS is in place, constituents will go to it instead of to MSPs or to legal advice and assistance to ask what they can do—reducing, we hope, the advice and assistance bill. Also, advice and assistance is means tested, so people who would normally have to pay for assistance will get it, too. Is that one of the aspirations for the PAS service?

Fiona Montgomery: Yes—but, as you say, it would not be full legal advice. It would be something to get them over the first hurdles, which some people find difficult and which are sometimes why people do not complain.

The Convener: Richard Simpson has a different question.

Dr Simpson: Part of my question is actually a supplementary to Rhoda Grant’s question, but then I have my main questions.

The supplementary question is just for clarity. You talked about mediation and advocacy, which are important elements of what we need to provide for patients to help them through the system. You said that the patient rights officer will signpost
mediation and advocacy but not actually undertake them. Is that correct?

10:45

Alastair Pringle: Yes. The officers will not undertake those very different activities. An advocate stands beside someone to help them to negotiate systems. It is complex for a patient even to understand what is available. The independent patient advice and support service and the patient rights officer will work with an individual to help them to identify the best possible mechanism for them.

In the work that we have done on NHS complaints, we have found that most people do not necessarily want to make a complaint, but want to feed back or enter mediation-type activity. The role of PASS is not to undertake that work, but to understand someone’s issue and to signpost them, or introduce them to, the appropriate mechanism, be that mediation or advocacy. It has a role in providing an independent view on the advocacy provision that is available within health boards, so it is not a totally hands-off role. It is about standing beside the patient, helping to identify the issue and then identifying the most appropriate route through which to address their concern or feedback.

Dr Simpson: Does that differ from the IASS role?

Alastair Pringle: It builds on it.

Dr Simpson: The CAB will act as an advocate and will mediate.

Alastair Pringle: IASS will not act as an advocate for a patient.

Dr Simpson: It may not do it specifically within that part of its contract, but because it has an integrated, holistic service—which is the point that Rhoda Grant was making—it will assign somebody who will be able to act as an advocate although not as a mediator, which is something slightly different. It will more than just stand by a patient’s side; it will promote that patient through the CAB, although it may not do that formally as the IASS.

The point that Ross Finnie and all of us are trying to make is that we want patient rights and we want the patient to understand them, but we must treat the individual patient holistically and get away from silo services. The individuals who come to me have problems with community care that are partly to do with health services, partly to do with social work and partly to do with benefits. I am concerned that we are creating a new set of officers who are simply going to say, “Health is my role and that’s what I’m going to deal with. I’ve got nothing to do with benefits or community care. It’s a community care package that’s part health but, I’m sorry, I don’t deal with the other bits.” I am concerned that we are creating another stand-alone silo.

The Convener: I am trying to get short questions from members, remembering the earlier conversation that we had. Who will pay for PASS? Who will pay the people who will be acting for PASS?

Fiona Montgomery: Currently, health boards pay for the independent advice and support service. We have said that we expect that contribution to continue and that we will pay the additional money from central Government funds. We think that the final bill for the PASS service will be £2 million.

The Convener: Mr Pringle kept using the term “independent”. If someone is paid within the system, there could be seen to be a conflict of interests when they challenge that system on behalf of patients.

Fiona Montgomery: We are producing a national contract, and the funding will come through that national contract. It is important to have a local understanding between the service and the board. For local resolution and to know what is going on in the board, there needs to be some sort of local interaction. The service will be very much independent.

The Convener: That is the key. I am not complaining about local knowledge or local this, that and the other, but local people can sometimes get too pally. When we are using the term “independent”, we want something robust. We do not want patients to feel that he who pays the piper calls the tune; we want them to feel that they are speaking to somebody who is independent and who will give them straight advice. I just want you to confirm on the record that that will be the case.

Fiona Montgomery: Yes.

Mary Scanlon: I have an A-list question that has not been raised. It is about the exclusions from the treatment time guarantee, which are important. I will list one or two. Assisted conception is one, but there is obviously an age bar to that. The three exclusions that concern me are direct access services such as X-rays, diagnostic tests and outpatient treatments. Given that there is a treatment time guarantee of 12 weeks, health boards could easily extend the waiting times for X-rays, diagnostic tests and outpatient treatments so that patients could wait as long as the boards wanted for those, which would ensure that the treatment time guarantee of 12 weeks could be adhered to. They are surely integral parts of patients’ treatments, but they are
all excluded from the treatment time guarantee. Will you explain why?

Fiona Montgomery: Certainly. The 12-week treatment time guarantee is within the 18-week referral-to-treatment time. I pass you over to Margaret Duncan for further explanation.

Margaret Duncan (Scottish Government Health Delivery Directorate): As Fiona Montgomery said, the 12 weeks will be incorporated in the 18 weeks. To achieve an 18-week referral-to-treatment time, we will need short waits for outpatients for diagnostics. Most patients will be treated much more quickly than 12 weeks because the whole journey should be 18 weeks, but diagnosis takes a while for a few patients’ conditions; such patients may need four, five or six different tests before we can diagnose their conditions. Their journey may exceed the 18 weeks, and the idea of introducing a legally binding treatment time guarantee is to ensure that, once they have been diagnosed for treatment, they will receive it within 12 weeks.

Our view is that most patients will be seen much more quickly than within 12 weeks for inpatient day-case treatment because we need that to deliver an 18-week referral-to-treatment time.

Mary Scanlon: I hear everything that you say, but do you agree with the points that I am making? Unless a patient has had an X-ray and a diagnostic test and has been at an outpatient clinic, we do not really know what treatment they need. Although most patients may be treated within 18 weeks, the treatment time guarantee could be manipulated to build in a delay that could be detrimental to patients. Why do you exclude diagnostic tests and outpatient treatment from the treatment time guarantee? That is not beneficial to the patient journey. I still do not understand that.

Margaret Duncan: The 18-week referral-to-treatment time is the big policy.

Mary Scanlon: I understand that.

Margaret Duncan: We know that there will be a tolerance on that because it will not be possible to treat every patient within that time because of the complexity of some cases. However, to deliver that time, all the individual steps within it must be as short as possible and we will continue to monitor that, even as part of the 18 weeks, so we will get feedback if people wait a very long time for outpatient appointments. The diagnostic four-week target will still stand, so we will expect most diagnostic tests to be done within four weeks.

We will still have those targets behind the treatment time guarantee, but we are not making them legally binding because, if we have an 18-week target, it may be appropriate for a patient, based on the referral system, not to be seen until 10 weeks down the line. It is not until the consultant has seen the patient that they need to get the diagnostic test, so we need to ensure that the patient gets the diagnostic test quickly and then goes on to treatment.

The Convener: Could we leave it there, Mary? We can put the question to the minister.

Ian McKee (Lothians) (SNP): As I am sure you are aware, the vast majority of patient contacts with the health service are with independently contracted general practitioner practices. The bill says:

“For the purposes of this Act, a ‘relevant NHS body’ is—
(a) a Health Board,
(b) a Special Health Board,
(c) the Common Services Agency”.

Do any of those categories cover independent contractors who are contracted to health boards rather than employed by them?

Fiona Montgomery: I am sorry—I missed part of the question.

The Convener: Will you repeat the question, please, Ian?

Ian McKee: A large number—the vast majority—of patient contacts with the health service are with independent GP practices that provide a service under contract to health boards. They are not directly employed by health boards. Section 3(2) of the bill defines the relevant NHS bodies, but I am not 100 per cent convinced that independently contracted GP practices are covered. Are they covered or not?

Kathleen Preston: Perhaps I could come in on that. Section 3(1)(b) provides that each relevant NHS body must

"ensure that any person with whom it enters into a contract ... to provide health care has regard to the health care principles in so far as they are relevant to the service being provided."

The health care principles will therefore apply to independent contractors. Section 1 states that every patient has the right to receive health care that complies with the description. If the patient receives health care from their GP, the provisions of the bill will apply. There are also provisions regarding the complaints procedures, and relevant bodies will have to ensure that the persons whom they contract to provide health care have compliant complaints procedures. The bill has been drafted on the basis that the provisions will apply where health care is provided by independent contractors within the NHS.

Ian McKee: I am not a lawyer, but my work on the Subordinate Legislation Committee has led me to be wary of certain words. Can you tell me the
legal meaning of “has regard to”? Does it mean that you have to do it or just that you have to take it into account and you could then decide not to do it?

Kathleen Preston: It is not mandatory. “Has regard to” means that the relevant NHS body must take the principles into account. It cannot ignore them and its final decision has to be justified in terms of the principles. In each circumstance—in each individual case of treatment—the person who provides the care will have to consider the principles at that stage.

Ian McKee: If the person is in a hospital, it would be mandatory. Is that correct?

Kathleen Preston: It is the same. “Has regard to” applies wherever care is received, so it also applies to hospitals.

Ian McKee: So, as long as the NHS body shows that it has had regard to the principles, it can go against what the bill says.

Kathleen Preston: I am talking only about the health care principles, because that is where the term “has regard to” appears. Other provisions in the bill are differently worded.

Ian McKee: Would independent contractors have to obey those other provisions in the bill? The link seems more tenuous than it is for health boards and hospitals.

Kathleen Preston: Health boards have to have contractor arrangements for the provision of primary care services. When they make those arrangements or enter into those contracts, they will have to transfer the obligations, if I can put it in that way, so that the independent contractors are obliged to comply in the same way as hospitals would be.

Ian McKee: Is that just to have regard to the principles rather than to obey them?

Kathleen Preston: Yes, because the circumstances will be different for each patient.

Ian McKee: So it is the same for patients throughout the health service. Anyone in the health service just has to have regard to the bill rather than obey it, to put it in simple terms.

Kathleen Preston: There is a duty to have regard to health care principles. They cannot be ignored. If someone makes a decision in a particular way, they will have to justify their actions.

Ian McKee: Okay, I turn to a point that Consumer Focus Scotland made. Several suggestions were made about the wording of the schedule to the Patient Rights (Scotland) Bill with which I agree. However, a more important point was made about paragraph 16 of the schedule, which states:

“Waste of resources in the provision of health care is avoided.”

We all want such waste to be avoided, but does that statement really have a place in the bill? It is a motherhood-and-apple-pie statement that relates to all aspects of the health service. Given that the bill is about patient rights, it is wrong to focus at the end on waste of resources.

11:00

Fiona Montgomery: The issue of responsibilities has not come up much, but one of the things that we looked at when we were looking at patient rights was what we can do about patient responsibilities, to give both sides of the picture. Part of that is about a patient’s responsibility to avoid waste. It is about how we get the information across to patients to ensure that they attend appointments, so that we do not have so many missed appointments, and so that they take the drugs that they are required to take for the length of time that they have been told to and therefore do not require a repeat prescription because they have not finished the treatment. It is partly about patient responsibilities, resources and waste.

Ian McKee: I appreciate all that, but patient rights seems to be a different field. However, I will leave it there.

The Convener: I am in your hands. Helen, please make your question short.

Helen Eadie: You will be pleased to know that Ian McKee has covered my point.

The Convener: Richard, make your question tiny.

Dr Simpson: My first question, which you superseded with questions about money, was a supplementary to Rhoda Grant’s question.

The Convener: Am I being blamed for something there, Richard?

Dr Simpson: Yes—but do not worry about it.

The Convener: I am not.

Dr Simpson: Does the bill confer on patients in primary care any rights to have a patient participation group in primary care, so that they can alter the services provided by their general practitioner? For example, only 60 per cent of practices in Scotland provide advance appointments, which is of concern to many patients. Does the bill confer on patients any rights to influence that?
Does the bill give patients any rights to be represented in community health partnerships or equivalent bodies?

Does the bill give patients any right to drug treatment as is contained in the English NHS constitution, which lays out 27 rights for patients, which are quite clear, including a right "to drugs and treatments recommended by NICE for use in the NHS".

The Convener: Those were three straightforward questions. Can I have three yes-or-no answers, please?

Fiona Montgomery: The answer to the first two questions is no. Other work is going on about patient participation and involvement.

The Convener: The answer is no. What about the third one?

Fiona Montgomery: The right to drug treatment is not included. We also have similar Scottish Medicines Consortium guidance.

Dr Simpson: Yes, but it does not confer a right as in England.

Fiona Montgomery: The English right is not in primary legislation.

The Convener: Right. You got that in at last. I am sorry to hurry you, but I want to bring this evidence session to a close. Thank you very much for taking questions. I will suspend for a few minutes to allow the next panel to take their seats and members to exercise their feet.

11:03

Meeting suspended.

11:10

On resuming—

The Convener: I am sorry to rattle on so fast. There are various demands on members’ time this afternoon. I welcome our next panel of witnesses, who sat through the evidence that we heard this morning. Christine Lang is the independent advice and support service development worker at Citizens Advice Scotland; Suzanne Dyer is an IASS caseworker at Peebles citizens advice bureau; Liz Macdonald is senior policy officer at Consumer Focus Scotland; and Jim Martin is the Scottish Public Services Ombudsman. Thank you for your written submissions. We move straight to questions.

Mary Scanlon: Given that I asked the first panel about comments that were made by Consumer Focus and the SPSO, it is only reasonable to give the second panel an opportunity to comment. I probably do not need to repeat the passages that I read out earlier. The SPSO also said:

"the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist."

He said that the approach in the bill could lead to an increase in legalism and litigation.

Consumer Focus Scotland said:

"patients in Scotland already have rights in relation to the healthcare they receive. These rights go well beyond those mentioned in or created by the Bill."

Citizens Advice Scotland expressed concern that there might not be a consistent approach to the provision of advice. Will the witnesses comment on those points and say whether they think that the bill is justified?

Jim Martin (Scottish Public Services Ombudsman): The submission that we made speaks for itself, by and large. I am delighted that it has been quoted so often in the meeting.

The anti-legalism approach in section 18 is to be welcomed. My biggest concern in relation to complaints in the NHS—and I think that the complaints system in the NHS works well—is that there seems to be a view that people who have to respond on behalf of health boards and others cannot say sorry, for fear of litigation. If we could change that culture in the NHS, that would be a big boon. Anything that suggests that we move to legalism should be opposed.

The Convener: A shudder has just gone down the spine of every lawyer out there.

Liz Macdonald (Consumer Focus Scotland): We welcome the bill in the sense that it might give additional status to the idea that patients have rights. As we said in our submission, patients already have an extensive body of rights. Some of those rights derive from legislation, such as disability discrimination legislation and legislation on how to see our health records. Some rights derive from the common law, such as our right to consent to treatment, so that we cannot be assaulted by a doctor.

There is also the body of things that I think can legitimately be described as rights although they are not legal rights in the sense that the Scottish Government lawyer described. Those are things that people are entitled to expect when they are in contact with the health service. The health care principles that are set out in the bill reflect those kinds of rights. The publication, “The NHS and You”, which was referred to earlier, sets out those kind of rights. For example, people have a right to be treated by a doctor who is properly qualified. I am not aware that that is set out anywhere in
legislation, but there is a professional regulatory body that ensures that all doctors are properly qualified. So it is legitimate to describe that as a right.

For us, the real issue is not that all those rights are brought together, because I do not think that a bill can do that, and the bill does not try to do that. The bill is valid in so far as it says that patients have rights, and I would like something to be added to the bill that says that not all the rights that patients have are in the bill: the bill is simply flagging up the importance of patient rights.

Moving on from that, how people’s rights are made a reality is important. How do we ensure that people are more engaged in their health care, and that when they have the right to make choices and be involved in decisions, they do that? How do we change the culture so that that is more of a reality?

11:15

Christine Lang (Citizens Advice Scotland):
Citizens Advice Scotland, or CAS, is in favour of policy and practice that helps people to understand and exercise their rights. The current set-up for the independent advice and support service is inconsistent in different health boards because of how it was funded and the way in which its structure was set up. We would welcome more consistency.

The Convener: Do you want to add to that, Ms Dyer?

Suzanne Dyer (Citizens Advice Scotland):
We want to advise patients on their rights. The bill will be worth while only if it offers a completely holistic and person-centred service.

Mary Scanlon: Convener, no one answered the question that I asked about whether the bill is necessary or justified.

Christine Lang: The bill would make the independent advice and support service—or the patient advice and support service as it would be—statutory, so health boards would have to fund it. That has been an issue during the past year when some health boards have cut the funding for the service.

The Convener: Does anyone else want to comment on whether the bill is necessary or justified?

Jim Martin: We said in our submission that, with the exception of the treatment time guarantee, there is really nothing new in the bill. Earlier today, the Scottish Government representatives talked about wrapping up rights in primary legislation. It is a matter for you as parliamentarians to determine whether that is the right way to go with all the debates that that approach throws up. So with the exception of the treatment time guarantee, there is nothing new in the bill that confers a new right.

Rhoda Grant: How does the new patient advice and support service differ from the current service? In evidence that we have received, and from comments that we heard this morning, it is clear that two improvements could be made to the current service. It could be contracted nationally, and Ms Lang said that it would be good to have the same level of service in every health board area. Also, the current service is not seen as proactive in advising people of their rights, and it should be going out there. The comment was made that the bulk of the money that has been set aside for the new service is for advertising the service and getting involved in making people aware of their rights. Could the current service be changed to take into account those improvements without the need for a whole new bureaucracy and raft of spending? I imagine that the witnesses would welcome additional finance, but could the new service be set up more easily and cheaply, allowing patients to access a holistic service as they do at the moment and not just a service centred on patient health?

Christine Lang: That would be possible. As I said, it would be easier if the service was contracted at the national level and if changes were made so that proactive marketing could be included. I know that many health boards have found it difficult to get the message out there, and because so many people work in the NHS, it is difficult to get those higher up in the NHS to buy in and support the service.

Suzanne Dyer: At present, marketing activity in the Borders includes newspaper articles and appearances on BBC Radio Scotland. We have given presentations to associations such as Parkinson’s UK and the carers forum, and we have leaflets for people to pick up in our citizens advice bureaux, of which there are six in the Borders. In addition, we have delivered leaflets to the NHS. The idea was that they would be distributed in all hospitals, cottage hospitals and GPs’ surgeries. Activity in that area could be strengthened on a national basis.

Rhoda Grant: My reading of your responses is that you would welcome changes to the current service that would remedy your concerns, but health boards’ lack of buy-in might be causing issues with getting the service out there and recognised by patients.

Christine Lang: Yes, that has been a problem. IASS is starting to make a difference in some health boards where it has been established for longest. The first health board came on board four years ago. There, relationships between the NHS
complaints officers and the IASS workers are extremely good, to the point that the complaints officers were phoning me up to ask for leaflets to distribute.

In other areas, people from within the NHS who have come across IASS through other routes might or might not contact me. People are saying that they have not got enough work, so they are not marketing that service. I think that that is partly because they have poor relationships with the NHS board, which does not see the value of the service.

Suzanne Dyer: In the Borders, we have a very good relationship with NHS Borders. In fact, I get referrals from the board when it has a client with specific problems whom it may not have enough time to deal with. I can dedicate time to such people.

Rhoda Grant: When you deal with a person, can you advise them on broader issues—for example, if they have debt or welfare benefit issues—or can you direct them to other people in the citizens advice network?

Suzanne Dyer: I am able to advise people on benefits to do with illness, such as disability living allowance or attendance allowance. There are people who are more expert on other benefits in our office. I would sit with the patient while the other person came in, to ensure that the patient got a person-centred approach and dealt with the same person right the way through their care.

The Convener: You have dealt with a supplementary that I was chewing over. It seems that PASS will be much more restricted. Even though the provision of IASS can vary throughout Scotland, in general it has a greater range than PASS. It is not as constricted as it appears that PASS will be. Is that correct?

Suzanne Dyer: I do not think that that is for me to say.

The Convener: Please feel free to say it—that is why you are here.

Suzanne Dyer: IASS offers an extremely broad range of services to clients.

Christine Lang: I add that the service that is provided varies, depending on the background of the IASS caseworker. A caseworker who has a CAB background will be able to provide more holistic advice; someone who does not will have to refer a patient to a colleague.

The Convener: So, if we improved IASS and standardised its provision throughout Scotland, we might have a better service than the one that the bill proposes. Is that the point that you are making?

Christine Lang: Yes.

Ross Finnie: I am sorry, but I would like to go back to the issue that Mary Scanlon raised; it is not the same point, but it is related.

As a member of the committee, I am finding the bill difficult. Let me explain that. I am absolutely clear in my own mind about the importance of patient rights, but I am concerned that the agenda that has been set for members of the committee, in which you are participants, almost suggests that unless one believes that patient rights should be contained in an act of Parliament, one is somehow guilty of believing that patient rights are not important. I am concerned about that. I am also concerned that people watching or listening to today’s proceedings might get the impression that unless patient rights have the status of being enshrined in an act of Parliament, the Parliament is somehow not dealing with them adequately.

I do not want to put words into Ms Macdonald’s mouth, but I was very taken by the response in which she said that she did not believe that it was possible to encompass every patient right in a single act of Parliament, even if one wanted to. I am interested in your views, as people who deal directly with the individuals affected, about the curious perception that is emerging that, unless the Parliament makes acts of Parliament to deal with matters, those matters will somehow not have the appropriate status. I have never believed that an act of Parliament is a status symbol; I have always thought that it is a matter of law that could be enforceable in a court. One or two principles emerged in this morning’s evidence session, and I would be interested to know whether you think that it is essential that there be an act of Parliament or whether there are other ways in which the current body of rights could be expressed that would be equally effective.

Liz Macdonald: The position of Consumer Focus Scotland is that it is not essential to have legislation. As I said earlier, we have said that perhaps the fact that there is legislation gives the matter some status in some people’s eyes. That might be more the case in relation to people within the national health service rather than members of the general public. I do not think that it makes a great deal of difference to the general public, except that, when you try to raise people’s awareness of the rights that they have, it might make the message slightly stronger if you can say that all patients in Scotland have rights in certain areas, and that that is, in some way, endorsed by the Parliament or Government.

Legislation adds value only in so far as it can lead to stronger messages about what people’s rights are. However, in terms of making people’s rights a reality, how you communicate with them is more important, as is the support that is in place to help make those rights a reality. Those issues can
be dealt with through an independent advice and support service—which we feel is clearly essential—or through mechanisms that the NHS puts in place in its premises. In our evidence, we have argued that there is some value in attaching the fairly strong title of patient rights officer to the people in the NHS who are currently described as patient liaison officers or complaints officers. Having them as a more visible and accessible presence in NHS premises would be useful, and would mean that issues could be dealt with when they arose, which would avoid them becoming complaints or going anywhere near litigation, which you discussed earlier. The aim must be to solve things as early as you possibly can.

Sorry if that was a bit of a long-winded answer.

Ross Finnie: No, that was helpful.

Jim Martin: The best way to answer your question is to consider how the bill would make a difference to the way in which a patient or a patient’s family approached my organisation. It would make no difference. It might impact on how the providers of the service across the NHS think about how they go about things. However, there is no new route by which rights can be pursued, which means that someone who had a complaint about the NHS and wanted to take it to the ombudsman would be in the same position that they are in at the moment, were the bill to be passed.

There are a number of dangers in the bill. One of the dangers that I see is that, as far as complaints are concerned, the structure could become more bureaucratic than it need be. There is a danger that people might see their rights as being confined to the rights that are set out in the bill. More important, there is a need to manage carefully the possible impact on the culture of the NHS and the relationship between patients and families and health care providers. Earlier, Dr Simpson made a point about people having contact with the NHS but also with a range of services that need to be included. That is a considerable concern that needs to be taken into account.

The only thing in the bill that I would have regard to that I do not currently have regard to might be the treatment time guarantee. It is important to remember that the PASS and PRO set-up that is proposed in the bill is building on the strong base that IASS has put in place. Therefore, we are talking about a possible improvement rather than anything new.

11:30

Mary Scanlon: Section 8 of the bill outlines what happens where there is a breach of the treatment time guarantee. It states that the health board must

“make ... arrangements ... to ensure that the agreed treatment starts at the next ... opportunity, ... provide an explanation ... as to why the treatment did not start within the maximum waiting time, ... give the patient details of ... advice and support”

and tell them “how to complain”. Is that any different to what patients have just now? How is that a move forward? That already happens if the treatment time guarantee is breached.

Jim Martin: I am sorry—I am not sure whether that is a rhetorical question.

The Convener: Mary is good.

Mary Scanlon: There is no legal redress, but that is basically what the patient rights are at present.

Jim Martin: I think that is right.

The Convener: I think that you have given evidence, Mary.

Jim Martin said that only the treatment time guarantee was new, but I think that the bill does something else new. I am thinking about what Christine Lang said about the variability in the provision of IASS in Scotland. New section 10ZA of the National Health Service (Scotland) Act 1978, which is inserted by section 14 of the bill, states that the agency “must” ensure the provision of the patient advice and support service—it is mandatory. Christine Lang said that some health boards are cutting IASS back, but the bill will prevent that.

New section 10ZA(4) also states that

“The patient advice and support service is not to be provided by ... a Health Board, ... a Special Health Board,”

or

“the Agency.”

So the independence of the service that I was bothered about is secured by the bill, and its provision is mandatory. Do you agree, Mr Martin, that although that is a small part of the bill, it will change things in terms of the adequacy of the service that provides patients with independent advice prior to coming to your organisation?

Jim Martin: I prefaced my response to Mr Finnie’s question by saying that I start by asking which elements of the bill would make a difference to patients. I am reading the section on PASS, which will build on the existing IASS. In a legal sense, you are correct that the inclusion of the word “must” makes things different but, in practical terms, it would not make a difference to how my organisation considers a complaint.

The Convener: That is not the point that I was making. I was saying that because there is
variability throughout Scotland, people may come to you directly—although I do not know about the specific cases that you deal with—because the service is not provided in a particular NHS board area. The bill will make that service mandatory throughout Scotland and independent of NHS boards. That must—I am using the word “must” rather a lot here—make it better for the patient or their family or friends at the first stage if they feel that something is not right and that they want independent advice.

**Jim Martin:** I see many complaints systems throughout the public service in Scotland. Among the 32 local authorities in Scotland, which work against roughly the same legislative background and on the same delivery, there are many variants in terms of how things are delivered. They are complying, because they have done what they must do, but when things come to me, I see breakdown and failure. You may be right that we will start to get complaints about that, but currently we do not.

**The Convener:** I do not know—I am just proposing that as something that is different in the bill. I see that Christine Lang—who raised the point initially—is nodding her head.

**Christine Lang:** Yes. The fact that the service “must” be provided is important to us, because that is not the case at present.

**Michael Matheson (Falkirk West) (SNP):** Mr Martin, you said that the provisions in the bill will not change how you consider a complaint. I understand that, on the basis that the bill contains nothing that is new or substantially different from the current situation. However, I think that you said in your submission that you will be able to uphold complaints with regard to the rights in the bill, which you cannot currently do. Will you explain that? Are you saying that although the bill will not change how you look at a complaint, the net outcome will be different? That is what I took from your submission.

**Jim Martin:** That is not exactly what I meant. I meant that if there were an act we might make reference to it when we issued a report or made a decision on a case—that would be different. The bill contains no new rights, however, so there is no change in that regard. Currently, when someone comes to us with a complaint we find for or against them. If the same complaint were to come to us once the bill had been enacted, we could make reference to the act. That is all.

**Michael Matheson:** Thank you for that helpful clarification.

Mary Scanlon mentioned your concern that the enshrining of rights in legislation has the potential to light up pound signs in the eyes of Scotland’s solicitors. Are the provisions in section 18 sufficient to address your concern that the approach in the bill might result in more litigation?

**Jim Martin:** The answer to that is a broad yes. I have been ombudsman for about 15 months—maybe a bit more—and I have seen many cases in the NHS, some of which have been horrendous. Many cases have involved deaths, sometimes of young children, but I have never yet had a complainer come to me with a view to going to litigation. My concern is that we should not move to the kind of system that there is in the United States and other places, where the first thing that people do when something goes wrong is lift the phone to the lawyers. I am not a lawyer, but my reading of section 18 is that it protects against such an approach; others might want to ensure that that is the case.

**Michael Matheson:** People have argued that section 18 fundamentally undermines the bill, in that it will prevent people from taking legal action to enforce their rights. Has the Government got the balance right between enshrining rights in legislation and preventing us from going down the avenue of generating a great deal of litigation?

**Jim Martin:** When we consider whether we have got the balance right we must comment on two parts of an equation. In this context, the second part of the equation is the desire to avoid a litigious culture in the NHS. If that is the Government’s intention it is doing the right thing. It is for you to determine whether the other side of the equation is right. The question for parliamentarians is whether, given the presence of section 18, the rest of the bill is worth having and is in any way enforceable with methods other than those that we currently have.

**Liz Macdonald:** The question whether people want to get involved in litigation is separate from the bill. As Mr Martin said, section 18 explicitly takes away that possibility in relation to enforcing the treatment time guarantee, but nothing in the bill stops people going to court to ask for damages, or for a range of other reasons.

As I said, people do not really want to go to court. That is partly because they want to continue to have a good relationship with the people who provide their health care and partly because they want not financial compensation but an apology and an assurance that what happened will not happen again—there is good evidence that that is what people want. They want a proper investigation and an explanation of what went wrong and why. It is important that we take opportunities to strengthen the ways in which people can deal with issues as quickly as possible rather than worry about litigation.

**Suzanne Dyer:** I would like to add to that. The majority of my clients are not looking for litigation;
they are interested in feedback from the NHS to give some meaning to the suffering and loss that they might have endured. This is probably outwith what is being discussed, but there is also a case for no-fault compensation for cases in which people are not trying to blame someone, but they end up with a lasting disability due to some misadventure in hospital that may be no one’s fault. For those people, it is very important to have information about how a service has been changed or improved so that there is no chance of the same thing happening to someone else.

The Convener: I am just reminding myself about this issue, but I think that the Government is looking at no-fault compensation schemes. That is a piece of information from the convener, with the vice-convener’s assistance.

Rhoda Grant: The committee is struggling with the lack not of legal redress but of redress anywhere in the bill. Everyone is happy that we are not entering into an American-style NHS in which people are sued all the time, but it is clear that the bill gives people rights but no way of enforcing them. Is there a way to enforce people’s rights? The Scottish Public Services Ombudsman obviously carries out some of that work, but it involves a long process. If someone is waiting for treatment, they do not want to have to go through a complaints procedure and then through the ombudsman, by which time they will have either died or had their treatment. They want some way to remedy the situation immediately, so that they get their treatment and pass through the service. Do the witnesses have any thoughts about how that remedy could be found other than through legal redress?

Jim Martin: The NHS complaints structure has two times: one is three days for an initial response and the other is 20 days for a substantial response. By and large, health boards are very good at meeting those targets. The problem in the NHS is that by the time that someone has reached the point at which they want to complain, usually the damage is done and we are looking at what happened rather than how to prevent things from happening.

After that stage, we often get into a situation that I was appalled by when I arrived as ombudsman, in which the health board takes as its first position that it will not find in favour of the complainant on anything that is clinical. One or two health boards do that. I have been astounded by the number of cases that have come to the ombudsman in which we have taken independent medical advice, played it back to the health board and the board—this has happened in more than one—has then said, “Yes, we now accept that you are right.”

The difference is that I am the ombudsman and I have independent medical advice while the ordinary family does not. If we are going to go down the route of complaints, we must take account of the fact that it is far more complex and that the ordinary citizen, who becomes a patient only when they engage with the national health service, does not necessarily have the technical knowledge to discuss, explore and reach a solution on medical issues without considerable assistance. One thing that IASS has been very good at is guiding people through that process; one hopes that PASS would build on that.

The Convener: May I interrupt on that point? I am not saying that this is a whole solution, but is it possible for an individual patient to then seek legal advice? There are huge issues about access and finance, but an independent opinion would be available through advice and assistance, as I understand it, or by paying for one to determine whether someone has a substantive case.

Jim Martin: I note that the question related to the long process of taking a case to the ombudsman. I hope that we are no longer in the position of having three-and-a-half-year delays, as we did a year ago or more. However, we notice that when someone takes a complaint to the average solicitor, it tends to add not only time but expense. The complaint usually goes to a solicitor whose knowledge of NHS procedures is, to be kind, rudimentary.

11:45

The Convener: Having once acted in medical negligence cases, I declare an interest and wince at that comment. I will let it go past because it was many years ago. We will move on.

Liz Macdonald: Rhoda Grant asked whether the bill should provide for some means of enforcing the rights. We can look at the matter positively or negatively. At the minute, there is a range of rights, such as the right to see one’s own health record. However, if a patient does not know that they have that right or how to exercise it, it will have no impact on their health care or their life. Part of the answer is to consider how we enforce rights positively. How do we help people to realise that it is a good idea to see their health records and to ask how to go about doing that? We need to support people to be involved. How do we support and encourage them to use their rights to be involved, participate and consent?

That is a positive approach. I think that Rhoda Grant is looking at enforcement more negatively. She is thinking of penalties for rights—waiting times in particular, I suppose—not being enforced. However, it is important to think about the matter positively, not just negatively. People’s rights are so varied and different that there is no single way of ensuring that they can be enforced.
The Convener: I have—
Suzanne Dyer: Can I add—

The Convener: Oh, I am sorry, Ms Dyer. You are from Peebles, too.

Suzanne Dyer: Rhoda Grant asked whether anything could be added to improve the situation for existing patients. If I complain on behalf of a patient who is already in treatment, NHS Borders is good at speeding up the matter and it moves as quickly as it can. However, perhaps there could be a fast-track rule for people who are in treatment, otherwise we would have to take them through the whole procedure and, potentially, on to the SPSO. Patients like that, because they get an independent view on their treatment, but usually after the treatment has been received.

The expense of litigation and the quality of advice about medical issues that is offered if patients go on to litigation have already been mentioned. We can refer clients to an organisation called Action against Medical Accidents—AvMA. If we send it all the case papers, it will review the case and offer independent legal advice free of charge to the client, who can then decide whether they wish to go down the legal route.

The Convener: I have a feeling that there will be a queue of people who want to know the contact number for that free legal advice. Mr Martin may regret some of his words, but I will leave that to the Law Society.

Christine Lang: I will add to what Mr Martin said about health boards meeting timescales. I have had anecdotal feedback from IASS case workers that NHS boards often do not meet timescales. Sometimes, clients get feedback on the reasons for that and are told that there will be a delay. Often, the delay goes on for a long time. Sometimes, if a person is receiving treatment, they are told that they cannot access their health records. Sometimes, the case is not dealt with quickly enough and the person ends up outside the timescale for complaining to the SPSO, so they are stuck between a rock and a hard place in pursuing their complaint.

The Convener: We will keep a note of the points that are made.

Ross Finnie: I have a question that I should have asked earlier. It was, again, prompted by a remark that Ms Macdonald made. I think that she was present in the earlier evidence-taking session, during which I referred to the document that tries to set out the range of rights that we have. It comes from the health rights information Scotland project, which was established in 2003. It is a project within Ms Macdonald’s organisation, Consumer Focus Scotland, and is funded by the Scottish Government health directorate. The bill aims to replace that service by setting everything down in an act of Parliament. What is wrong with the current service? I do not think that anything is wrong with it.

Liz Macdonald: I do not think that the bill is seeking to replace the information that the health rights information Scotland project produces. It produces information for members of the public about their rights. When the bill is passed, information will still need to be given to members of the public about their rights. I hope that the health rights information Scotland project will be involved in that, because it has expertise in and understands rights and how to produce information for members of the public. I do not see those two things as alternatives.

Ross Finnie: Indeed not. Your answer is interesting, and I share the view that you require a slightly different version of the HRIS document. For those people who want to find out what their rights are, perhaps the document is not publicised well enough or the organisation is affected by funding restrictions.

You said that you believe that you need both HRIS and the bill. I asked the Government’s lawyer what the difference is between them. The bill will set out patients’ rights but, because people do not want to enter into litigation, they will not be able to act on it. The HRIS document sets out where a patient has rights at law, so it is almost more valuable. That was rhetorical.

The Convener: I was beginning to wonder.

Ross Finnie: I got that trick from Mary Scanlon.

The Convener: I think that we will be able to dispense with witnesses. They are surplus to requirements. We will ask the questions and answer them.

Liz Macdonald: The bill seeks to set out broad health care principles in different categories, so we have things that are to do with participation and people being involved in their own care, and things about communication and safe and effective care. People have to be treated in certain ways in different areas. “The NHS and You” sets out simple, clear information that tells people what that means in practice and what they should expect. If it is passed, the act will require such information. Should people expect there to be a patient participation group? What should they expect the board to be doing? That is equally true for staff. What will the law and HRIS mean for how staff do things? We are looking for guidance on what those broad health care principles will mean in practice and what people are entitled to expect.

Ross Finnie: Yes, but, Ms Macdonald, the cabinet secretary could issue a direction under the 1978 act about those matters, and that kind of
The Convener: Is there a question?

Dr Simpson: My question is whether the bill will achieve anything in relation to redirecting the provider and ensuring that the provider acts timeously, not just in respect of people who are receiving treatment but subsequently, to ensure that the systems are corrected to allow the patient to be a mutual participant in the improvement of the service.

Christine Lang: That is why we have raised the point about feedback. We have found that some IASS workers are now getting feedback—either directly or through their clients—explaining the changes that have been made to policy and practice as a result of complaints that have been made. From what you say about the state hospital, it sounds as though that is happening there: the number of complaints is decreasing and instead concerns are being raised. We would welcome the inclusion of that in the bill; otherwise, people will not know whether any changes have been made as a result of complaints.

Suzanne Dyer: In our system, we always try to go in at the lowest level to resolve issues in the best way possible for both parties. We would never go in, or encourage our clients to go in, with all guns firing. We see raising a concern as more about working with the NHS to get good outcomes for patients. A lot of my clients are bereaved, and it is a question of trying to resolve the loss in some way, working through it on a good level.

I agree that no-fault compensation is a completely different issue. In the three and a half years for which I have been in post, I have had probably only one client in that position, and it was a terrible situation.

I totally agree with you on the need to go down the concerns route before making a complaint. In that way, we will get more information from the NHS and a better outcome for the patient. However, I am not sure how much the bill will assist with that.

Jim Martin: I am not certain that the bill sets out what you have set out. The bill reads to me as almost a consolidation of rights and a move into primary legislation. Yesterday, we finished a consultation on setting standardised complaints procedures across the whole public service. One thing that we are exercised about is the need to enable front-line staff to meet concerns head on before they become complaints and to empower those people to find solutions. That is a cultural thing. The General Medical Council’s advice on apology is very good, and the no-fault compensation debate must be had more openly. I would very much welcome our looking at that seriously. As far as the bill is concerned, however, I am not certain that it sets out to deal with the problems that you have set us.

Dr Simpson: The second part of my question is the question that I asked the first panel of witnesses. Under the new system, should the patient rights officer be involved in advocacy—in trying to solve problems—or will they be only rather expensive signposters?

Suzanne Dyer: I can tell you about the situation in our area. My role is to act on behalf of the patient in any way that the patient requires in order to empower them. I may write letters on behalf of the client, attend meetings with the client and make phone calls on behalf of the client, if necessary. I do not know whether you would call that advocacy.

The Convener: Do you ever tell people that they have no case or no complaint? Do you sometimes have to tell people tough things?

Suzanne Dyer: Yes. One of the most important requirements of the role is not to raise expectations inappropriately. However, the client has to decide whether they wish to take their complaint forward, although I can give them my best advice based on my experience and training.

The Convener: MSPs do the same in our profession. When we are asked questions, we give our advice, but what to do is up to the
constituent. At the end of the day, they might not have a real issue that they can follow through. We have to be tough and give them our advice.

12:00

Jim Martin: As I read the bill, PROs are designed for signposting. My worry about PROs and, to an extent, PASS stems from my experience in setting up the Police Complaints Commissioner for Scotland. For about the first six months, the first question that 80 per cent of callers to that commission asked was, "Are you, or have you ever been, a police officer?" In positioning PROs and PASS, we will have to be careful that, although they are funded by health boards and Government, they are capable of giving independent free advice.

Christine Lang: We see it as a benefit of basing inquiry centres in bureaux that we will be able to do that.

The Convener: We have dealt with the independence and robustness of PASS.

I give Helen Eadie the glory of the last question, knowing that it will be short and to the point.

Helen Eadie: Maybe it will be two questions, convener, as Alex Neil would say.

The Convener: Make it a two-part short and to-the-point question.

Helen Eadie: Mr Martin's comment about apologies is important. However, very often, it is where the apology comes from that matters. I had a dreadful case of an elderly man who lost his entire family—his wife and two sons—as a consequence, he believed, of NHS actions. His apology came from an official, not from the chairman of the board, which was disgraceful. That was Lothian NHS Board.

Ross Finnie was absolutely right to say at the outset that anyone who views this process should be absolutely certain that we are trying to improve patients' experience of complaints. I was interested in Liz Macdonald's answers. At first, I got the impression that she feels that the bill will change things significantly, but I was glad when, under questioning by Ross Finnie, she arrived at a point at which she did not think that the bill will change things. I will quote something and ask her to comment on it. It states that the bill deals with "the way a person should be treated by the NHS rather than what they are entitled to from it."

Will you expand on that point?

Liz Macdonald: Sorry, but what were you quoting from?

Helen Eadie: In your paper—your evidence—you said that the bill deals with "the way a person should be treated by the NHS rather than what they are entitled to from it."

The Convener: Was that in the written submission or in the evidence that has been given today?

Helen Eadie: It is in the evidence given today, by Consumer Focus Scotland. It is on page 3, under the heading "Healthcare Principles".

The Convener: So it is in the written submission.

Helen Eadie: Yes. I am concerned that Liz Macdonald, speaking on behalf of Consumer Focus, believes that the bill does not address what patients are entitled to from the NHS.

Liz Macdonald: Your quotation relates specifically to the health care principles. One of the rights that we could say people will be given by the bill is the right to be treated in accordance with the health care principles, whatever that means, so when we say that the bill gives people the right to be treated in a certain way, that relates specifically to the principles. The bill also claims to give people a right to complain and a right to treatment within a treatment time.

Helen Eadie: But you have said that the bill is about the way people should expect to be treated, rather than what they can expect to get from any complaints. That is the substance.

Liz Macdonald: We are saying that that is what the health care principles attempt to do—they set out how people should be treated.

Helen Eadie: But with that statement you are saying that the bill does not address the issue of what people can expect to get from it.

The Convener: Let us have Ms Macdonald's final answer.

Liz Macdonald: As an example, imagine that somebody says, "Does the bill give me a right to an NHS dentist?" The bill does not deal with what rights people have in relation to accessing services; that is outside the bill's remit. The bill restricts itself to how people should be treated—in other words, in accordance with the principles. It covers the right to complain, which we argue people already have, and the treatment time guarantee, which is one specific guarantee in respect of one kind of treatment in the context of lots of other things.

Helen Eadie: You are saying that the bill does not tell people what they can do if they do not receive such treatment.

Liz Macdonald: I do not think that that is what we are saying there. As I said earlier, people's rights are varied, both in the bill and beyond, so
they might seek to enforce them in a wide range of ways.

The Convener: I am going to stop you—

Helen Eadie: I have one last question on a different matter. Before becoming an MSP, I was involved for numerous years with an NHS primary care complaints committee. It offered one way of dealing with NHS complaints, but it was changed. When the Scottish Parliament was established, the minister decided that we would not have a complaints system that went through the local health councils, which were then abolished and replaced with the Scottish Health Council. Then CAS was given the contract for dealing with patient complaints. That takes us back to the independence question. I would like CAS to comment on its experience, because I do not believe that making PASS independent in the NHS is the right way to go. The right way to go would be to have PASS or its equivalent within CAS rather than as part of the NHS. In my opinion, it is wrong to have a system that deals with complaints about the NHS in the NHS.

Christine Lang: Yes, I agree.

The Convener: I knew that you were going to say that. That is a yes from you, but I see that Mr Martin disagrees.

Jim Martin: No, I just did not want to contribute.

The Convener: He does not want to contribute—that is a nice thing to hear at this time of the day.

Suzanne Dyer: That independence is important for my clients, a lot of whom feel, rightly or wrongly, a little anxious about going in to complain about a doctor or medical staff. They really need to come to an accessible place. We have offices in virtually every town, where people can come and feel that they are in a totally independent environment. It is fine whether people go to a CAB or another independent location, but to have NHS complaint officers in NHS buildings would not be helpful.

Helen Eadie: The location of the buildings is not the issue; it is a question of who pays the piper and provides the funding. It would be better for adverse comments about the NHS to come from a totally independent, voluntary organisation, rather than from someone who is funded by the NHS and is feeling pressure from on high about next year’s funding.

Suzanne Dyer: Our funding comes from the NHS, but I guarantee that we are totally independent, to the extent that recently we were able to take NHS Borders right through the ombudsman process. There was no feeling of—

Helen Eadie: That is not universal in Scotland. I have spoken to independent advice and support services who say that it is not the same in every part of Scotland.

The Convener: We are kind of going round in circles now. We have taken a view that we want the service to be independent. Independence must be not only a reality but a perception.

I thank committee members for asking their questions at a brisk pace and I thank the witnesses for their evidence. We will now move into private session, as previously agreed.

12:09  
Meeting continued in private until 12:20.
Dear Seán

PATIENT RIGHTS (SCOTLAND) BILL

I am writing to clarify a number of points raised in the Scottish Parliament Health and Sport Committee stage 1 oral evidence sessions held on 29 September and 6 October 2010.

In relation to the treatment time guarantee (TTG), on 29 September questions were raised about whether the prohibition in the Bill that would affect legal action in respect of failure to meet the 12 week TTG would compromise the right to take legal action in respect of the 18 week referral-to-treatment target. I can confirm that the current waiting time targets are not legal rights, but targets which are set and measured by the Scottish Government. Patients do not, therefore, have any legal basis for going to court if these rights are not met. The inclusion of the 12 week treatment time guarantee does not therefore remove any rights in this respect.

A number of comments and questions were raised, at the session on 6 October, around the exclusion from the Bill of patients with mental health needs. Patients with mental health needs are not excluded in the Patient Rights (Scotland) Bill; the Bill applies to all patients. There was also a misconception that mental health treatments are excluded from the TTG, or that only child and adolescent mental health services are included. It is proposed that the TTG will apply to all planned and elective care delivered on an inpatient or day-case basis, unless the treatment or service is in the list of proposed exclusions. The proposed exclusions for the TTG are in paragraph 36 of the Policy Memorandum, summarised here:

- Assisted conception;
- Obstetrics;
- Complementary and alternative medicines, including homeopathy, provided on the NHS;
- Organ/tissue transplants;
- Direct access services;
- Diagnostic tests;
- Treatments undertaken in a hospital outpatient department;
- Certain designated national specialist services (scoliosis);
- Services on the Department of Health’s specialised service definitions list, where no equivalent clinical services are offered in Scotland; and
- Alcohol and drug misuse services.

With reference to comments made on the exclusion of cognitive behavioural therapy (CBT), this is not specifically excluded from the TTG. However, where a service is not delivered as planned or elective care on an inpatient or day-case basis, it will not be covered by the eligibility criteria for the TTG: this is the same for all services. It is my understanding that CBT is not usually delivered in this way. (Some aspects of child and adolescent mental health services are delivered as planned or elective care on an inpatient or day case basis and these were therefore given in the Policy Memorandum as an example of a mental health service covered by the eligibility criteria).

In relation to the Patient Advice and Support Service (PASS) and Patient Rights Officers (PROs), it was commented, at the session on 29 September, that there was a potential loss of the holistic service currently provided to patients by multi-disciplinary Citizens Advice teams under the Independent Advice and Support Service (IASS). However, the current IASS is commissioned to provide advice about health issues only. The location of IASS, within the Citizens Advice Bureaux (CAB), means that patients are able to access other advice that CAB provide, but IASS itself is not commissioned to provide this service.

Comments were also made by the CAB, during their oral evidence session, about funding cuts for the IASS, made over the last year. I wish to add that, in cases where there have been reductions in funding, these were carried out after negotiation with CAB. The reductions were not because of any problems with the service, but to do with looking at appropriate funding levels.

Regarding the role of PROs and whether they would become involved in advocacy and resolution of complaints for patients or whether they would simply act as signposts, I would like to clarify that PROs will not act as advocates; the current IASS is also not commissioned to provide advocacy services. Advocacy services speak on behalf of people who are unable to speak up for themselves. PROs will provide advice and support; assist with complaints; and signpost people to other services, such as advocacy.

Lastly, with reference to the oral evidence given by CAB on 29 September, the point was made that very few of the complaints cases handled by CAB involved the use of no-fault compensation. At the moment there is actually no system of no-fault compensation operating in Scotland. This is something that is being discussed separately by the No-fault Compensation Working Group, who are due to publish a report shortly.

I am aware that one further issue, around the delivery of the TTG in the primary care sector, still needs to be addressed and I am in the process of clarifying this with colleagues, but will endeavour to get back to you shortly with a response on this.

I hope that you find the above information helpful.

Yours sincerely

Lauren Murdoch
Patient Rights Bill Team Leader
Submission from Citizens Advice Scotland – 20 October 2010

Further to CAS’s oral evidence session with the Health and Sport Committee, please find attached information about Health Board funding extensions for IASS for 2010/2011.

In cases where there have been reductions, these were carried out after negotiation, and the bureaux in the consortium were willing to operate IASS on reduced funding.

These reductions were not based on any problems encountered with the service provided but instead looked at funding levels in general. For example, in one health board, cuts made were in line with cuts made throughout the NHS.

Kind regards,

Alizeh

Alizeh Hussain
Social Policy and Parliamentary Officer
Policy and Public Affairs Team
Citizens Advice Scotland
20 October 2010
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* The bureaux involved felt this figure was sufficient for the service, given the number of enquiries
INTRODUCTION

The Law Society of Scotland has considered the draft Patient Rights (Scotland) Bill and has the following comments to make. The Society is generally supportive of the Bill but submits that it could be improved by making its provisions enforceable and clarifying certain terms.

COMMENTS

Enforceability

The Society’s biggest concern is that the Bill contains valuable principles and guarantees but does not contain the necessary provisions to make them enforceable.

In an enhanced rights environment, one of the objectives should be to ensure people are aware of their rights. The Bill goes a long way to meeting that objective and to enhance awareness of these entitlements. The Society is pleased to see sections which focus on informing patients about rights to the treatment time guarantee, facilities for complaints and feedback and provisions relating to the patient advice and support service.

However, if rights are to be grounded in reality and not just aspirational, there needs to be greater provision for enforcement to back up those rights. Section 18 confirms that the act does not give rise to any new liabilities to pay damages, right of action for specific implement, right of action for interdict or right of action for suspension.

The same concerns apply to section 3, which states each relevant NHS body must “have regard to the health care principles in so far as they are relevant to the functions being performed.” The bill should clearly define what is meant by ‘have regard to’ and should also contain provisions setting out how this duty will be enforced.

Proportionality

Section 2(2)(b) requires the “desirability of action in delivering health care [to be] proportionate”. The Society believes that the term “proportionate” should be clearly defined.
Mental Health Services

The Society supports the treatment time guarantee and is generally in agreement with plans for mental health services set out at paragraph 38 of the Policy Memorandum. However, the Committee also believes that the treatment time guarantee should be made available for psychological services, including talking treatments, which are generally in short supply and for which there are long waiting lists at present particularly in some areas of Scotland.

Linda Anderson
Senior Administrator, Law Reform
The Law Society of Scotland
13 May 2010
Patient Rights (Scotland) Bill

British Medical Association Scotland

Introduction

The British Medical Association is a registered trade union and professional association representing doctors from all branches of medicine. The BMA has a total membership of around 140,000 representing 70% of all practising doctors in the UK. In Scotland, the BMA represents around 15,500 doctors.

BMA Scotland welcomes the opportunity to provide written evidence to the Health & Sport Committee setting out our position on the Patient Rights (Scotland) Bill. BMA Scotland supports the Scottish Government’s intention to encourage a stronger sense of public ownership of the NHS and welcomes the renewed commitment to a service which is publicly funded and owned, and free at the point of delivery. As such we welcome the commitment to articulate the rights and, to some degree, the responsibilities of all those using and providing NHS services as outlined in the health care principles. Many of these reinforce long-standing values and principles embodied by the NHS. They also reflect doctors’ established professional standards as set out in the General Medical Council’s Good Medical Practice 1.

During the consultation process, the BMA questioned the need for legislation on patient rights and we remain unconvinced of the purpose of legislating in this area. Instead, we believe that many of the rights listed in the Health Care Principles are more suited to a patients’ charter style approach, particularly since there are no rights to legal recourse set out in this Bill.

We are also deeply concerned over the proposals to enshrine an inflexible 12 week treatment time target in law which, we believe, will have adverse consequences and is likely to distort clinical priorities in order to satisfy a political imperative which is contrary to the objectives of this Bill.

Patient rights and healthcare principles

BMA Scotland supports the move to strengthen and clarify the rights of patients in accessing and receiving NHS services. The policy memorandum supporting the Bill accepts that rights already exist for patients but these are articulated in disparate ways. Many of the health care principles detailed in the schedule are already covered by professional codes of conduct and in existing legislation (e.g. Human Rights Act and Data Protection Act). As such, few of these are new principles or aspirations and there are already processes in place to take action, such as reporting a professional to the regulatory body or making a complaint to the health board or ombudsman. The only possible benefit of having these principles stated in legislation would be if there was a new process of redress for patients who believed that these principles have not been met. However as the Bill makes clear that nothing in the Bill is enforceable by legal action (Section 18(2)(a)). While we accept that

1 General Medical Council (2009) Good medical practice
there is always room for improvement to the existing processes, BMA Scotland believes that this supports our position that there is no need to legislate and that producing a charter to bring together these rights and responsibilities in a single document would be equally effective and would give these principles the enhanced status desired by Government.

*Health care principles*
While these principles or ‘rights’ are commendable it remains to be seen how they can be defined in the legal sense. For example, while nobody would disagree with the principle that patients should be treated with dignity, it is hard to define what this might mean in a legal sense as there are strong elements of subjectivity involved in its assessment.

Under the proposals of this Bill, every NHS body has to have regard to the health care principles when performing health service functions (Section 3(1)(a) and (b)). We would request the Committee to seek assurances from the Government and perhaps consider amending the Bill to explicitly state that clinical judgement will prevail. At present, it is not clear how the Government intends to evaluate decisions made by Boards and, should this Bill become law, we would be keen to be consulted in developing guidance on this matter, particularly for the implementation of Treatment Time Guarantees.

The results of the *Patient Experience Programme: priorities for inpatient care*, published in 2009 found the top priority for patients was a clean ward\(^2\). Preventing healthcare associated infections is a priority for patients and NHS organisations and therefore should be considered as a principle for inclusion e.g. that “Patients are treated in a safe and clean environment”. It is our view that this could apply equally in the hospital, community or general practice environment. However, again we would restate our opinion that these principles and rights would be equally effective in a Patients’ Charter.

A mutual NHS should be one in which all those involved have both rights and responsibilities – patients who use services, those who work in the NHS and provide services, and all of those who pay for the NHS through taxation. As such, we believe it is important that any measures which strengthen rights should also reinforce appropriate responsibilities. As with patient rights, we are unconvinced that legislation is the best way to articulate these responsibilities, but if this is the approach the Committee wishes to support, we would at least ask it to consider strengthening the healthcare principle number 12 to remove the word ‘encouraged’.

*12 Week Treatment Time Guarantee (TTG)*
For individual patients waiting for NHS treatment can be a difficult time and it is important that those with the greatest clinical need receive appropriate care within a reasonable timescale. BMA Scotland has welcomed recent waiting times figures that demonstrate the commitment and hard work of NHS staff to achieve targets.

However, we do not believe that any political guarantee regarding specific waiting times should be placed in legislation and would recommend the removal of this entire section of the Bill. The widespread use of centrally imposed treatment time targets has many unintended consequences, distorts clinical priorities and harms patients\(^3\). All centrally-set targets have the potential to distort clinical care. Any objective which encourages clinicians to take actions which are potentially not in the patient's best clinical interests is unhelpful. This is even more problematic if there are associated managerial imperatives which may further distort clinical decision making. As an overarching principle, clinical decisions should take precedence and clinicians should be supported in making such decisions\(^4\).

It has been difficult to pin down exactly what the TTG is and when the clock starts. It is our understanding that the 12 week clock begins when the doctor and patient agree on a course of treatment. However this treatment guarantee falls within the existing (non-legislative) 18 week Referral to Treatment (RTT) target. Again we are unclear what this legislation adds.

The current waiting time targets contain ‘tolerances’ at the margins to make allowances for cases that do not achieve the target, e.g. 95%. This provides Boards with flexibility where the target cannot be achieved. Systems are also in place to enable the Cabinet Secretary for Health and Wellbeing to intervene in cases where waiting times targets are not achieved. However there is no flexibility within the legally binding TTG and Boards will be expected to meet the guarantee in all cases, this inflexible system increases the likelihood of distortion to clinical priorities. It is not yet clear what interventions the Cabinet Secretary will where Boards fail to achieve the TTG.

Doctors tell us that waiting times targets and the subsequent distortion of clinical priorities can result in patients with less serious complaints being treated before those with more complex medical problems. We believe that without a significant increase in resources, and the provision of extra capacity in the system for periods of unexpected activity, legally binding treatment time guarantees could be of detriment to those who may be most in need of urgent care. Reductions in waiting times have only been achieved through substantial investment in the NHS, including significant increases in the number of staff. There is little recognition of these costs in the financial memorandum. To ensure that all Boards fully comply with the legally binding TTG (and risk breaking the law if they do not) it will be necessary to increase resources.

As we enter a period of constraint in public sector funding, such an increase in resources is likely to be unaffordable and the BMA does not believe that these guarantees can be justified, particularly in this financial climate.

The TTG will apply only to planned/elective inpatient and day case services. Therefore only patients awaiting surgical interventions will benefit from this

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\(^3\) BMA (2009) ARM 2009, 144

new ‘right’, patients requiring medical interventions will not. There should be guarantees in place to ensure that those services not covered by the TTG are not disadvantaged. For example, services where admission is generally not elective or planned are often required by the most vulnerable members of our society (services such as care of the elderly, learning disability and some mental health services. This will create a difficult balancing act between the rights of different patients and there is a risk that others with more serious conditions will have to wait longer.

An integral aspect of the doctor’s role is to be an advocate for their patients, providing advice and support to navigate treatment options and services. For every patient, there will be different and often unique needs and doctors are concerned that this new target, enshrined in law, will create an inflexible system that forces doctors to rush patients into treatment without consideration of the particular needs of the patient.

It is not yet clear what penalties a Board will suffer as a result of breaching the TTG, however they will be breaking the law. The BMA considers this approach to be counterproductive and of little benefit to the improvement of patient care.

**Complaints and patient feedback system**

The NHS is a bureaucratic organisation where even people who work in the system can find it difficult to navigate their way through. For the general public this problem is magnified. The lack of access is a barrier for people who want to find information or to make a complaint about their care. The BMA often receives correspondence from patients who do not know where to turn and have little understanding of how to have their voice heard.

There is evidence that suggests that many cases of complaints within the NHS are the result of poor communication. The BMA has welcomed moves to introduce communication skills training into undergraduate and postgraduate medical education programmes. In addition, the GMC’s guidance on Good Medical Practice already places an emphasis on the need for effective communication between doctors and their patients.

We recognise that complaints provide an opportunity to learn and believe that the structures in place should ensure that professionals and patients are dealt with appropriately and fairly. Systems should be developed to ensure that complaints are dealt with and we would seek assurances from the Scottish Government that NHS time and resources are not wasted when explanation and apology may be all that is required to resolve a complaint.

Any measures that clarify and ease the existing complaints process are welcome. We would support a mechanism that encourages local complaint resolution within the multidisciplinary team at the practice, department or ward

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6 General Medical Council (2009) Good medical practice
level. We believe that local resolution to complaints can often be found, leaving the NHS boards to deal with more complex cases. Retaining control of complaints at the local level will ensure that complaints are handled quickly and appropriately with satisfactory input from all those involved.

**Patient advice system and the role of Patients Rights Officer**

The Bill makes provision for the establishment of an 'independent' Patient Advice and Support Service (PASS). The aim of this service is to promote an awareness of rights and responsibilities of patients, advise and support those who wish to make a complaint and provide other information about the NHS and how to access services.

The policy memorandum supporting the Bill includes reference to an analysis of the current Independent Advice and Support Service (IASS) which found that users believed it offered a valuable resource for people who may be vulnerable. It also found that in more than half of the cases where an IASS worker becomes involved in a complaint, they are resolved or no further action is taken. It is proposed that the new PASS will 'build' on the work of IASS by promoting an awareness and understanding of patient rights and responsibilities, provide advice and support in relation to local resolution if things go wrong.

We are concerned that when a patient or relative wishes to complain about care or treatment, this new system creates an automatic default whereby the patient is immediately referred to the Patient Rights Officer. This 'over formalising' of the process detracts from the doctor-patient relationship when in fact the system should be encouraging better communication between doctor and patient.

We would like to encourage more complaint resolution locally within the multidisciplinary team, where there is the clinical expertise and knowledge to appreciate the finer details of a particular patient's grievance rather than referring the complaint to a support worker who may or may not have clinical knowledge.

It is difficult to see why provision for this service and the Patient Rights Officers should be necessary in primary legislation, particularly with all the ensuing cost and bureaucracy to change the legislation, particularly when the existing service appears to be functioning relatively well.

**Financial Memorandum**

The Financial Memorandum that accompanies this Bill suggests that initial costs will begin at £862,000 in 2010/11 rising to around £3.5 million by 2012/13.

As stated previously, the achievement of existing waiting times targets has largely been achieved because of significant investment in the NHS. There is little recognition in the Financial Memorandum of the less obvious costs associated with ensuring capacity is available (for example, the cost of waiting
list initiatives, the running costs of national/regional centres at Stracathro and the Golden Jubilee in Clydebank). If resources are not available, it is likely that Boards will divert funding from elsewhere in the budget to ensure that they do not break the law.

Given the current economic climate, we are concerned that additional resources will not be available and that managing patients’ expectations will become more difficult.

**Conclusion**

The BMA does support the clarification of the rights and responsibilities of NHS patients and staff and the principles of equality and compassion on which the health service is based. However we do not agree that this should be placed into law, instead we believe a modern and improved patients’ charter would serve an equally effective purpose.

The Patient Rights Bill enshrines inflexible targets as legal rights which, even without any means of legal recourse, could result in unintended consequences such as distorted clinical priorities which are detrimental to patient care. Boards which breach the 12 week TTG will be breaking the law and it is difficult to understand why this should be necessary, particularly when there are no penalties within the bill and no rights of recourse for the patient.

The BMA believes that the proposals outlined in this Bill place political achievements ahead of the needs of patients and would urge the Committee to reject the general principles of this Bill on the basis that it is unnecessary.

Gail Grant  
Senior Public Affairs Officer  
BMA Scotland  
13 May 2010
Patient Rights (Scotland) Bill

Royal College of Nursing Scotland

The Royal College of Nursing (RCN) Scotland welcomes the opportunity to submit evidence to the Health and Sport Committee on this key issue for health care. RCN Scotland is committed to promoting the rights of the people of Scotland to person-centred care, providing optimum benefit to health and wellbeing. We are fully supportive of patient rights and the principle of mutuality; a health service owned and supported by patients and staff together. We remain concerned that primary legislation is not the most effective means of achieving this.

The need for primary legislation?

The Policy Memorandum to the Bill states that “The Patient Rights (Scotland) Bill is intended to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland.” RCN Scotland welcomes this commitment yet considers that primary legislation about patients’ rights will not have the desired effect on patients’ experience.

‘Patients’ rights’ language has confrontational and litigious associations. It suggests a one-sided NHS and could be construed as unbalancing a mutual approach. The language of mutuality and the Quality Strategy is more relational and therefore more appropriate to convey the rights and responsibilities for patients, staff, and the wider public as co-owners of the NHS. Delivering patient-centred care requires patients and clinicians to take on different and complementary roles. This balance should not be lost in the promotion of patient rights.

Most of the rights outlined already exist in one format or another in current legislation, regulation, or codes of practice. Some of these existing rights are summarised in Appendix 1. If the concern is that these rights are not being met, is further legislation the answer? Where existing rights are not being fulfilled this may be due to a combination of awareness, system barriers, culture, and capacity within the NHS.

Given the potential unintended consequences of legislation, we need to be sure that this Bill is clear about how it will add value. We remain unconvinced that legislation is more useful than a review of how rights and responsibilities are promoted and implemented.

The resources to provide health care principles

Care which is delivered as set out in the health care principles is dependent on staff having the time and resources to give individuals the attention they deserve. The RCN Nurses Employment and Morale Survey Scotland found that 51% of nurses say there is not sufficient staff to meet patients’ needs. Nurses wish to deliver person centred care, but work in a system where that is
often difficult to achieve. Unless barriers to person-centred care are addressed so that frontline staff have the time to attend to patients' needs and concerns, to the standards their professionalism demands, patients' rights become merely rhetoric and staff are set up to fail.

The RCN endorses the health care principles as set out in the Bill, although do not think that they require primary legislation. We are also concerned about managing expectations at a time of tightening financial resources. The patient focus section reinforces the aspirations set out in the NHS Scotland Quality Strategy. The document states that Scotland should become a world leader in person-centred health care, to improve patient experience and support people in participation in their health care.

We accept the Scottish Government's intention that the quality strategy, including initiatives such as ‘Releasing Time to Care’, will support nurses' desire to spend more time in direct patient care. However, this is set against the reality of current cuts in posts and expected significant further reduction in budgets.

RCN Scotland is concerned that in the face of ongoing pressure on public spending in general and on the provision of adequately trained staff, equipment and treatment measures in particular, health care professionals will increasingly become the subject of complaints relative to alleged breaches of the health care principles.

The treatment time guarantee

There remains anxiety that health boards may encourage clinicians to prioritise new patients in caseloads, over patients requiring review, or follow-up, so that 12-week guarantees could be met. RCN Scotland is concerned that the 12 week guarantee being enshrined in legislation will create perverse incentives for ‘gaming’, or other unintended consequences, as has occurred elsewhere when such systems have been introduced.\(^1\)

Ensuring NHS staff are knowledgeable and prepared

Experience from the implementation of the Patients’ Charter suggests that a huge amount of time and resource is required to support staff in the early implementation phase. Patients required significant time and explanation as to implications of the Charter for their care. NHS staff need to be prepared for this role.

RCN Scotland is concerned about the extent to which health care professionals, will receive training and updates on the health care principles and the treatment time guarantee as well as other legal rights and remedies

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available to patients so they are fully informed as to what is expected of them and where the responsibilities lie.

The RCN is also concerned to see that resources will be made available to enable professional bodies and trade unions representing health care workers and health care professionals to engage and collaborate with NHS bodies and organisations representing key interested patient groups, in arriving at common understandings as to how the principles are to be understood, applied and disseminated.

**Patients’ responsibilities**

RCN Scotland agrees that a mutual NHS requires responsibilities to be shared by patients as well as staff. We would like to see more discussion about expectations of patients in meeting the proposed responsibilities. The health care principles state that ‘Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect’. RCN Scotland would like to see this statement strengthened replacing the word encouraged with expected.

RCN Scotland is concerned that recent extensions to the Emergency Workers (Scotland) Act have not been translated into changed behaviours at health board level. It is important that sanctions now available under the Act against those who abuse staff are taken up by boards.

For incidents of abuse that fall short of thresholds set out in the Act, there must also be avenues for staff to make complaints or seek support. It is particularly important that intolerance to abuse of any kind against staff is translated into action, with clear processes in place for managing situations where patients do not fulfil their responsibilities.

**Promoting equality**

Experience of patients’ rights legislation in other countries has shown that inequality can be an unintended consequence of legislation. Individuals with the means and motivation to pursue options of choice and redress are more likely to make use of their enhanced rights. A core principle of the NHS and a policy priority for Scottish Government is equality.

The Bill introduces patient advice and support service (PASS) with a staff of patient rights officers. We understand that the PASS and its staff will promote awareness of patient rights and responsibilities, provide advice and support to those wishing to make a complaint, raise concerns or give feedback and provide information and advice on the health service.

The RCN welcomes the enhanced support for patients through this service. We are however concerned at the extent to which patient rights officers will have the training, skill and experience to direct patients to the full range of legal remedies available to them in the light of a breach of any of their rights, including the rights under the Bill.
Applicable to the whole of the NHS

RCN Scotland is concerned that the overall model suggested has greater applicability to acute health care. Many of the specific rights, from the treatment time guarantee, to the role of patient rights officers, and measures for feedback and redress, have a more natural fit with secondary care. Given the vast proportion of health care in Scotland which is already delivered in the community, and the policy of continuing to shift the balance of care, we would expect the proposals to have a strong emphasis on community and primary care. Demonstrating the relevance and application to services in the community will be an important part of making this real for patients and staff alike.

In summary

RCN Scotland has the following concerns:

- That the Bill would unbalance relationships and work against the development of a mutual NHS;
- Health care professionals may increasingly become the subject of complaints relative to alleged breaches of the health care principles, and the treatment time guarantee;
- The 12 week treatment time guarantee could create perverse incentives for ‘gaming’, or other unintended consequences;
- The Bill could serve to increase inequalities in health care;
- The cost and time associated with training and updating staff around the health care principles and their responsibilities is severely under estimated;
- Principle 12 should be amended to read ‘Patients are expected to treat any person involved in the delivery of health care with dignity and respect’; and
- That the Bill in its current form focuses on issues of relevance to hospital based care and does not address primary and community care.

RCN Scotland would like to emphasise support for a mutual NHS, enhanced through clear, meaningful, and equitable patient rights and responsibilities which sit alongside those rights and responsibilities of staff. However, we do not believe that legislation is required to achieve this.

Elinor Jayne
Parliamentary and Media Officer
RCN Scotland
13 May 2010
Appendix 1 - Existing Patient Rights

Patients already have a range of legal rights which come from duties owed to them by NHS bodies and by the individuals who care for them by virtue of the common law and under enacted law. Many of these rights and duties overlap with the health care principles set out in the Bill. These rights and remedies include:

(a) the right to claim compensation, which can arise -
   (i) when an NHS body or health care professional owning the patient a duty of care breaches that duty and causes the patient loss, injury and damage. That duty might arise at common law which is the basis of most clinical negligence claims, the test for which is to be found in the case of Hunter v Hanley 1955 SC 200, including claims in respect of failures to obtain informed consent;
   (ii) when an NHS body or health care professional breaches their duty of confidentiality to the patient causing loss, injury and damage;
   (iii) when an NHS body or health care professional breaches a duty under enacted law designed to protect the health, care and welfare of the patient, for example the Occupiers' Liability (Scotland) Act 1960 or the Consumer Protection Act 1987.

(b) the right to seek relief or remedy, including damages for just satisfaction in terms of section 8 of the Human Rights Act 1998, given that NHS bodies are public authorities in terms of section 6, in relation to any unlawful act which is incompatible with a Convention right. Key ECHR articles in this context are:
   (i) Article 2 (right to life);
   (ii) Article 3 (freedom from torture and ill-treatment);
   (iii) Article 5 (liberty);
   (iv) Article 8 (right to protection of the home, private and family life, including autonomy in decision-making and the right to live with dignity); and
   (v) Article 14 (non-discrimination).

Other human rights standards which may be relied upon by the patient include the above mentioned International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the UN Principles for the
Protection of Persons with Mental Illness and the Improvement of Mental Health Care and the UN Convention on the Rights of the Child.

(c) Patients have rights to freedom of information in terms of the Freedom of Information (Scotland) Act 2002.

(d) Patients have rights to the protection of their data and their personal sensitive data and to access their medical records in terms of the Data Protection 1998 and the Access to Health Records Act 1990.

(e) Patients have rights in certain circumstances in terms of the Mental Health (Care and Treatment) (Scotland) Act 2003.

(f) Patients have rights to complaint to the Scottish Public Service Ombudsman in terms of the Scottish Public Services Ombudsman Act 2002. In terms of section 11 of the Bill which deals with complaints and other feedback nothing done under or by virtue of that section is to preclude an investigation under the Scottish Public Services Ombudsman Act 2002 in respect of any matter. (See section 11(7) of the Bill).

(g) Patients have a range of rights to complaint to professional regulatory bodies, including the NMC in relation to nurses, the GMC in relation to doctors, the GDC in relation to dentists, and the Health Professions Council in respect of 15 other health professions, including therapists, chiropodists, paramedics, physiotherapists and radiographers.

(h) Patients have the protections and rights afforded to them by the criminal law and can report circumstances to the relevant authorities, most usually the police.

(i) Patients are given protections in relation to the prescribing, dispensing and administration of medicines.

(j) Where a death has occurred as a result of a medical accident, the patient’s family and other representatives will be entitled to enter into a dialogue with the health care providers, the police and the Crown Office Procurator Fiscal Service with a view to holding a fatal accident inquiry in terms of the Fatal Accident and Sudden Deaths (Scotland) Act 1976.

This is by no means an exhaustive list but serves to illustrate the range of rights already in place.
The Royal College of General Practitioners (RCGP) is the academic organisation in the UK for general practitioners. Its aim is to encourage and maintain the highest standards of general medical practice and act as the ‘voice’ of general practitioners on education, training and issues around standards of care for patients.

The College in Scotland came into existence in 1953 (one year after the UK College), when a Scottish Council was created to take forward the College’s interests within the Scottish Health Service. We currently represent over 4000 GP members and Associates in Training throughout Scotland. In addition to a base in Edinburgh, the College in Scotland is represented through five regional faculty offices in Edinburgh, Aberdeen, Inverness, Dundee and Glasgow.

The consultation document was reviewed by GP members of the RCGP Scottish Council, the RCGP Scotland Executive Board, the RCGP Scotland Membership Liaison Group (MLG) and lay members of the RCGP Scotland Patient Participation in Practice Group (P³).

Overall responses received found the standards reasonable. However there were concerns raised regarding the intentions of the Patients’ Rights Bill to be used as a legal framework. It was felt that as objectives, the improvements outlined in the document have great merit, but enforcing them as statutory legislation would be perceived as unnecessarily bureaucratic. There were also concerns raised that legal costs would prove extremely high for the healthcare system. Despite the fact that a ‘mutual’ NHS is discussed, it would be highly unlikely that patients themselves would have legal action taken against them. Ultimately it was felt that the creation of legislative framework is unnecessary.

‘We are delighted the government is reviewing Patients Rights, however we remain unconvinced of the need for their codification. It must be remembered that with rights also come responsibility. These responsibilities extend to using the services appropriately and treating those who provide those services with respect.’

Dr Ken Lawton, Chair of RCGP Scotland

1. The Right to Access

12 weeks was considered an acceptable target for waiting times, though it should be noted that a member of our patient group suggested that 10 weeks for inpatient treatment and 14 weeks for outpatient treatment would also be an acceptable model.
Concerns were raised that, whilst a focus on meeting targets is desirable, the implications of implementing such guarantees in a legal sense may not necessarily be feasible and would lead to a drain on both administrative and financial resources. Members felt that current HEAT targets have been, and will continue to be highly successful in reducing waiting times. We would welcome the successful implementation of 12 week waiting targets for patients but do not feel that there is currently the need to develop these targets into legal and statutory requirements.

GP members in rural areas also raised concerns about the need to take into account patients in rural communities who may not have access to certain treatments in their own board areas. This is particularly relevant to small island communities where patients may be referred to other health board areas for (for example) certain psychiatric services. Any legislation introduced regarding patient rights must ensure that the geographical diversity of Scotland is taken into account in order to ensure that such legislation is relevant to all.

2. The Right to Respect
Members were in support of the ideas addressed in this section; however concerns were raised as to whether adequate funding is in place to guarantee this as a legal right.

Responses also raised the concern that it is difficult to define terms such as ‘dignity’ and ‘respect’, these abstract terms could prove problematic especially where legal implications would be involved. It was also felt that care must be taken to ensure extra vigilance on this issue with regards to more vulnerable patients (such as the elderly, those with psychiatric problems and children).

3. The Right to Safe and Effective Care
Overall we agree with the inclusion of the entitlements and responsibilities as laid out in the draft. However it was noted that the term ‘continuity of care’ requires definition in order to distinguish whether this refers to continuity of the person providing care or the type or care offered.

Responses also cited the need for amendment of ‘complying with advice on medication and treatment’. It was felt that this wording removes the contemporary need for transparency. It is important for both patients and clinicians to come to a mutual understanding of the treatment plan and therefore we would suggest that the section referenced above be amended to ‘patients will be responsible for adhering to agreed treatment plans.’

It was also noted that patients have the right not to comply with therapy and that health professionals may seek concordance but cannot insist on it. It may be necessary to outline this in the bill.
4. The Right to Communication
We would welcome the moves to encourage patients to ask questions and to interact in this way with members of the healthcare team.

Additionally, we feel it is important to note that it is difficult to define clear and appropriate communications as views of this may vary considerably between parties. We are also aware that currently it may not always be possible to access the services of an interpreter and feel that this entitlement should be amended to include the phrase ‘where available’.

5. The Right to Information
Respondents were generally happy with the points outlined and were supportive of the patient’s right to information. Continued investment on those for whom English is not a first language would be needed to ensure this is possible (for example by improving access to interpreter services). It was also noted that it would be time consuming and costly to copy all correspondence to a patient should they request it and that it was largely unclear who would be responsible for the administrative work involved. It will be necessary to provide a definition of ‘any letters, faxes or emails’ as the level this is set at will have a direct affect on the feasibility of this guarantee.

6. The Right to Participation
The over arching principles outlined in this section seem reasonable and members of our patient group, P3 welcomed the notion that patients are entitled to be involved in decisions about health services. The importance of ensuring that patients are aware they can withdraw consent at any time was highlighted as a positive move as many patients may not realise this to be the case.

However, there were concerns over the demand on healthcare professionals to provide full information on all options open to a patient regarding their treatment. One member asked whether a ‘care information specialist’ would be introduced for this purpose or whether it would fall onto the patient’s doctor to provide this additional service themselves. It will be time consuming for members of the healthcare team to research and provide this service to the level outlined and we feel it would be useful to see further research on how the additional appointment time required for this service would fit into the promises to drastically cut waiting times. We would also welcome a more detailed proposal on informed participation.

7. The Right to Privacy
General consensus was in approval of a patient’s right to privacy as outlined, though it was noted this section does not add anything to existing documentation. As an additional comment it was noted that it should be made clear in the document that the right to privacy is not absolute and may be overridden in
exceptional circumstances such as that relating to statutory legislation and public interest.

8. The Right to Independent Support and Redress
Both GP and patient respondents welcomed the principles of achieving a culture of feedback and learning. We agree that staff should be encouraged to view complaints not as a threat but as a learning opportunity. We support the responsibility of patients in providing (as far as possible) positive and constructive feedback, though one response commented that negative feedback can also be of value.

We hope that these comments are useful. If you wish any further information from RCGP Scotland please contact at:

Dr. Kenneth Lawton
Chair
RCGP Scotland
13 May 2010
Patient Rights (Scotland) Bill

Inclusion Scotland

1 Background

1 Inclusion Scotland is a network of disabled peoples' organisations and individual disabled people. Our aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people’s everyday lives and to encourage a wider understanding of those issues throughout Scotland. We have consulted widely with disabled people to obtain their views of the proposals contained within the Patient Rights Bill.

2 Patients’ Rights & General Principles of Bill

2.1 Almost a third of Scottish NHS Service Users are disabled people. Although many receive an excellent service, many others have experienced discriminatory assumptions about their quality of life or strict adherence to a 'medical model' of disability adversely influencing the sort of service received.

2.2 Discrimination within the health service can affect disabled people from birth ranging from insensitive treatment of disclosure of disability, restrictions or refusal of treatment, to posting of unsought ‘Do Not Attempt Resuscitate’ (DNAR) notices.

2.3 The Disability Agenda published by the Disability Rights Commission (DRC), found in ‘Tackling Health Inequalities that: People with learning disabilities have much lower rates of cervical screening, mammography and other routine tests than other citizens; Some groups of disabled people die younger than non-disabled people; Learning-disabled people were four times more likely to die from treatable illnesses; Learning-disabled people were 58 times more likely to die before the age of 50 than non-disabled people; Large causative factors were barriers in accessing health promotion, assessment, screening and treatment.

2.4 Over half of those taking part in the DRC’s consultation said that, as people with mental health needs or a learning impairment, they had difficulties when trying to use services provided at primary care level. A small number reported not being able to register or being struck off a GP’s list, for instance for being ‘too demanding’. It is unlikely that similar discrimination is not faced by those with mental health problems or learning disabilities north of the border.

2.5 A large body of evidence proves inequalities in health outcomes between disabled and non-disabled people and of significant problems in access, staff attitudes and quality of service. Reports published on the continuing institutional
discrimination faced by disabled people as service users, include ‘Disability equality within healthcare’ (British Medical Association June 2007); ‘The experiences of visually impaired users of the NHS’ (Guide Dogs for the Blind Association, 2004).

2.6 In 2004 Fair For All Disability undertook a survey of all Scottish NHS Boards, to establish their knowledge of Part 3 of the Disability Discrimination Act 1995, which prohibits discrimination in the provision of goods & services. Results indicated poor knowledge of the Act. The conclusion was that this lack would likely lead to difficulties when disabled people attempted access to health services.

2.7 In 2006/7 inclusion Scotland surveyed our own members on their experience of the NHS. Results showed that they experienced a lack of sensitivity and understanding of their health care needs in all areas of the health service. This Bill could help ensure that such discrimination does not persist within Scotland’s NHS.

2.8 We acknowledge the commitment and professionalism of many NHS staff but we report that many disabled people are concerned at the ongoing erosion of caring attitudes, cleanliness and common sense within the NHS. At present NHS staff carry out established protocols, with their emphasis on reducing “risk”, rather than adapting the care provided to suit disabled patients’ needs. We therefore welcome the principle that health care is henceforth to be patient focused.

Example 1: When admitted to hospital a disabled person’s Personal Assistant (PA) is not allowed to be present as the NHS assumes all responsibility for care. Yet some disabled people have had food left beside their beds and been unable to feed themselves because NHS staff have been too busy or were unaware of their needs (even though previously disclosed). In such circumstances why are PAs not allowed to assist?

2.9 Disabled people report that the ‘Does he take sugar?’ habit persists within the NHS. Doctors and health staff tend to communicate with family members, carers, friends or PAs rather than disabled people themselves. Wherever possible, disabled people should be communicated with directly about their care and treatment. Advocacy support must be made available for those with learning difficulties, brain injuries or other impairments which hinder understanding. We therefore welcome the principle that patients are to participate as fully as possible in decisions relating to their own health and wellbeing.

2.10 Inclusion Scotland are extremely disappointed that the Bill will only require the NHS to “…have regard to the importance of providing such information and support as is necessary to enable the patient to participate…” instead of the stronger right to be communicated with which was included at the Bill’s
consultation stage. It effectively negates the rights of some disabled people to participate as fully as possible – for example there will be no clear right for BSL or Braille users to be communicated with in formats of their choice. Instead the NHS need only have ‘regard’ to that choice.

2.11 This weak requirement falls far short of disabled people’s rights as established under the UN Convention on the Rights of People with a Disability to which the UK is a signatory. Article 21 of the Convention states that:

“States Parties shall take all appropriate measures to ensure that persons with disabilities can…. receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

2.12 The Scottish Government has a clear duty to work towards progressive achievement of these rights. The proposal in the Bill to direct NHS Boards to merely have “regard” to communication support is at odds with that obligation. Disabled people, like all other patients, should have a clear right to be provided with information and support enabling them to make informed decisions about their treatment. Anything less is an erosion of their rights and likely to result in negative health outcomes.

Example 2: A deaf BSL-user is admitted to Accident & Emergency. He is allergic to penicillin. Doctors consider providing a BSL interpreter to outline treatment options but as this will attract additional expense to the unit, after due “regard” they instead decide to proceed without one. The patient suffers an adverse reaction and dies as he was unable to communicate effectively with them.

3 The 12 Week Treatment Guarantee

3.1 Inclusion Scotland cautiously welcomes the commitment to deliver a maximum 12 week wait from referral to treatment but without additional resources it is unclear how this is going to be achieved

3.2 The adoption of a “target” culture tends to distort NHS service delivery with management more concerned with meeting targets than improved outcomes for
patients. Inclusion Scotland strongly urges the Government to monitor whether speeding up the process is genuinely delivering good medical care.

3.3 There is a feeling that some GPs delay making referrals resulting in a longer patient journey even though there is a guaranteed waiting time after referral. Inclusion Scotland urges the Government to bring forward proposals on how this potential problem will be addressed.

3.4 We deplore the Scottish Government’s failure to include mental health treatment within the guarantee. NHS Highland reported that some mental health patients wait for more than four and a half years to see a psychologist. Referrals to mental health services can be subject to considerable delays far exceeding the proposed 12 week treatment guarantee. There is no commitment in the Bill to tackle this.

3.5 The argument that access to mental health services can be adequately met by crisis admissions is dangerous and is an effective abandonment of any guarantee of treatment for mental health service users.

3.6 The Government’s case seems to be that patients with long term mental health needs (depression, anxiety, schizophrenia, bi-polar disorder) should not be guaranteed early access to recognised and effective treatments until such time as their condition enters a crisis phase when their admission is required. If there is early access to adequate mental health services there will be fewer crisis admissions. Rationing care until a crisis occurs is likely to intensify longer term psychological damage by leaving serious conditions unaddressed and untreated.

3.7 The mental health of Scotland’s population is already extremely poor compared to other developed nations. With an estimated one in five Scots seeking some form of mental health treatment last year, only the United States has a higher incidence of mental health issues (Source: World Health Organisation). Scotland also has woefully high suicide rates particularly amongst young men.

3.8 There is a strong relationship between poor mental health and the incidence of (and ability to recover from) conditions such as heart disease, stroke and cancer. We posit that poor provision of mental health services partially explains Scotland’s poor life expectancy, particularly amongst those suffering stress from poverty and deprivation.

3.9 Similar guarantees for waiting times for mental health issues must be established for the present undervalued, under resourced Scottish mental health services as those applying to physical health services. Otherwise, those with mental health issues will be treated less favourably. Such guarantees will mean investment in extra staffing requirements.
3.10 In terms of the proposals contained within the Bill we remain unsure as to the enforcement mechanism if the 12 week guarantee is not met. The Minister’s power to make directions seems reasonably powerful but lacks clarity on how, and when, it will operate in practice.

4 The complaints and patient feedback system

4.1 Inclusion Scotland welcomes the proposed establishment of an independent Patient Advice and Support Service as a step towards establishing better advocacy for patients within the NHS.

4.2 However problems exist with the integrity of the mechanism of a service whose funders are those against whom complaints will be raised. Determination to advocate on behalf of clients can be influenced by fear of jeopardising funding.

4.3 Fears were expressed that lodging complaints could jeopardise future relationships with the medical profession. It is, for example, all too easy for a GP to remove a patient from their list.

4.4 Patients need to be protected from victimisation by health professionals if they raise a legitimate complaint. This should be a robust right similar to those contained in the Equalities legislation.

5 The patient advice system and the role of Patient Rights Officers

5.1 We welcome the proposed establishment of a patient advice system and the introduction of Patient Rights Officers (but note our concerns above). However such a system cannot operate effectively without the development of parallel advocacy services for disabled people as some disabled people (e.g. those with learning difficulties; deaf/blind people) will neither be able to initiate nor pursue complaints without specialised advocacy support.

5.2 Patients Rights Officers must be able to communicate with or support patients who have communication needs (BSL, Braille, etc.) and these remain unaddressed. The officers must be required to take all appropriate measures to enable them to support and communicate with disabled patients and to provide information on their service and the progress of cases in appropriate formats.

6 Conclusion

6.1 Inclusion Scotland confirms its support for the main principles outlined in the Patient Rights Bill but calls on the Scottish Government to amend and improve the legislation in line with seeking progressive achievement of disabled people’s rights.
Footnotes:
1. The 'medical model' of disability focuses on the impairment of the individual as the core problem believing medical treatment or cures should be used to 'normalise' the individual. The 'social model' of disability aims to address the problems of social and environmental barriers in terms of society's discriminatory policies, practices and attitudes which cause social exclusion.


Bill Scott
Policy Officer
Inclusion Scotland
7 May 10
General comments

LTCAS welcomes action to strengthen the rights of users of the NHS. The Patients’ Rights Bill should aim to contribute towards a mutual NHS, including:

- People becoming the leading partners in their own health and care
- Users of services being central to service planning and development
- Cultural change away from the traditional model of people as passive recipients of NHS services

LTCAS strongly welcomes the commitment in the policy memorandum (paragraphs 22, 40 and 62) to increasing provision and funding of services such as independent advice/support services, advocacy, translation, interpreting and communication support services.

During the Scottish Government’s previous consultation on proposals for the Patient’s Rights Bill LTCAS raised questions over how the legislation would be turned into a reality. This issue still requires further consideration but the intention to develop a training programme for NHS staff (Policy Memorandum paragraph 60) will help to achieve this. This training should be rolled out across all levels of the NHS and mainstreamed into future undergraduate education for health staff.

Consideration should be given to producing a Code of Practice to accompany the legislation. This would help illustrate how the aspirations of the legislation should translate into reality.

Rights and health care principles (Sections 1 to 5)

- Section 1.2(a) describes ‘patient focused’ as ‘anything done in relation to the patient must take into account the patient’s needs’. This should be strengthened to state the patient’s needs should be paramount.
- It is essential that people are given information to support their participation in their own health and wellbeing, however this does not happen consistently. LTCAS therefore welcomes the provision in section 1.2(d).
- The health care principles outlined in the schedule are welcome, in particular the requirement that ‘health care is provided in a caring and compassionate manner’. However:
  - Principle 5 relates to a key issue for health inequalities. Many people experience barriers to health services, and in turn poorer health outcomes. This may be caused by lack of support for
people with sensory impairments, English as a second language, learning difficulties or people living in residential settings. The provision should be strengthened so that support is not just available but proactively offered.

- Support from a voluntary organisation can make a significant difference to people’s experiences and health outcomes. LTCAS would like to see the ‘quality care and treatment’ principles state that consideration will be given to other organisations or agencies (for example from the voluntary or local government sectors) that could support a person’s health and wellbeing.

- Self management should be reflected in the ‘patient participation’ principle, for example by stating ‘patients are encouraged to work in partnership with health professionals and to take the lead in managing their own health and wellbeing’.

**Treatment time guarantee (Sections 6 to 10)**

Timely treatment is essential for people who live with long term conditions. However this right must also apply to follow-up appointments and ongoing care. If these rights and guarantees only apply to a person’s first appointment there is a risk that people with long term conditions who require ongoing health services will be pushed to the back of the queue. LTCAS would expect to see this reflected in the further provision to be made by Scottish Ministers.

**Complaints and patient feedback (Section 11)**

LTCAS strongly welcomes provision for feedback and complaints to help inform improvements to health services. It would be appropriate if NHS Boards were required to report on how this had been done as part of their Annual Reviews.

**The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)**

The patient advice and support service and Patient Rights Officers should help to make rights a reality. More information is needed on how this service would interact with the many voluntary organisations that provide information, support and advocacy.

LTCAS would suggest adding to Section 16 a line stating that the Patients Rights Officers can signpost people to support organisations relevant to a person’s health needs (for example voluntary organisations dealing with specific conditions).
About LTCAS

The Long Term Conditions Alliance Scotland (LTCAS) is an independent charity funded by the Scottish Government. LTCAS has over 170 member organisations from across Scotland and aims to ensure the voice of people living with long term conditions is heard by policy makers and service planners.

LTCAS’ vision is for a Scotland where people with long term conditions enjoy, not endure, full and positive lives, free from discrimination and supported by access to high quality services, information and support.

Shelley Gray
Director of Policy & Campaigns
LTCAS
13 May 2010
Patient Rights (Scotland) Bill

SAMH

1. SAMH

SAMH is Scotland’s leading mental health charity and is dedicated to mental health and wellbeing for all. SAMH provides both direct services and an independent voice on all matters of relevance to people with mental health and related problems.

SAMH has over 80 services throughout Scotland which address a range of individual needs. Our services support people who have experience of mental health problems and other forms of social exclusion including homelessness and addictions.

SAMH promotes the development of legislation, policy and practice that is based on the real life experiences of people with mental health and related problems and respects their human rights.

2. GENERAL COMMENTS

SAMH welcomes the opportunity to comment on this consultation. People with mental health problems are currently afforded rights under the Mental Health Act, and are protected by legislation such as the Human Rights Act and the Disability Discrimination Act. However, people experiencing mental health problems continue to face significant inequalities in our society, and it remains true that they often do not receive the same level of healthcare when compared to people with physical health problems.

The Patient Rights (Scotland) Bill could go some way to rectifying this situation. The strengths of the Bill are in the creation of a set of patient rights and health care principles which will serve as the foundation of a patient centred NHS. The Bill also creates numerous provisions in relation to patient advice, support and advocacy. It does, however, remain extremely disappointing that mental health has been largely excluded from the treatment time guarantee. The Patients Rights Bill must be further developed, to ensure that it incorporates advancements in relation to mental health waiting time targets and treatment time guarantees.
3. SPECIFIC COMMENTS

The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

For too many people with mental health problems, the balance of power in terms of decision making lies with others, or decisions about their lives are influenced by legislation and the availability of treatment or services. Many people have also been treated with a lack of dignity and respect; including not being told their diagnosis, and not being given adequate information about the treatments, services and support they receive.

The patient rights and health care principles outlined in this Bill provide a platform for redressing this situation, and could go far to help improve the experiences of people with mental health problems when coming into contact with the NHS. Health care principles in relation to patient focus, quality care and treatment, participation, communication, and information are all vital in ensuring a responsive and patient centred NHS. Similarly, the inclusion of the rights to make complaints, to raise concerns, and to give feedback are all fundamental to ensure an NHS which is transparent, accountable and well equipped to deliver the level of care required.

SAMH welcomes the direct inclusion of the human rights principles of dignity and respect in the schedule of health care principles. It is greatly encouraging that discussions on the Bill have been informed by Human Rights legislation and, in particular, by Article 12 of the International Covenant of Economic, Social and Cultural Rights. While it is true that some of the conditions necessary to achieve the highest attainable standard of physical and mental health sit outwith health care, SAMH would argue that directly embedding the language of Article 12 within the schedule of health care principles would help give this right practical effect and foster a greater understanding amongst NHS staff and service users of how human rights relate to their lives and their work.

It is interesting to note that Scottish Ministers may, by order, modify the stated rights and health care principles. Given the fundamental importance of these rights and principles, SAMH would expect that any such modification would be subject to the appropriate levels of consultation and parliamentary scrutiny.

The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

It is disappointing that mental health has been largely excluded from the treatment time guarantee (TTG); meaning that the vast majority of mental health service users will not benefit from this aspect of the Bill.

The Scottish Government intends that the TTG will predominantly apply to planned and elective care delivered on an inpatient basis. SAMH understands
that, in relation to mental health, admissions in this context are almost exclusively in the context of crisis and that it would not be appropriate to apply a maximum waiting time guarantee of 12 weeks to this type of admission.

It is stated that mental health care/treatment delivered on an outpatient or day patient basis is also to be excluded from the TTG. A very large proportion of mental health care/treatment is delivered on this basis; whether it be within outpatient clinics, GP surgeries, day-centres, or within people's own homes. It is commented that the focus of the TTG is on one-off elective treatments (such as surgical procedures), while mental health treatment is primarily of an ongoing and progressive nature. Whilst it is true that many mental health problems are unlikely to adequately addressed by a brief one-off intervention, this fact alone should not preclude mental health from inclusion in TTGs. The TTG applies from the time of agreement to treatment to the actual commencement of that treatment. It is, therefore, irrelevant how long a particular course of mental health treatment may last as the focus is on the time to commencement of treatment, and not the completion of it.

It is also true that mental health problems can fluctuate and often entail varying degrees and types of support over time. Where a person requires several different types of treatment for the same mental health problem, the TTG could still apply individually each time they agreed to a particular course of treatment to the commencement of that specific course of treatment.

SAMH welcomes the Scottish Government’s recent commitment to introduce a waiting times target for access to psychological therapies. It is recognised that NHS resources are under significant strain, and that establishing waiting time guarantees applicable to the full range of mental health services is not something which can be achieved overnight. It is essential that the Scottish Ministers ensure supplementary changes are made to the Patients Rights Bill to incorporate developments in relation to mental health waiting time targets and guarantees; in accordance with the progressive obligation placed on them by Article 12 of the International Covenant of Economic, Social and Cultural Rights.

As some aspects of child and adolescent mental health services may take place on a planned basis – and in particular admissions to inpatient care – these are to be covered by the TTG. There are also some aspects of adult mental health services which are delivered on a similar basis, and these should be considered for inclusion; for example, in relation to admissions for eating disorders and self-harming.

Complementary and alternative medicines are to be excluded from the TTG as, it is stated, these services are likely to be in addition to the clinical care which a patient receives; as opposed the primary basis of a referral for diagnosis and treatment. Recently, there has been a growing emphasis on how physical activity can be used to promote mental health and help people manage mental
health problems. Exercise can now be included as part of the treatment plan for a range of mental health problems, and GPs prescribe exercise sessions and activities. In addition, a growing number of innovative projects – such as Stress Centres – provide holistic and complimentary therapies, with the aim of working with people to help them manage stress levels and improve their health/well being and quality of life. Excluding these types of treatments from TTGs could send the message that they necessarily inferior to more conventional approaches, and that they should not be utilised or taken seriously.

Alcohol and drug misuse services are to be excluded from the TTG as there is a HEAT target for drug treatment of 3 weeks from referral to treatment. HEAT targets are a core set of objectives, targets and measures set for the NHS over a three year period. The Patient Rights (Scotland) Bill, in contrast, is about the fundamental rights of patients; which are not of a fleeting or transitory nature. Excluding alcohol and drug misuse services, as there is a HEAT target in this regard, confuses these distinct roles; HEAT targets are not about patients rights and do not offer any protections, rather they relate only to the allocation and management of NHS resources.

People with co-morbid problems can face particular difficulties accessing services and obtaining the help they need in a timely fashion. Often they run the risk of being turned away from mental health services if seen to have a drug or alcohol habit, and turned away from drug and alcohol services if seen to be involved with mental health services. It has yet to be seen how the drug treatment HEAT target will apply in these situations; for example, will people with co-morbidity receive simultaneous treatment for their mental health problems and addictions within 3 weeks, or would treatment only seek to address their addictions within this timescale? While SAMH greatly welcomes the 3 week target, there is a danger that this will create an inequality in access to care; where people receive timeous mental health treatment if coupled with addictions issues, while others are forced to wait until their mental health has deteriorated to crisis point before receiving support.

It could also be made clearer how the TTG differs from the current waiting time target of 18 weeks from general practitioner referral to treatment. The 18 weeks standard does not focus on a single stage of treatment, e.g. the time from referral to first outpatient appointment, or the time from being put on a waiting list until treatment starts; the 18 week standard applies to the pathway from a GP referral up to the point where each patient is actually treated.

The Bill means that, where there is a breach of the treatment time guarantee, Health Boards must make such arrangements as necessary to ensure that treatment starts at the next available opportunity; while patients must be made aware of available advice and support, and the option to complain. These provisions may help to ensure the timeous delivery of those services which are covered by the TTG. However, as nothing in the Act will give rise to any liability
to pay damages, action for specific implement, action for interdict, or any right of action for suspension, it is unclear what the outcome of any complaints might be or how Health Boards will be held to account for breaches of TTGs.

The complaints and patient feedback system set out in the Bill (Section 11) & The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

SAMH welcomes recognition of the existing right to make complaints in the Bill. This should serve to improve patients’ awareness of their right to lodge a formal complaint and also increase understanding of how such complaints will be handled. This will be supported by requiring NHS bodies to have adequate arrangements in place for publicising the complaints procedure, as well as the advice and supports which are available to all patients.

It is vital that complaints are monitored with a view to identifying any areas of concern and ultimately improving performance. It is stated that, through secondary legislation, the Scottish Government is to set out clearer monitoring procedures and feedback mechanisms. SAMH awaits the development of this legislation, and hopes that it will be effective in establishing appropriate timescales, as well as ensuring that complaints are better utilised to improve performance.

SAMH fully supports the assertion that the Patient Rights Bill should not be allowed to become a ‘charter for lawyers’. However, as none of the rights set out in the Bill are enforceable by any legal action, and nothing in the Bill gives rise to any right of action for implement, interdict, or suspension, it remains unclear how effective the Patients Rights Bill will really be in ensuring that patient’s rights are respected, and that breaches of these rights are prevented. Without - at least some - possibility of recourse, patient’s rights may not be afforded the appropriate levels of priority and attention they deserve.

NHS bodies are to encourage patients to raise concerns or give feedback on health care, and must consider all feedback received with a view to improving the performance of its functions. Listening to, and taking on the board, the views and experiences of people using NHS services will greatly assist the NHS in creating services which are of the highest standard and responsive to individual need.

An independent Patient Advice and Support Service is to promote awareness and understanding of patient’s rights and responsibilities, and also assist people to make complaints, raise concerns or give feedback. Traditionally, mental health service users have often been ‘done to’ and their views and rights have either not been considered, or asked for and then ignored. The creation of the patient advice system and Patient Rights Officers could go far in helping to address this situation. It will be vital that patient advice and support services are
created in relation to each Health Board and that they operate effectively at a local level.

The activities that a Patient Rights Officer may undertake include providing information about representation and advocacy services. It is the case that some people may require advocacy to access the Patients Rights Officer in the first instance and greater clarification should be given as to where the responsibilities to ensure access to advocacy will sit. SAMH greatly welcomes the Scottish Government’s commitment to make further funding available to support the provision of advocacy. There is a great need for continued investment in the advocacy services across Scotland, both generally and in terms of meeting the needs of specific groups and communities. Advocates often help to address issues relating to healthcare which occur outwith hospital settings; for example, in relation to care plans, medication, or problems with services or after-care services. As such, significant investment will be required for advocacy services both within the community and within the NHS.

Patients Rights Officers will require mental health awareness training in order to ensure that they have a sound understanding of the needs of people with mental health problems, as well as how to communicate effectively with mental health service users in times of distress. It is vital that the Patients Rights Officers feel comfortable in dealing with all patients’ or carers’ queries, and know how to respond appropriately.

The introduction of the Patients’ Rights Bill serves as an opportunity to ensure that inequalities are not allowed to persist in Scotland’s NHS, and that anyone coming into contact with the NHS receives the highest attainable standard of treatment and care. SAMH welcomes much of what is proposed in this Bill but it could go much further to ensure that mental health is afforded equal priority when it comes to patients’ rights.

The continued exclusion of mental health services from the treatment time guarantee, and from the 18 week waiting time target, is a glaring inequality. The Scottish Government must give further consideration as to how it can ensure mental health service users are also able to benefit from such guarantees, and have their human rights upheld.

Mr Aidan Collins
Policy Officer
SAMH
12 May 2010
About us
1. RNID Scotland, NDCS Scotland and RNIB Scotland welcome the opportunity to submit evidence on the Patient Rights (Scotland) Bill.

2. There are 758,000 people who are deaf or hard of hearing in Scotland. RNID Scotland's vision is a world where deafness and hearing loss do not limit or determine opportunity and where people value their hearing. We aim to achieve this vision by campaigning and lobbying, with the help of our members, raising awareness of deafness and hearing loss, providing services and through social, medical and technical research.

3. In Scotland there are 188,000 people with significant sight loss. RNIB Scotland is one of Scotland's leading sight loss charities. RNIB Scotland seeks to ensure that blind and partially sighted people are able to live as full and independent lives as possible. RNIB Scotland is firmly committed to campaigning to ensure equal access to public services.

4. RNID Scotland also works with the National Deaf Children’s Society (NDCS) Scotland to support their aims of a world without barriers for every deaf child. NDCS Scotland estimates that there are around 3,500 deaf children in Scotland today.

Deafness and hearing loss
5. It is estimated that 1 in 7 of the general population has some degree of hearing loss. There are many reasons why some people are deaf or hard of hearing or lose their hearing. The most common is age-related deafness with more than 50% of people over the age of 60 with some hearing loss. Deafness can be congenital, and Universal Newborn Hearing Screening, introduced in Scotland in 2005, is identifying more deaf babies than ever before. NDCS Scotland estimates that 2.6 in every 1,000 children have a significant hearing loss, and many more have mild to moderate losses.

6. Depending on their level of deafness and on when they became deaf or hard of hearing, people who are deaf or hard of hearing use a range of methods to communicate. Between 5,000 and 6,000 deaf people in Scotland use British Sign Language (BSL) as their preferred or first language; many rely on lip reading, others use note takers or rely on equipment such as hearing aids; and some use a combination of these. For those who use BSL as a first language, often English is a second language and access to written English can be challenging.

Blindness and Sight Loss
7. In 2009, 35,588 Scots were registered with their local authority as blind or partially sighted, with 2,934 new registrations per year. Research suggests about 10 per cent of eligible people do not register suggesting the true figure is around 40,000. A further 148,000 people in Scotland are
estimated to have significant sight loss\(^1\). By 2031, with no intervention beyond the current provision, sight loss is expected to double to almost 400,000 people with significant sight loss. This will be as a consequence of increases in the elderly population and a variety of health factors.

8. This will put significant pressure on health and social service and RNIB Scotland argues that through strategic investment in order to prevent eye disease and to ameliorate the impacts of sight loss the pressure on public budgets can be mitigated. This includes accessible health information so that blind and partially sighted people can manage their own health needs more effectively.

**Patient Rights and Health Care Principles**

9. RNID Scotland, NDCS Scotland and RNIB Scotland welcomes the patient rights and health care principles outlined in the Bill including: healthcare to be ‘patient focused’; allow and encourage the patient to participate as fully as possible in decisions relating to their health care; have regard to providing information and support to enable patients to participate in their health care; and the right to make complaints, raise concerns and give feedback about healthcare received.

10. However, to make these rights a reality, health care needs to be accessible to disabled people, including people who are deaf or hard of hearing or people with significant sight loss. Currently, many disabled people still struggle to access health care.

11. For example, the Scottish Government issued its report on progress towards equality of opportunity between disabled persons and other persons\(^2\) in which it quotes the baseline study of health boards’ understanding in relation to disabled people carried out by Fair for All-Disability. This shows that “effort was concentrated on making services physically accessible, though with lesser apparent activity on other aspects of accessible service delivery and some of this appeared to arise from a lack of understanding about the definition of access to services.” The same report quotes a survey by NOP for the Disability Rights Commission in 2003 which showed that 24% of disabled people polled in Scotland mentioned difficulties in the course of an appointment or visit to a hospital and 18% in accessing a dentist\(^3\). For those with sensory impairments who had faced difficulties, barriers mentioned included staff attitudes and absences of induction loops.

12. People who are deaf or hard of hearing or blind and partially sighted experience barriers when accessing NHS services, in both GP surgeries and hospitals.

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\(^3\) Chowdhury, R and Worley (2003) a Survey of Disabled People’s experience of access to services in Britain
13. According to the British Medical Journal, thousands of profoundly deaf people still struggle to communicate with healthcare professionals on a daily basis, while new research by RNID Scotland, Are You Listening?, found that having a hearing loss made it hard for patients to access health services. Two key barriers for people who are deaf or hard of hearing include staff not being deaf aware and a lack of adaptations such as induction loops.

14. RNID Scotland’s research found that 43% of respondents to our survey agreed that ‘being deaf or hard of hearing makes it hard for me to access health services’. Given that most people lose their hearing in older age, most of our respondents used health services prior to losing their hearing as well as after and their patient experience in relation to accessibility has clearly changed.

15. RNIB Scotland also surveyed its members on accessible information in the health service. RNIB Scotland discovered that only 10% of information was provided in the patient’s preferred reading format, with 91% of participants felt they had a right to a format which they could read.

Communication Barriers
16. Other issues of concern identified in RNID Scotland’s research mainly relate to difficulties patients who are deaf or hard of hearing experience with health care staff. For example:

- One quarter of our respondents have to rely on a friend or relative to make telephone appointments with health professionals on their behalf.
- While 46% of respondents made appointments over the phone themselves, one-third said they had difficulties communicating with staff because staff did not speak clearly on the phone (too fast or too softly).
- While 24% made appointments in person, over a third found staff did not speak clearly in person (receptionists shout or talk behind a glass partition or do not face patients so they cannot lipread).
- There is often background noise in the waiting room/reception area and loop systems are not often available which means hearing aid users cannot hear the receptionist.
- Half of all respondents said they could not hear their name being called out in GP practices while 40% could not hear their name being called out when attending hospital as an outpatient.
- 42% experienced difficulties communicating with their GPs and half of our respondents had found it difficult to communicate with staff working in audiology departments – the very place where staff should be deaf aware.

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6 Ibid
7 Thurston & Thurston (2010). The accessibility of health information for blind and partially sighted people. RNIB Scotland
8 Ibid, pp 5-6
• Nearly a quarter of respondents did not use communication support in a health care setting (for example a BSL interpreter or a notetaker) because they did not know they could ask for it.
• 22% of respondents who said they did require communication support used alternatives such as lipreading, while others used relatives to act as their communication support worker.

17. Having to rely on friends and relatives to make appointments or to act as a communication support worker undermines patients’ dignity and privacy as well as their independence to control and manage their own health care.

18. NDCS Scotland would also point out that whilst 90% of deaf children are born to hearing parents who support them throughout childhood in accessing NHS services, deaf children have the right to understand and be involved in decisions being made about their care. Deaf parents of deaf children also require full access to information about their child’s care.

19. In addition, for both deaf children and deaf and hard of hearing adults, experiencing difficulties communicating with health care staff even in person, again undermines the principles of a ‘patient focused’ health service that the Bill is trying to bring about.

20. RNID Scotland ran a consultation event in 2009 on accessing health services9 for our members and supporters and they told us about some of the barriers they face which echoes the findings of our research:

"My GP clinic uses a loudspeaker to call the next patient in. How can I lip read a loudspeaker?"

"When I want to make an appointment with audiology, I have to rely on a friend phoning for me"

"I had the experience of sitting in a waiting room in an audiology department and the nurse came and called out the names of the patients. Obviously, nobody was coming. I said to her: 'Why do you not write the next name on a board' but she answered: 'It would be so insulting!'"

21. The BMJ has noted that "… studies of deaf service users have shown that 70% had no interpreters in consultations in accident and emergency departments. Feelings of confusion and dissatisfaction are reported by scores of deaf people with whom this issue has been discussed10."

22. In addition to this, people who are deaf or hard of hearing are also more likely to experience mental health problems. Up to 40% of the deaf community experience mental health problems at some point - nearly double the proportion in the general population of one in four11. There are numerous barriers in accessing mental health services, for example, staff

9 RNID Scotland's consultation event on accessing health services, Glasgow, 8/01/09.
10 Paddock, M et al, Op Cit.
11 Ibid
are not always deaf aware and do not know what are the best resources available for deaf and hard of hearing people depending on their level of hearing loss.\textsuperscript{12}

23. This pressure on adult services is exacerbated by the lack of specialist child and adolescent mental health services for deaf children. It has been estimated that over 40% of deaf children experience mental health problems, compared with 25% of hearing children\textsuperscript{6}. If the NHS is not equipped to address mental health issues for deaf adolescents, the system will ultimately fail those deaf children who are facing difficulties in achieving emotional wellbeing, and leave them potentially requiring more acute mental health support in adulthood, of which there is a dearth for deaf adults as outlined above.

24. We hope that the Patient Rights Bill will underline the critical importance of communicating with patients in a language or accessible format they can read and understand. Adjustments necessary for people who are deaf or hard of hearing or blind and partially sighted to access to health services are relatively simple and not too costly.

**Information**

25. With regard to the health care principle in section 1 of the Bill on providing information to enable patients to participate in their own health care, we would like to see information made available in an accessible format. For people who are BSL users, this may include video clips in BSL or written texts in clear written English.

26. Barriers that people who are deaf may encounter when accessing websites include a lack of clear and simple language or a lack of captions or transcripts of audio on the web, including webcasts. RNID has published a guide on *Deaf and hard of hearing users and web accessibility*\textsuperscript{13} with key recommendations that include: user testing (testing with real people remains essential to establish the accessibility and usability of any website); separation of content and presentation is the most important principle in designing accessible websites; or audio-visual clips should be subtitled for deaf and hard of hearing people.

27. Concerns raised by RNIB Scotland members in its research revealed\textsuperscript{14}:

- Blind and partially sighted respondents reported a loss of autonomy and privacy regarding their experience of accessing health care information.


\textsuperscript{13} RNID (2004) *Deaf and hard of hearing users and web accessibility*.

\textsuperscript{14} Thurston & Thurston (2010). *The accessibility of health information for blind and partially sighted people*. RNIB Scotland.
• On average only 10% of all communications from health services to blind and partially sighted participants were received in their preferred reading format.
• 91% (213 out of 223) of blind and partially sighted respondents thought they had a right to receive health information in a format they could read.
• 96% (219 out of 228) of blind and partially sighted respondents reported that they had a preferred reading format.
• The majority of blind and partially sighted respondents did not complain when information was received in an inappropriate format.
• Blind and partially sighted respondents reported difficulty identifying and using medication.
• Blind and partially sighted respondents reported difficulty experiencing health care due to a general lack of understanding of their additional needs.
• Blind and partially sighted respondents reported frequently relying on others to help them access health care information.
• The effects of not receiving health information in a preferred reading format were reported to be largely buffered by carers and relatives.

28. Again, patient focus has to be at the heart of the Bill. RNIB Scotland research highlights the following concerns on accessible health information from its members\textsuperscript{15}:

“For blind people, there are serious problems with different packaging of the same medicine from different suppliers. This is important!! The variable in packaging is a very serious potential calamity for the blind”

“All notices of hospital appointments are in ordinary print”

“We once had to write a sign over our son’s bed in hospital.’ My name is Matthew. I am blind. Please talk to me and tell me what you were going to do before you do it.’ On the whole, ward staff and hospital teams are still very ignorant of visual impairment issues”

Solutions for improving access to communication and information
29. We recommend that for people who are deaf or hard of hearing:

• Technical solutions are implemented. These range from e-mail appointment systems; SMS used either to make an appointment or to confirm appointments; Text Relay; induction loop systems; visual displays in reception areas (instead of relying on patients to hear their name being called); to BSL interpreters via webcam or web-based communication systems.
• Procedures are in place to secure the services of personal communication support such as BSL interpreters, lip speakers or note takers. These need to be booked at the time of making an appointment.

\textsuperscript{15}Thurston & Thurston (2010). The accessibility of health information for blind and partially sighted people. RNIB Scotland
• All written communication, such as letters confirming appointments, should be written in clear English for BSL users.
• The appointment time for deaf and hard of hearing patients is extended so that medical staff have enough time to communicate with the patient effectively.
• All medical staff, in particular frontline staff are trained in deaf awareness.

30. We recommend for people who are blind or partially sighted:

• Health care professionals need to understand that the confidentiality of patients is seriously compromised when health information is not sent in an accessible format.
• There is an identified need for education opportunities for health care staff regarding different types of blindness and the impact that this could have on communications with their patients.
• There is an identified need for improved access to health care facilities and information for blind and partially sighted patients.
• Health care providers need to reflect on how they provide information for blind and partially sighted patients to ensure that they have access to their preferred formats for health information, appointments, medication and hospital menus.
• There is a need for further awareness raising and education amongst blind and partially sighted people to ensure that they are aware of their rights regarding receiving health information in their preferred reading format.

Participation
31. With regard to the proposal in the Bill to encourage patients to participate in their own health care, for patients who are deaf or hard of hearing or blind and partially sighted, information needs to be communicated in an appropriate way so patients are making genuinely informed decisions about their care and treatment. As highlighted above, many patients who are sensory impaired have problems communicating with health professionals.

Making Complaints
32. With regard to the Bill’s proposals on patient’s rights to make a complaint, RNID Scotland research found that while a significant proportion of our respondents experienced difficulties accessing health services, nearly a quarter did nothing about it\textsuperscript{16}. Some said this was because they did not like to complain, some said they did not have enough time or were too ill or tired to complain, while others felt it was useless and would not improve the situation\textsuperscript{17}. RNIB Scotland research demonstrates that blind and partially sighted people are very reticent about making complaint as they

\textsuperscript{17} Ibid
do not feel they want to cause any problems and are unaware of how the processes may work.18

33. One respondent who is profoundly deaf told us19:
'Difficult to change everyone’s attitude. Try to appear strong and calm, I will say if I am disappointed with the lack of respect from the person. I hope they will see me and the next deaf person and give more patience, respect and understanding. I try to put it behind me and move on but the memory and the hurt sometimes comes back and it affects confidence.'

34. Another respondent told RNID Scotland: ‘I don't like complaining and I understand that all services cannot be perfect’, while another said ‘It is difficult to complain without (a) making the relationship difficult in the future, (b) without feeling a burden. Ideally you shouldn't have to complain – facilities and support should automatically be in place to make this unnecessary’.20

35. We would like to see all GP practices and hospitals ensure that patients who have sensory impairments can comment or give feedback on services they have received. There should also be email addresses available as not everyone with a hearing loss is able to use the telephone. We welcome the proposed role of the Patient Rights Officer to facilitate complaints and feedback. We hope that this is a genuinely independent service to give patients confidence in the system and that the Officers are trained in deaf and sight loss awareness to make the service accessible.

12 Week Treatment Time Guarantee
36. In relation to adults, RNID Scotland strongly welcomes proposals in the Bill for the introduction of a treatment time guarantee (TTG) of a maximum of 12 weeks once in-patient or day case treatment has been agreed, within the overall 18 week waiting time period of referral to treatment. In particular, speeding up referral to audiology for hearing aids to actually fitting hearing aids will help people with a hearing loss lead a more fulfilling life as they will be able to benefit from the equipment earlier.

37. We would welcome a commitment from the Scottish Government that while audiology is included in the 18 week waiting time guarantee from referral to treatment by 2011, audiology will also be included in the 12 week TTG.

38. Notwithstanding this, NDCS Scotland believes that even a maximum wait of 18 weeks is too long for deaf children. There are 38 weeks in a school year. Eighteen weeks is the equivalent of almost half a year’s education. In the most serious of cases, this could mean a deaf child facing half an academic year with little or no hearing, which obviously has serious implications for their educational progress and ability to develop and learn

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18 Thurston & Thurston (2010). The accessibility of health information for blind and partially sighted people. RNIB Scotland
19 Op cit, p 32
20 Ibid, p 33
at the same rate as their hearing peers. Whilst in practice, NDCS Scotland understands that paediatric waiting times are very rarely anywhere near 18 weeks; we believe that this good practice should be formally recognised with a shorter maximum waiting time for paediatric audiology.

39. In addition to this, both RNID Scotland and NDCS Scotland welcome NHS Information Services Division’s recent efforts to routinely collect data on audiology waiting times. We hope that this work will continue and the issues surrounding gaps in data collection will be addressed. We further hope that data on referral times will be collected by ISD and monitored so as to give us a better indication of the whole patient journey as with other conditions that come under the 18 week waiting time guarantee by 2011.

40. RNID Scotland would like to see the Bill provide further impetus to health boards to fully modernise audiology and reduce waiting times through investment in staff, facilities and equipment. We would also like to see the Scottish Government reaffirm its commitment to ensuring that as well as achieving shorter treatment times, the quality of treatment should not suffer. This includes continued support for implementing the Adult and Paediatric Audiology Standards21.

Case study
James is very hard of hearing and has been wearing hearing aids for over 30 years. He needed to go to audiology to update his hearing aid to digital hearing aids which was important for his work as a lift engineer. He told us:

"I was told they only see emergency patients but to be classified as an emergency patient, you have to see a consultant first. It's a vicious circle. I asked my GP to be referred to another consultant but he advised me to go private. I could not afford it so I saw another GP who eventually got me another appointment with a different NHS Board and that cut the waiting time."

Conclusion
41. RNID Scotland, NDCS Scotland and RNIB Scotland welcome the opportunity to comment on the Patient Rights (Scotland) Bill. We hope the Bill will address the issues raised in our evidence which affects the 758,000 people in Scotland who are deaf or hard of hearing and the 188,000 people in Scotland with significant sight loss.

42. We are prepared to give evidence in person to the Health and Sport Committee.

Shabnum Mustapha
Communications and Campaigns Manager
RNID Scotland

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and

James Adams
Campaigns Manager
RNIB Scotland
13 May 2010
Patient Rights (Scotland) Bill

Age Scotland

Age Scotland welcomes the opportunity to respond to the Health and Sport Committee’s consultation on the Patient Rights (Scotland) Bill.

Older people make up the majority of users of NHS services and as such Age Scotland has a keen interest in any effort to improve the experience, as well as health outcomes, of patients.

We responded at length to the Scottish Government’s consultation before the Bill was introduced and we are pleased that a number of our concerns have been taken into account.

Most notably, we had raised the question of what sanctions were available against patients who failed to meet their responsibilities towards NHS staff and property, particularly where there could be mitigating factors such as dementia or even mental illness. From our perspective it seemed problematic to define responsibilities in legislation whilst not also legislating for the consequences of failing to meet them. This has been taken on board and the Bill as introduced does not attempt to create legally binding responsibilities for patients. However, we strongly welcome that the Scottish Government has committed to furthering the agenda of respect towards NHS staff and property by other means: it is certainly not an issue that should be ignored or kicked into the long grass.

Responses to the specific questions posed by the Health and Sport Committee.

The patient rights and health care principles, and the criteria on which those rights are based

There is no doubt that laying out the rights and healthcare principles of patients in legislation is helpful in as much as it provides in one place a full list of patient rights as decided by the will of Parliament. However, as is stressed in the Bill and its accompanying documents, it is not intended to provide recourse to compensation or litigation where those rights are not met. In this context it is questionable whether they are in fact ‘rights’, although we would suspect that some cases where patients rights as described in the Bill are not met could fall foul of human rights law or other existing legislation.

Further to this, the rights as described in Section 1 are highly subjective. While this is in part a reflection of the fact that providing health care to patients is an enormously complex task that depends highly on the expert judgement of NHS staff, it does again raise the question of how useful the rights will be in practice. Patients and NHS staff
could have widely differing interpretations of how well the rights have been met and without a readily available arbiter it seems likely that this will simply lead to complaints.

Similarly, the health care principles are welcome and largely uncontroversial. For example, we very much doubt if requiring that health care take account of patients’ needs would garner much opposition. However, deciding whether or not the health care principles have been met in practice will often be a highly subjective decision.

There is also a question about how the Bill’s provisions would help tackle existing, well-documented problems in the provision of health care for older people. For example, nutrition is one of the key issues for older people in hospital but it is unclear how or if the provisions made in the Bill would help ensure that staff meet the existing requirements.

The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee

In responding to the original Scottish Government consultation we said we did not have a particular view as to whether there should be a treatment time guarantee (TTG) and we remain neutral on the issue. The Bill seems to imply that there will be a range of underlying criteria and contexts in which the TTG will apply and it may be the case that this creates confusion among patients and their families about whether they are eligible for it and, if not, why not.

In general we are in favour of any measure which can be demonstrated to improve the experience and health outcomes for NHS patients but we do not have the expertise to judge whether a TTG will have a significant beneficial effect for older people receiving NHS care. This is not to say that it won’t have a beneficial effect.

The complaints and patient feedback system set out in the Bill

A robust complaints system could help mitigate the subjectivity of the rights and healthcare principles in the Bill. Such a system should enable the majority of complaints to be resolved to the satisfaction of all parties and to minimise the number of complaints that need to be taken to the Scottish Public Services Ombudsman. However, the Bill lacks detail on what ‘adequate arrangements’ are in relation to the requirements set out for complaints procedures. The Bill confers powers on Scottish Ministers to specify through regulation exactly what adequate arrangements might mean in practice but at this point it is impossible to comment on their adequacy.

The patient advice system and the role of Patient Rights Officers

The patient advice system is welcome and helps explain how patients with dementia, alzheimers or other cognitive decline (and their families) would be supported to make
complaints or give feedback, as is alluded to in the healthcare principles. Similarly, the
new role of Patient Rights Officers would help reach this objective. However, it would be
imperative that Patient Rights Officers were trained and supported for communicating
with patients who have difficulty communicating for any reason. There may also be
cases where the family members of patients require support to articulate their
complaints, feedback or other concerns.

Nick Waugh
Senior Policy and Parliamentary Officer
Age Scotland
11 May 2110
Dear Mr Wixted

Call for evidence on the Patient Rights (Scotland) Bill – GMC Response

Please accept our sincere apologies for the delay in submitting our response.

The General Medical Council (GMC) is the independent regulator for doctors in the United Kingdom. Our statutory purpose is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

We are grateful for the opportunity to respond to the committee’s call for evidence on the Patient Rights (Scotland) Bill.

General Comments

In principle the GMC welcomes any measure to increase patient safety and we are happy to engage in discussion around the Bill.

With regard to the Bill as it is currently drafted, it is not entirely clear to us how the rights and responsibilities proposed within it would be implemented, measured and enforced. The Bill makes clear that it does not create any new legal rights - perhaps the Bill could usefully make clear the basis of legal rights that do currently exist.

On a related note; one of the Government’s stated objectives is to bring together and restate existing legal rights. This might be made clearer in the Bill. Some existing rights are not covered (e.g. the right to refuse treatment and the right to non-discrimination on protected grounds). It is also not clear in the Bill, what is an existing legal right and what is not.

It would appear that different language has been used in the Bill to describe current rights than is used in the relevant original, and other, legislation (e.g. the test of benefit under the Adults With Incapacity (Scotland) Act 2000 would appear to be the equivalent of ‘optimum benefit’). This is likely to be confusing and may be open to different legal interpretation by the courts.

Paragraph 25 of the Policy Memorandum to the Bill states that ‘the quality care and treatment principle will help to provide added status for quality as well as quantity of care’.
We are unclear as to what is meant by ‘quantity of care’. The level of intervention is a matter of clinical judgement and case-dependent decision-making.

Overall, there is a danger in passing legislation that is not clear or enforceable that, rather than increasing the focus on person centred care, it might have the opposite effect. Clinicians and others may be led to feel that person centred care is less of a priority. There is also potential for confusion as there are existing obligations on doctors which are enforceable, including those described in our guidance.

**Patient Rights**

The fundamental existing legal right of patients to refuse treatment appears not to have been included. This existing right extends beyond just being encouraged to participate fully in decisions relating to health and well being, as is proposed in the Bill. On a related note the Bill does not seem to recognise the distinction between patients with capacity who have a legal right to consent to or refuse treatment, and patients who lack capacity.

Much of this section of the Bill is unclear. For example, we are not certain what is meant by the statement that anything done in relation to a patient must ‘take into account’ the patient’s ‘needs’. This is particularly true in the absence of more detailed guidance or an apparent method of enforcement. Similarly, ‘optimum benefit to the patient’s health and wellbeing’ is unclear and is not in line with other language used, either in our guidance or in legislation (e.g. the Adults With Incapacity (Scotland) Act 2000).

We welcome the recognition in the Bill that even where patients have capacity to make decisions, they may need additional support such as interpreters, advocates and the support of family, to be able to understand information and make an informed decision about whether to consent to or refuse a proposed treatment option.

We also welcome the statements in the Bill that regard must be given to the importance of providing information and support to patients. However these statements appear to be relatively weak when compared with existing GMC guidance. Patients with capacity must be given the information they want and need to make a decision about whether to consent to a proposed investigation or treatment (see our guidance Consent: patients and doctors making decisions together, paragraph 9). Information must be shared in a way that patients understand and must recognise, and be tailored to, individual needs. Patients may need additional support (see paragraph 22 of our guidance). These provisions in our guidance are key to ensuring equality of treatment, a principle which the Bill might deal with in greater depth.

**Health care principles**

The Bill states that each relevant NHS body, ‘must, in performing its health service functions, have regard to the health care principles in so far as they are relevant to the function being performed’ (emphasis added). The explanatory memorandum outlines some examples of this but it is not comprehensive. It would be helpful to get greater clarity about what this means and about when the principles are not relevant.
The principles state that the patient’s ability, characteristics and circumstances are to be considered. This may be referring to patients who lack capacity and the need to treat patients as individuals. Clarification of this point might be useful.

As the Bill states, the range of options available in the patient’s case should be considered. To this could be added ‘and where clinically appropriate, offered to the patient’.

The Bill asserts that healthcare should be based on current recognised clinical guidance. However, guidance is not always available. This might be because;

1. the condition is rare,
2. standard treatments haven’t worked and the doctor is offering an innovative treatment designed to meet the patient’s individual needs,
3. there is uncertainty about the best treatment or
4. treatment is provided as part of a research project.

The language we use in our core guidance, Good Medical Practice is ‘you must provide effective treatments based on the best available evidence’ (paragraph 3c).

The Bill emphasises that patients should participate as fully as possible in decisions about their care and treatment. We welcome this in principle. However, a patient may not always wish to participate as fully as possible. Our guidance Consent: patients and doctors making decisions together discusses this scenario and explains that patients will always require basic information in order to give their consent (paragraphs 13-17).

Patient Feedback

It would be useful to clarify whether the same rights of feedback will be available to family or carers of patients who lack capacity, e.g. to have concerns or feedback passed from a Patient Rights Officer to the relevant NHS body. As currently drafted the Bill states that this can only be done with the consent of the patient. This might be expanded to state that this can be done with the consent of the patient or the person who has made the complaint on their behalf. There is also the issue of feedback or complaints by family or carers about the care or treatment of a patient who has died and whether the complaint or feedback would be on behalf of the deceased patient or the right to feedback would be that of the carer or family member. The Bill might usefully address this point.

Section 4 of this part of the Bill states that the relevant NHS body must consider all concerns raised and feedback received with a view to improving the performance of its functions. There is also, however, the responsibility of NHS bodies to respond to complaints in relation to the individual patient. In our core guidance, Good Medical Practice (paragraphs 31-32) we discuss the right of patients to expect a prompt, open, constructive and honest response including an explanation and, if appropriate, an apology.
Duties to share information

This section describes the kind of information that should be shared with the proposed Patient Advocacy & Support Service (PASS). This appears to be straightforward and uncontentious. The Bill then states, however, that this information should be shared ‘where reasonably practicable and otherwise appropriate’. This appears to weaken the earlier statement.

We welcome the statements on maintaining patient confidentiality. With regard to sub-section 3 there are circumstances in which a patient’s right to confidentiality might be justifiably breached in the public interest (e.g. to protect someone else from a risk of serious harm).

We hope that this response is useful. If you have any questions regarding the response please contact me.

Yours sincerely

Jane Malcolm
Head of Scottish Affairs
General Medical Council
Submission from UNISON Scotland on the Patient Rights (Scotland) Bill

UNISON supports the idea of patient rights and is supportive of many of the principles contained within the bill. We note however that many of these rights listed in the Bill already exist, and are unconvinced that legislation is the most effective way of ensuring they are adhered to. UNISON Scotland support healthcare being provided in an atmosphere of mutuality, we are concerned that a Patients Rights Bill will encourage a ‘culture of contract’.

UNISON Scotland is supportive of the idea of patients rights believing that our health service is at its best when services are designed around the needs of patients their carers and families. UNISON Scotland believes that the NHS in Scotland must listen and respond to patients if it is to be into an effective and efficient patient centred service.

UNISON Scotland believes that patients and other users of the NHS in Scotland should be the focus of the service, not as ‘customers’ but as partners with rights and responsibilities and an entitlement to be treated with dignity and respect. We are concerned that whilst creating little by way of new rights the Bill assembles those rights which do exist in a manner that suggests a relationship based on contract, rather than mutuality. The framework of the bill suggests recourse to legal redress in the event of difficulties, rather than encouraging the resolution of difficulties via mediation.

We are unconvinced of the necessity for legislation in this area. The Bill does not add significantly to the rights and standards of treatment that patients can rightfully expect. Save through an entitlement to seek judicial review - an avenue that few are likely to explore. If there is a perception on the part of Government or Parliament that patients are not enjoying all the rights to which they are entitled we think that a more productive course of action would be to examine the reasons why and seeing what can be done to tackle them.

If there are impediments to patients receiving all of their existing rights these may be down to structural issues in treatment design or application, there may be issues of organisational culture, a lack of awareness of rights on the part of staff or patients or of course issues of funding and resources. Examining and remedying which of these (or which combination of these) actually exists is likely to be more productive in making rights a reality than passing legislation.

The Bill plans the creation of a Patients Advice and Support Service may be a step forward in supporting advocacy for patients. We can accept that there may be validity in the arguments that a nationally rather than locally, constituted service could provide for a more consistent level of service. If this potential is to be realised Patients Rights Officers will require to be properly trained and adequately resourced.
We believe that the question of patients rights and standards cannot be disentangled from the issue of resources. The Scottish Government published NHS Board workforce projections in June. These estimated figures from all boards show a total predicted reduction in whole time equivalent (WTE) posts by the end of 2010/11 of 3,790 (2.8%).

The largest reductions are in nursing and midwifery (1,523 WTE) and in administration services (1,053). The figures come from management information in which the potential effect of service redesigns or changes in skill mix are assessed. The reductions will be achieved by not replacing staff who leave or retire. Services will of course have to be delivered by remaining staff.

We find it interesting that the intention that guarantees over treatment times and standards are being put on those staff via primary legislation. Yet no legislative guarantee exists to ensure that NHS staff are adequately resourced to deliver on those commitments.

Along with others we have concerns that the treatment Time Guarantee may serve to skew clinical priorities. We believe that an emphasis on outcomes and total time spent within the healthcare system may be better measures of effectiveness.

UNISON Scotland believes that highly trained and motivated staff who are ‘fit for purpose’ are the greatest resource within the NHS and need to be valued within the organisations where they work. UNISON Scotland recognises that as a result of certain illnesses, aggressive violence can occur, however what we are not prepared to tolerate is disrespect of NHS staff by some members of the public. As such we would have preferred the statement of principles of healthcare to go further in asserting patients responsibilities.

UNISON Scotland
September 2010
Patient Rights (Scotland) Bill:
Stage 1

09:32

The Convener: Item 2 is our second oral evidence session on the bill. We will hear from three panels of witnesses, the first of which is from the Law Society of Scotland. I welcome Hilary Patrick, the vice-convener of the mental health and disability sub-committee, and Katie Hay, who is a law reform officer. I thank the witnesses for their written submission.

Mary Scanlon (Highlands and Islands) (Con):
I will concentrate on mental health. I am not quite sure whether the Law Society is in favour of the bill, given that it has expressed various reservations. There is a paragraph on mental health in the Law Society’s submission, but the best submission on mental health is from the Scottish Association for Mental Health. It says that mental health is “excluded from the treatment time guarantee” and that mental health treatment can be delivered on an out-patient or day-patient basis, in out-patient clinics, general practitioner surgeries, day centres, and in people’s homes by community psychiatric nurses and cognitive behaviour therapists.

There seems to be a flavour of some patients having more rights than others under the bill, and it appears that patients who have mental health issues will receive no benefit at all from the bill. Would the witnesses like to voice their concerns about how the bill will not apply to mental health?

Hilary Patrick (Law Society of Scotland):
Obviously, the bill’s general principles about treatment being patient focused would apply to patients with mental health issues, but the treatment time guarantee does not appear to apply at all to such patients. I think that the Government is now saying that the treatment time guarantee could apply for child and adolescent services, but I do not really understand why. Some treatments might be available to adults on a planned basis, such as treatment for a long-standing eating disorder or an obsessive compulsive disorder.

I got very excited when I read the bill, because I thought that it might help to deal with the shortage of psychological services that has been an issue over the years. However, the treatment time guarantee cannot help with that. Looking at the situation legalistically, if a provider cannot provide the service within 12 weeks, they will just not agree the service. To be perfectly honest, because of the nature of the treatment time guarantee, if I was a health board lawyer and I knew that the
health board would have problems in delivering a service or treatment, I would just try not to agree the treatment. I would say to the patient that, although they might need a hip replacement or some treatment for a mental health issue, we will not agree the treatment and propose that they get it in 12 weeks. The treatment time guarantee kicks in only when there is an agreement between the clinician and the patient.

Have I made that clear? That is just a little technical problem with the way in which the treatment time is guaranteed. Any lawyer would immediately be able to find a loophole or way around it by delaying the period in which treatment is agreed.

The Convener: If someone is going to be told that although they need treatment they are not going to get it, so that the health board can comply with the legislation, that sounds like a bit more than a technical problem.

Hilary Patrick: Why would the health board not do that? That is what I would advise.

The Convener: I am not disagreeing; I am just saying that it is more than a technical problem.

Hilary Patrick: If I were a health board legal officer, I would say, “Please don’t agree the treatment until you know that it can be delivered within the 12 weeks.” I would advise the board to make noises that the treatment would be a good thing and to say that it will get back to the patient. Unless I am missing something, that seems to me to be an easy way of avoiding the impact of the legislation.

Mary Scanlon: The committee did an inquiry into child and adolescent mental health and wellbeing. The treatment time guarantee is to be introduced for children under the age of 16 but, as far as I am aware—there are other experts here—there is no treatment time guarantee and no waiting time target for patients who have mental health issues.

Hilary Patrick: Yes. I suppose that the question is why that group of patients is being discriminated against.

Mary Scanlon: The point is that the Patient Rights (Scotland) Bill brings no more rights to mental health patients. From what you have said, and from what the convener has picked up, am I right in saying that because a mental health patient could get antidepressants or cognitive behavioural therapy by telephone from NHS 24, inappropriate treatments could be given so that targets can be met?

Hilary Patrick: Cognitive behavioural therapy is a good example. Everyone might agree that I need it and that it could help with my depression, but there is no urgency about it. Why could a planned intervention like that not fall within the treatment time guarantee? Is it because it is not being given to an in-patient, and if not, why not? Why is that not discriminatory? Why are adults with mental health issues not being given those rights? It appears to be slightly discriminatory.

Mary Scanlon: I was coming to that point. If the Patient Rights (Scotland) Bill is for all patients, but it excludes mental health patients, is it discriminating against that patient group in law?

Hilary Patrick: I think that I would have to come back to you on the question whether the Government was discriminating. I would have to look again at the Equality Act 2010, but the provision clearly appears to be discriminatory under the normal meaning of the word.

Mary Scanlon: Most patients will have rights but certain patient groups—such as those with fertility problems, for which there are no waiting time targets, and those with mental health issues—will be excluded. Is it fair to say that, according to the bill, some patients will have rights and others will have none?

Hilary Patrick: Yes.

Mary Scanlon: Concerns have been raised about the requirement for mental health patients to have a dual diagnosis for drug and alcohol treatment. Given the health improvement, efficiency, access and treatment—or HEAT—target for drug addiction services, how can they achieve the HEAT target treatment time guarantee while being excluded from the mental health one? Do you understand what I am saying? Those patients need two types of treatment, but only one comes under the guarantee.

Hilary Patrick: I wonder whether it would be fair to suggest that part of the problem is putting such a guarantee in legislation and therefore fixing it in stone. It could be argued that it would be more sensible for the NHS and the Government to deal with treatment time guarantees, waiting time targets, HEAT targets and so on as priorities change.

Mary Scanlon: Reading the British Medical Association submission last night, I noted its comment that waiting time targets distort clinical priorities. Is it fair to say that to make the bill non-discriminatory and to ensure that patients have equal rights every treatment would require to be underpinned by a treatment time guarantee?

Hilary Patrick: I do not know whether I would go quite as far as that, but I think that it is invidious not to include mental health patients in the treatment time guarantee. That said, I question the value of that particular guarantee anyway.

The Convener: That was very clear.
Ross Finnie (West of Scotland) (LD): I want to pursue the introductory comments in your submission about the bill’s general principles and, in particular, enforceability. The committee is dealing with two quite separate issues. You think that the bill would be improved if its provisions were enforceable. I can understand that approach—having a lawyer at every bedside is bound to be good for the Law Society—but surely it is not the most logical way of addressing the problem.

However, the committee faces a fundamental difficulty here. This is not really a matter for the Law Society, but I have no doubt that patients’ rights would be improved enormously if the work that the Government has done in marshalling them cohesively and coherently were to be issued as a clear direction from the minister, in terms of section 1 of the National Health Services (Scotland) Act 1978, of what she and patients should expect and of what patients should get from the service.

I do not think that the bill really makes sense. For a start, I am not at all clear why these particular rights should be enshrined in a bill, particularly not one that includes section 18, which renders the whole thing a complete nonsense as law. Do you really think that the bill’s provisions would be improved if they were made enforceable or, given that more than 90 per cent of those who responded to the consultation said that they did not want to have recourse to the law, would it have made more sense for the Government to produce a document setting out patients’ rights instead of putting them in a bill?

09:45

Hilary Patrick: First, Katie Hay will make a few brief comments about where our committee is coming from on this matter.

Katie Hay (Law Society of Scotland): I would like to set our appearance this morning in some sort of context. As you know, the Law Society is a statutory body with the dual function of promoting the profession’s interests as well as promoting the interests of the public in relation to the profession. Our role with regard to law reform is very much part of the latter function. Our law reform department has a number of committees—Hilary Patrick, for example, is vice-convener of our mental health and disability sub-committee—and those who sit on them give their time voluntarily with the sole purpose of suggesting how law can be improved to clients’ benefit.

Hilary Patrick: The point is that, on this occasion, we are not trying to drum up business for the legal profession.

The Convener: I think that Mr Finnie was making a light comment. You must not feel wounded by it.

Ross Finnie: Maybe you should also have a sub-committee for understanding humour. That might be more appropriate.

I accept that you are not here to promote lawyers or ensure that they get more business, so let us not attempt humour or have any more silly comments and just get down to business and deal with the facts. The nub of the matter is this: if you are interested in promoting good law, do you think that it is good law to have a purported bill that gives people rights but does not set out any way of enforcing them?

Hilary Patrick: I think—

Ross Finnie: Yes or no would do.

Hilary Patrick: Under the bill, someone can still go to court and get what is known as a declarator, or statement from the court, that a health board is breaching the legislation and therefore acting illegally. That will be a charter for lawyers. If a health board—

Ross Finnie: Is that good law?

Hilary Patrick: I do not think that it is particularly good law. We could have expanded our response to make it clear that either you have something that is enforceable and meaningful or you do not have this legislation at all. To be honest, I feel that if the provisions in the bill are not meaningful—I have suggested as much in relation to the treatment time guarantee—and given that the rest of the bill is made up of principles that are hedged with woolly phrases such as “have regard to”, “aim to” and so on, I find it difficult to see how they could be enforced.

Before the meeting, I made a list of about 17 rights that patients already have under law, under statute, under common law or under national health service practice. Some of them are actually much tougher than the rights that are set out in the bill, including—

The Convener: Before you list them all, I wonder whether it might be useful if you just give us a number of examples and then provide us with the list in writing.

Hilary Patrick: I will do so.

There are, for example, rights to confidentiality; rights to access to records and to advocacy; human rights, which the bill does not mention; and common-law rights about information. All those rights are tougher than what is set out in the bill. The bill, for example, says that health boards should “have regard to” confidentiality. Actually, under the Data Protection Act 1998 and their own
codes of conduct, they have to respect confidentiality.

The bill will not weaken the general law, but what will it add to it other than information about changing the complaints system? Law is not needed to do that; the NHS has its own complaints system. The question for the committee is: what is the benefit of enshrining such a system in legislation? I remain to be convinced that the bill will add anything.

Ross Finnie: Why try to encapsulate all that in a bill and create a law that, apart from providing recourse to judicial review, which you might have in other circumstances anyway, could circumscribe your course of action by including section 18? Most people who were consulted on the matter said that they did not want a right to law, which begs the question why one is trying to introduce a law. However, that is a matter for the Cabinet Secretary for Health and Wellbeing.

From a legal point of view, if instead of producing this bill the Government had sought to draw together all the existing rights—indeed, it might have thought of additional rights or of different ways of expressing them—and published them in a single document, with no particular legal status save only that the cabinet secretary might issue a general direction for how health boards and other health bodies were to act in respect of the general principles of section 1 of the 1978 act, would that have diminished patients’ current rights and accesses?

Hilary Patrick: Guidance or even a direction could have been issued to the NHS—power exists to give directions to the NHS. I was going to say that the one change under the Patient Rights (Scotland) Bill would be that someone could still go to court to get a declaration that the health board had behaved illegally. However, if ministers issued guidance to the NHS, one could still go to court and judicial review to say that the health board had not acted in accordance with the guidance.

No; I do not think that enshrining those rights in primary legislation increases patient rights, other than in relation to the treatment time guarantee, which I do not see as a powerful tool anyway.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): We have an ombudsman system and this Parliament has established a number of ombudsmen to try to improve people’s rights. The Labour-Liberal coalition Government and the SNP Government have endeavoured to improve patient rights in general, and I think that they have improved in the past decade. Would it be better to have a patients charter, as the English have? I do not know whether you have looked at the charter, but it makes a clear declaration of something like 35 rights that are referenced to the legal underpinnings of those rights.

Would it have helped to have a simple measure that, for example, required the health boards to respond to any report of the ombudsman by laying something before Parliament to indicate that they had complied with the decisions of the ombudsman? Such decisions are only a recommendation; as I understand it, the ombudsman currently has no powers to direct a health board and I am not saying that they should. If a report was laid before Parliament, at least that would provide an opportunity for debate if the board refused to—

Hilary Patrick: I might have this wrong, but I thought that if health boards did not comply with the ombudsman’s report, he or she could lay a report before the Parliament. Although it is always said that the ombudsman does not have powers, I thought that it was quite a sanction that he or she could lay such a report before Parliament.

Dr Simpson: The ombudsman makes reference to those issues in its annual report, but I have not been aware of any—

The Convener: Instead of having a general discussion, we will clarify that matter before the end of the meeting.

Dr Simpson: My question stands regarding the patients charter. If the National Institute for Health and Clinical Excellence issues guidance to a health board on a question of medication with a particular drug, under the English charter the patient is entitled to that drug and the health board must supply it, if that is clinically appropriate. There are no such rights in Scotland, and there will be no such rights in the bill.

Hilary Patrick: If the patient in such a situation in Scotland came to me, I might well challenge the health board. Judicial review would be available if our equivalent of NICE had recommended the treatment and the health board had disregarded the recommendation. There could be legal challenges, although I do not know whether legal challenges would be the way to go. Personally, I prefer to address complaints through ombudspeople rather than using litigation in the health service.

Dr Simpson: To return to Ross Finnie’s point, the Government could issue a direction that if a medication is approved by the Scottish Medicines Consortium, it should have to be delivered, if it is clinically appropriate.

Section 18 states:

"Nothing in this Act prejudices—
(a) the exercise of clinical judgement".
However, if the doctor’s clinical judgment is that the patient should have the medication and the health board disagrees with the medicine being prescribed, that would interfere with clinical judgement, so the law seems to be a complete nonsense. Am I misunderstanding the situation?

Hilary Patrick: No, I do not think that you are.

Dr Simpson: My main question is about people with disability and, in particular, sensory problems. We have heard today about a further report on the provision of proper information whereby people who are blind are able to use the health service effectively.

The Royal National Institute of Blind People Scotland’s submission states:

“One quarter of our respondents have to rely on a friend or relative to make telephone appointments ... While 46% of respondents made appointments over the phone themselves, one-third said they had difficulties communicating with staff”

and so on. The Royal National Institute for Deaf People Scotland’s research identified a list of concerns.

Do you have any comments on people who are not only blind but deaf and have other sensory deprivations, such as the 5,000 people in Scotland who are deafblind? Does the bill confer upon them any fresh rights? Does it ensure that the progress that has undoubtedly been made is followed through to a point that gives them a legal right to receive the information that they need, in the form in which they need it?

Hilary Patrick: I do not see what new rights the bill gives to those people. Are you talking mainly about communication issues?

Dr Simpson: Yes.

Hilary Patrick: One of the principles in the bill is about the provision of information and support and encouraging the person to participate, but patients have far wider rights under the Equality Act 2010 in respect of reasonable adjustments and non-discrimination. As I said previously, under that act it is not just about requiring people to “have regard to” those principles, because health boards have to make reasonable adjustments and must not discriminate. One of my concerns is that the bill’s principles almost undermine the much tougher law that already exists.

Dr Simpson: That answers one of my main concerns about the bill. My other concern—

The Convener: I appreciate what you have said about existing rights and I am not disputing that. However, section 16(e) refers to

“publicising the patient advice and support service in such a manner as is likely to bring it to the attention of patients”.

Would that not be of assistance in respect of the blind and the partially sighted?

Hilary Patrick: Yes, it would, but masses has been done under the Disability Discrimination Act 1995 and more will be done under the Equality Act 2010. I do not have any particular problem with the bill’s provisions on the issue. All I am saying is that, if one asks, “Does it add anything?” the answer is no, because this is already happening and people already have a public equality duty to ensure that people with disabilities are not discriminated against.

10:00

The Convener: Playing devil’s advocate, however, I point out that it is not working at the moment. The people whom Richard Simpson has spoken about do not know their rights and do not get prescriptions in the appropriate manner—mind you, I cannot read a prescription either. They are not getting the medical advice or being told about stuff—they are already in the position of not being communicated with. Would that provision not help to get the information provided in a way that they can understand it?

Hilary Patrick: Part of my problem as a lawyer is the fact that people do not know the law.

The Convener: We are talking about helping them to know the law.

Katie Hay: The provision would not hinder that, necessarily. However, the fact that the wording is that a patient rights officer “may undertake” does not strengthen the position.

Dr Simpson: The word “may” is the problem. One thing that I have learned in seven years as an MSP is that these small words have a significant effect.

I want to return to the question of exclusions. We are being asked to consider a bill that entrenches discriminatory rights in law. That is one of our main concerns. The list of exclusions is: assisted conception; obstetrics; complementary and alternative medicine; organ transplant; direct access to services such as X-rays; diagnostic tests; out-patient treatments; certain national specialist services; specialist services that are delivered in England and used by Scottish patients—which I really do not understand; and alcohol and drug misuse services.

I will focus on the last of those exclusions. I draw attention to my being a member of the Royal College of Psychiatrists and having been a specialist in addictions. With the excellent HEAT targets that are being proposed, which we are all signing up to, we are already going to discriminate further between drug services and alcohol services. At the moment, even with the additional
money that the Government is investing—for which I give it considerable credit; it has done a very good job in putting in the extra £40 million—there are still long waiting times for specialist alcohol treatments, which will be specifically excluded from the treatment time guarantee as I understand it.

Hilary Patrick: I am sorry to repeat what I said. My concern is that the treatment time guarantee will not help to challenge waiting times because it is an individual relationship between the clinician and the patient. There is no obligation on a clinician to agree a treatment within a certain time limit. If the treatment is not available, it will not be offered and accepted in that sort of contract and the time will run.

I am afraid that I cannot get very excited about the treatment time guarantee. I presume that it is mainly a case of the doctor saying to me, “You need a hip replacement, Hilary,” me saying, “Yes,” and the time running from that point. The doctor will do that only if he or she knows that I can have the operation within 12 weeks. Therefore, as I said, I do not see the treatment time guarantee as being a tool for tackling waiting lists. For me, one of the issues is psychological services, and those will not be included. I suggest that it is not a particularly effective tool.

Dr Simpson: That is very helpful. Thank you.

Helen Eadie (Dunfermline East) (Lab): Let us return to the point about the Scottish Public Services Ombudsman. I believe that all the reports are published on the website. I am interested in the fact that you think that that is a sanction. Some parliamentarians read the reports but others do not; therefore, how do you think that it would be a sanction?

Hilary Patrick: I do not think that it is a sanction; I just think that it is an effective remedy.

Helen Eadie: Why do you think that?

Hilary Patrick: Using the ombudsman is free and does not require much work by the patient, whereas going to lawyers costs a great deal of money. Also, the ombudsman is familiar with and has an understanding of NHS practice. Often, complaints are not about breaches of legal rights but about poor practice, rudeness and delays. As you know, the test that the ombudsman uses relates to maladministration—bad management. That is more common than some dramatic breach of legal rights.

Helen Eadie: You used the word “sanction” when replying to an earlier question. Given that the general thrust of our discussions has been that there are no enforceable rights under the bill, was your use of that word misplaced?

Hilary Patrick: My understanding is that the ombudsman makes a recommendation to the health board to pay compensation to someone or to apologise. Generally, most health boards or others criticised by the ombudsman comply with his or her recommendations. I understand that, if they do not, the ombudsman can lay a report—not the general report—before the Parliament. I thought that it would be a sanction for Lothian NHS Board, for example, if a report were laid before Parliament describing the awful thing that had happened, setting out the ombudsman’s recommendations and indicating that the board was refusing to act. That is not a legal sanction, but the Parliament would ask questions and the board would have to—

The Convener: Forgive me, but I want to move on, as we have exhausted the issue. We will get a note on whether an ombudsman’s report can be laid before Parliament. I imagine that the press, too, will pick up reports and use them.

Helen Eadie: My other question is about evidence that the committee has received. Some people believe that, if the rights for which the bill provides are enshrined in law, patients will come to believe that they are their only rights. What is your view on that issue?

Hilary Patrick: I believe strongly that that is the case. I was making the point that people have much stronger rights. People will take the view that the rights for which the bill provides are their only rights because, under section 15(4), the patient advice and support service, with its new duties, will be able to give patients advice only on their rights under the bill, rather than on all their rights. That is a clear weakness; the service should be able to give advice on patients’ other rights. It is a great concern that patients will get the message that they have no other rights.

Mary Scanlon: I have a brief supplementary on the back of Richard Simpson’s question. The convener pointed to section 16(e), on publicising the patient advice and support service. However, section 1(2) states that health care is to “be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs”.

If the bill is passed, what additional rights will a patient have on the basis of that provision?

Hilary Patrick: I was going to say, “You tell me.”

The Convener: That has answered the question.

We have exhausted the issue of enforceability. If the committee is content, I will move on to the next panel. I thank our witnesses.
The Convener: The committee has a heavy agenda this morning, so I am racing on to the second panel of witnesses, who represent healthcare professionals. They sat through the previous evidence session, which was useful for us and for them. The witnesses are Dr Sally Winning, who is deputy chair of the British Medical Association Scotland; Theresa Fyffe, who is director of the Royal College of Nursing Scotland; and Dr Bill Mathewson of the Royal College of General Practitioners Scotland. Thank you for your written evidence. We move straight to questions.

Ross Finnie: Good morning. You may or may not have heard the evidence that was given in the previous session. In your written evidence, all of you express grave reservations about whether legislation is the right way to articulate and lay out patient rights. I put it to a previous witness from the Law Society of Scotland that, although it is clearly desirable that we have a body of text that sets out patients’ rights, that might be better expressed by publishing those rights and the cabinet secretary issuing them to all relevant health bodies as a direction under the National Health Service (Scotland) Act 1978, given that the bill gives people only a limited right of judicial review and section 18 effectively nullifies all other remedies. Do you share the view that expressing rights in that way would be preferable to creating a piece of legislation that appears not to be enforceable? In my opinion, it is doubtful whether we would want it to be enforceable.

Theresa Fyffe (Royal College of Nursing Scotland): We agree absolutely that there is a problem now and much of what is happening in the health service is as a result of the bill being unreliable and not enforceable. Rights may be clear to particular professionals, but that the bill may not be the solution. I do not understand why the problem has not been addressed for a long time.

Dr Bill Mathewson (Royal College of General Practitioners Scotland): I agree with my colleagues. Many of the patient rights that are mentioned in the bill are included in codes of practice, especially those that are issued by the General Medical Council, which provides good clinical practice guidance.

Theresa Fyffe: We have an NHS booklet and we have other means by which people can find out about their rights, but it is not clear that patients or the public know how to use them, so it is not clear that those rights are being enabled. It is about communication.

I agree entirely with my colleague that patients’ rights may be clear to particular professionals, but sometimes professionals do not spell things out. From the perspective of my profession, I know that professionals might not make the situation as clear as they could do. Something is not working for patients, and that is a concern. I believe that we need to look at what is there and ask why it is not working. We must work with patients to find out what is not working for them. Something is not right and I am concerned that patients think that they have rights but do not know how to have them met.

Dr Winning: The waiting list initiative is perhaps an example of how a patient’s perception of what their rights are has become distorted. Patients now tend to look at quantitative measures of rights, such as that they must be seen within X amount of time, but there are layers and layers of rights beneath that, including rights to do with how they are treated. Patients have made complaints on, for example, being treated with dignity or being dealt with in such a way that they understand the language that is used. Looking at more easily measurable things such as treatment time guarantees and waiting list initiatives can
sometimes give patients the wrong impression about what their rights are. We need to shift away from numbers to quality of care. The excellent quality strategy that is currently being implemented will tackle many of those issues.

Mary Scanlon: I am still struggling to understand how the bill will increase patients’ rights. The BMA says on page 3 of its submission:

“we are unclear what this legislation adds.”

I am getting to the stage of wondering just how bad the bill might be for patients’ rights. Jim Martin, the Scottish Public Services Ombudsman, said that he thought that it would make things worse.

In its submission, the RCN says:

"the Bill would unbalance relationships and work against the development of a mutual NHS"

and

"could serve to increase inequalities in health care".

It appears that the bill will not only not add value, but will make things significantly worse. I ask Theresa Fyffe to explain those two points. To say that the bill “could ... increase inequalities” is a serious claim to make.

Theresa Fyffe: As far as relationships are concerned, we have worked extremely hard on the concept of mutuality that the Government brought in, and we fully understand the importance of having a partnership that involves patients, staff and all those who seek to provide a service. We are looking for a role between patient and professional that is complementary, not one that increases tension.

The bill suggests that patients have rights, but it does not strengthen patient responsibilities. As someone who has been a clinician, I know that that makes it difficult for clinicians, when they know that a particular course of action is the best judgment in terms of treatment or intervention, to say that that is the best judgment. I am talking about situations in which there is risk. I am unhappy to see the absence of mutuality between patients and professionals.

There is a lot of evidence from America that I could send to the committee about the change in the relationship between doctor and patient. We looked at that extensively, because a lot of work has been done there to try to redress that imbalance, and to get back to the respectful relationship between doctor and patient that Dr Winning mentioned. I would support that from any other health care professional.

My second point about inequality was addressed in the previous debate. On setting certain things out in and excluding certain things from bills, our experience of any form of process that goes to the NHS is that people will, quite understandably, tackle what they need to do. There is a lot to be done. When a person is considering a process, they will say, “This is what I need to do to meet that.” That is why we have said that we are not against targets but are concerned when targets skew people towards meeting them and it is forgotten that a loss of dignity, for example, can be a consequence. That is why we have called for dignity proofing of policy. It is a concern that, when one is dealing with a very big board that must address everything that it meets, inequality could become an issue for groups that are not included. The question is, how does what has been included stand the test of time?

Mary Scanlon: That takes us to issues such as mental health.

Theresa Fyffe: Mental health is a major concern. Again, I agree with my colleague Dr Winning. It can be said that things are easy when there are quantitative measures. However, I have spent a lot of time working with patient groups, and have said to them, “You want to have your target, but what about the experience? Did you feel that you got what you needed? Did the experience match what you wanted and leave you feeling that you had left the care experience in the best way?” That is important. Outcomes are about what happens afterwards, not the treatment.

Dr Winning: I will illustrate that with fairly extreme examples. If I were an orthopaedic surgeon who wanted to replace an elderly lady’s hip and I absolutely had to meet a target, she might have to go on to someone else’s theatre list. That happens in order to achieve waiting list targets. Surgeons have unknown patients to operate on appearing on their lists. I would want to have a good relationship with my patient, and perhaps I would wait a little bit longer so that she could reduce her body mass index to make the operation safer and I could ensure that she fully understood the procedure, or perhaps I would bring forward the operation or delay it a little until her daughter could arrive from England to be with her during the recuperation phase. A target-driven culture might be to the detriment of good-quality patient care.

Mary Scanlon: That is helpful. Thank you.

Dr Simpson: I am finding it difficult to hear Dr Winning, as there is a big buzz from the sound system. I wonder whether there is a problem with her microphone.

Dr Winning: Shall I try another seat?

Dr Simpson: Would that be possible? I have a slight hearing problem, and am finding it difficult to hear you.
All our witnesses are from organisations that have United Kingdom counterparts, and I am interested in what they have done to compare the bill with the English NHS constitution. That constitution is not, of course, enshrined in a particular act, but it underpins many common law, statutory and other rights in England.

Earlier, I used the example of a clinician recognising that a medicine had been approved by the Scottish Medicines Consortium and recommending it for a particular patient’s use. As I understand it, under the bill, the clinician will have no rights in that regard if the health board determined that that medicine should not be used. That is just one example.

It seems to me that, if we are going to pass a bill in Scotland, the committee should be convinced that it will take us ahead of what is happening in England, as we were with the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003. Those acts enshrined new rights in their principles that protected patients and took us ahead of the rest of the UK. Will you comment on the additional rights in the bill? What will it do for Scots patients that will be at least equal to, and preferably better than, what happens in England? If the answer is nothing, just say that.

Theresa Fyffe: I think that the answer to that question is nothing.

Dr Mathewson: I agree.

Dr Winning: So do I.

The Convener: There we are. Those were short answers to a long question. That is not bad.

Michael Matheson (Falkirk West) (SNP): It is clear from your submissions that all the professional bodies that you represent are in favour of patients’ rights, that patients already have certain rights, and that you have codes of practice and so on that help to inform professionals in their practice about patients’ rights. Theresa Fyffe commented that she believes that patients’ rights should be enshrined, but not necessarily in legislation. I am not clear how they could be enshrined by any other means. Given that you are in favour of patients’ rights, what do you believe we should be doing, other than in legislation, to ensure that patients can exercise their rights more effectively?

Theresa Fyffe: There are a number of solutions. I believe that we should look at the constitution that has been developed in England. There are elements within it that would perhaps need consideration for Scotland, although I would rather not go into that today because I have not brought it with me. However, as a process, it has brought rights together in one place and made them much more accessible. That is what I meant by enshrining patients’ rights. The NHS constitution has made the rights clear to people.

We have also called on the Government to dignity proof its policy. That is about dignity, equality and respect. The Government should look at its policies and ask how they enact dignity. As my colleague Sally Winning does, I believe that the equality strategy will go a long way towards supporting that process.

You will probably be aware from my written evidence that I went to Norway to find out and understand what has been done there. What concerned me was that those who seemed to know the most about patients’ rights were the more articulate and able people. I am concerned that, if we do not do something, the very people whom we want to understand their rights and express them will be those who are least able to do so. I am not just talking about mental health in that regard; I am talking about enabling a range of people to access their rights.

I believe that there is work to be done. The next step should be to consider what we can do to ensure that we enable people in the way that I described. We have not done that thinking yet—at the moment, we are just responding to the bill—but I want my organisation to commit to considering what could work and what could make things better.

Michael Matheson: Do any of the other professional bodies want to comment?

The Convener: Please indicate to the chair if you want to comment. I call Dr Mathewson.

Dr Mathewson: The Royal College of General Practitioners Scotland would agree with Theresa Fyffe. We welcome clarification and amplification of patients’ rights, but not codification—or whatever the appropriate word is—in legislation. There is a need to make patients more aware of their rights. There is also an enormous burden on general medical practitioners to act appropriately—to indulge in mutuality with the patient, to exchange information, to respect the patient, to encourage them to take up services, and to explain things. All of that is already part and parcel of everyday general practice, as it should be. It is expected and, as I have said before, it is in the strong guidance that is given by the General Medical Council. All those rights and privileges are inherent in the codes of practice that already exist, but we welcome the statement of them, the strong support for and amplification of them, and some method of ensuring that patients become more aware of those rights.

Michael Matheson: And the BMA?
Dr Winning: I agree with everything that my colleagues have said. If we are looking for what the solutions might be, I think that the independent advice and support service is exactly that. It is independent and it is holistic as it covers all sorts of issues such as welfare. If patients’ rights were laid out clearly, there are facilities and places where patients can go to get that information in an easily understandable and digestible format.

The Convener: Do you have another question, Michael?

Michael Matheson: Yes. I have a couple of points, if you do not mind.

My difficulty in the debate about rights is what lies behind the word “rights”. It is all very well to say that patients have rights, but if the health service in some way fails to meet my rights, what form of recourse do I have to enforce those rights?

10:30

My problem with the bill is the lack of enforceability when it comes to rights. When someone talks about me as an individual having a right, I expect some sort of backbone to that right to enable me to pursue it in the way that I think is appropriate, which, if necessary, should include legal recourse, for example under the European convention on human rights. I have heard a lot of talk about a greater focus on informing people about what their rights might be, but I feel that there is no spine behind the word “right” when it is applied to certain circumstances. Do you oppose in principle the idea of having any form of legally enforceable rights in relation to provision within the NHS, over and above the rights that can be pursued through legal recourse at the moment?

Dr Mathewson: There are two aspects to that. One is that legally enforceable rights would inevitably alter in some way the atmosphere or the doctor-patient relationship in the consultation, despite people’s best intentions, because there would be awareness that the consultation was on a legal footing.

Secondly, I understand that rights imply legal recourse or sanctions. There are perhaps three levels at which the patient can clarify whether the rights that they are due are being exercised. The first level is simply to have a discussion—to make a complaint or a statement of concern that their rights are not being respected within the primary care team. The patient should be able to do that. If they do not feel that they can do it on their own, they can do it with local help.

The second level is a complaints procedure that will entertain any complaint that is made against general practitioners, which is the proper way to seek redress, explanation and remedy, although not financial remedy.

At the third level, if the patient feels that in any breach of their rights they have suffered some loss or damage, there is recourse to the civil law to seek redress formally. There are levels of redress or explanation. The best way forward, at least initially, is to look for explanations and apologies at the point at which the care is being delivered, or not being delivered.

The Convener: Have we exhausted that issue?

Michael Matheson: I am keen to hear whether the Royal College of General Practitioners Scotland is opposed in principle to the idea of enshrining rights in law.

Dr Mathewson: RCGP Scotland is opposed in principle to that.

Theresa Fyffe: The RCN Scotland is also opposed in principle to that. As an organisation we are working very hard around the no-fault compensation scheme; I think that recommendations are coming out in late October. It is becoming clear that there is work to be done around the complaints system to redress the balance. That is why we have been committed to that work. For us, the consequences, which Mr Finnie addressed earlier, of having legal redress would not be in the best interests of patients or others.

Dr Winning: The BMA supports the principle of patient rights, but we defer to the views of our legal colleagues, who do not think that the bill will add anything to the rights that already exist.

The Convener: The bill will not add or take away; it is neutral.

Dr Winning: Yes.

Helen Eadie: I get a sense from this morning’s discussions and from other discussions that we have had in the committee that everyone wants change that will enhance patients’ rights. The question is, how do we do that? We politicians can give you chapter and verse about cases of injustice about which we get enraged on behalf of our constituents. Some of those cases result in death. How can you ever bring back a loved one for someone who has been bereaved in that way?

When you believe passionately, as some of us do, that there needs to be change, one of the first things that you do is to sit around a table and identify who your key allies and other stakeholders are, and who shares your objectives. A lot of thinking is being done in various organisations, but has anyone ever pulled together everyone for a discussion about how we can make things better for patients?
Theresa Fyffe: That is the challenge that we now face. The Government has opened up a good debate about why patients’ rights are as they are and how patients feel.

We recently ran a workshop around the co-production concept that is coming out of the Health Foundation. I am not keen on the title of the concept, but we are interested in how it might enable new ways of partnership working between patients and professionals. We are only in the preliminary stages of that work, but I believe that such an initiative might help in relation to what we are discussing.

As I said earlier, if the bill does not go through, we should be considering what we need to do. As an organisation, we would be committed to that.

Helen Eadie: In a sense, we are all saying with hindsight that that should be the way forward. However, has it ever been done before? Did the Government call you to meetings to get your views and those of patients and everyone else in the medical profession before it went to the drawing board to prepare its consultation document? Was there an attempt to get a consensus on the appropriate way forward before the Government came to the Parliament? If that had happened, we could have had a more rounded debate.

Theresa Fyffe: That has been happening around various areas of work, such as the work that has been done on no-fault compensation. We have been at the table in relation to some issues and have been very committed to that work. We have had extensive discussions with the Government on the dignity work and our views have been listened to and well received. That is the way it has been happening, rather than—

Helen Eadie: So, it has been a fragmented and piecemeal approach, rather than there being a round-table discussion with all the parties involved.

Theresa Fyffe: Perhaps.

Ian McKee (Lothians) (SNP): I have three questions. First, I gather from everyone’s submissions that you are all concerned about the possible distortions that could arise from the 12-week waiting time guarantee—for example, there is a worry that ensuring that someone gets an operation within 12 weeks might mean that the operation of someone who needs it more urgently is delayed. Is that correct?

The Convener: I think that that point was made by previous witnesses, but members of this panel might want to comment.

Dr Winning: I agree. That is correct.

Ian McKee: Section 8(3)(a) deals with the arrangements that apply when a health board has exceeded the 12-week treatment time. It says that the health board

“must not give priority to the start of any treatment where such prioritisation would, in the Health Board’s opinion, be detrimental to another patient with a greater clinical need for treatment”.

Would it be better to include that phrase earlier in the bill—perhaps replacing “Health Board” with “treating clinician”—so that it appeared in the section that deals with the meeting of the 12-week guarantee rather than its breach?

Dr Mathewson: Yes, I think that that would be better. The statement should be given prominent consideration in the bill because, without it, individual clinicians, who might be reviewing patients and changing the clinical position to make appropriate actions, would have no latitude. We in the college have discussed the issue; no doubt you will have spoken to secondary care colleagues, who might also have a view on the matter.

Ian McKee: I share Theresa Fyffe’s enthusiasm for a concept of mutuality in the health service, but how would that work in practice? What if the bill were to contain responsibilities for patients? Having worked in primary care, I am very well aware that some of the people in greatest need are those who, at first sight, do not seem to meet their responsibilities. Instead of mutuality being some nice, happy concept, I wonder whether introducing such responsibilities would in practice simply increase health inequalities by coming down heavily on the very people whose health needs might be greatest, even if they were not so good at co-operating with the health service.

Theresa Fyffe: That is the conundrum. Once you begin to talk about balancing rights and responsibilities, you get into that very dilemma. As set out in the schedule, the 12th principle is:

“Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect.”

In our written submission, we say that we found the choice of words to be interesting. I would have thought that, if the aim was mutuality, the phrase would have been “are expected” rather than “are encouraged”. However, this is where I struggle with what the bill is trying to do. I cannot tell you what the other solutions might be, because that is the issue that we need to examine and it will be a very tough challenge to get rights and responsibilities right at the same time.

Dr Mathewson: I agree. As we all know, there has been enormous movement in the area of rights and responsibilities over the past 10 or 20 years, and the very fact that we are debating it this morning represents another step forward. Those who are less likely to be able to speak for themselves are likely to be more disadvantaged in
the mutual aspects of the doctor-patient relationship.

As I say, things are moving on. There will be no big bang; the process will be gradual—though getting faster, I hope—with the doctor-patient relationship improving and rights and responsibilities being recognised and acted on. However, this is a continuation of an enormous change that has been taking place slowly but surely over the past 10 to 15 years.

Ian McKee: You agree, though, that setting out in a bill the requirement for people to keep their appointments and so on might have an effect contrary to improving the country’s health.

Dr Mathewson: Yes. Setting out minutiae such as that—well, perhaps not “minutiae”; it is an important element—could be counterproductive.

Ian McKee: My third—and last—question, convener—

The Convener: I have been counting. It seems more than three, but I am sure you are right.

Ian McKee: It is three.

We know that many more procedures are being carried out totally in primary care and that general practitioners and people who work in primary care can do many more things than they used to be able to. In a previous evidence session, we were told that primary care has a responsibility under the health board for such procedures. If a GP agreed with a patient about removing a cyst or something like that, would the health board have to monitor that? How would it work?

Dr Mathewson: As it works at the moment. There would be an exchange of information between the patient and doctor; an understanding would be reached of the problem and the options for dealing with it; and information would be disclosed about possible outcomes and follow-up. As you say, that is an increasing part of primary care and the extended primary care team’s activities; indeed, it has become an even greater part, with long-term conditions being looked after by other primary care colleagues.

I do not know whether the health board plays a particular monitoring role in that respect. There are procedures in place for people to make complaints and express dissatisfaction. Professional monitoring, however, is another matter, and there are routes for complaining about professional standards that would not necessarily involve the health board playing Big Brother. It already has an insight into practice through the quality outcomes framework procedures, which is more of an accounting mechanism than a quality one.

10:45

Ian McKee: But the bill places a duty on health boards to monitor each treatment time guarantee and to make the necessary arrangements for the procedure to happen somewhere else if it is not going to happen within 12 weeks. Surely, if that is a health board responsibility, it will involve more bureaucracy than simply leaving the matter to the GP. What if someone says, “I’ve been waiting 15 weeks,” and the health board has not known anything about it?

Dr Mathewson: I am sorry—I think that I might have misunderstood your question. Are we talking about procedures being carried out in primary care or about GPs’ role in monitoring the treatment time guarantee?

Ian McKee: I am sorry if I am not making myself clear. I am talking about a treatment such as a minor surgical procedure that is carried out in primary care, which will now be subject to a 12-week waiting time guarantee if the GP and the patient agree to the treatment. As I understand it, that treatment will be treated in exactly the same way as procedures carried out in hospital. Under the bill, the health board has an obligation to monitor the treatment time guarantee and ensure that, if it looks as if it might not be met, it is met elsewhere. Will that not involve more bureaucracy?

Dr Mathewson: Yes. If the bill is enacted, there will have to be a mechanism to allow notification of the procedure to be carried out and its completion. However, in most general practices it is likely that patients will not have to wait anywhere near 12 weeks, for a minor surgical procedure, which often can be done, if not immediately, then fairly quickly.

Ian McKee: But you are aware of all that.

Dr Mathewson: Yes.

Ian McKee: And you have discussed it with the Government.

Dr Mathewson: Not yet.

Mary Scanlon: So far, our discussions have focused on the treatment time guarantee. In its submission, the General Medical Council says:

“The fundamental existing legal right of patients to refuse treatment appears not to have been included. ... the Bill does not ... recognise the distinction between patients with capacity who have a legal right to consent ... or refuse ... and patients who lack capacity.”

That seems to me to be a very serious issue. I am not a lawyer, but does the fact that there is no legal right to refuse in the bill not put at a disadvantage patients who refuse treatment or do not wish to comply with the recommended treatment?
Dr Mathewson: The short answer to that is yes.

Mary Scanlon: Are you saying that patients will not be allowed to refuse treatment, which is a right that they have at present?

Dr Mathewson: Perhaps I am not in understanding mode. Patients would be disadvantaged by not having the legal right to refuse treatment, or a patient with incapacity would be disadvantaged if the bill were to go through.

Dr Simpson: Perhaps I might intervene, convener. The matter is probably covered in section 18(1)(c), which refers to “any other enactment or rule of law”.

As patients will retain common-law rights to refuse treatment, I do not think that what Mary Scanlon suggests will be a problem.

Ian McKee: Moreover, according to section 6(1), we are talking about “an agreed treatment”.

The Convener: Committee members seem to be giving evidence now. Once I let them loose, Mary, there is no holding them back. I am getting medical opinions to the right of me now.

Mary Scanlon: There are too many experts. However, as the GMC is not giving evidence, I thought it appropriate to ask the BMA, the RCN and the Royal College of General Practitioners for their views on the issue.

The Convener: Before we proceed, I want to pick up on capacity, which is surely an issue in all walks of life. One of the main concerns of any professional is whether a patient has the capacity to consent to anything, whether that capacity is of a temporary or a permanent nature. Therefore, I do not think that we need it in primary legislation—it is just there.

Dr Mathewson: It is part and parcel of everyday doctor-patient exchanges.

The Convener: That is the ex-lawyer speaking to the ex-medical practitioners. Have you finished, Mary?

Mary Scanlon: The RCN and the BMA have not responded, but maybe they do not want to respond.

The Convener: Well, that is grand.

Ross Finnie: Can I ask a supplementary question? Mary Scanlon has properly asked these witnesses about the GMC’s evidence, but I would like to ask them what they think section 18(1)(c) means.

Dr Simpson: I say, for the people in the public gallery, that the section states: “Nothing in this Act prejudices ... any other enactment or rule of law.”

Michael Matheson: I presume that that means the Adults with Incapacity (Scotland) Act 2000.

Theresa Fyffe: That is what I understand.

Dr Simpson: And the Mental Health (Care and Treatment) (Scotland) Act 2003.

The Convener: And the rule of law, which is not necessarily in statute but may be judgments.

Thank you very much. That concludes this session. Our witnesses may change places, but I will keep us on the record because time is rolling on and I want to say something.

Members asked what happens to the reports that are published under the Scottish Public Services Ombudsman Act 2002. Section 15 of that act, “Reports on investigations”, states:

“(1) After conducting an investigation, the Ombudsman must—

(a) if the investigation is pursuant to a complaint, send a report of the investigation to the persons specified in section 11(2) and to the Scottish Ministers,

(b) if the investigation is pursuant to a request, send a report of the investigation to the persons specified in section 11(4) and to the Scottish Ministers,

and must lay a copy of the report before the Parliament.”

The phrase “before the Parliament” means in the Scottish Parliament information centre. The report will also be publicised in the Business Bulletin.

Helen Eadie: It will be on the website as well.

The Convener: That is separate from parliamentary procedures. In terms of the Parliament’s procedures, what I have said is what is meant by that phrase. I hope that that answers the question that members raised.

Dr Simpson: That is very helpful. Thank you, convener.

The Convener: As the next witnesses take their seats, I advise members that, after this evidence session, I will suspend the meeting for five minutes before we move on to the final items on the agenda, the most important of which is the Alcohol etc (Scotland) Bill at stage 2.

The witnesses in the final panel represent patient groups. I also welcome John Gallacher, the secretary of Unison, who was meant to be on the previous panel but was unavoidably detained. We have before us Shelley Gray, director of policies and campaigns at the Long Term Conditions Alliance Scotland; Carolyn Roberts, head of policy and campaigns at the Scottish Association for Mental Health; and Delia Henry, director of the Royal National Institute for Deaf People Scotland, who was on the radio this morning. Beside them are Jim Elder-Woodward, board member of...
Inclusion Scotland, and Bill Scott, who is here to assist him. Completing the panel are Mhairi Thurston, lecturer in counselling at the University of Abertay Dundee, and Dr Allen Thurston, reader in education at the University of York, both of whom are representing the Royal National Institute of Blind People Scotland. When we go through our questions, I will ask you to self-nominate. You do not have to answer every question if you do not feel that it pertains to you. If you just want to agree, say, “I agree.”

Dr Simpson: I will direct my question to John Gallacher from Unison and, as he has listened to the earlier panel’s evidence, give him the opportunity to comment on any of the issues that were raised. The philosophical point that we were discussing with Bill Mathewson is contained in the third paragraph of Unison’s written submission:

“We are concerned that whilst creating little by way of new rights the Bill assembles those rights which do exist in a manner that suggests a relationship based on contract, rather than mutuality.”

We are all pursuing mutuality. Would you like to comment on the point about contract and mutuality? Also, you say the bill creates “little by way of new rights”, which suggests that it creates some new rights; I would love to hear what they are.

John Gallacher (Unison): Thank you, convener. I apologise for the delay in my arrival.

The concept of mutuality is relatively new in NHS Scotland; it has been bandied around for the past year or so. We have had a strong tradition of staff engagement in policy and decision making in the health service; mutuality is about engaging the patient voice. There is a plethora of patient voices here this morning.

Various aspects of involving patients in service planning and delivery have been put into operation. There is the experimentation with elected health boards. Patient engagement forums have played an increasing role at board level. We believe that the concept of mutuality is about putting patients at the heart of planning and delivering the health service, not as customers —— to use the jargon —— but as users of other services. It is about the population and the staff who work in the health service having the right to co-manage and co-produce—to use the jargon—the services that are delivered.

Much of our submission is about the introduction of a litigious, commercial culture that we do not want in NHS Scotland. Significant legal challenges are already being made to decisions. Complaints have been made about staff, for example, and there are other challenges.

To answer your specific question, we do not believe that the bill would introduce any substantive new rights. It would simply assemble rights that exist in other pieces of legislation and can be enforced elsewhere. The only right that would be introduced is the right to seek judicial review, which it is clearly beyond the resources of most individuals to do. We do not believe that the bill will bring any significant new legal benefit to individual patients. We want the concept of mutuality to be introduced without introducing litigation into the debate.

Dr Simpson: That is very helpful. I have a small supplementary question and I might come back to the issue later if we have time.

One of my concerns is about whether enshrining all these concepts in primary legislation, which is difficult to amend, will in any way reduce staff rights. For example, when I was a practising consultant psychiatrist, some patients were extremely aggressive and difficult. They were not just not complying with treatment, which was their right, and they were verbally and physically abusive to staff. We denied some of those patients their rights to access general practice. If they wished to access a primary care service, they had to go to a particular special unit elsewhere. Those were extreme cases, but I am slightly concerned that, because the bill finds it so difficult to tackle responsibilities—we all understand that—it will put some staff at a disadvantage by creating new legal rights for patients. Do you have any comment to make on that?

11:00

John Gallacher: Yes. Violence and improper behaviour towards staff are huge problems in the health service. A particular case springs to mind from Edinburgh. A patient who is in prison has to attend for dialysis and, every time he attends, he routinely physically and verbally abuses staff. As you say, the withdrawal of treatment is usually done only in extremis. It is unusual for clinicians or general managers to decide that treatment can be withdrawn. We do not believe that patients’ responsibilities are stressed highly enough in the framework that is set up.

The other staffing issue is that the bill seeks to enshrine rights at a time when staffing resources in the health service are shrinking. The committee will be aware that, in this year alone, some 3,790 staff are being withdrawn. Far from what is written in the press, the NHS budget will not be featherbedded or protected in the next comprehensive spending review. Boards in Scotland are already planning for significant reductions next year of up to 4 per cent in efficiency savings. The number of staff losses will grow significantly. That means that, at the very
Good morning. I am rather perturbed by the time when there might be rights to assert, the staff who are left to deliver services under increasing pressure will suffer ill treatment, which is unacceptable.

Ross Finnie: Good morning. Unison expressed concern in its written evidence about the advantages of enshrining patient rights in a bill. Inclusion Scotland expressed concerns about the use of the words “have regard to”. Long Term Conditions Alliance Scotland seeks an additional code of practice. The others before us generally appear to support the bill. How will we benefit by enshrining our rights in the bill, when section 18(2) expressly states:

“Nothing in this Act gives rise to—
(a) any liability to pay damages,
(b) any right of action for specific implement,
(c) any right of action for interdict,
(d) any right of action for suspension”?

I am not getting into the argument about whether we need rights, but what is the benefit of bringing the rights that exist into this bill, given that it outlines those specific exclusions?

Shelley Gray (Long Term Conditions Alliance Scotland): This was picked up on in the previous panel. Many of these rights are already in codes of practice and so on, but it is clear that they are not being implemented sufficiently. If the bill prompts work to embed patient rights throughout the NHS—the Government has talked about increasing advocacy services and introducing a programme of training for NHS staff as a result of the bill—and to embed a culture of rights in the NHS, that would be of major value. Some elements of the bill, such as the expectation that staff will communicate with patients in a certain way, could be strengthened, such as by stating that information will be provided in an accessible way. If the expectation was all there in one bill, that would make a difference.

Ross Finnie: Do you need the bill to do that? The health secretary could issue a direction under the 1978 act calling for that to happen. Why do we need an act of Parliament that implies that you have some legal right, when section 18(2) removes it?

Shelley Gray: It is about individuals having rights, but it is also about the expectation on staff working in the NHS not just to tell people about their rights but to do things proactively such as providing information in accessible formats, supporting people’s right to access advocacy, communicating with them and so on. We think that having that in a bill would help.

Jim Elder-Woodward (Inclusion Scotland): Good morning. I am rather perturbed by the paternalism of professional bodies in relation to the use of the word “mutuality”. By mutuality, I understand that there is equality between the two groups; otherwise, mutuality cannot exist. When Theresa Fyffe was talking about mutuality this morning, I wondered whether her argument could have been used against equality for women because it would upset mutuality between men and women—although obviously, it does not.

Mutuality arises only when both sides are equal and both sides have some resource. I think that having a right gives the patient a resource so that they can come to the table on a mutual basis. We know that disabled people face a vast amount of inequality in health. People are left unhelped to feed, and disabled people are not given the same access to screening as other people—there is a whole host of areas in which inequality exists. If we are to work on the basis of mutuality, each person around the table needs to bring a resource with them. For patients, the resource will be the Patient Rights (Scotland) Bill when it comes into force in 2011 or whenever.

The Convener: So you are saying that the bill will redress an imbalance.

Jim Elder-Woodward: Yes, it will redress an imbalance. We cannot have mutuality if one actor is less resourced and less empowered than the other.

Dr Allen Thurston (University of York and Royal National Institute of Blind People Scotland): I guess that the question is really: what might the bill add? I have looked at the history, and our main evidence obviously relates to communication in accessible formats for blind and partially sighted people. There is already legislation, such as the disability discrimination legislation, which should ensure that people who are blind and partially sighted receive information in an accessible format.

Written into the professional standards of the Royal College of Physicians, the General Medical Council, the Nursing and Midwifery Council and the Royal Pharmaceutical Society are statutes that say that their professionals should communicate with blind and partially sighted people in an accessible format. However, the RNIB has now produced four reports—including reports in 1998 and 2008, and one in 2004 from Guide Dogs for the Blind—and 12 years on we still have the same problem. Although all the professional bodies state that communication in an accessible format is part of professional standards and behaviour, 12 years on and four reports later, not a lot has changed. There are issues of confidentiality, for example—if you have to hand someone a letter to read it to you, your confidentiality is breached.
Perhaps there is a need for something to focus the minds and change the behaviour of the professional bodies that work with people who require information in an accessible format. It is not for me to say what is the best way to do that—Parliament will have its own ideas—but something has to change. It is unfair to continue with the way things are.

Ross Finnie: I happen to agree with you, but I also think that it is up to you to tell us what is the best way forward. I suppose that we have the ultimate decision and power in that respect but a question has crystallised around the bill that the Government has proposed. You and your organisation have raised very real concerns that the various things that have been implemented are not actually being done. As a parliamentarian taking evidence from all the organisations before me—including, at the moment, the RNIB—I have to wonder whether we need to address the situation through the bill, which expressly removes access to law in so many ways, or whether we take some of the subsidiary work that the Government is very properly carrying out and introduce a range of other documentation that sets out the various rights. My concern is whether we actually need a new bill.

Dr Thurston: Despite the regulatory and professional conduct standards of the bodies in question, despite the laws that have been introduced and despite the fact that this has been a persistent problem for a long time, nothing has changed. Perhaps the bill is required to change practice.

Ross Finnie: So what would it do?

Dr Thurston: It might well focus the minds of those who work with patients. To some extent, I am a one-trick pony; my main interest this morning is about protecting patient confidentiality through communication in accessible formats. There are wider issues, which you have debated with other witnesses, but I guess that I want the focus to be put back on to the chain. Perhaps the doctor thinks that the patient has been communicated with in an accessible format and does not give it much thought once the patient has left the waiting room and the letter has been printed off by the receptionist or passed on by the nurse. We need something that will focus the minds of all the people in the chain on ensuring that none of its links is broken and that we do not have situations in which patients get letters that they cannot read or, as far as the RNID is concerned, in which patients get letters that they cannot read.

The Convener: I should clarify that although nothing in the bill can be enforced, it does not affect pre-existing provisions. We are not saying that all current rights will be wiped out.

Delia Henry (Royal National Institute for Deaf People Scotland): As we say in our written submission, the important issue is the practical implementation of the bill’s provisions. I am encouraged that we are having this debate, but I have to say that, when I reread our submission, I was struck by the fact that it highlights fairly basic principles of communication in respect of people who are deaf and hard of hearing and talks about a fairly basic lack of access to health in certain fundamental areas. For example, people have to get someone else to make phone calls for them because health departments—even audiology departments—expect people to contact them by phone. I am sure that everyone around the table finds that shocking, but the fact is that we regularly hear such stories.

In the work that we carried out to inform the submission, our members kept telling us that they did not want to make complaints but simply wanted to access health in a quality way. That notion of quality underpins our submission and we need to think seriously about whether the bill can enforce that. As I say, our membership and organisation support the practical implementation of the bill’s principles and hope that they help to make a level playing field for patients and to ensure that health care professionals and patients work in a mutual way to deliver a good-quality health service.

11:15

Ross Finnie: What has been said highlights the dilemma for me. I do not in any way disagree with the point that there is a need to make some of the existing statements work—Delia Henry said something not too dissimilar, and her written submission also makes that point. What is less clear—although it is not Delia Henry or Allen Thurston who is less clear—is whether setting that out in a bill that does not give any new rights is the appropriate way to ensure that that happens. That is the difficulty. It is about the vehicle. I have no difficulty at all with the purpose that Delia Henry wants to achieve for her members and the purpose that Allen Thurston has identified. That is not my problem. I am clear that we need to do something slightly differently so that their members get a better kick at the ball. However, I am not clear whether the bill is the right way of delivering that. That is the dilemma.

Mhairi Thurston (Royal National Institute of Blind People Scotland): One finding of the survey that was conducted for the RNIB was that people do not complain. Largely, there is no voice from blind and partially sighted people about not receiving information in an accessible format. That is where the bill could provide a benefit. In a way, there is no complaints culture among blind and
partially sighted people. Although complaints procedures are in place, people do not use them because they do not have enough energy or they do not want to be troublemakers or cause waves. The mechanism in the bill takes away the onus to complain and puts in place rights. That legal framework might help.

Ross Finnie: Let me pursue that for one second. You say that the bill will help by putting in place a legal framework. To return to my colleague Michael Matheson’s point, normally if I confer on you a right, I also confer on you a right to have recourse to a court of law. However, that is not how the bill is drafted, and that is the difficulty. I am not sure that you want that, but are you telling me that your members would be better off if they had a right to go to law?

Mhairi Thurston: The point is more that, rather than have the onus on them to go to law, there should be an awareness on the professional and clinician side. In a perverse way, it is about emphasising the responsibility on the clinician side, rather than the patient side, if that makes sense.

Jim Elder-Woodward: I would take Ross Finnie’s big step and allow patients to go to law. There is an argument for that. How else can we underpin the power of the patient to be at the table on a mutual basis? The patient needs to have power behind them to equalise the relationship between them and the professional. The bill has big holes in it. One of them is a lack of awareness of how to spend the £500,000 on advocacy. To empower certain patients, they need an independent advocate, and I do not think that £500,000 a year is sufficient for a national advocacy service. If we are to have patient rights officers, we need to equalise that by having independent advocacy in each board area. I am talking about how to empower patients in the professional-patient relationship. I agree that the bill does not go far enough in the empowerment of patients.

Dr Simpson: My supplementary fits well with Jim Elder-Woodward’s point. If I understand the witnesses correctly, they are saying that the problem lies in the fact that people do not exercise their rights. There are rights in existence. The Disability Discrimination Act 1995 alone gave enormous rights—

Jim Elder-Woodward: Ah!

The Convener: Wait before you come in. Richard Simpson has stirred a hornet’s nest by mentioning the DDA.

Dr Simpson: —which are not being enforced. The message that I am getting is that it is not working.

I just do not see how spending £1.6 million on patient rights officers will help, because their role is one of signposting, not advocacy. If the current situation is that the people whom the witnesses represent do not know to complain, they will not even get to the patient rights officer. The problem lies at an earlier stage. It is about ensuring that it is communicated to people, clearly and precisely and in the correct format, what their rights are and how they can take them forward. The IASS works quite well, but funding is being cut from half the service, so if we are serious about the issue, that is where the money should be going, not on the new patient rights officers.

The Convener: I think that you are giving evidence, Richard.

Dr Simpson: There was a question: do the witnesses agree?

The Convener: There was a question only because I prompted you.

Jim Elder-Woodward: What a leading question!

Dr Thurston: The results of our survey indicated that blind and partially sighted people were aware of their rights—nine out of 10 of them knew that they had a right to receive information in an accessible format, but only one out of 10 actually received it, and the proportion who complained was even smaller. It is about disempowerment—it is more to do with the fact that people are disempowered when it comes to the complaints procedure. People know that they have rights; they know that they are there. The point that Mhairi was making is that a top-down approach is necessary. It is the hospitals and the clinicians that need to change what they are doing. We are not necessarily calling for more things that people can complain or sue about; we are calling for something that addresses systemically the wrongs that are occurring in the NHS at the moment.

Dr Simpson: I gather that there has been a 20 per cent increase in the number of complaints in England since the new constitution and the patients charter came in, so perhaps something is happening.

The Convener: I say to the witnesses that they have to be less than subtle if they want to enter the discussion, as my eyes are trying to see everything.

Shelley Gray: I echo what Allen Thurston said. One of the key things about the present situation is that the onus is on organisations such as ours to highlight issues such as the failings that are happening, which include people not being given information in the way that they need it or communicated with appropriately. I am not a legal
expert, but I think that one advantage of the bill would be that it would put an onus on the NHS and the Government to monitor how effectively it was implemented, which would pick up many of the issues that our organisation has put a lot of time and work into picking up. That would be a key benefit of the bill.

**Mary Scanlon:** Carolyn Roberts has been sitting quietly and patiently, so I—

**The Convener:** She will not be doing so for much longer, now that you are targeting her.

**Mary Scanlon:** Carolyn, I am not sure whether you were here for the discussion earlier in the meeting about patient rights in relation to the treatment time guarantee. I think that you were extremely diplomatic and courteous in your submission, but is it not the case that every mental health patient in Scotland—apart from children—whom you represent will be excluded from what the bill provides? I will obviously ask whether you agree with me and what your concerns—

**The Convener:** Excuse me. I do not want such questions to become infectious.

**Mary Scanlon:** As far as mutuality is concerned, are there any aspects of the bill that would benefit adult mental health patients?

**Carolyn Roberts (Scottish Association for Mental Health):** We support the Patient Rights (Scotland) Bill. I have been quiet so far because everyone else was making the points that I would have made.

**The Convener:** I thank you for that.

**Carolyn Roberts:** Our main concern is about access to mental health services, which is excluded from the 18-week target, and from the Patient Rights (Scotland) Bill. That has a knock-on effect: because there is not the same guarantee about access to mental health services, less is done to gather waiting time statistics in that area. I am sure that the committee is aware that it is difficult to get information on how long people wait for adult mental health services because there is no requirement to meet any of the current waiting times guarantees. We are concerned that the lack of provision in the bill in that regard could perpetuate the situation.

We see benefit in the bill, but we are disappointed that there is little in it for adults with mental health problems. That could be addressed, either by extending the treatment time guarantee to mental health services or by including a section in the bill to say that the position will be reviewed later. A number of options could be considered. At the moment, however, we are disappointed that mental health services are not mentioned in the bill.

**Mary Scanlon:** I made a freedom of information request two years ago regarding psychology services in Easter Ross, in the Highlands. Patients there were waiting for four years and seven months to see a psychologist, and I do not see any benefit for them in the bill.

The final point in your written submission is:

“The Scottish Government must give further consideration as to how it can ensure mental health service users are also able to benefit from such guarantees, and have their human rights upheld.”

I am no expert in human rights, but does the bill bring forward some form of discrimination, bearing in mind that some patients have more rights than others? Adult mental health patients have no rights under the bill. Are you alluding to some potential legal challenge, on the basis that equal rights will not be upheld under the bill?

**The Convener:** Could I clarify the point? Patients have rights; what they do not have are rights specifically concerning mental health services. They have rights relating to services being patient focused and providing optimum benefits.

**Mary Scanlon:** But nothing that relates to the bill—there is no treatment time guarantee.

**The Convener:** Indeed—that is specific.

**Mary Scanlon:** There is a right to be treated with dignity and respect, as we would always assume, but as far as the bill is concerned, adult mental health patients are excluded.

**The Convener:** Yes—we accept that as regards treatment time guarantees. I am making it plain to anybody listening that the bill is not called the patient rights (but not including people with mental health issues) bill. It relates to some aspects, but not to guarantees about treatment times—that is the point.

**Mary Scanlon:** And that is at the core of the bill.

**Carolyn Roberts:** I take all the points that have been made. We had some discussions with the bill team while the bill was being drafted regarding its human rights implications, and we are pleased that there was mention in the policy memorandum of article 12 of the International Covenant on Economic, Social and Cultural Rights with regard to

“the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”,

so there is some recognition of human rights in there. However, we are concerned that the bill perpetuates what started with the 18-week guarantee—most mental health services are excluded from it. That could be addressed, however—there is still room to change the bill so
that it could be of assistance to people with mental health problems.

I take the point that only the treatment time guarantee excludes mental health services. The other areas of the bill would benefit people with mental health problems as much as they would benefit other people, as long as there was proper training for the patient rights officers so that they had some awareness of mental health. The exclusion from the treatment time guarantee is, however, a disappointment for us.

Jim Elder-Woodward: We are particularly concerned about the remoteness of the PROs, in that there will be only one or two of them per health board, and there will not be any in local hospitals. They will be very remote, and their remit in providing information will be limited. There is nothing in the bill to say that they will facilitate the provision of information from professional to patient. We feel strongly that the PROs will not be able to do their job effectively.

11:30

Helen Eadie: As a consequence of previous Governments’ decisions, we already have an independent advocacy support service in Scotland. I am interested to know the witnesses’ perceptions as to why the service is not working. The service is there as a result of a Government decision and it is funded by health boards, although it was established by Citizens Advice Scotland. What is it about the service that is not working but which you think the bill could change, given that such change is proposed?

Jim Elder-Woodward: I do not think that the service is well enough organised. It is also there to give information and advice; it is not there to advocate and it is not there to facilitate dialogue between professional and patient. If the independent advisory and support service is to be developed, it needs to be beefed up, it needs to be local, it needs to be visible and it needs to be beside the patient, not miles away in some office.

Helen Eadie: Is that not a matter of monitoring, managing and getting feedback about the existing service? I know from my work as an MSP that the independent advocacy support service does advocacy work in my area. I do not know about the experience of other MSPs on the committee, but it certainly works in that way in my area.

Jim Elder-Woodward: It does not in mine.

Helen Eadie: Is that not an issue about Government monitoring, evaluating, assessing and putting right the problems that exist in a service that is already enshrined in legislation? We would not be introducing something new; it already exists. The bill would duplicate something that is already in place.

Mhairi Thurston: You have made a really good point, but the findings of our survey show that there is an onus on the patient to pursue and activate the service. In the case of our client group, the patient is often quite disempowered and weary from living with a condition that excludes them from society. The thought of pursuing advocacy is sometimes an option that they do not want to take. They do not have the strength or the stamina to pursue that, even though the service may be accessible. We have said that it will be of benefit if the Patient Rights (Scotland) Bill introduces more systemic change, which means implementation by clinicians and a greater emphasis on clinicians tackling the problems that we highlighted in our report.

Helen Eadie: I am totally in sympathy with your concerns, as, I think, all committee members are. However, we face a challenge, which is why we need answers from you. The DDA and all the different acts are there—I have campaigned for years, for example, to get accessible railway stations for my community; such access is enshrined in legislation. However, the bill has no means of enforcement, so it does not give me or my constituents any power. The question that we are struggling with is whether a piece of legislation that does not give you any way to enforce it is worth the paper that it is written on. That is what you have to persuade me about this morning.

Mhairi Thurston: If I may, convener—

The Convener: It is lovely to have someone who defers to me, as I am so unused to it. You can come back—teach members something.

Mhairi Thurston: There is almost an analogy with a nuclear deterrent. If we have it in place, will it make a difference?

The Convener: The nuclear deterrent clause—or is it mutual deterrence? [Laughter.]

Helen Eadie: In what way is the bill a deterrent? There is nothing that I can enforce if a clinician does not do something that they should do. Where does that leave us? Where is the bomb?

The Convener: I do not want us to get frivolous—it has been a long session—but I think that that word might just bring security in here. [Laughter.]

We seem to have ended that discussion, but Mr Elder-Woodward wants to come in. Let us get sensible again.

Jim Elder-Woodward: I just want to make the distinction between giving advice and advocating on behalf of someone. There is a difference between independent advice and support services
and advocating on behalf of a patient to have his rights secured. If a patient has no rights, there is no need for an advocacy service and we might as well all go home now.

It is difficult to have a right that is not enforceable. Disabled people have a big book about a foot high of United Nations rights that are not enforceable. I could quote article 2 and article 25 of the United Nations convention on the rights of disabled people, which give me the right to equality in the health service, but because that is not in domestic legislation, we cannot enforce it. The bill gives one more right on top of the rights in that big book. The only thing that it will do is highlight the need to treat disabled people and patients with respect and dignity. I am sorry, but no amount of patronising talk from doctors and nurses about wanting to give dignity and work in mutuality with patients will satisfy me unless I can come to the table empowered to assert my dignity and my rights. That is important to disabled people.

**The Convener:** I was going to stop there because I think that that is a powerful argument, but Dr Thurston has indicated that he wants to speak. I am sure that he will make a powerful point, too.

**Dr Thurston:** I thought you were going to stop there, convener. I just thought that I would go into extra time.

The problem is how to bring about systemic change within the NHS in order to ensure that these things happen for people who are either deaf or blind or partially sighted. Self-regulation by professional bodies has not been working for a long time, so I would turn the question around and ask what will change without the bill and without something happening. Nobody in the NHS is self-employed. The employees work for a large, systemic Government organisation that is paid for by taxpayers. What change will happen without an overarching bill that says, “This is how you need to behave if you are employed by us”? It is not necessarily about empowering individuals to go to law or to seek compensation; it is about trying to bring about systemic change throughout the NHS.

**Helen Eadie:** When you spoke earlier about issues of confidentiality, you said that you are here as a one-trick pony. I sympathise with that, but the issue is that we already have the data protection legislation. What is wrong with that in terms of protecting patient confidentiality?

**Dr Thurston:** Perhaps people in the NHS do not see it as applying to them. There are Caldicott guardians in the system who protect patient confidentiality in the transfer of electronic information, but I guess that there is a disconnect between people seeing the disability discrimination legislation and the data protection legislation and their understanding how it applies to them in their job. Perhaps it is the bill’s job to bring those things together and say, “This is how the legislation applies to you in the NHS. You can improve care and outcomes for patients by behaving in this way.”

**The Convener:** I think that we will stop there because we have pretty well exhausted all sides of the argument. I thank everyone for giving evidence. I suspend the meeting for five minutes.

11:40

*Meeting suspended.*
Patient Rights (Scotland) Bill

Supplementary Evidence from the Law Society of Scotland
September 2010
INTRODUCTION

Hilary Patrick, the vice-convener of the Society’s Mental Health and Disability sub-committee gave evidence to the Health & Sport committee at the Scottish Parliament on the Patient Rights (Scotland) Bill on 29 September 2010. At the evidence session, Ms Patrick made reference to a number of statutory or common law rights conferred on patients which are either not referred to in the bill, or are alluded to in weaker terms than the rights which are otherwise conferred elsewhere.

As requested by the convener of the Health & Sport committee, the annex to this document contains a wider list of patients’ legal rights, where they derive from and the extent to which, if at all, they are referred to in the bill.

The Society would reiterate its concern that even if the bill fulfils the policy intention envisaged by the government, namely “to send out a strong message” that patients have rights, it does not give a full enough picture of what those rights are. The numerous other rights conferred on patients both under statute and common law run the risk of being overlooked or forgotten if people assume that the Patient Rights (Scotland) Bill is where to go for a comprehensive list of their rights.
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<thead>
<tr>
<th>NATURE OF RIGHT</th>
<th>REFERRED TO IN BILL</th>
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<tr>
<td><strong>Access to records</strong></td>
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<td>Medical reports issued for insurance purposes</td>
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<td><strong>Autonomy</strong></td>
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<td>Right to consent to or refuse treatment</td>
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<td>Right to adequate information about treatment, side effects and risks (‘informed consent’)</td>
<td>‘Have regard to’ need to provide information necessary for patient to participate</td>
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<td>Right to appoint welfare attorney / make advance directive</td>
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<td><strong>Confidentiality</strong></td>
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<td>Legal right to confidentiality under common law / Data Protection Act / professional codes of conduct</td>
<td>‘Regard should be had’ to confidentiality</td>
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<td><strong>Equality and respect for patient’s needs</strong></td>
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<td>Right not to be discriminated against</td>
<td>‘Have regard to need to’ consider patient’s abilities, characteristics and circumstances</td>
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<td>No degrading treatment</td>
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<td>To a GP</td>
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<tr>
<td>To a second opinion</td>
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<tr>
<td>To be supported by a family member / friend / carer</td>
<td>‘Have regard to need to’ provide support</td>
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<tr>
<td>Waiting time guarantees</td>
<td>Supplemented by treatment time guarantee</td>
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<tr>
<td>To make complaints to service provider</td>
<td>Yes</td>
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<tr>
<td>Access to Scottish Public Services Ombudsman</td>
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**Standards of treatment** (Government guidance to professionals and health boards)

Health professionals must show due care
Guidance from government about treatments should be given due consideration (judicial review available)

| Standards of treatment | No |

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Introduction

A focus group comprising members of NHS Forth Valley PFPI steering group, members of the Patient Public Panel and representatives of the PPFs was held to respond to the Call for Evidence. The following report is a summary of the feedback from the group.

1. The patient rights and health care principles.

Overall comments were positive with group members welcoming the Bill. The Bill was thought to be ‘sensible and achievable’

Some felt that the Bill does not go far enough. Particular concerns were raised about the provision of dentistry.

More information on support arrangements regarding mediation and / or an appeal system would be helpful in relation to patient rights.

The right to accessible information needs to consider low levels of literacy and particularly ‘health literacy’ amongst the population.

If person centred care is to be achieved then identifying individual’s unique needs will be fundamental. People need to be encouraged and supported to make their needs known.

Difficulty in balancing patients rights with their responsibilities. People do not always have the necessary skills or resources to help them be fully responsible for their own health care.

2. Treatment time guarantee

Need be clear about when treatment time commences. There is a need to make explicit which groups are exempt from treatment time guarantees and an explanation of why they are exempt.

The bill needs to be supported by clear and consistent information to the public. The first consultation is important in explaining to patients about waiting time targets, giving accurate timescales and managing expectations.

Need more clarification as to the consequences for Boards when targets are not met. Are waiting time targets being met at the expense of other services?
3. Complaints and feedback

Many participants felt that the Bill focused too much on complaining formally rather than on sharing experience and giving feedback. It was felt that the language is negative and gives an impression of an adversarial culture rather than one which supports local resolution at the point of the 'complaint'.

There were comments that this may lead to staff being defensive and perpetuate a culture of complaining and litigation.

There was discussion about the numbers of people who do not complain about their care or treatment even when they are unhappy about the service they have received. Although the group agreed that having the right to complain within the Bill may make it easier for some, it was felt unlikely that it would increase the engagement of seldom heard groups.

There was also concern about the ability to challenge habitual complainers and about managing peoples' expectations.

4. Patient Advice and Support

In principle it was agreed that this was an important role, although there were mixed views as to whether this should be a service provided directly by the Board or an independent service.

There was some discussion about whether the resources set aside would be adequate and whether there would be a significant difference from the current Independent Advice and Support Service (IASS). It was also suggested that IASS is able to act as a ‘one stop shop’ for those needing advice with benefits and housing as well as health issues. The concern was that people would have to speak to the PRO for health issues but still have to go the Citizens Advice Bureaux for other advice.

Some of the group expressed concern that there needs to be clear communication to patients and staff about the PRO role. Patients who need support should be able to access the PRO service before, for example, they feel the need to make a formal complaint to support patients to raise concerns directly with clinical service.

It was felt that patients might be confused between Patients Rights Officers (PRO) and Patient Relations Officers (PRO) and that there could be overlap between the roles.

Jacqueline Richardson
Patient Focus and Relations Manager
Department of Nursing - NHS Forth Valley
13 May 2010
Patient Rights (Scotland) Bill

NHS Lothian

The opportunity to comment on the proposed Bill is welcomed by NHS staff. Set out below is the response on behalf of NHS Lothian. There are some general comments at the start, followed by specific comments about the particular sections of the Bill, together with the policy memorandum where relevant. The final section refers to the financial memorandum, both the comments and financial detail contained within that memorandum, and which raises major concerns.

The patient rights set out in the Bill are supported by existing legislation, good practice and are already part of NHS Lothian’s fundamental objectives. It could also be reasonably argued that the right to make a complaint and the guaranteed treatment time do not require to be enshrined in legislation since they are already effectively in practice, e.g. only 0.7% of patients nationally needing inpatient or day case treatment were waiting longer than 12 weeks from decision to treatment at December 2009 and Boards are expected to treat within 9 weeks from April 2010. This is even more so as the legislation is not enforceable by legal action.

1. Sections 1-5 Rights and Health Care Principles

1.1 The rights of every patient as set out in section 1 of the Bill are supported.

1.2 In addition the health care principles, which echo the rights of the patient in the Bill, but in more detail (and set out in the schedule at the end of the Bill), are also supported. The principles for example, of being treated with dignity and respect, privacy and confidentiality, are all that staff in NHS Lothian aspire to deliver.

1.3 The term “person centred” should be used rather than patient focused, which reflects the current thinking in the NHS Scotland Quality Strategy. This emphasises more the concept of partnership and mutuality.

1.4 A further patient right should be added as this is an opportunity to promote individuality aligned to Human Rights, equality and cultural sensitivity that is: have regard to the importance of age, disability, culture, gender, faith/belief sexual orientation and socio-economic circumstances of the patient in relation to the provision of care.

1.5 While feedback is mentioned at the end of the “right to make a complaint”, and within Section 12 of the Bill, this is not stated in the health care principles, where the emphasis is only on issues of concern. It would be helpful if there could be a balance with the opportunities for positive feedback. It is a boost to staff to know
that patients are satisfied with their care, while realising there are occasions when the service does not get it right. In addition the way the word feedback is used in Section 12 implies that feedback will lead to improved performance, i.e. feedback is only about things that are wrong and need to be improved. While this is sometimes the case, again this does not recognise that the health service is getting most things right most of the time and that this is valued and recognised by patients, carers and families.

1.6 NHS Lothian is in the process of modernising its complaints procedures and services in order to ensure that complaints are responded to promptly, with sensitivity and that services are improved and learning shared across the organisation. We wish to emphasise however that all staff are encouraged to respond directly to patients, carers and families at the time that concerns and complaints arise. While it is vital that there is a clear complaints procedure that is accessible to patients and relatives, the emphasis should also be on putting things right at the time that concerns and issues arise. Given the consultation on the future of a no-fault compensation scheme (similar to that proposed in Wales) it may have been more appropriate to introduce comprehensive legislation when this consultation is completed.

1.7 The Policy Memorandum states that the key to participation is that staff and health care practitioners are reciprocally treated with dignity and respect by patients. However the health care principles only recognise the patient’s perspective. The enactment of this bill would provide an excellent opportunity for the Scottish Government to give a very high profile lead on this issue, with an emphasis on mutuality. The indication in the Policy Memorandum that it will be left to Health Boards to encourage patients to treat staff with dignity and respect is disappointing. It is hard to understand why the legislation can not embody the rights of staff in the same way it can patients (given that neither would be legally enforceable in individual cases). In addition, the previous proposals consulted upon during 2008-09 also made reference to patient responsibilities, but the Bill does not make any reference to this. There are references in the Policy Memorandum to “patients recognise and accept that they have responsibilities on them to support their own health and in their use of the health system”. This needs to be explicit in the Bill. It needs to be about co-ownership and co-creation: reciprocity of behaviour and explanation.

1.8 The importance of people being able to make informed decisions based on good communication is an existing legal duty, and an ethical and moral requirement. While the Financial Memorandum recognises that there are cost implications for the necessary provision of the importance of interpretation, translation and communication support services, it does not fully appreciate both current and future demands that will rightly be placed on NHS Boards to ensure
people are able to make informed decisions. We cannot underestimate the breadth and variety of support people need to help them engage with health staff about their own health and lack of it can be seen as systematic exclusion.

2. **Sections 6 – 10 Treatment Time Guarantee (TTG)**

2.1 We recognise that unacceptably long waits cause anxiety to patients and families. It could reasonably be argued it does not require to be enshrined in legislation since it is already effectively in practice: nationally only 0.7% of patients needing inpatient or day case treatment were waiting longer than 12 weeks from decision to treatment at December 2009 (see the ISD Scotland website [http://www.isdscotland.org/isd/5619.html](http://www.isdscotland.org/isd/5619.html) for the information) and Boards are expected to treat within 9 weeks from April 2010.

2.2 The issue for NHS Lothian will be in relation to services where we are not currently delivering the maximum wait of 12 weeks (e.g. IVF treatment, organ transplant) and the extent which these services are covered by secondary regulation which will specify treatments and services to which the treatment time guarantee will not apply. Careful consideration of this will be needed to avoid unreasonable and unattainable expectations. It will need to be very clearly stated where the maximum wait will not apply.

2.3 The treatment time guarantee will only apply to planned / elective care delivered on an inpatient or day case basis and therefore presumably will not apply to out-patient treatment e.g. physiotherapy, phototherapy, out-patient procedures. Given our expectation that more treatments will be available in this way in future, there may be a case for extending the potential remit of the treatment time guarantee to all treatments in due course. The guidance indicates that these will be covered by the 18 week standard only. Guidance indicates that the small number of excluded services will include assisted conception, complimentary and alternative therapies and scoliosis and other national specialist services. An opportunity should be taken to state that patient rights do not extend to non-evidence based treatment.

2.4 Alcohol and drug misuse services appear to be excluded from the treatment time guarantee on the basis that a new HEAT target for drug treatment waiting times requiring 90% of clients to wait no longer than 3 weeks is being introduced. It would be easier for staff and patients to understand if the treatment time guarantee was applied as universally as possible to all in patient and day case activity. It will be helpful for any exceptions to be agreed and defined nationally. To satisfy the guarantee more detailed local records may need to be kept on delays, Do Not Attends (DNA) and postponements than at present, bearing in mind that in Lothian DNA varies systematically be socio-economic groups.
2.5 NHS Lothian has set local targets across a range of services where no national targets exist. There are sufficient controls from SGHD to set treatment target times without the need for additional legislation and costly bureaucracy. This is even more so as the legislation is not enforceable by legal action.

2.6 The current system of waiting time management as set out in the Bill within section 8 (3) of taking into account the greater clinical need of another patient and having regard to the patient’s availability is supported as it is the current practice. The statement that the emphasis is on rectifying a situation and delivering treatment rather than instituting a financial penalty or compensation when the Treatment Time Guarantee is not met is also welcomed.

3. Sections 14 – 17 Patient Advice and Support Service

3.1 The proposal to introduce an independent Patient Advice and Support Service (PASS), its functions and the role of patients’ rights officers are noted. It is noted that the Policy Memorandum states that the provision of Patient Rights Officers will legislate to level out the balance of power between healthcare staff and patients. This seems an unfortunate tone given the emphasis in Better Health Better Care Action Plan on people and staff as partners. If this is its purpose then it is disappointing when other policy documents and guidance stress the value of NHS staff directly engaging with patients and carers. NHS Boards are expected, rightly, to engage directly with patients, carers and public and inform them about the services available, which NHS Lothian does in a variety of ways in a range of locations. NHS Lothian through various strategies wants to build on these activities, yet the proposal would see a significant sum of money allocated to a third party. While an independent service may be important, the replacement of an existing much lower cost independent service (IASS) should be questioned.

3.2 It will be important if PASS is established that it interfaces well with local complaints teams and processes and is able to relate to children and young people as well as adults. Training and cultural competence will also be important.

4. Section 18 - Protection and Limitations

4.1 The statements contained within the Policy Memorandum (paras 50 and 51) that this Bill will not be enforceable by legal action are welcomed.

5. Financial Memorandum

5.1 Healthcare to be received in a particular manner and principles
5.1.1 The Patient Rights Bill is a small proportion of the totality of existing legal duties and rights for patients and the public. There is a mixture of routes for raising awareness and support for individuals who wish to seek redress or question the application of rights. These include issues related to confidentiality, privacy access to health records, registration with a GP or Dentist etc. For the majority of existing patients’ rights people access local services or Health Boards as the first port of call for enquiries or complaints. Where formal recording is in place, NHS Lothian handles approximately 1,150 complaints. This figure excludes enquiries where receptionists, healthcare professions, complaints staff and other staff sign post and inform people about their rights. In contrast, NHS Lothian IASS service formally recorded 58 cases in 2009-2010. As well as that, NHS Lothian produces patient information for the public, Health News for each Local Authority area, regularly updates its web page and has a number of specific information leaflets about patient rights.

5.1.2 All Health Rights Information (HRIS) leaflets are printed and distributed by NHS Lothian. Documentation including the HRIS leaflets must also be locally relevant, produced and locally distributed. These costs are currently met by NHS Boards. It is difficult to calculate the costs to NHS Lothian to support and uphold patient rights in NHS Scotland – it is however not an insubstantial amount.

5.1.3 It is disappointing that the financial memorandum contains no new funding to geographic or service provision boards. Nor is it evident that there has been any detailed dialogue with Boards on what their costs base for the implementation of new patient rights. An example might be the implementation of the Carer Information Strategy to support carers’ rights, which the government funded to the sum of £9m for 3 years.

5.1.4 The financial memorandum sets out in paragraph 58 considerable investment, all of which is national for the next 3 years. At a time when there will be serious and significant pressures on NHS Board budgets, the case for legislation is debatable. There is however evidence that if such legislation is enacted then Boards will be involved in the service delivery and potential additional cost.

5.1.5 Even taking into account the significant sums for training, these programmes, as is stated, will work best when integrated and delivered into existing local training plans.

5.1.6 Paragraph 59 details £1.6m to NHS Education Scotland to develop materials and a workforce educational development plan. This investment, if focused on the totality of patient rights awareness and cultural competence, is to be welcomed. However if focused on only the parameters of the bill then a significant proportion of the money should be directed to Boards. Models of education delivery must be local and relevant and accessible to frontline staff.
5.1.7 Paragraph 66 states NES will develop and deliver a communication and awareness raising plan for staff. It is very much hoped this is lead by Directors of Communications and localised as far as possible. Furthermore, NHS Lothian’s Director of Communications along with all Directors of Communication must be involved in the public awareness raising.

5.1.8 Translations of leaflets should be produced and paid for nationally. Alignment of patient rights and HRIS within NHS Inform would be welcomed.

5.2 Support and Recourse

5.2.1 Complaints and Patient Advice Support Service (PASS)

5.2.1.1 NHS Lothian will be implementing systematic fast, frequent feedback from patients to improve quality of care. Large scale surveys have been shown to be of variable impact for localised improvement. Small scale, frequent, real time measures which frontline staff can act upon is the direction of travel for NHS Lothian. This, coupled with the considerable infrastructure on Quality Improvement Teams and a variety of patient focused audits to test person centred care are in place or being developed in NHS Lothian.

5.2.1.2 Paragraph 97 – Our modernised complaints function will have single point access where enquiries, comments and other requests for information by phone and web will be centralised. This new Hub will have ‘feeds’ from our website and be supported by call centre type technology. Giving patients and the public access to expert advisers in our system, who are able to instantly connect with services, advise on rights and solve problems is the benchmark standard NHS Lothian is aiming to achieve.

5.2.1.3 The current funding for IASS would appear to have benefited a very small proportion of people who complain, comment or raise a concern or enquiry – see para 5.2.1.10 below.

5.2.1.4 There is a significant question as to why, with an established and well regarded organisation as the CAB, the SGHD have decided to opt for procurement for a new national structure. An alternative could also be community health and voluntary organisations being commissioned by each Board under local service level agreements.

5.2.1.5 The vast majority of patient rights issues are dealt with by Boards. Independence becomes – and can be seen to be – an issue for a small proportion of complainants. Our complaints, patient liaison and other staff currently deliver advice and support to a high standard. Being in the ‘business’ supports effective, fast communication and resolution.
5.2.1.6 The ability of an external organisation, possibly a new PASS service provider, to become integrated in the health service is potentially problematic and bureaucratic. It is also noted that the SHC with an existing legislative duty on patient focus and a considerable budget was not asked to take on this PASS role.

5.2.1.7 Paragraph 106 and 110 describe the role of PASS as undertaking information and support on patient rights and responsibilities. Yet no patient responsibilities are detailed in the Bill. Currently most information and awareness on patient rights is undertaken by Boards.

5.2.1.8 Para 106 - Annual reporting to Boards is insufficient. PASS would need to establish very close and regular communication with the service. Otherwise people could become frustrated by an arms length independent service disconnected from Boards where the real influence and sorting of problems happens in reality. NHS Boards need to have this type of feedback as well as that from patient experience.

5.2.1.9 The Policy Memorandum states that there will be at least one Patient Rights Officer per Health Board while the Financial Memorandum in para 111 refers to the provision of around 40-50 new full-time equivalent Patient Rights Officers across Scotland. In para 114 however it states that total funding is expected to provide for 65-80 full time equivalents, when the current funding by Boards to the Independent Advice Service (IASS) provided by Citizens Advice Bureaux, is added to the proposed Scottish Administration funding of over £1,000,000 per year.

5.2.1.10 NHS Lothian funds the Independent Advice and Support Service (IASS) to the sum of £78,702, which currently supports people making complaints. This funds the 10 Citizen Advice Bureaux in the Lothians for initial advice on the complaints process before referral to an advice worker in more complex cases (approximately 15 per quarter). The Board is expected to make this sum available for the new service. This assumes that the current funding is value for money and given the current and future financial pressures that NHS services are facing it cannot be assumed that such sums available in the current year will continue. This support by 14 Boards together with funding from the Scottish Administration amounts to almost £2 million per annum. This seems a considerable expenditure for a service which in large part will actually be delivered by Boards.

5.2.1.11 Paragraph 112 talks of the 14 territorial Health Boards having commissioned IASS. NHS 24, Scottish Ambulance Service, the State Hospital, the Golden Jubilee all provides services to patients. It is not clear why these Boards were excluded.

5.2.1.12 It would also be helpful to know what the outputs were from the investment of £60,000 detailed in paragraph 115.
5.3 Advocacy (para 119) and Translation, Interpretation and Communication Support (TICS) (para 127)

5.3.1 Paragraphs 119 and 128 refer to funding to national organisations which do not provide frontline services. If the Bill is enacted the pressures, already considerable on both these budget areas will be added to with increased demand, but with no additional financial support to Boards. Already advocacy services, jointly commissioned with Local Authorities are being reviewed to ensure compliance with legal duties and national guidance.

5.3.2 For face to face interpretation services national contracts are unlikely to demonstrate cost benefits, but national translation procurement may. This therefore is to be welcomed as is a move to reducing costs for phone interpretation and other “e” or IT enabled solutions. The TICS strategy mentioned in the memorandum has not formally been adopted nor agreed by all Boards in Scotland.

5.3.3 Further investment to Boards for service provision to meet growing need would be preferred to additional national funding.

5.3.4 The role of Better Together is set out in paragraph 136. We understand this programme was established for 3 years to March 2011. We would however welcome more detailed discussions on audit tools which service providers could use to audit patient rights compliance currently and for the Bill.

In Conclusion

It is of concern that all the additional funding will go to national bodies. While in local service delivery Boards will face the costs of implementation:

- Heightened awareness
- Localised and additional information
- Workload pressures on enquiries and complaints teams and PFPI resources in general
- Potential demands on TICS and advocacy services

In NHS Lothian we believe that patient support is most effective when local, efficient and focused on resolution by informed caring staff. Very small numbers of people currently access IASS in Lothian and other models of local developments could be considered.

Melanie Hornett
Nurse Director
NHS Lothian
13 May 2010
Patient Rights (Scotland) Bill: Stage 1

10:03

The Convener: The next item is our final oral evidence-taking session on the Patient Rights (Scotland) Bill. We will hear evidence from two panels of witnesses, the first of which comprises representatives from the health boards that responded with written submissions to the committee’s call for evidence. I welcome to the meeting Jacqueline Richardson, patient focus and relations manager with the NHS Forth Valley PFPI steering group, and Melanie Hornett, nurse director at NHS Lothian.

We will move straight to members’ questions.

Ross Finnie (West of Scotland) (LD): Good morning. I thank the witnesses for their written submissions. In the second paragraph of its submission, NHS Forth Valley welcomes the bill, saying that it “was thought to be ‘sensible and achievable’”, while NHS Lothian, in generally welcoming the bill, notes however that it “is not enforceable”. None of the witnesses who have given evidence on the bill to the committee over the past few weeks has thought that patients should not have rights. Why do you think that it is better to put such rights in an act of Parliament when, as one of you has expressly noted, the legislation “is not enforceable”? What difference will the bill make? It is, of course, good to set out the rights in a single format that every patient can access and understand, but what in your opinion is the benefit of putting them into an act of Parliament that will not be enforceable?

Jacqueline Richardson (NHS Forth Valley): We on the PFPI steering group feel that the bill goes beyond and builds upon existing legislation. The issue is not just complaints or waiting time targets but the fundamental delivery of care. Much as we talk about being patient centred and providing patient-focused care—on which, I should say, we have made huge leaps—we still have a long way to go. In any case, it is important to underpin the fundamental principles of care in legislation.

Ross Finnie: But how does that affect the patient if the legislation cannot be enforced? I am not suggesting that it would not be helpful to have these rights written down or clearly articulated on a single piece of paper, but what is the advantage of their being set out in law when you cannot enforce that law?

Jacqueline Richardson: The focus group members found the issue challenging, but in our...
conversations we made it clear that we did not want a lawyer at every bedside. This is not about being adversarial in getting feedback but about giving boards the direction that being patient focused and patient centred is a need-to-do rather than a nice-to-do.

**Ross Finnie:** Could you not do that in other ways?

**Jacqueline Richardson:** You could do it through guidance, but that would be about saying what you would like to do or what you could do. For me, the bill enforces patient-centredness as the fundamental principle of care.

**Melanie Hornett (NHS Lothian):** I recognise the importance of patients’ rights, and putting them into legislation might have the benefit of allowing patients and the public to understand a little more the seriousness with which the Government and health boards take them. However, the rights that are set out in the bill are, by and large, already in place as a result of Government direction, guidance and strategies. For example, patient-centredness is an element of the new quality strategy that boards are all enthusiastic about implementing and using. Because of the lack of enforcement, I am not certain about the bill’s absolute benefit.

**Ross Finnie:** That is helpful.

**The Convener:** Before we move on, I said that Ms Richardson was representing the PFPI steering group. We get that PF means patient focus, but we are a bit bemused by the PI bit. What does that mean?

**Jacqueline Richardson:** Public involvement.

**The Convener:** Now we are all happy.

**Mary Scanlon (Highlands and Islands) (Con):** NHS Forth Valley’s submission refers to “positive” comments and says that the bill is “sensible and achievable”. I want to explore the treatment time guarantee, which, given that it takes up almost a third of the bill, must be seen as its central focus. I should also add that the guarantee does not apply to patients with mental health issues, so it appears that we have a bill on patient rights in which certain patients have more rights and others have none.

Having had that rant, I point out that under the bill a health board that breaches the treatment time guarantee

“must ... ensure that the agreed treatment starts at the next available opportunity, ... provide an explanation to the patient as to why the treatment did not start”

and

“give the patient details of ... advice and support”

including

“how to complain.”

Are those provisions not already in place? Why do we need a bill that does something that is already being done, or is it actually doing more than I think it is doing?

**Melanie Hornett:** Those measures are in place already. We work hard to meet the 18-week referral-to-treatment time and the stretch target under that of treating patients within nine weeks. Should we fail to achieve those targets—we fail for a small number of patients—we do exactly what you described. We offer such patients alternative dates as soon as possible, apologise and explain how they could seek further information or complain. That is nothing new.

Different waiting times for different matters and different targets could create confusion. As you say, the important point is that the focus is on acute and elective in-patient day-case care, which leaves large sections of patients and their treatments uncovered by the bill.

**Mary Scanlon:** I will move on to exclusions. Mental health services and diagnostic tests are not included in the treatment time guarantee. Until a person has a diagnostic test, they do not have a diagnosis, so they cannot be referred for treatment. Could a longer time be taken for the diagnostic test to manipulate the treatment time guarantee? If the time for the test was extended, that would allow more time for treatment. Are you concerned that diagnostic tests are excluded? The treatment time guarantee is fairly meaningless until a test has been conducted. Should tests such as X-rays be excluded?

**Melanie Hornett:** All the work that has been done for the 18-week referral-to-treatment time means that considerable work has been done on examining the times that people wait for diagnostic tests. To be able to refer and treat someone within 18 weeks, diagnostic tests must have been undertaken. Of course, people do not need diagnostic tests just because they will have an operation; general practitioners might refer people for tests. For all patients, a short waiting time for diagnostic tests is important. The work that has been done means that the timescales are much shorter than they used to be. I am sorry that I cannot cite an example of that, but the point is important.

**Mary Scanlon:** The point is very important. When a GP refers a patient for a diagnostic test, it could take 20 weeks, after which the patient could suddenly have a treatment time guarantee for treatment of one week. That is a serious point.

The Scottish Public Services Ombudsman knows a wee bit more than most of us about patients’ rights and responsibilities. His submission says:
“With the exception of the treatment time guarantee, the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist.”

I do not understand why we are scrutinising a bill that gives patients not one additional iota of rights. Has the ombudsman got that wrong? Does the bill contain anything that will enhance patients’ rights?

Jacqueline Richardson: I would not say that the ombudsman is wrong.

The Convener: Do not be frightened to say that, although I am not tempting you to do so.

Jacqueline Richardson: The bill is subtle. As I tried to say, it is not just about patients’ rights to complain and to have treatment at a certain time. I am aware of no other legislation that defines the principles and puts patients at the heart of care delivery. That is the most important part of the bill.

Mary Scanlon: Do we really need legislation for that? Is that not part of what health professionals do every day?

Jacqueline Richardson: What is described is what health professionals would like to think that they do every day, and it is what they endeavour to do every day, but I am not convinced that we have gone far enough to make that happen and that we have truly achieved mutuality in all aspects of health care.

Mary Scanlon: I am struggling to understand and find a justification for the bill. If the bill is passed, what will the average nurse in the average ward, who perhaps does not do as much as she should to meet patients’ rights, do that she does not do now?

10:15

Jacqueline Richardson: I am not sure that the bill alone will change the culture of the health service, but it definitely sets the tone that this must happen. Of course, it would have to be underpinned by staff training and by information that was readily available and easy for the public to understand.

Mary Scanlon: Sorry, convener—I ask you to bear with me. Jacqueline Richardson said “this must happen”. What must happen?

Jacqueline Richardson: It is about changing the culture to a certain extent and the understanding of patients’ involvement in their care and their decision making about their care. We can say that that happens, but we know from complaints and from patient feedback that we do not achieve 100 per cent success.

Melanie Hornett: I agree with the SPSO. It is not about legislation; it is about quality of care. As I said, the quality strategy has been favourably received. It is about achieving a culture change, education, training and things that you cannot legislate for. In NHS Lothian, we have found that work that we are doing around compassionate care with Edinburgh Napier University has been significant in changing the way that staff work together with patients. It is about putting the patient at the centre of all aspects of their care and treatment. That programme, which is much more in depth and in some ways much more sophisticated, is bringing about change, whereas the legislation will give us a legal position on the matter but it will not necessarily make people think about their own practice and how they interact with patients day to day.

The Convener: I will let Rhoda Grant in with a supplementary before Mary Scanlon asks another question.

Rhoda Grant (Highlands and Islands) (Lab): It is okay. The matter has been dealt with.

Mary Scanlon: My final point is that we have quite a few student nurses in the audience today, and I imagine that they are attracted to the profession because they are committed to looking after patients. I do not imagine that when they graduate any of them will seek out the Patient Rights (Scotland) Bill to gain an understanding of how to care; I imagine that everyone of them wants to care already.

The Convener: That was not a question.

Mary Scanlon: No, it was not, but it was worth saying.

The Convener: It was evidence.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): We seem to have made significant advances in the past 10 years. Melanie Hornett described what is going on in Lothian, where I worked for four years and was certainly conscious of the efforts that were being made.

One of my concerns about the bill is not that it is not worthy—it is extremely worthy—but that it is damaging to patients’ rights, because it changes, for example, the right of the patient to consent to or refuse treatment to

“allow and encourage the patient to participate as fully as possible”.

That change in the language is understandable in the sense that we are trying to encourage mutuality, but it is not helpful.

On equality and respect for their needs, patients have a right not to be discriminated against on the grounds of race or other equality issues, but the bill just refers to having regard to

“The patient’s abilities, characteristics and circumstances”.

“I am not tempted, you to do so.”
Human rights legislation is not mentioned in the bill, which just says that it is necessary to “have regard to” the need to treat a patient with dignity and respect and to “have regard to” the need to respect privacy and confidentiality. Apart from the bill not mentioning human rights, except in that way, it reduces those rights. There is a right under NHS legislation to be supported by a family member, friend or carer, but the bill simply says that it is necessary to “have regard to” the need to provide support, and so on.

My concern is not only that the bill does not help, but that it does not encompass all the rights that patients have. The Law Society’s supplementary submission lists nine or 10 rights that are not even mentioned in the bill. Jacqueline Richardson referred to the bill being “sensible and achievable” and Melanie Hornett also made some comments. Would they like to comment on that aspect of the bill?

The Convener: My only point by way of observation on what you said on human rights, Richard, is that all bills that are lodged in the Parliament must, according to the Presiding Officer, be compliant with the European convention on human rights. I accept your phraseology, but—

Dr Simpson: You are absolutely right, convener. I was saying not that the bill is not compliant but that, if the purpose is—as the witnesses said—to enshrine, enforce and promote patient rights, the fact is that substantial numbers of rights are not referred to in the bill. The implication is therefore that the rights in the bill are greater than other rights. When I was drawing up legislation as a minister, the matter was referred to constantly—

The Convener: I was just correcting you from the point of view of—

Dr Simpson: I accept that the legal position is not altered, but we are not talking about that. The witnesses have said that the bill is worthy and will improve rights that they promote already. My point is that that is being done in a discriminatory way, as Mary Scanlon described—I will come to that in a minute—and that, by neither emphasising nor listing the other rights in the bill, the effect is not to promote but to demote them.

The Convener: I wish that I had not said what I said; we are getting more evidence. I simply wanted to make it plain that while your point is perfectly valid, all bills need to be ECHR compliant.

Now I have lost the question. Do we remember what it was?

Ian McKee (Lothians) (SNP): It was: do the witnesses agree with him?

Dr Simpson: No, it was not that. The question is whether the bill promotes all patient rights or whether it discriminates between different types of rights.

Melanie Hornett: I agree that the bill does not demonstrate all the rights that patients have at the moment. The information from the Law Society of Scotland was helpful in that regard. In our submission, in thinking of education and development, we said that, if the bill were to go ahead, we would welcome investment for the totality of patient rights as that would be helpful to the public and patients. We also said that it would not be so helpful to focus only on the rights that are enshrined in the bill, as people might think that those rights excluded other rights. We know how difficult it is to share with people some of the complex messages that are in the bill. We need to be very clear on the matter.

Dr Simpson: My second question is on the patient rights officer, the patient advice and support service and the existing independent advice and support service. I have read your submissions. Do you think that IASS should be strengthened and improved—even given the new set-up—or should the new set-up be a complete substitute for IASS? In other words, is the money totally new? Will the new set-up do the job that IASS does? What problems might arise from close association with health boards, which contrasts with the present independent citizens advice bureau-run service?

Jacqueline Richardson: Having worked closely with IASS and having had feedback from patients and the public on it, I can say that IASS has been a very positive service, although I am not sure that it has been consistent nationally. Some boards have had a very positive experience, whereas the experience of other boards has not been quite so positive. Having a national system with a national framework, agreed standards for practice and agreed outcomes would benefit the service. From discussions with our public members, I understand that patient rights officers will build on the existing service and the good practice that has been achieved.

Melanie Hornett: Citizens advice bureaux are well-known institutions; people understand what they do and how they can help them. It has been helpful to have IASS working in the CAB network. When people go to a CAB to seek help, they can solve more than one problem at a time. Individual experience of the IASS is largely positive, albeit that the number of people who have accessed it has been small. That brings into question IASS’s value for money. There would be benefit from evaluating and enhancing that, as opposed to trying to start up something completely new from scratch. There must be things that we could learn.
from the work of IASS that we could use to strengthen the service.

**Dr Simpson:** I understand your argument for consistency, but could that be achieved just as easily and without the cost of all the new officers by taking IASS into a national contract? A service-level agreement with Citizens Advice Scotland that was delivered locally would retain the independence, allow for national audit and ensure consistency, but not rip things up. I ask that in light of the fact—I wonder whether the witnesses are aware of it—that funding for at least half the services that are provided by IASS has been cut this year. Will the witnesses comment on that?

**The Convener:** The role of patient rights officers differs from that of IASS, does it not? I ask you to clarify that, because I might have got that wrong.

**Jacqueline Richardson:** I understand that we are talking about an enhanced role and that patient rights officers will support patients to exercise their rights and responsibilities, whereas IASS focuses mainly on supporting people who wish to raise concerns with the health service. However, as IASS sits in citizens advice bureaux, our patient panel members feel strongly that it is almost a one-stop shop, such that people who have concerns about not only their health care but their housing or other benefits can go to one point of contact and be signposted quickly.

**The Convener:** That is what I want to be made clear. Is one a signposting service whereas the other gives people advice and advocacy? I am not clear about that.

**Dr Simpson:** That description is not right.

**The Convener:** That is why I am asking for clarification from the witnesses. The jobs are not the same—or are they? I understand that one job involves signposting. Patient rights officers will say, “You go here for your advice.” Is IASS exactly the same?

**Jacqueline Richardson:** IASS is a signposting service; it does not have an advocacy role. Its role is to provide advice and support.

**The Convener:** Is that correct, Ms Hornett?

**Melanie Hornett:** Yes, as far as I understand it. The support depends on the case—it is different for different individuals—but a support function is present.

**The Convener:** I am sorry—I interrupted Richard Simpson’s question about funding.

**Dr Simpson:** Implementing the bill will cost £6 million in the first three years. In the current climate, will that money be well spent? Apart from signposting, what additional services will the bill give us?

**Melanie Hornett:** I am not certain about that in many respects, given the financial climate and given that existing services could be enhanced and that boards could work to improve their structures to enhance signposting functions for people.

Most of the time, patients who have concerns or complaints want the situation to be fixed there and then by the people who are present. If that cannot be done, patients want to be told that, to have an apology and to have the problem fixed as soon as possible. When issues become complicated, patients want an objective view, for which the ombudsman provides excellent services.

I am not certain that all the extra infrastructure will help patients or members of the public. The bill will establish a layer of administrative services for the NHS to deal with—we will need to consider how we work with patient rights officers and how we ensure that there is communication, which will be needed if we are to help with issues that arise.

**The Convener:** I am sorry to return to the distinction between patient rights officers and IASS—I am nibbling away at that. NHS Forth Valley’s submission says that patients

“suggested that IASS is able to act as a ‘one stop shop’ for those needing advice with benefits and housing as well as health issues.”

So IASS gives out advice, whereas

“people would have to speak to the PRO for health issues but still have to go to the Citizens Advice Bureaux for other advice.”

That means that the roles are different—I was trying to get at that. The issue is not just that IASS is lumpy or inconsistent throughout the nation, as we have heard in evidence; it is that a distinction exists between the two roles.

**Dr Simpson:** Convener, I am sorry to interrupt you, but the second function of PASS and its PROs in paragraph 45 of the policy memorandum is to

“provide advice and support for patients”.

PASS will signpost services and provide advice, so it will duplicate IASS.

**Melanie Hornett:** I am not certain about that in many respects, given the financial climate and given that existing services could be enhanced and that boards could work to improve their structures to enhance signposting functions for people.

10:30

**The Convener:** I accept what you say about the policy memorandum, Richard. Notwithstanding that, the witness agreed with you that they did the same thing and, given that her written evidence does not say that, I am simply asking whether she still stands by her submission. Do you agree that there is a distinction between your written submission and the oral evidence that you are giving this morning?
Jacqueline Richardson: Our written evidence probably reflects the fact that the public are not clear about the patient rights officer’s role. I do not think that any of us is. We are confident that we know what IASS does, but we are not quite sure what the difference will be.

The Convener: I am sure that in her evidence the cabinet secretary will clarify things for Dr Simpson and me.

Ian McKee: You might be relieved to learn that I am not going to rehearse my stage 1 speech, convener.

This is not a trick question—I am simply not familiar with her role—but I wonder whether Jacqueline Richardson will explain the mechanism for selecting and electing the people on her group. How are you and your colleagues chosen to represent the public voice?

Jacqueline Richardson: There was no election. My role as an operational lead for patient focus and public involvement in NHS Forth Valley is a paid post, but I have a number of other jobs and other issues on which I take the lead. Because this was a bill on patient rights, we chose not just to respond as a board but to involve our network of patient and public partners in developing our response to your call for evidence.

Ian McKee: So you are an arm of the board.

Jacqueline Richardson: I am employed by the board.

Ian McKee: That is helpful.

I suppose that my next question, on the treatment time guarantee, is more for Melanie Hornett. It has been suggested in evidence that there could be a risk of managerial imperatives altering clinical imperatives slightly. For example, if a load of people needed ingrowing toenail operations and the 12-week deadline was coming up, you might have a whole list of those treatments and put back someone with a more serious condition who had been on the waiting list for only three weeks. Is such a worry realistic or simply hypothetical?

Melanie Hornett: Patients and clinical staff might well have such a worry, and the health board would want to ensure that patients were dealt with according to clinical need and prioritised according to their illness or the treatment required. That is not to say that a significant amount of work does not go into managing waiting lists and ensuring that people keep moving through in a timely way.

In reality, there is not a huge risk that all the ingrowing toenails would suddenly be operated on and that all the aneurysms and cancers would be put back. Most of our current waiting time targets—for accident and emergency and cancer, for example—have a degree of flexibility; we are not expected to hit 100 per cent all the time in recognition of the fact that with certain clinical conditions the target will not be met and the patient will have to be dealt with differently. In other words, there are opportunities within the targets to manage things. On the ground, the clinical priorities take the overriding position.

Ian McKee: And management accepts that.

Melanie Hornett: Yes. Although we are managers, we also care for and look after patients. Indeed, many of us have clinical backgrounds. One of the other submissions referred to gaming, but we would not want to do that.

Ian McKee: I am not exactly certain what gaming is, I have to say.

Melanie Hornett: I think that it goes back to your point about manipulating the waiting list in some way to achieve the target by not treating patients according to their clinical requirements. I certainly would not want that to happen.

Ian McKee: When certain targets were set for people to be seen at A and E, some areas developed the welcome nurse function. Someone would simply see the patient and say hello, which not only allowed the target for the time between someone entering the hospital building and seeing a professional to be met but meant that treatment could be delayed. It has been suggested that the treatment time guarantee, which I believe starts from the moment the clinician and the patient agree on a form of treatment, could be slightly manipulated if clinical staff were instructed not to agree at a certain point that a certain treatment was necessary. Is that a possible risk?

Melanie Hornett: Your colleague mentioned that earlier, but I do not know who you think is going to instruct clinicians to manipulate things in that way. I am sure that if we tried to do so we would get very short shrift. No matter what professional group they belong to, our clinical staff adhere to their own codes of conduct and regulations and I am sure that they see those as overriding any such instruction that a manager might give.

Ian McKee: That is reassuring.

How do health boards intend the provision to apply in primary care, where more and more procedures are taking place? For example, I know of primary care practices that carry out vasectomies: indeed, with the skill that is available in primary care, many more operations that were done in hospitals are now being carried out in such settings. However, most primary care practitioners are agents for rather than employees of the board. Does the bill contain any mechanism
that would allow what is going on in primary care to be supervised on your behalf?

Melanie Hornett: As yet there is no such mechanism. As I said earlier, one of our concerns about the bill is that it focuses on acute in-patient elective care and does not cover the huge area that you have described or the area of mental health. NHS Lothian has its own mental health targets, for example, and is managing to deliver them in line with the current targets for other forms of care. Such a mechanism could be put in place, but we have yet to try it with primary care. However, a huge issue for patients and the public is waiting times that are not seen.

Ian McKee: Although I accept that the bill does not cover mental health issues—and that that will be a matter for discussion—it is my understanding that it covers the other operations that I have mentioned. Although they are done on your behalf, if they were carried out in secondary care they would certainly be covered by the waiting time target.

Melanie Hornett: That would depend on who was carrying out the operation, where it was being carried out and how things were working. As you know, different circumstances apply. Although the bill would cover day-case surgery carried out in community hospitals, for example, it would not cover other treatments such as physiotherapy that people might need. That is a concern.

Ian McKee: But, in NHS Lothian’s opinion, if a GP offered to remove a sebaceous cyst, carry out a vasectomy or whatever, would the procedure be covered by the bill?

Melanie Hornett: To be honest, I cannot answer that. I am simply not certain how we would deal with that situation. However, I am happy to consider it and come back to you.

The Convener: I realise how difficult it is to give evidence before a committee, so if you have any information to add on that or any other question, you can send it to us in writing and we will look at it in considering our stage 1 report.

I suspend briefly to allow a change of witnesses.

10:38

Meeting suspended.

10:39

On resuming—

The Convener: I welcome to the meeting Nicola Sturgeon, the Cabinet Secretary for Health and Wellbeing; Lauren Murdoch, bill team leader, and Kathleen Preston, health and community care solicitor with the Scottish Government legal directorate. So little time has elapsed since we last met, cabinet secretary, that I am tempted to talk about déjà vu or to say welcome back. I understand that you wish to make a brief opening statement.

The Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): Thank you, convener. I am very pleased to be giving evidence on the Patient Rights (Scotland) Bill, which I believe to be an important piece of legislation that gives life and meaning to the principle of a patient-focused mutual NHS. It is about raising the status and profile of patients’ rights and clarifying both those rights and health boards’ duties with regard to the manner in which patients are treated—by which I mean, of course, treatment in its broadest sense, not just clinical treatment. In short, the bill seeks to change the health service’s culture and dynamics and, if you like, to level the playing field in the relationship between the patient and the NHS.

I know that we will go into more detail about these matters, but at this point I wish to address a number of concerns that have been raised, the first of which is that the bill does not create any new rights. That is not the case: the bill creates the right to complain and establishes the treatment time guarantee. However, it is true that a variety of rights already exist and that we already expect health boards to treat patients in line with certain key principles. In many cases, that is what happens, and I know that boards work very hard at providing patient-centred care.

That said, the existing rights come from disparate sources, are not clearly understood and often relate to very specific matters, such as access to records, rather than to the very essence of the relationship between the patient and the health service. Of course, expecting or hoping that health boards will treat patients in a particular manner is not the same as putting them under a clear duty to do so.

The second concern that has been raised is that the bill contains no right of redress. I admit that it does not give patients an additional right to go to court, but it does not remove patients’ existing rights in that or any other regard. Of course, that is not the same as saying that there is no right of redress. The bill provides, for the first time, a legal right to complain, which is very important for reasons that we will no doubt discuss later, and to give feedback and—crucially, in my view—it puts boards under a duty to learn lessons from complaints. It also lays out the steps that boards are required to take in relation to the treatment time guarantee.

In some respects, the debate about redress misses the bill’s point. Fundamentally, the bill is not about adding to existing methods of redress to
deal with situations that go wrong or do not go as patients might expect—although I point out that it does strengthen them—but is about changing the health service’s culture and dynamics and the way in which patients are treated in order to raise satisfaction levels and minimise the chances of things going wrong.

My passion—I use that word deliberately—for the bill comes directly from my three and a half years’ experience as health secretary. Like everyone else around the table, I am a big advocate of the health service and know how hard it works to deliver patient-centred care, but I have been struck by the fact that—ironically and perversely—patients’ loyalty to and high regard for the health service mean that sometimes they accept things that should not be accepted. I often speak to patients who feel that making a complaint is somehow disloyal to the health service and those who work in it, or that it might affect their future care or might not make a difference. I have spoken to patients who, because they receive very good clinical care, feel that they should not raise issues about not being listened to or not being treated with the dignity that they deserve.

Although the bill provides immediate legal rights, it is also concerned with changing the health service’s culture in the longer term—indeed, with continuing the culture change that I believe is already under way—and ensuring a more level playing field between the patient and the bureaucracy and big organisation that is the health service.

That is all I wish to say by way of introduction. I am, of course, happy to answer members’ questions.

10:45

Ross Finnie: Thank you, cabinet secretary. That was helpful. In taking all that you said at face value, I say that you nevertheless raise an important matter of principle—and we are talking about the principles of the bill. I do not doubt in any way your passion for the health service, which has been evident in the way in which you have discharged your duties as a minister, nor do I doubt the need for patients to be clear about their rights.

However, the principle that you are introducing and the inference that I think you allow to be drawn is that, unless a Government measure that needs to be given life and meaning, that needs status and focus and which is going to change the colour of something, is set out in statute rather than by direction or in a policy document, it will be ineffective. If you are right, that has clear ramifications for the future, because we will be entitled to infer that policy documents and directions are to be regarded as being of a much lower order. That is the bit with which I have real difficulty.

You received many responses that suggested that people do not want a lawyer at every bedside. You could have elected to interpret that as meaning that the respondents did not wish primary legislation, but instead you have elected to introduce primary legislation and, at the same time, in section 18, effectively to emasculate the most obvious ways of enforcing it.

I invite you to explain to us the principle that, in the future, measures that are not set out in primary legislation from your Government are not to be regarded as being capable of delivering anything meaningful.

Nicola Sturgeon: I will take on all those points. They are important points of principle and—dare I say it—philosophy.

I do not take the view that no measure is meaningful or effective unless it is in primary legislation. This Government, previous Governments and future Governments have done and will do many things by means other than primary legislation. That is right and proper, but some measures are of such import that they should be in primary legislation. Their being in primary legislation raises their importance and meaning as a matter of fact and law, as well as through the message that it sends. The clarifying of, and the giving of status to, certain key rights that patients have that are highly pertinent to their relationship with the health service falls into that category.

However, that is not all that primary legislation does; there is hard import to it as well. At the end of my answer, I will come back to that point.

On whether people saying that they do not want a lawyer at every bedside means that they do not want primary legislation, I will be as reasonable and as open as possible in my answer. I dare say that for some people—perhaps Ross Finnie is one of them—that is what that comment meant. However, other people, including some who have given oral evidence to the committee, interpret it differently: they do not want additional rights for patients to go to court, but nevertheless agree that putting patients’ rights in primary legislation is very important for effecting the change about which I am talking.

Therefore, we cannot say that somebody saying that they do not want the proverbial lawyer by the bedside translates in all cases into meaning that they do not want the rights in primary legislation. It is interesting that those who tend to focus on the lack of enforceability also say that they do not want the lawyer by the bedside.
On the third and final part of Ross Finnie’s question, I take issue—not in any confrontational sense—with the suggestion that section 18 emasculates the bill. It does not do that; it says that nothing in the bill gives rise to the ability of patients to sue for damages. I will not quote the section in full, because members have it in front of them.

The point that I was trying to make in my opening remarks is that that is not to say that the rights that are in the bill have no import and no effect. For the first time patients will have a legal right to complain but, more than that, if the bill is passed, boards will be under a legal duty to do certain things in response to complaints to ensure that the complaints process is not just a process that allows patients to let off steam or vent their opinions but that it becomes a dynamic part of the improvement process in the health service. That is a very important consequence of that particular right in the bill, because it means that when health care is being delivered, boards are required to have regard to particular principles. We do not just hope that they do—they are required to do so and, if they do not, patients have that as a basis for complaint and, if the complaint is upheld, change and improvement has to happen. Boards have to take specific steps around the treatment time guarantee to ensure that it is delivered and, in cases when it is not delivered, they have to do certain things in consequence of that. These are hard rights with hard consequences.

I make the point that the bill is, in addition, about something bigger; it is about changing, in a positive way, the culture of the health service and the dynamics between the patient and the health service. More than anything else, that is what, for me, brings to life what I know we all feel strongly about, which is the mutuality principle: the idea of a patient as a partner in, not just a user of, a service.

Ross Finnie: Cabinet secretary, when your bill team was before us I asked Kathleen Preston about the right to complain. She answered by referring to section 1(3), which states that

“It is the right of every patient to make complaints”. I asked whether that was a new right and she responded by saying that

“It will be the first time that the right has been set out in primary legislation.”

I went on to ask whether the document produced by the health rights information Scotland initiative should have had the caveat that, although it tells patients that they have a right to complain, actually, they do not. Kathleen Preston replied:

“No, that is not what I am saying.”

I asked whether, in that case, we already had the right to complain and Kathleen Preston answered:

“I am saying that it will be the first time that the right has been put ... in primary legislation.”—[Official Report, Health and Sport Committee, 8 September 2010; c 3245.]

There seemed to be some confusion about whether we already have a right to complain but have not been able to complain. Your bill team suggests that we already have that right. Can you respond to that point?

Nicola Sturgeon: I can. With the greatest respect to Ross Finnie, I do not think that there is confusion. Patients can complain: complaints systems are set up in health boards and patients can and do complain, but they do not currently have a statutory right to complain. You may say that that will not make much practical difference, but it will make a difference in the case of the anecdotal patient who says either “I don’t really like to complain, because I don’t think it’s fair because the staff work really hard and it’s not their fault”, or “If I complain, it will not make a difference”, or “If I complain, it might mean that in the future my care might not be as good—maybe there will be repercussions.” It is important to be able to say that making a complaint is not just something that patients can do, but something that they, as patients, have a right to do.

For me, the more important part of the bill in respect of the right to complain is the duty that it puts on health boards in relation to what they have to do to respond to complaints. You might say to me that good health boards—I think that most health boards, at most times, are good—should do that anyway; they should take complaints and learn from them.

I make it a practice when I chair the annual reviews of health boards always to ask them, “How do you respond to complaints? How do you ensure that you use them as part of the learning process?” It is good practice that they do that.

The bill makes it clear that the complaints process has a point. Boards must monitor and consider how they learn from complaints and must make improvements as a result. That is important, because it allows people to look a patient in the eye and say, “Not only do you have the right to complain, but you can make a difference by complaining, because your complaint—you raising what did not go right for you—will minimise the chances of that happening to somebody else in the future.” For those reasons, an important difference exists.

Ross Finnie: Notwithstanding that, people who believe equally passionately, I suspect, in the delivery of health care—including the witness this morning from NHS Lothian, the British Medical Association, the Royal College of Nursing, the
Royal College of General Practitioners, Unison, which represents some NHS workers, the Scottish Public Services Ombudsman, who has duties in relation to patients’ rights, and Consumer Focus Scotland—all expressed the clear view that the bill is unnecessary. I do not wish to miscall the Law Society of Scotland, but it is perhaps not as impressed about the health service. However, it certainly has an interest in good law, and it suggested not only that the bill is not needed but that it might diminish existing rights. How do you respond to that?

Nicola Sturgeon: Your question had different parts; I will try not to forget any of them. Like you, I will not miscall the Law Society. I suspect that, if there is an organisation in the country that would quite like a lawyer at every bedside, maybe it is—

Ross Finnie: I inadvertently put that point and received a tart response from the Law Society.

Nicola Sturgeon: I am sure that the Law Society would deny the point vigorously. The law is the convener’s former profession and mine—it could be our future profession; that depends on the whims of the electorate—so we should probably say no more about that.

It is interesting that, although Ross Finnie has quoted health boards, doctors’ organisations and unions, he has not quoted the many patient-focused bodies that are enthusiastic about the bill.

Ross Finnie: I referred to Consumer Focus.

Nicola Sturgeon: I am talking about patient-focused bodies. Consumer Focus has a wider remit and does good work on the whole public service agenda for consumers.

I do not criticise in any way health boards, the BMA, the RCN or Unison—I have nothing but admiration for the way in which NHS staff do their incredibly difficult jobs and for the way in which health boards deliver the health service. However, it is not surprising that those who run and those who use the service might express disparate views about a bill that is directly about changing the balance of the relationship between those who run and those who use the health service and about levelling the playing field.

I have listened carefully to views and I will continue to listen throughout stage 1. I will pay lots of attention to the committee’s stage 1 report in considering whether we can improve or strengthen the bill. The bill is unashamedly about strengthening patients’ position in the health service. I make no apology for that.

Ross Finnie: I will ask my final question. I do not dissent from your wish to elevate patients’ rights. My disagreement is not with that but with the use of primary legislation as a matter of principle.

Your department has produced documentation in developing and setting out patients’ rights. Could you achieve the same aim by setting out the rights in a single document and publishing that by way of direction, under the powers that are open to you in the National Health Service (Scotland) Act 1978?

Nicola Sturgeon: I can do many things under the 1978 act. If you ask whether what you propose would be an equally good or better way of achieving not just the immediate change but the longer-term culture change that I want to bring about, the answer is no—that would not be as desirable a way of doing it.

The Convener: Shall I tick you off my list, Richard?

Dr Simpson: No.

The Convener: I see you deleting questions.

Dr Simpson: Perhaps I could ask a supplementary, as Ross Finnie has asked one of my main questions.

The Convener: That would mean going in front of your colleague Helen Eadie, who is next on my list. That can be done only with her consent.

11:00

Helen Eadie (Dunfermline East) (Lab): Okay.

Dr Simpson: One of the concerns that has been raised is that, by emphasising and strengthening certain rights, such as the right to complain—which the cabinet secretary has majored in today—the bill suggests a variation in rights from other rights that are either given by direction or enshrined in law. Examples are discrimination—which is in primary legislation—confidentiality and patient consent, and the right to be supported by family members. The Law Society says that all those rights are already covered, and is concerned that by emphasising some rights over others, there is going to be discrimination. We will come to the areas of health later, which my colleagues have been looking at.

Did you look very carefully at the English “NHS Constitution” as an approach? It lays out 29 rights very clearly in approximately two pages, and it includes the specific right to medicine under the National Institute for Health and Clinical Excellence. We do not have that specific right in Scotland, and it is not included in the bill. In no way do I doubt your good intentions in introducing the bill, but I feel that it will not help patients in the way you expect it to. A constitution or charter for patients that has the force of direction from your office, and the energy behind it to make sure that patient rights are properly promoted, will achieve what you are seeking to achieve.
Nicola Sturgeon: We did look carefully at the “NHS Constitution” and the legal underpinning for that in England. We also considered practice in Australia and other countries. We are not alone in giving a legal underpinning to patient rights; it is an international trend and I happen to think that it is important.

We decided that we want a set of rights in primary legislation that are about the manner in which patients could expect to be treated rather than about specific individual rights. We also decided that we do not want the bill to repeat a plethora of existing individual rights. The bill is clear that it does not affect any existing rights.

I have read carefully some views that the bill should contain something that shows that other rights are given elsewhere. I will listen to all that and make a judgment on it. Of course, it is open to anyone to suggest that particular provisions should be added to the bill. However, to go back to my earlier point about changing the culture and dynamics of the patient relationship and levelling the playing field, we came to the conclusion that the bill should be about the manner in which patients are treated rather than their specific rights.

Dr Simpson made a point about NICE, and one of its principles is that patients should be treated in line with current clinical guidance, which would include, for example, Scottish Medicines Consortium directions. That is the thinking behind our approach.

It is important to clear up two things, although I think that I have already cleared up one of them. The bill will not remove any existing rights. I have heard some people say that it will, but it will not. I am not saying that Richard Simpson has said that, but I have heard others say so. The second point is—I think that I meant to make one point. I have forgotten what my second point was. If it comes back to me, convener, I will be sure to make it later.

The Convener: It has been a long week for all of us.

Dr Simpson: Thank you for allowing me in to ask my question, convener.

The Convener: It was your colleague, Helen Eadie. She has been so gracious and she is coming in now.

Helen Eadie: As Ross Finnie said, and as I know from my time on the Health and Sport Committee, you are very committed, cabinet secretary; I do not demur from that point of view. I admire much of the commitment that your work shows, although I do not always agree with your policy decisions at the end of the day.

Nicola Sturgeon: It is okay, I have noted what you have said.

The Convener: There is a “but” coming.

Helen Eadie: I will try to avoid using the word “but” now that you have said that. However—[Laughter.] Among all the submissions that we have received, the points that the Law Society of Scotland raised are compelling.

Cabinet secretary, I heard you say that the outcome of the bill will be to give patients additional rights. I have been an MSP for approaching 12 years and I am lucky to have a fairly sophisticated means of measuring the cases that come into my constituency office. Of all the concerns that I receive, housing is at the top of the tree, followed quickly by health. I have had to deal with some—in fact, probably many—really horrid, nasty, serious cases. We get to the end of the line, which is usually the ombudsman, and yet my constituents still feel that, at the end of the process, not one single iota of good has been done. The bill does nothing to change that.

In your preamble, you spoke of access to records. The Law Society of Scotland’s evidence is that the following are not referred to in the bill:

- “Right to access medical records ... Medical reports issued for insurance purposes ... Right to advocacy services (for mental health service users) ... Right to appoint welfare attorney/make advance directive”
- “Human rights”.

Under the heading “Rights under NHS legislation/government directions and statements”, the Law Society says that the rights “To a GP” and “To a second opinion” are not referred to in the bill. Under the heading “Standards of treatment (Government guidance to professionals and health boards)”, the Law Society further says that the following are not referred to in the bill:

- “Health professionals must show due care”
- “Guidance from government about treatments should be given due consideration (judicial review available)”.

The Law Society also lists rights that are referred to in the bill, but highlights wording such as having regard to those rights. Any rights that you are purporting to give patients under the bill are very qualified.

Those who have been in politics for a long time know that one of the worst things that you can do as a politician is raise public expectations. People expect a magic bullet and, plainly, the bill is not that. I invite you to respond to the criticism that the likely outcome of the bill is that the health service will tend to prioritise minimum legal requirements for patients. As the Law Society of Scotland said,
there is a danger that the bill will diminish rights. There is a set of clear rights for all across society. The question is how we use and pursue those rights, which is why the charter approach that Richard Simpson suggested should be considered.

I have a further question, convener.

The Convener: Forgive me, but that was a long speech and not a question.

Helen Eadie: In case you do not let me back in again, I will raise the issue of patient advice and support about which I have had real concerns for a long time. First, there is the issue of cost. I am not against the proposal in the bill—we should have more patient support—but the reality is that health boards will not be able to afford it. I had to battle tooth and nail—

The Convener: Question, please.

Helen Eadie: My question is: how will you fund all these extra services, cabinet secretary? Will you give health boards more money? Will you ensure that the proposed service is truly independent—that it is outwith the control of any NHS body?

The Convener: I think that the questions were on additional rights, the patient rights officers and money.

Nicola Sturgeon: I will take on them all. I am sure that Helen Eadie’s intention was not to make the case for the bill, but she did that rather well in a way.

With the greatest respect to my former professional colleagues, the Law Society of Scotland is plain wrong when it says that the bill diminishes existing rights. It does not. The bill does not affect existing rights. Helen Eadie gave a long list of rights from the supplementary paper that the Law Society provided to the committee. None of those rights is affected in any way by the bill. It is really important that that point is well understood.

Helen Eadie’s pertinent point—it was this point that made me think that she was making a better case for the bill than perhaps even I had done—was on the constituency cases that we all receive. She spoke of people going through the whole system and getting to the end of it feeling that no difference has been made. That is one thing that the bill is specifically trying to deal with.

Giving patients the right to complain is one issue that the bill tries to deal with. The aim is not just to say that patients can complain, but to make that a specific right and to put a duty on boards, as section 11 does, to monitor complaints with a view to identifying areas of concern and improving performance as a result of those complaints. In other words, the aim is to close the loop in the complaints process so that patients will be assured that going through the process will improve things in future for other people, even if making a complaint will not change things for them. Sometimes nothing can change what has happened for a patient who makes a complaint. That the process will improve things in future for other people is exactly what patients want to hear. For me, that is one important aspect, although not the only important aspect, of the bill.

I assumed that we would come on to the patient advice and support service as a specific topic, but I will answer Helen Eadie’s questions about it now. She said that she has concerns about the current operation of the independent advice and support service, but the proposals have been made exactly because those concerns exist. There are concerns about patchiness, lack of consistency, there not always being clear lines of feedback and communication between the service and the health board, and information not always being shared to ensure that patients’ experiences are used in the improvement process. The bill seeks to put the service on a national footing, and to make it consistent and statutory so that boards could not cut it even if they wanted to in order to save costs. The service is seen as a core part of what the health service does. We are providing additional funding for it, which is important, and it will be independent. The health service will fund it, as it must be funded by somebody, but the Government will give the health service additional funds. We intend it to be contracted in a way that is similar to how the independent advice and support service is contracted at the moment. That will ensure that the people in question are not directly employed by the health service and are not under its control. Patient rights officers will be independent.

The bill will also strengthen the current system by making it clear what patient rights officers are there to do. Among other things, they will aim to raise the awareness and profile of patient rights, including awareness of the options that are open to patients if they are not satisfied with the treatment that they have received.

Many of the personal constituency cases that Helen Eadie mentioned—we can all recount such cases—strengthen rather than weaken the case for the provisions in the bill. Members have been kind enough to say that they do not doubt my intentions or my passion for the health service. I do not doubt members’ commitment to patient rights, but we need to consider how we embed and strengthen the concept of patient rights in the current system.

Helen Eadie: I—
The Convener: I will let Helen Eadie back in later. The cabinet secretary has had quite a long spiel.

Helen Eadie: I just do not know where the magic bullet is. The cabinet secretary has not said where that is.

Nicola Sturgeon: I am beginning to echo my contribution to the minimum pricing for alcohol debate. I am not saying that the bill is a magic bullet. Anybody who—

The Convener: I will just stop you there, cabinet secretary. I do not think that there is any such thing in life as a magic bullet. It is mythical.

Nicola Sturgeon: Exactly.

Helen Eadie: The question is whether the bill will make a difference to my constituents.

Nicola Sturgeon: I think that it will for the reasons that I have outlined.

The Convener: Halt! Helen Eadie can come back in later; I will let Rhoda Grant in first.

Rhoda Grant: I want to ask about patient rights officers, but I have a couple of supplementaries first.

Like everybody else, I welcome moving to change the ethos in the health service to give patients more rights and make them feel more included in their own treatment, but I am not sure that we can legislate for that change; rather, training and how the health service is run need to be considered. The cabinet secretary outlined the process for dealing with complaints. A good health board should deal with complaints at the moment, but she talks about patients getting more satisfaction if they see that their complaint has led to a change in the way that things are handled or done. How will that be monitored? How will health boards be held to account? It seems to me that, at the moment, it is down to the health board to do things, but nobody oversees that and the patient has no sanction available to them if the health board does not act. Will the Government monitor and hold health boards to account if they fail to act?

11:15

Nicola Sturgeon: I agree with most of what Rhoda Grant has just said. I am not suggesting that, just by virtue of passing a piece of legislation, we can change the ethos and culture of the health service. I hope that nobody takes what I am saying to mean that I think, to use Helen Eadie’s phrase, that the bill is some kind of magic bullet—I do not.

The Convener: I am going to ban magic bullets, along with scenarios and directions of travel. I hope that you all accept that. On you go, cabinet secretary.

Nicola Sturgeon: I do not think that I have been issued with the list of words that are banned at the Health and Sport Committee.

The Convener: Ah, that list is growing.

Dr Simpson: Coffee cups are banned, too.

Nicola Sturgeon: My train of thought has been completely interrupted.

The Convener: I am so sorry.

Nicola Sturgeon: I do think, however, that putting these rights in legislation helps the process. It focuses the minds and the efforts of those who deliver health care on what they must have regard to in delivering health care.

Rhoda Grant is absolutely right about the importance of monitoring. Assuming that the bill is passed and that we introduce further regulations, monitoring will be a part of the process. The bill deliberately and expressly says that monitoring will be one of a health board’s duties, so it will become part of the performance management of the health service to ensure that monitoring is part of the way in which complaints are dealt with. I said earlier that, as a matter of practice at annual reviews, I ask health boards about monitoring. As it becomes a legal duty on health boards, monitoring will become a more formal and systematic part of the process of dealing with complaints.

The Convener: That answers the question that I was going to ask about how the provisions in sections 11(3)(e) and 12(4) would be enforced. You are saying that, if the bill is passed, the review of performance management of NHS boards will cover whether they are compliant. My question was going to be about—

Nicola Sturgeon: Yes—the reviews will be one way of doing that.

Rhoda Grant: I move on to patient rights officers. We have been made aware of the concerns that exist about the system as it stands, but most of those concerns are about how seriously health boards take the service. They each contract individually for the service. Some do not provide it at all and others are very good at providing it, which has created a patchy service. It was put to us that one of the benefits of the bill would be that a national service would be provided; however, I am not sure that we need legislation for that to happen. Would it not be possible for the Government to contract with CAS at a national level to carry out the service in the various health board areas, ensuring that there was consistency nationally? All health boards would have a financial responsibility for that and the service would be paid for.
One of the concerns about the bill is that it would damage the service that is available where it is of a good quality. At the moment, people go to CABx not only to get health service advice and information, but to get housing and benefits advice—they have only to go to one place for the whole spectrum of advice, which is where the current arrangement works well. Is there no way of changing the service that is currently available to ensure that we keep the best parts of it while acknowledging that there are problems and sorting them out through having a national contract rather than local contracts?

Nicola Sturgeon: Of course, we could contract nationally rather than locally. However, it is important to address the matter in the bill, as a future Government might believe that the service was not particularly important and decide not to contract for it any longer. You may argue that a future Government could change the law, but that would be a bit harder to do and would require more scrutiny. We are embedding the service firmly as a core service that is available in the NHS to help patients to exercise their rights. That is the simple answer to your question why we should legislate on the matter rather than simply contract nationally for the service.

I have found the evidence on the need for holistic service provision interesting, and I absolutely agree with the points that have been made about the provision of advice and support to patients. It is not just about health; it is about dealing with other issues and complaints that may impact on people’s health or their ability to access the health service. It is, nevertheless, important to stress that the ability of the current independent advice and support service to do such work comes not from the health boards contracting with the provider but from the fact that it is the CABx that are providing the service. The CABx can give the patients who use the service access to all their other services. If CAS or a similar organisation were to get the contract to deliver the service in the future, the same holistic approach would still be possible and would be very desirable. However, it is important to recognise that, right now, that approach is possible because it is the CABx that are providing the service, not specifically because of the way in which the IASS is contracted for. There is nothing in the bill that will reduce or diminish what is already provided—it will only strengthen and improve the current system.

Rhoda Grant: Would it be possible for the bill to state that whoever ran the contract for the new advice and information officers would have to be able to provide more holistic advice?

Nicola Sturgeon: I am happy to consider that. This is only stage 1. The committee will know, from its consideration of previous bills, that I take on board all the suggestions that it makes. I am not sure what might be possible under procurement rules, so I do not want to give a definitive yes or no answer. However, as with all the suggestions that the committee makes, I am more than happy to consider that suggestion.

Mary Scanlon: As with the scrutiny of all the bills that come before the committee, it is important that people are not given the impression that there are party-political divisions. The Conservatives introduced a patients charter in 1991; 10 years later, the Labour-Lib Dem coalition created health rights information Scotland; and now, 10 years down the line, the SNP has introduced this bill. I hope that, in our deliberations, it is not assumed that one party cares more about patient rights than others. We all have a huge commitment to the subject.

I will ask a couple of questions that I have asked before—you will have heard the arguments and will have read the evidence, cabinet secretary. My first question is on the exclusions from the treatment time guarantee. I struggle to see why diagnostic tests, out-patient treatments and mental health patients should be excluded from the treatment time guarantee. I understand why organ transplants and obstetrics are excluded, but why have you decided on the other exclusions?

Nicola Sturgeon: Mental health services are not excluded—it is important to correct that misapprehension. The treatment time guarantee is intended to relate to planned and elective in-patient services. Where mental health treatment is to be provided in that way, it will be covered by the treatment time guarantee. There is no exclusion of mental health services. As Mary Scanlon takes a close interest in mental health services, she will know that much of mental health hospital care is provided on an emergency, unplanned basis. It would, therefore, not be appropriate to have a 12-week waiting time for that, as it will be provided instantaneously. A lot of mental health care is also provided on an out-patient basis, which is why, along with other out-patient services, it will not be covered by the treatment time guarantee. Nevertheless, I make it absolutely clear that, when mental health treatment is to be provided on a planned, in-patient basis, it will be covered by the treatment time guarantee just like any other service. I want to make that very clear.

Mary Scanlon’s question also referred to diagnostic tests. The 12-week treatment time guarantee that is provided for in the bill sits within the 18-week referral-to-treatment target that we currently have. In order for that target to be met, diagnostic tests require to be done quickly; we already have waiting time targets for key diagnostic tests, which health boards are meeting.
Right now, our waiting time targets are individual stage-of-treatment targets. We have a waiting time target for out-patient treatment, a waiting time target for key diagnostic tests and a separate waiting time target for in-patient treatment. So, although somebody might need several diagnostic tests and it might take weeks or—as can be the case—months to diagnose them, at the point of diagnosis the in-patient target will still have to be met.

When we move to a referral-to-treatment target, because that is a whole-journey waiting time target it requires to have tolerances attached to it, given that sometimes diagnosis takes longer than 18 weeks. The 12-week treatment time guarantee ensures that if, for argument’s sake, it takes 18 weeks to diagnose a condition, the patient will have the backstop of the 12-week treatment time guarantee, rather than be left hanging because they are already outside the 18 weeks, fall into one of the tolerance areas and therefore have no guarantee of how long treatment will take. I think that it is important to see the 12-week guarantee within the overall context of the 18-week referral-to-treatment target. There is a hard target and guarantee in the bill: once someone is diagnosed, they will be treated within 12 weeks. We all know how much importance patients attach to waiting times; they are not the only thing that they value, but they value them very strongly.

I hope that my answer both clears up some misapprehension about mental health treatment and explains how the treatment time guarantee sits within the Government’s wider waiting times agenda and aspirations.

Mary Scanlon: Paragraph 38 of the policy memorandum specifically states, in relation to mental health, that

“Through secondary legislation, the Scottish Government intends that the TTG will apply to planned and elective care delivered on an inpatient or day case basis”.

The cabinet secretary knows as well as I do—and I appreciate that there is a psychiatrist at the table—that a large number, if not the majority, of mental health patients are not waiting for planned and elective care. When they receive a diagnosis, they might be referred to a psychologist. Two years ago, the wait for an appointment with a psychologist in Easter Ross in the Highlands was four years and seven months. The cabinet secretary might say that there is a 12-week diagnosis-to-treatment guarantee—that is the case for hip operations, for example. However, the wait is not 12 weeks for a mental health patient waiting to see a psychiatrist or waiting for cognitive behavioural therapy; there can be, and has been, a wait of up to four years and seven months to see a psychologist. That is the length of time from diagnosis to treatment; let us get the situation clear and let us try not to be misleading.

One of the ladies in the first panel of witnesses mentioned physiotherapy. I made a freedom of information request across the health boards last year and discovered that more than 26,000 patients in Scotland were on a waiting list for physiotherapy. The diagnosis may be that a patient requires physiotherapy, but their treatment is not delivered within 12 weeks. I could go on about infertility treatment and so on. We must be careful to make it clear that mental health patients who require talking therapies are not included in the bill.

Nicola Sturgeon: I did not, either deliberately or unintentionally, mislead the committee. I was very clear that the treatment time guarantee is about in-patient, elective treatment. Any treatment that is not provided on that basis is not covered by the treatment time guarantee. I have explained why we think that a treatment time guarantee is important within the context of the 18-week referral-to-treatment target. Of course, other treatments that are not required on an in-patient basis are still covered by the 18-week referral-to-treatment target.

Mary Scanlon is right to talk about unacceptably high waiting times in areas such as mental health and physiotherapy. We inherited some of that and we have made it clear that our intention is to get waiting times in such areas down so that we can bring them within the ambit of the 18-week referral-to-treatment target. We have already taken action to do that in audiology. The committee will know, from previous discussions, about the work that we are doing to reduce waiting times in mental health services and in child and adolescent mental health services in particular. In return, let us be careful not to mislead in the other direction. These treatments are covered by the 18-week referral-to-treatment target. Within that, we think that we need a specific in-patient treatment time guarantee to take account of what can be the unintended consequences of a whole-journey waiting time target.

11:30

Mary Scanlon: I will refer to the bill. I am not a lawyer, but I point out that section 1, on “Patient rights”, states:

“Health care is to ... be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs”

and

“have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing”.
Why is it necessary to put that into legislation? Are our trained and experienced health professionals not doing that just now?

Nicola Sturgeon: That is not the case. Most health professionals aspire to that on most occasions, and they deliver care very well. This goes back to the points that I made earlier about changing the culture and levelling the playing field.

The committee received evidence from the Royal National Institute of Blind People last week or the week before about the fact that, although the clinical care that they get might be very good, patients sometimes get appointment letters that they cannot read—they cannot access them. The bill is about putting into print and into action the principle that we believe in, which is not just about the clinical care that a patient gets; it is about taking into account their needs in the widest possible sense. It raises the import and the status of that principle to have it in a bill such as the one before us, which makes a very clear statement of intent in describing how we intend patients to be treated in the health service.

Mary Scanlon: The breach of the treatment time guarantee is undoubtedly the central focus of the bill. If the guarantee is breached, the health board “must ... ensure that the agreed treatment starts at the next available opportunity ... provide an explanation to the patient as to why the treatment did not start within the maximum waiting time ... give the patient details of ... advice and support” and of “how to complain.”

Does that not all happen at the moment? Is that not just basic good practice?

Nicola Sturgeon: Again, that goes back to my earlier point. We can have a set of patient rights whereby we hope that that all happens as part of good practice, or we can ensure that it happens as a matter of rights that patients have in law. I prefer the latter course. That is, of course, a matter of judgment for everybody.

It is important for patients to have certainty and clarity. Health boards have done a fantastic job in bringing down waiting times, and my expectation is that the treatment time guarantee in the bill will be delivered in the vast majority of cases. Where it cannot be delivered, for whatever reason, it is important for patients to have clarity about what then has to happen, and for them to be given support and advice in exercising their rights.

Mary Scanlon: That is the point. Helen Eadie spoke about the bill raising expectations. We are all in favour of patient rights, but under the bill patients just have a right to an explanation and a right to details about how to complain.

Nicola Sturgeon: If Mary Scanlon is suggesting—

Mary Scanlon: Those rights do not seem to be any greater than those that are contained in the patients charter and the HRIS publications, which Labour and the Lib Dems introduced. I am struggling to see why those rights have to be in the bill, as I have no doubt that when a patient anywhere in Scotland asks why they have not been treated within 18 weeks, what the bill covers is exactly what already happens.

Nicola Sturgeon: Sometimes it does, but there will be occasions when that does not happen to the patient’s satisfaction. I reiterate that either we just hope that patient rights will happen, or we ensure that they happen. I think that the latter approach is better.

The Convener: I think that we have exhausted that line of questioning—if the committee forgives me for saying so.

Joe FitzPatrick (Dundee West) (SNP): People have raised concerns that the bill would place additional financial pressures on the health service just when money is getting tighter and tighter. I invite the cabinet secretary to respond to that, and to say how the bill fits into the tightening fiscal situation that we are moving into.

Nicola Sturgeon: There are direct and specific costs resulting from the bill, which are all detailed in the financial memorandum. However, I guess that your question is a bit broader than that—should we solidify and embed patient rights at a time when the health service is strapped for cash? There is a view that says we should not put health boards under any more pressure to deliver good, patient-centred, high-quality care. I actually think that times such as this, when money is tight, are exactly when we should be increasing our focus on putting patients at the centre and ensuring that, as boards work through financial pressures and difficulties, they do not lose focus on what the health service is all about, which is delivering high-quality care.

I am asked the same question about our quality strategy—is it the wrong thing to do at a time of financial difficulty? I take completely the opposite view. It is exactly the right time to put a focus on quality and, in this context, on patient-centredness, patient focus and the rights of patients in their interaction with the health service.

The Convener: The final set of questions is from Ian McKee. [Interruption.] I should never say that, as a hand always goes up. Ian McKee will be followed by Richard Simpson.

Helen Eadie: You promised me a question, convener.
The Convener: I was hoping that you had forgotten.

Helen Eadie: You were hoping that I had gone to sleep.

The Convener: I was going to shoot you with my magic bullet. Ian McKee will be followed by Richard Simpson and a tiny smidgen of a question from Helen Eadie.

Ian McKee: The cabinet secretary has said several times today that the treatment time guarantee applies to elective in-patient services. Does it also apply to day surgery, which is not an in-patient service?

Nicola Sturgeon: Yes. The treatment time guarantee applies to elective planned treatment, whether that be in-patient treatment or day-case treatment. That is an important clarification. When I say that things apply only to elective planned treatment, I am talking only about the provisions of the bill relating to the treatment time guarantee. The rest of the bill applies not only to planned treatment but across the board.

Ian McKee: Is it your intention that the treatment time guarantee should apply to the same procedures if they are carried out in primary rather than secondary care settings?

Nicola Sturgeon: Yes. If I had long enough, I could cite the relevant section, but the bill makes it clear that boards will have to ensure that the same principles and rights apply to services for which they contract with other organisations.

Ian McKee: I am sorry, but your use of the term “in-patient services” confused me slightly.

I turn to section 8, on breach of the treatment time guarantee. Section 8(3)(a) states that the board “must not give priority to the start of any treatment where such prioritisation would, in the Health Board’s opinion, be detrimental to another patient with a greater clinical need for treatment”.

That seems sensible, but can you explain why the provision is included only in the section on breach of the treatment time guarantee? Is it not important to include it in the section on the treatment time guarantee? Rightly or wrongly, there have been concerns that there may be pressure on clinicians to alter their priorities to fit in with treatment time guarantees.

Nicola Sturgeon: I am happy to look at the issue and to consider whether an amendment should be made. Section 2 states that, when applying all the rights for which the bill provides, account must be taken of the rights of other patients.

Ian McKee: I appreciate that. However, given that you include a specific provision in the section on breach of the treatment time guarantee, I should have thought that one might be included in the section on the treatment time guarantee.

Nicola Sturgeon: I am happy to consider whether the section should be amended at stage 2. I am often asked whether targets skew clinical priorities; I am sure that the same question was put to previous Governments. Targets are intended not to skew clinical priorities but to ensure that patients are treated timeously; everyone recognises that point. Ultimately, decisions about treatment should be clinical decisions. Section 8(3)(a) seeks to make that clear, although I take the point that the same provision should be included elsewhere in the bill.

Ian McKee: That would be helpful.

Dr Simpson: I know that you have been doing a lot of work on no-fault compensation, which has been discussed for a considerable period. Do you agree that the ethos of no-fault compensation might move things forward more quickly than many of the provisions in the bill? One reason that patients do not get the rapid response that they seek when something goes wrong, or when they feel that things are not working, is that clinicians think that they might get into a litigious situation. Defence unions used to advise clinicians not to give out any information if they thought that they would be the subject of litigation. How does that point relate to the timing of the bill? I am seeking to understand your general approach.

Nicola Sturgeon: Changes along the lines of no-fault compensation could well be complementary to what the bill is trying to do. I do not think that it is an either/or situation. I am hesitant about saying too much about what our approach to no-fault compensation might be, as I am mindful of the fact that Sheila McLean’s expert group is due to report soon. I would not want to pre-empt that report.

My estimation and my judgment at the outset of the process around the consideration of no-fault compensation was that, should the process result in legal changes, those legal changes would be quite substantial and would probably merit primary legislation in their own right, rather than being dealt with as part of the broader Patient Rights (Scotland) Bill. Should we end up going down that road—I emphasise the word “should”, as we do not know yet what will happen—that would in many respects be complementary to the changes that we are seeking to make with this bill.

The Convener: Helen, is your question on subordinate legislation?

Helen Eadie: It is not on subordinate legislation, nor will I use the dreaded words. Instead, I will refer to a fix-all solution. We will not have a fix-all solution in this bill.
I gather that NHS Lothian is in the process of upgrading and modernising its complaints procedures and services to ensure that complaints are handled in a way that we would all like. That is absolutely right, as we all want there to be change and improvement. Would it not have been better to work with NHS Lothian, which is one of the biggest health boards in Scotland, to find the absolute best practice that is out there and then, once that had been piloted, to come back to Parliament with all the lessons that had been learned from that exercise and propose that we go ahead with all the changes for all the reasons that you could set out? Work has been done in England and in Wales, and there is also the no-fault compensation scheme that you have just talked about with Richard Simpson. I feel that you are, quite rightly, trying to bring a solution to Parliament but that, at the end of the process, people will not be any better off than they are today.

The Convener: The question is, will people be any better off?

Nicola Sturgeon: I think that I have already disputed the point of view that people will not be any better off.

In a sense, Helen Eadie makes a valid point. However, I do not think that anything she has said undermines what we are trying to do in the bill. Of course we work with health boards on a range of issues to improve their practice and procedure. The bill gives a right to complain and it puts a duty on health boards to do certain things in response to complaints. Underneath that, there is the question of what we can do practically to improve the process of complaints handling to give best effect to all that. We will consider anything that any board does in that regard, and see whether we can learn from that and apply it more widely.

The Convener: That brings this evidence-taking session to an end. I thank the cabinet secretary and her team for their attendance.

11:43
Meeting continued in private until 12:37.
To Whom It May Concern

HEALTH AND SPORT COMMITTEE MEETING – 6 OCTOBER 2010

Following my attendance at the Health and Sport Committee on 6 October 2010 to give evidence on the Patient Rights (Scotland) Bill I am now submitting further information as requested.

I was asked by Ian McKee MSP how procedures carried out by a GP would be covered by the Bill (Col. 3569). I am advised by Mr Duncan Miller (General Manager Primary Care Contracts, NHS Lothian) that any minor surgery carried out by GPs is covered under a “Directed Enhanced Services (DES). If there are to be changes to the current specifications of the DES I am advised that this would need to be addressed at a national level via the Scottish Government.

I hope this provides sufficient clarification on the matter.

I can also confirm that the report is an accurate reflection of what I said at the meeting on 6 October 2010.

Yours faithfully

MELANIE HORNETT
Nurse Director
The Scottish Government Stage 3 amendments to the Patients Rights (Scotland) Bill are due to be lodged with Parliament on 10 February 2011.

I am writing to advise you that I intend, as part of this process, to lodge one further set of amendments which seek to amend the provisions of section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 ('the 2005 Act'). The purpose of these are to introduce additional categories of persons to whom payments may be made by Scottish Ministers under a scheme for persons affected with hepatitis C through NHS treatment with blood/blood products.

**Background**

As you may be aware, in October 2010, Anne Milton MP, the current Parliamentary Under Secretary of State for Health at the Department of Health (DH) announced that she intended to review the current provisions for those infected by HIV/hepatitis C in this way. On 10 January this year, Rt Hon Andrew Lansley MP published the Review report which included recommendations on the provision of additional support to those patients and others associated with them, particularly those with hepatitis C infection. DH officials have now begun to implement the Review recommendations in England but I wished to hold off making an announcement in Scotland until I had discussed the recommendations with patient representatives here.
I had a meeting with patient representatives on 3 February 2011 who indicated that they wished time to further consider the detail of the DH proposals and agreed to let me have their further thoughts by 17 February. I intend to make a formal announcement regarding plans for Scotland shortly thereafter.

However, in order to have the legislative authority to make payments to a new category of claimant, I need to secure an amendment to s.20 of the 2005 Act. The PRB gives us the only opportunity to do this before dissolution.

Purpose of Amendment

The provisions contained in section 28 of the 2005 Act give Scottish Ministers powers to set up a scheme to make payments to those infected with hepatitis C through NHS treatment with blood/blood products. It also defines the general categories of persons to whom payments can be made under any such scheme, with further eligibility criteria being specified in the terms of the scheme(s) made under that section. Should I wish in due course to make payments to a new category (or categories) of claimants under any existing or new scheme, as they have decided to do in England, section 28 would need to be amended. As a result, to ensure that, if I chose to do so, I can put in place any such new arrangements in Scotland, quickly, following my announcement and thus ensure that any newly eligible claimants can submit applications for support quickly thereafter (and not have to hold off until legislative changes in the new Parliamentary session later in 2011 at the earliest), I am putting forward these amendments, using the Patient Rights Bill as a vehicle.

I hope this is helpful in explaining, in advance, the background and purpose of these particular amendments.

NICOLA STURGEON
ANNEXE C: OTHER WRITTEN EVIDENCE

Angus Council
Arbuckle, Thomas
Association of British Pharmaceutical Industry Scotland
Breast Cancer Care
British Dental Association
British Heart Foundation Scotland
British Psychological Society
Chartered Society of Physiotherapy Scotland
Chest, Heart and Stroke Scotland
Children in Scotland
COSLA
COSLA (supplementary)
Diabetes UK Scotland
Faculty of Sports and Exercise Medicine
General Dental Council
Medical Protection Society
Melville, Ian
NHS Highland
Office of the Public Guardian
Rarer Cancers Foundation
Roche Products Ltd
Royal College of Physicians of Edinburgh
Scottish Council on Deafness
Scottish Disability Equality Forum
Scottish Health Council
Scottish Human Rights Commission
Scottish Independent Advocacy Alliance
Sinclair, Doreen
Patient Rights (Scotland) Bill

Angus Council

General comments

We strongly support the proposed moves towards increasing the degree of participation available to patients within a journey of care and also the moves to make easier how patients can actually participate. We are aware that this Bill will strengthen those rights which already exist and again we are supportive of this. Embedding the rights of service users within processes and procedures is already standard practice in other public service organisations and is therefore to be welcomed in the National Health Service in Scotland. We suggest that lessons learned by other agencies that have already established and embedded a strong rights agenda be shared with the NHS.

Specific comments

Sections 1 and 2 (patient rights)

We are broadly supportive of the content of these sections. Some clarification of the use of the term “proportionate” (section 2.2b) would be useful as what is proportionate health care may be difficult to define.

Section 3 (health care principles)

We welcome the inclusion of any third parties, with whom NHS bodies may contract to provide health services. (section 3 (1) (b)).

We agree with the content of the schedule of health care principles introduced in section 4(1). However, and with particular reference to principles 7 and 8, we would anticipate conflict arising through competing priorities for resource allocation.

Section 6 (treatment time guarantee)

Whilst welcoming the commitment to guarantee treatment within a specified time, there is perhaps danger that the pursuit of this standard for conditions that are not life threatening may compromise the ability to achieve this standard for more serious conditions. We would welcome further work around the categorisation and prioritisation of specific conditions, rather than a “one fits all” approach.

Section 11 (complaints and other feedback)

We broadly welcome the proposals in this section and in particular the publicising of how complaints will be made and will be handled. We support the encouragement that is to be given to patients to provide feedback to health authorities on aspects of their care.
Sections 14-17 (patient advice and support service and patient rights officers)

We are very supportive of moves to improving advice to NHS patients. From the experiences of other agencies employing this approach, we anticipate significant benefits for a whole range of patients, including vulnerable adults and others with special needs.

With the introduction of patient rights officers there is an opportunity to make the National Health Service more open and more inclusive, particularly so around the issue of explaining options and procedures (16b).

Thought should be given to the capacity of these officers to carry out their range of tasks effectively (i.e. how many officers will there be to each health authority.) Their effectiveness will be negated if they find themselves swamped by too many demands. We would therefore seek assurances that steps will be taken to provide resource including additional training.

A final comment relates to the present financial climate and the expectation that public spending including health spending will remain under severe pressure over the coming decade. While the proposals within this bill have no significant cost attached, neither are they completely cost neutral and their implementation will most likely have to come from existing resources. We have stated that we welcome the proposals within this bill but would pose the question as to whether this the optimum time for its introduction.

Mr Robert Peat
Director of Social Work and Health
Angus Council
5 May 2010
Patient Rights (Scotland) Bill

Mr Thomas Arbuckle

SUBMISSION FROM THOMAS ARBUCKLE in response to proposals within the Patients Rights (Scotland) Bill (SF Bill 42) on the role of Patients Rights Officers (Sections 14-17).

I consider that embedding Patients Rights Officers within the NHS would be contrary to patients' and patients' relatives' interests. Patients Rights Officers must be independent of the NHS and given strong powers of enquiry in order to be able to pursue patients' interests effectively.

This view is based on my experience in dealing with NHS Lothian following the death of my wife, Mary Arbuckle, on August 26th, 2008 and culminating in the Scottish Ombudsman's report, published March 2010 (Case 200901408) which found in my favour on my complaints against the Board.

The NHS based enquiry before the matter could reach the Ombudsman went through 3 stages producing 3 reports — A Significant Event Analysis by Liberton Hospital; An enquiry by the RIE Clinical Management Team via RIE Patient Liaison Office; An appeal to Professor James Barbour, CEO Lothian Health Board.

Full documentation of all three reports and my written responses is available. At each stage I was confronted by obfuscation, whitewash and denial of fault. For example the Significant Event Analysis was led by the same consultant responsible for my wife's treatment. This was criticised by the Ombudsman (See recommendation iii and paragraph 19 Ombudsman's report)

The SEA made unsubstantiated claims of other possible causes of death e.g. heart attack, pulmonary embolus, red herrings to cover the failure to give appropriate antibiotic treatment for pneumonia.

Dr. Ruth Young, the ward doctor on duty when my wife's deterioration became apparent was conveniently not available for SEA meeting and subsequently airbrushed out of further documentation.

RIE clinical team report was a rehash of the SEA report and included bizarre claims e.g. giving antibiotics intravenously is aggressive and invasive, also that patient dignity comes before essential life saving treatment. Some questions submitted via RIE patient liaison officers went unanswered.

Professor Barbour simply passed the buck to Liberton hospital again resulting in a report contradicting earlier reports claims concerning antibiotic administration and contradicting the original antibiotic regime planned for my wife.

These problems I had with NHS Lothian provide evidence that Patient Rights Officers must have strong powers of enquiry and be separate from NHS and therefore objective if they are to be of real help to patients and relatives struggling to penetrate questionable medical excuses for failure emanating from NHS staff. 

Mr Thomas Arbuckle

12 May 2010
Patient Rights (Scotland) Bill

Association of British Pharmaceutical Industry Scotland

The Association of British Pharmaceutical Industry Scotland, as the representative body of the research-based companies that operate across the medicines and vaccines sector, is pleased to make this contribution to the Health and Sport Committee’s call for evidence on the Patient Rights (Scotland) Bill.

General Comments on the Bill

ABPI Scotland strongly welcomes the Patients Rights (Scotland) Bill, and feels that it could make a valuable contribution to improving the standards of care delivered in Scotland.

We do however feel that the absence of more focus on the actual treatment that patients can expect represents something of a missed opportunity.

While it is right and proper that minimum waiting times and the rights to the correct and appropriate information are enshrined in law, such measures could be negated somewhat if the actual treatment given is not the best and most appropriate for a patient’s clinical needs.

There has been considerable progress in recent months on increasing the consistency and transparency of decision-making processes around the introduction of new medicines into the NHS in Scotland. However, we believe that there should be an expectation enshrined in the law that patients will receive the best available treatment wherever clinically appropriate based on the most recent guidance applicable to NHS Scotland.

For example, a patient should have the right to access an SMC accepted medicine where a clinician feels this is clinically appropriate. Such a provision would address the cross-border issue created by the NHS constitution in England that give patients rights to access NICE approved medicines.

The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to-5)

ABPI Scotland comments:

We do have some concerns regarding Sections 1(1) and 1(2) and how they relate to Section 2 (2)(b).

For example, while 1(2)(b) states that ‘health care is to have regard to the importance of providing the optimum benefit to the patient’s health & wellbeing’ section 2(2)(b) sets out that ‘the desirability of action delivering
health care being proportionate, and otherwise appropriate, to the circumstances of each case’.

While we agree with the sentiments, we believe that there is potential for contradictory interpretation. For example, terms such as ‘proportionate’ and ‘appropriate’ allow sufficient ambiguity that could lead to patients faced with the likelihood of poorer treatment outcomes not being deemed ‘appropriate’ for certain treatments.

In this regard, economic assessment tools of the cost benefit of a medicine such as the Quality Adjusted Life Year (QALY) allow a relatively subjective value to be put on prolonging life and, already widely used, might be used as a measure of ‘appropriateness’ of treatment, allowing that to take precedence over treatment being expected to offer the ‘optimum benefit for patients’ – something we believe would be contrary to the spirit of the Bill.

In section 5, we would like to see reference made to sanctions that can be taken by Scottish Ministers should a relevant NHS body consistently fail to meet Ministerial guidance in relation to the practical application of the health care principles.

The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

We are particularly supportive of the treatment time guarantee in section 6 – we feel that guarantees of minimised delays in treatment are an important step towards achieving the best possible health outcomes for patients in Scotland.

This provision should extend to include new treatments becoming available to patients already receiving care within NHSScotland. Where, for instance, you have patient on a medicine and the SMC approves an alternative new medicine which is more clinically appropriate, the maximum time from the publication of the SMC decision to the patient receiving the medicine should be 12 weeks. To be meaningful, this would then match the NICE time lines for national to local ADTC decision making and implementation.

We would however reiterate the point made in the general statement above that the benefits of being seen quickly could be negated if the best available treatment for the patient is not then administered. For example, the patient does not benefit if he or she is referred to a particular specialist only then to be diverted to another, perhaps less specialised clinician, to allow treatment to take place within the waiting time parameters.

Furthermore, in section 8(3)(c) we would like clarification as to how any Individual Patient Treatment Requests may impact upon the waiting time guarantee. For example we feel it would be unfair if a patient submitted such a request and then had their treatment delayed because the relevant NHS body
was unable to respond to the request in time to allow treatment to commence within the treatment time guarantee window.

Patients should not have to wait for long periods because a panel or committee of decision-makers only meets occasionally. We would ask that consideration be given to allowing provision for the setting of decision response times for patients to hear the outcome of any requests made for treatment decisions to groups or committees of decision-makers.

The complaints and patient feedback system set out in the Bill (Section 11 & 12)

While we understand the importance of the ability to complain and to seek redress, we feel that equal emphasis should be placed on the ability to appeal against decisions and to be aware of routes to seek clinical review of decisions.

This is important to ensure that patients are fully involved and informed in their treatment as partners, and that they are aware of all avenues open to them during the progression of their treatment to seek to avoid having to seek redress should they be denied the best available treatments.

The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

We feel that this section would be strengthened by the inclusion of a right to the best available care in the Bill, as mentioned previously in this response.

In section 15(2), we would like to see a specific reference in the role of the Patients Advice & Support Service and Individual Patient Treatment Requests in the same way that complaints, raising concerns and giving feedback about health care are explicitly mentioned.

In addition, we feel that it would be beneficial to patients if the role of the Patient Rights Officer included responsibilities around Individual Patient Treatment Requests.

This would have the added benefit of the Patient Rights Officer fulfilling the role of ‘liaison officer’ as outlined in the Public Petitions Committee’s report into the availability of cancer treatment drugs (published 18th June 2008) – an important step so that patients feel supported and comfortable in appealing for the best available treatment for their condition.

Andrew Powrie-Smith
Director
ABPI Scotland
13 May 2010
Patient Rights (Scotland) Bill

Breast Cancer Care

- The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

Breast Cancer Care firmly supports the principles of patient rights as set out in this Bill as a way of protecting the minimum levels of rights and standards that have developed in patient care over the years.

We suggest that there might be some consideration to include a point about healthcare to be based on clinical and patient-specific need that excludes discrimination on the grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age. Age discrimination is particularly pertinent in light of the Equality Act 2010, which makes unjustifiable age discrimination against adults unlawful in the provision of services and exercise of public functions.

Under the third right which stipulates that every patient is able to make a complaint and give feedback about healthcare received, it may be beneficial for patients to know that their concern will be properly investigated and that the outcome of the complaint will be made known to them.

- The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

Breast Cancer Care believes that enshrining the twelve-week treatment time guarantee is a progressive step towards ensuring every patient will receive a minimum standard of care. This target will go some way in alleviating the anxiety many patients face when waiting for treatment for a particular health condition.

In terms of action points concerning a breach of the treatment time guarantee, we feel that the assertion that “the Health Board must make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity” needs greater clarification. Does this include (as in England’s NHS Constitution) that alternative providers (which include private healthcare providers) could be used to ensure that the agreed treatment starts at the next available opportunity? This needs to be stated categorically either way.

We would also appreciate some clarification around the targets previously set out in ‘Our National Health: A plan for action, a plan for change’ (2000) and ‘Better Cancer Care: An action plan’ (2008) that cancer patients will receive treatment 31 days after a diagnosis. Presumably therefore the 12-week treatment time stated in the Patient Rights (Scotland) Bill is only relevant to non-cancer patients. This
should be made clearer in the Bill, as well as stipulating the maximum waiting time for treatment being 31 days for cancer patients.

- **The complaints and patient feedback system set out in the Bill (Section 11)**

Breast Cancer Care believes that a good complaints and feedback service is crucial in fostering a constantly improving NHS. It serves to empower patients by reminding them that they do have redress and that they are not merely passive recipients of healthcare, but active participants in how healthcare services operate for their benefit.

We agree with all of the points set out but would suggest an inclusion of a right around making a claim for judicial review if a patient believes that they have been directly affected by an unlawful act or decision of an NHS body.

- **The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)**

The Bill specifies that the patient and support service is not to be provided by the Health Board, Special Health Board or Agency, and that more than one provider of such services could be viable. Does this indicate that an external organisation (for example a voluntary sector patient advocacy group) could apply to provide these patient support and advice services? Or would new agencies created solely for this purpose be developed instead? More detail would be appreciated here.

Ms. Lorraine Dallas  
Head of Breast Cancer Care, Scotland  
Breast Cancer Care  
12 May 2010
This is the written evidence from the British Dental Association (BDA) to the Health and Sport Committee in relation to the Public Services Reform (Scotland) Bill. The BDA represents over 23,000 dentists and dental students throughout the UK. It works to support dental professionals and promote the nation’s health and well-being.

Last year, the BDA responded in some detail to the earlier consultation on the contents of the Patients Rights (Scotland) Bill. Our written evidence to the Health and Sport Committee focuses on concerns that the BDA has in relation to the 12 week waiting time guarantee. We wish to reiterate the difficulties we see in applying this to secondary care dental services where there are issues around recruitment to NHS consultant posts in some dental disciplines in some NHS Boards. The inclusion of a 12-week waiting time guarantee from 2011 could prove very challenging without further investment in secondary care dental services.

The BDA looks forward to the opportunity to comment on regulations associated with the Patients Rights (Scotland) Bill as they develop.

Fiona Angus
Senior Policy Officer
BDA Scotland
13 May 2010
Patient Rights (Scotland) Bill

British Heart Foundation Scotland

Comments on the principles (Sections 1 to 5)

BHF Scotland, the Nation’s heart charity, welcomes the key aims of placing patients at the centre of the NHS in Scotland, allowing and encouraging their full participation in decisions about their health and wellbeing, and ensuring they have the necessary information and support to enable participation.

Comments on the 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

Short waiting times for assessment, investigations, diagnosis and treatment are all important for patients and we are concerned that the focus on the right to a maximum 12 week wait for in-patient or day case treatment may have adverse effects on waiting times for other services.

Previous waiting time guarantees and targets have focussed on those requiring in-patient or day case treatment. The setting within which treatment takes place should not determine whether or not the patient has a right to receive that treatment within the maximum waiting time guarantee. Such a guarantee effectively ensures rights for patients waiting for elective surgery but for few other groups of patients. Section 10 appears to continue this focus as ‘treatment’ is defined as a medical or surgical intervention.

The requirement for the NHS to achieve these maximum waits for eligible patients will put pressure on resources for other services that are not subject to such guarantees, such as cardiac rehabilitation, psychological interventions, and palliative care. It is perhaps inevitable that the focus for NHS Boards will shift substantively to the achievement of the target at the expense of other priorities.

An individual waiting time guarantee raises further questions:

- How will this information be communicated?
- Will patients get a written statement of the treatment that they require and the date by which this will be provided?
- What if the patient does not think that the guarantee is appropriate?
- Who will be responsible for enforcement/disputes?

A 12 week guarantee for all compares unfavourably to the current national waiting time standards for patients waiting for angiography and for revascularisation procedures. Will there continue to be guaranteed shorter waits for these?

Comments on the complaints and patient feedback system (Section 11)

We agree that feedback from patients on NHS services should be actively encouraged and that steps must be taken to remove barriers that may prevent
this happening. We believe that one of these barriers is the fear that complaining will have adverse impacts on their care so it is important that support and advice is available to those who need it and that this is demonstrably independent of the NHS.

It is also important that Better Together is not seen as the only route for obtaining feedback from patients, but that there is continued support for the Patient Focus and Public Involvement process. When people are involved in such initiatives it is important that they receive feedback about the impacts of their input.

Comments on the patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

It is important that, along with strengthening patients’ rights, the implementation of a Patients’ Rights (Scotland) Bill includes steps to actively promote to patients and the public an understanding of these rights and responsibilities, so that it has a genuine impact on experiences of the NHS.

Materials must be written in plain English and translated into different languages, assisting patients from non English speaking backgrounds to fully understand their rights and responsibilities under the NHS system. There is also a need to consider how to meet the needs of those parts of the population for whom printed materials are not an appropriate medium. There should also be an active process of ensuring adequate levels of demonstrably independent support and advice is available to those who need it. There is a risk that unless both these aspects are actively promoted they could widen health inequalities as those in greater need may be less likely to actively seek out information and exercise their rights.

Andy Carver
Prevention & Care Adviser
British Heart Foundation Scotland
13 May 2010
Patient Rights (Scotland) Bill

British Psychological Society

The British Psychological Society in Scotland is pleased to have the opportunity to respond to the Health and Sport Committee call for written evidence on The Patient Rights (Scotland) Bill.

The British Psychological Society ("the Society"), incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. The Society is a registered charity with a total membership approaching 50,000, almost 3500 of whom are based in Scotland.

Under its Royal Charter, the objective of the Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge".

The Society is committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research. The Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

We are content for our response, as well as our name and address, to be made public. We are also content for the Committee to contact us in the future in relation to this response. Please direct all queries to:-

Policy Support Unit, The British Psychological Society, 48 Princess Road East, Leicester, LE1 7DR.

Email: psu@bps.org.uk  Tel: (0116) 252 9926/9577  Fax: 0116 227 1314

This response was prepared by

Dr Frances Baty, Chair, Division of Clinical Psychology -Scotland and Consultant Clinical Psychologist/Locality Head, Adult Psychology, West Fife

Dr Alison Robertson, Past Chair of the Division of Clinical Psychology – Scotland and Head of Learning Disability Psychology, Lynebank Hospital, Dunfermline, Fife.

And is co-signed by Dr Carole A. Allan, Chair, The Professional Practice Board of the British Psychological Society.
General Comments on the Bill

The British Psychological Society in Scotland is supportive of this Bill and its aims, which we believe are important in continuing to drive forward standards in NHS Scotland.

As the representative body of psychologists, we believe the Bill will allow for increased patient participation and partnership in decisions about their healthcare.

We believe that as a priority the Bill should allow a much clearer expectation that all patients should be offered the choice of non-pharmacological interventions as well as medicines wherever possible, and would welcome an overt statement to this end on the face of the Bill or, if more appropriate, in any secondary legislation that may flow from it. Our experience is that such a clear choice will allow the Bill’s core expectation that treatment should be of optimum benefit to the patient’s health and wellbeing can be realised.

The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

While strongly supportive of section 1(2) of the Bill, we would like to see the Bill specifically place an obligation on NHS Boards to offer talking therapies and other non-pharmacological, psychology-based treatments and interventions to patients where it is deemed that this would be beneficial and appropriate.

Central to this Bill is moving the NHS closer to the needs of the patients, and at the same time simultaneously engaging patients in their own care. Such ends would be best served by offering patients the best possible range of treatment options so that they are not forced into false choices.

Including the right to be considered for non-pharmacological treatments would allow a genuine choice for the patient and would strengthen this Bill in achieving its aims.

Such a provision will deliver two core goals of the Bill:
- that healthcare be of optimum benefit to the patient’s health and wellbeing: psychological interventions address root causes of illness rather than, as can be the case with medication, treatment to alleviate symptoms
- that healthcare should allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing: psychology-led services have partnership with the patient at their core and allow recovery through working with the patient to address together the issues that may be causing their ill health.
The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

We have welcomed the extension of time to treatment measures to mental health and would expect that provisions for a treatment time guarantee as envisaged in the Bill will apply to patients presenting with mental health problems.

We would seek the inclusion of a statement expecting equity of care for patients with both acute and chronic conditions as we do not wish the importance of responding to those with the greatest clinical need as quickly as possible to undermine the use of clinical resources to prevent further deterioration in mental health and/or promote mental well-being in people whose illness may be chronic or episodic.

“Eligible patients” in Section 10 must include patients for whom there may not be clear diagnosis, or for whom a diagnosis may take some time to be certain such as dementia.

We would seek assurance that the definition of “treatment” in Section 10 as being “a surgical or medical intervention ordinarily provided by the Health Board” be re-worded to include the word “therapeutic” before “intervention” so as to allow the delivery of treatment to be by other clinical professionals as well as surgeons and doctors.

The complaints and patient feedback system set out in the Bill (Section 11 & 12)

We have no comments to make on sections 11 and 12.

The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

If patients are to have genuine choice as to treatment options available to them, it is vital that the proposed Patient Rights Officers and the proposed patient advice and support service are fully supported and trained to ensure that information given to patients about services and treatments includes non pharmacological treatments where appropriate.

Dr Frances Baty; Dr Alison Robertson; Dr Carole A. Allan

British Psychological Society
11 May 2010
The Chartered Society of Physiotherapy Scotland

The Chartered Society of Physiotherapy (CSP) is the professional, education and trade union body representing physiotherapists, physiotherapy students and assistants. More than 98% of all physiotherapists in Scotland are members of CSP Scotland and physiotherapy is the fourth largest health care profession in the UK, and the largest of the allied health professions.

CSP Scotland has around 4,000 members in Scotland. Approximately sixty percent of chartered physiotherapists work in the NHS. The remainder are in education (including students), independent practice, the voluntary sector and other employers, such as sports clubs and large businesses.

Physiotherapy involves the skilled use of physical interventions to promote, maintain and restore physical, psychological and social well-being. Using problem solving and clinical reasoning, physiotherapists work to restore functional movement or reduce impairment utilising movement, exercise and the application of electro-physical modalities.

The Society welcomes the opportunity to respond to the Scottish Parliament Health and Sport Committee on the Patient Rights Bill. CSP Scotland has met with the Scottish Government to discuss the proposals, and is broadly supportive of the agenda to advise and inform patients of their rights and to emphasise the role patient centred care in meeting the expectations of service users.

Patient Focus

CSP Scotland supports the principle of patient rights, and welcomes the emphasis placed in the proposed bill on patient centred care. Indeed the physiotherapy profession prides itself as an excellent example of patient centred model of care, and follows a holistic or bio-psychosocial model and approach to treatment and self-management. The Society therefore views the values and codes underpinning the profession to be in tune with the legislative framework for patient care in Scotland.

Physiotherapists are committed to delivering patient focused services that are evidence based and lead to positive outcomes for service users. There are numerous examples of good practice in health promotion, preventative care and anticipatory care that is central to physiotherapy provision.

However it must be noted that a holistic approach to healthcare has resource implications. In order to improve the advice and support given to patients, clinician time with patients is necessary, and is precious. The time devoted to health promotion and preventative care (such as supporting smoking
cessation, increasing activity levels or improving diet) has resource implications on the time spent with patients. There are approximately 28,000 people in Scotland in need of physiotherapy, and waiting times vary across services and health board areas.

In this context, the rights of patients must be matched against the capacity of services and the available resource. In the case of physiotherapy provision, and against the backdrop of increasing efficiency savings, the legislation offers only limited scope for service improvement.

Waiting times

Other than via consultant referral, allied health professional led services are not currently included in the 18 week Referral to Treatment Targets, and are not set to be part of the proposed 12 week Treatment Time Guarantee. CSP Scotland considers that current capacity issues make it unlikely that this could prudently be delivered for physiotherapy services without increased investment.

Patient Information

CSP Scotland supports better advice and information for patients as service users. The creation of a central independent service is likely to change culture, by providing a reference of information beyond that available from the service provider. This may increase patient awareness and expectations, and access the complaints process when things go wrong. Patient Rights Services will advise on the referral of complaints to the regulatory bodies as well as to NHS Boards.

Patient Responsibilities

The rights of one patient are affected by the responsibility of others. Whilst it is recognised that the responsibilities of patients is not an area for which there can be simple legislative remedy in the current bill, there is scope for further action. The provision of better information presents the Scottish Government with the opportunity to educate service users of the impact of the irresponsible use of services. For example, where patients fail to attend appointments, or cancel at very short notice, this wastes resources that could otherwise be devoted to other patients and to improved services, particularly in relation to the some of the goals of patient centred care. Where resources are to be used to improve patient information, the importance of patient responsibilities can also be highlighted alongside patient rights.

Kennyck Lloyd-Jones
Policy Officer for Scotland
Chartered Society of Physiotherapy Scotland
13 May 2010
Patient Rights (Scotland) Bill
Chest Heart & Stroke Scotland

Chest Heart & Stroke Scotland (CHSS) aims to improve the quality of life for people in Scotland affected by chest, heart & stroke illness, through medical research, advice and information and support in the community.

Voices Scotland, based on the highly successful Hearty Voices Scotland programme, which CHSS have been delivering in Scotland in partnership with the British Heart Foundation for the last five years, is integral to gathering the views of patients and carers across Scotland. The Programme supports the Scottish Government’s vision of a mutual NHS by ensuring that chest, heart and stroke patients’ and carers’ views are represented, their voices heard and that they have the opportunity to be meaningfully involved in the work of NHS Scotland.

CHSS provides many services throughout the country, one of which is to support over 100 affiliated support groups; member/volunteer led groups which offer a wide range of activities and offer members, relatives and carers ongoing support, stimulation and companionship in a friendly and relaxed environment.

Through the Voices Scotland Programme and our affiliated group networks, CHSS has been raising the awareness of the Patient Rights (Scotland) Bill and asking members for their contributions which will be reflected in the responses below.

Patient Rights and Health Care Principles

- ‘Health care is to be patient focused’

CHSS are committed to supporting the NHS to meet this fundamental aim by providing training and support to patients and carers to get involved with NHS Boards, particularly at Managed Clinical Network level. We feel that it is important to embed the culture of including patients and carers in their own immediate care and are confident that the culture of NHS staff is moving towards ensuring this happens. However, we feel it is equally important to ensure that, if we are to have genuinely ‘patient focused’ services, we include patients and carers in the broader issues of development and redesign of services.
Patients tell us that they have confidence in the ability of NHS staff to provide first-class clinical health care. However, where the services sometimes fall down is on their ‘wellbeing’. It is important the bill provides sufficient emphasis on the NHS providing a holistic approach to health care, seeing the patient as a ‘person’ and taking into consideration family and social circumstances outwith the clinical environment.

- ‘allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing’

Again, feedback suggests the NHS are doing this on a more regular basis, although gaps still exist and there are inconsistencies across different areas of the NHS. The Bill should be clear that participation should be enabled and encouraged by all levels of NHS staff, from consultants to auxiliary support staff.

- ‘the importance of providing such information and support as is necessary to enable the patient to participate.’

The Voices Scotland programme can provide such support and to ensure consistency across Scotland on what support is offered to patients and carers, we would suggest the Bill could include a specific reference to the programme and other such support mechanisms.

- Healthcare Principles Schedule (section 4)
  - ‘Anything done in relation to the patient takes into account the patient’s need’
    
    CHSS would suggest that this statement makes reference specifically to ‘physical, psychological and social needs’ in the context of improved quality of life.
  
  - ‘Patients are treated with dignity and respect’
    
    We are aware this is a ‘patients’ rights bill’; however, how the carer is treated has a major bearing on the overall ‘patient experience’ therefore we would propose a mention of how the carer should be treated in the same way.
‘Health care is provided in a caring and compassionate manner’

Consistency is key here and NHS Boards should be encouraged to develop locally relevant principles which all staff adhere to.

‘Health care is based on current recognised clinical guidance’

Patients are often not aware that staff are following the correct guidance, therefore we would propose in addition to this statement: ‘which is shared with and explained to the patient’

‘Communication about a patient’s health and wellbeing is clear, accessible and understood’ ‘…about general services and processes and decisions…’

One of the top issues of the patients and carers who participate in the Voices Scotland programme is ‘communication’ (or more precisely ‘lack of communication’), therefore CHSS welcomes this principle wholeheartedly.

Health care principles: guidance and direction

It is of vital importance that the Patients Rights Bill is seen by the public as more than a ‘good practice’ guide and that supporting standards are developed to ensure consistency of the Bill’s application. Producing clear and concise tailored patient information is imperative and the Bill should be easily understood by patients/carers and published (in consultation with patients/carers) in an accessible and understandable format.

We would also suggest that the Bill is cited in future government action plans & guidance documents, where appropriate, to ensure that its credibility is maintained.

Treatment time guarantee

‘A Health Board must take all reasonably practicable steps to ensure that is complies with the treatment time guarantee’

There often appears to be an over-emphasis on waiting time targets however this is an area which is rarely brought to our attention by patients. They are more concerned that the increasing pressure on Boards to reduce waiting times will have a negative impact on the quality of care they receive. It is however important to have appropriate measures in place to assess whether Boards are meeting the waiting time guarantee
and it would be helpful to clarify for patients what ‘reasonably practicable steps’ entails.

- ‘…if it is unable to treat a patient in its own area, through another Health Board or a suitable alternative provider of the treatment’

We would propose that in addition to this statement, there is mention of communication being paramount with patients and their family, when proposing to treat in another Board area.

- Breach of the treatment time guarantee
  - ‘.. provide an explanation to the patient as to why the treatment did not start within the maximum waiting time’

The timing of such explanation is important therefore, as an addition to this statement, we would propose altering to a ‘timely explanation’ or even better stating what would be deemed to be an acceptable timescale for providing this feedback.

- Complaints
  - ‘It is the right of every patient to make complaints and otherwise raise concerns and give feedback about health care received’

Patients continually tell us that complaining during their period of treatment is very difficult and something they tend not to due to worries about any possible repercussions this may have on the care they receive. The Bill should ensure it is supportive in encouraging patient feedback at all stages in their care pathway, putting the emphasis on NHS boards to seek feedback from the patients so that it becomes more the ‘norm’ and does not appear from the patient’s perspective to be something to be scared of.

  - ‘monitoring the complaints received with a view to identifying any areas of concern, and improving the performance of its functions’

It is imperative that the NHS look upon complaints as positive constructive feedback and act on it as such making changes and improvements as suggested above. However, in addition to this, it is important that NHS Boards actively publicise what they have done as a result of complaints in order to increase the confidence of the public that they are willing to listen.

- Patient Feedback
  - ‘A relevant NHS body is to encourage patients to raise any concerns or give feedback on health care’
The Bill needs to make very clear the distinction between complaints and feedback as patients tend not to separate the two therefore currently Boards are missing the opportunity to learn from the people actually experiencing their services. There also needs to be distinction made between positive and negative feedback and more should be done to encourage the many people who have excellent experiences, to have a clear mechanism for feeding this back.

- ‘The relevant NHS body must consider all concerns raised and feedback received with a view to improving the performance of its function’

As with complaints, this process should be transparent and Boards should be encouraged to ensure this is integral in all the services they provide.

- Patient advice and support service
  
  - ‘.. the patient advice and support service is to promote an awareness and understanding of the rights and responsibilities of patients’

Any written information should be ‘patient friendly’ and patients should be given the opportunity to meet face to face with someone from the service to ensure they fully understand their rights and responsibilities.

- Patients’ Rights Officers

CHSS welcomes the introduction of this role and would propose that monitoring of the consistency and quality of implementation, especially whilst in its infancy. The Patients’ Rights Officer should be an empathetic, knowledgeable individual who can help the patient ‘dissect’ their experience to ensure the NHS gain full understanding of the feedback being offered.

David Clark  
Chief Executive  
Chest, Heart & Stroke Scotland  
13 May 2010
Patient Rights (Scotland) Bill

Children in Scotland

Introduction

Children in Scotland is pleased to take the opportunity to submit evidence on the Patients’ Rights Bill. We would like to reiterate the concerns we expressed in our comments on the original consultation paper, which I have attached for information. We believe the Bill is capable of improvement in respect of addressing the particular situation of children and young people. Specific reference to the position of children and young people in the Bill would be welcome; while clarification of the rights of parents and carers to act on behalf of a child would be helpful, the capacity of a child to exercise their rights as a patient independently of the parent is also of great importance.

Children in Scotland, along with our equivalent agencies in the other UK administrations, was recently asked by the General Medical Council to assist, with the direct involvement of young people, in producing material to make young people aware of their rights as patients. Below is a link to the poster they developed. Material of this type should be developed in conjunction with the Bill, to ensure that the rights it confers are well known and understood.

http://www.gmc-uk.org/guidance/children_and_young_people.asp

The UN Convention on the Rights of the Child recognises the right of every child to ‘the highest attainable standard of health’, and states that governments should ‘ensure that no child is deprived of his or her right of access to health care services’ (Article 24). Articles 3 and 12 state respectively that public services should ensure that ‘the best interests of the child shall be a primary consideration’, and that ‘the views of the child are given due weight’ in any proceeding affecting them. As the Scottish Government is committed to the implementation of the UNCRC, it seems appropriate to reflect this in the legislation.

Comments on the original consultation paper

Children in Scotland represents over 450 statutory, voluntary and professional organisations concerned with promoting the best interests of children and young people. We welcome the opportunity to comment on the proposed Patients’ Rights Bill. We have chosen to respond by letter as we wish to make some general comments on how the needs of children and young people are reflected in the proposal.

1. **There is no specific reference to, or consideration of, children and young people in the document.** While we support the general direction and underpinning principles of the proposals, we believe that there would be practical problems in making these meaningful for children without clearer direction and duties. It is essential that information that enables children and young people to exercise rights and choices consistent with good practice and their legal entitlements
is made available directly to them, using methods that are appropriate to their age and stage of development.

2. **It is essential to ensure that children and young people are informed about, and enabled to exercise, their proposed rights when they are patients.** It should not be assumed that: (a) the interests/decisions of children will always coincide with those of their parents/carers; or, (b) parents/carers will always have the capacity or willingness to ensure that the rights of children and young people as patients are safeguarded fully and effectively in practice.

3. Guidance should be developed for health and other relevant professionals as to effective communication, meaningful consultation processes and active partnership with children as patients. The implications of the law as it applies to different ages and under various legal circumstances (e.g., looked after children) should be an essential component of this guidance.

4. Advocacy services or other support to ensure access to (and proper provision of) appropriate services should be available to parents/carers on behalf of young children or those unable to represent their own interests effectively— as well as directly to competent young people.

5. In relation to patient responsibilities, such as keeping appointments, it must be recognised that children will not always be able to discharge these responsibilities independently of their parents. It is likely that the families who will have most difficulty in fulfilling these obligations are those who experience greatest social and economic disadvantage. It is vital that children are not denied access to essential health services as a consequence. This means that delivery methods should be considered such as provision of clinics in local health centres, home visiting and school based services. Where appropriate such issues should be considered within the *Getting it right for every child* (GIRFEC) framework.

6. The particular situation of children should be carefully considered in relation to issues of: access to records; privacy and confidentiality; data-sharing; informed consent; and, choice about treatment.

7. Opportunities to complain or to comment on care, both in terms of individual experience and in general, should take account of the particular needs and perspectives of children and young people.

8. Before legislation is drafted, it would be productive to consult with and involve children and young people in a *meaningful* manner about how they would best benefit from the proposals.

Marion MacLeod  
Senior Policy and Parliamentary Officer  
Children in Scotland  
13 May 2010
Patient Rights (Scotland) Bill

COSLA

Introduction

1. COSLA, as the umbrella organisation representing all 32 of Scotland’s councils is pleased to have the opportunity to submit written evidence to the Health and Sport Committee on the Patient Rights (Scotland) Bill. This submission has been informed by the views of member councils, but does not attempt to summarise those individual views.

2. In the time available it has not been possible for the matter to be debated by COSLA’s Health and Well Being Executive Group and as such this submission is made with the proviso that members of the Group may wish to make additions/amendments when it meets on 20 May.

Principles

3. The general principle of the Bill, of increasing the degree of patient participation, is welcomed. COSLA is committed to empowering individual citizens to engage and influence the delivery of key services, both within councils and Scottish civic society more generally. Insofar as the Patient Rights (Scotland) Bill has the potential to improve accountability to patients within the NHS, we believe that it should be welcomed. It is right that patients, families and carers should have a clearer understanding of their responsibilities and rights in order that they can take full advantage of the support and care offered to them.

Challenges

4. At the same time, COSLA has a number of concerns relating to the Bill, specifically in relation to guaranteed treatment times and the inflexibility this could create with respect to the management of resources.

5. Councils and Health Boards are together facing intense resource pressures, which will make it difficult to deliver key policy objectives, including our ambition to shift the balance of care from institutional to community settings. An effective shift in the balance of care is predicated on a capacity to disinvest in acute hospital care in order to reinvest in community health and social care.

6. However, that ambition is being curtailed by the fact that NHS Boards are having to channel resources to competing priorities. Specifically, prior to any resource transfer decisions, Health Boards will be required to fulfil their statutory duties, meet HEAT targets, invest in the future hospital estate, find additional Cash Releasing Efficiency Savings to tackle growing funding pressures, and fund pay progression,
advancements in clinical practice and medication, and new technologies.

7. COSLA is concerned that guaranteed waiting times, when combined with current financial pressures (projected to last for another decade) and an increase in demand (as a result of our ageing population), could act as an additional barrier to reform and will only serve to draw resource to the acute sector. NHS Boards, given the proposed statutory duty, will of necessity look to satisfy treatment time requirements before addressing competing priorities. It could lock NHS Scotland into the continuation of a model of health provision which largely serves to deal with the consequences of poor health.

8. We are further concerned that it removes the flexibility of NHS Boards to address need in innovative ways and improve outcomes. The Bill focuses on inputs and outputs. COSLA would hold that we need to drive forward the outcomes agenda, particularly as we look to embed Single Outcome Agreements. Centrally driven targets and commitments can make an integrated effort around delivering priority local outcomes more difficult.

9. Finally, the Financial Memorandum states that the Scottish Government does not anticipate any additional costs falling on local authorities as a consequence of the legislation. We feel this misses the point. As we move towards integrated budgets, adopting a more holistic approach to the management of resources across health and social care, if finances become locked into supporting acute sector targets, there will be less money in the overall pot to direct towards community support. Every policy and spending decision within the health and social care environment has an opportunity cost. More money spent on guaranteeing treatment times means less money spent on, say, community healthcare or family health services. If we continue to invest in the acute sector, then we continue to miss the opportunity to reform our health and social care system, which is unsustainable in its current form. We urgently need to shift resources towards early intervention and prevention, and guaranteed treatment times only serve to make that ambition more difficult to achieve.

Oral Evidence

10. COSLA would be pleased to amplify this submission at an oral evidence session if this would be helpful.

Sylvia Murray
COSLA
13 May 2010
17 June 2010

The Clerk
Health and Sport Committee
Scottish Parliament
Holyrood
EDINBURGH

Dear Sir/Madam

PATIENT RIGHTS (SCOTLAND) BILL

I refer to COSLA’s evidence submission in relation to the Patient Rights (Scotland) Bill and am pleased to confirm that this has been endorsed politically by our Health and Well Being Executive Group.

In confirming their support for the submission, members stressed their view that according rights to patients should not obscure the fact that patients themselves had certain responsibilities. One example is that of keeping appointments. Missed appointments are a serious problem for Health Boards across Scotland; rescheduling them incurs staff time and increases waiting times generally.

I should be grateful if this point could be added to our earlier submission.

Many thanks.

Yours faithfully

Sylvia Murray
Policy Manager
Patient Rights (Scotland) Bill

Diabetes UK Scotland

Diabetes UK Scotland is one of Scotland’s largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without diabetes through care, research and campaigning. With a membership of over 11,000, including over 600 health care professionals, Diabetes UK Scotland is an active and representative voice of people living with diabetes in Scotland. We welcome the opportunity to submit evidence to the Health & Sport Committee on the Patient Rights (Scotland) Bill.

Facts about Diabetes

- There are over 228,000 people with diabetes in Scotland, over 4% of the population.¹
- Diabetes is set to increase. It is predicted that diabetes prevalence will double world-wide, rising to at least 5% by 2010, accounting for 300,000 people in Scotland²
- Diabetes affects the young and old, and has particularly poor outcomes in those of lower socio-economic status and in those from black and minority ethnic groups³,⁴
- The number of people with diabetes is growing as a proportion of all long-term conditions⁵
- People with diabetes, who comprise about 5% of the general population, occupy 10 –15% of hospital beds

Summary of Main Points

- We welcome the main principles of the Bill, in particular those relating to access to health care which is patient focused and healthcare which provides optimum benefit
- We welcome the proposed waiting guarantee but suggest that more clarity is needed in relation to its scope
- Enforcement and feedback mechanisms are welcome but there are significant concerns about additional bureaucracy arising from a Patient Advice and Support Service and Patient Rights Officer posts

Background

As part of our preparation for this submission we undertook a short survey by email of members/supporters. 40 individuals completed the survey, 37 of whom had diabetes. The survey and its results are not being presented here as a scientific measurement of opinion. However, the results, including direct statements from individuals, present a picture of patient opinion and portraits of individual patients in relation to possible new rights. We have also drawn on the data generated by an extensive patient consultation carried out in 2009 in preparation our submission to the Better Diabetes Care consultation.
Patient Rights: Principles and Criteria
People with diabetes, patients’ organisations and healthcare professionals attach significant expectations to the delivery of diabetes care standards through, for example, the implementation of the Scottish Diabetes Framework and subsequent Action Plans, Clinical Standards and SIGN Guidelines. Standards relating to patient access to clinical review, information, patient education and clinical management of complications have formed a raft of quasi-rights and are now significantly embedded in the patient/service relationship. More recently, the NHS Quality Strategy has been developed to ensure that quality care, including patient experience of care, is embedded across NHS provision. The Quality Strategy will be a key component of the forthcoming Diabetes Action Plan. It is in this context that legislation for patient rights needs to be understood and against which the key principles of the Bill need to be set.

Patient views:

“The right to be treated as an individual rather than one of the pack. Diabetes is unique to each person who has it”

“The right to be listened to by diabetic consultants/nurses as they sometimes dictate to the patient and tell them they are doing things the wrong way. The person who only really understands their condition is the diabetic and they know only too well the good days and the bad days and what to do to fix it. Some consultants/nurses talk to you like you are a 5 year old when in fact I am 53 years old and have had diabetes since I was 10 so I think what I am saying is a bit of respect for the patient would not go amiss”

“The right to have access or consideration for the best personal treatment option irrespective of Healthcare guidelines/procedures, i.e NICE Guidelines for insulin pumps. The right to be treated with respect by healthcare professionals to work with patients, not to lecture them”

The patient feedback we received prioritised two areas where rights would be most valued: for health care to be patient-focused and for healthcare to provide optimum benefit to the patient. Over half of patients responding to our survey prioritised the latter. At present both of these rights are open to wide interpretation. However, it is clear that people with diabetes value respect and mutuality as cornerstones of care. As such, the implementation and enforcement of rights is about cultural shifts as much as it’s about systemic and institutional change. The work on capturing and focusing patient experience on service change in initiatives like Better Together is a
fundamental part of the patient rights process and needs to be formally tied in to the Patient Rights (Scotland) Bill.

Waiting Time Guarantee
Diabetes UK Scotland welcomes the commitment in the Bill to establishing a waiting time guarantee. We can see real potential, for example, in the application of the guarantee to patient access to structured patient education. This would go to the core of the kind of cultural change which the measures are designed to deliver, i.e. to categorise an intervention like patient education as, in effect, treatment and to fully incorporate it in to a system of service guarantee.

Patient views:

“It must be reduced from 12 weeks for cancers and other potentially life-threatening conditions”

“I find 12 weeks too long”

“I don’t know about this as surely it depends on what the treatment is for”

“In some cases the time frame should be quicker”

“If you are quite ill you need treatment quicker than 12 weeks I’d think”

“Delays in the past in diagnosing my diabetes resulted in my losing mobility in both legs (neuropathy) and total loss of sight on one eye”

“To ensure a patient receives treatment within a suitable timescale to prevent an onslaught of problems as a result of the initial problem which if treated sooner would not become severe”

“Actually in my practice...I am seen on a very regular basis by Practice Nurses, Podiatrist, Retinopathy Clinic and Doctor”

Over half of patients in our survey welcomed the waiting time guarantee and around a third didn’t know. Only a handful rejected the idea. However, the main concern expressed by a number of patients was in relation to the need for quicker access when clinical need demanded it. It is important, therefore, that the intention of the Bill to create a basic right to access does not become a barrier to quicker access based on clinical need.

Management of diabetes is, in practice, about optimum self management and this in turn is based on access to patient education. The development of a waiting time guarantee is an opportunity to systematically drive forward the patient education agenda by including patient education in the guarantee itself. The principles laid down in the Bill seem to be consistent with this; however, future policy guidance should reflect specifically on ‘non-clinical’ areas where the guarantee would apply.
Complaints
Diabetes UK Scotland supports the right to independent support and redress and would emphasise feedback and learning as opposed to complaints and blame. No respondent to our survey prioritised access to complaints processes in the proposed patient rights. This may be because the experience in diabetes care over the past 8 years in Scotland largely demonstrates a culture of feedback and learning through local managed clinical networks, the Scottish Diabetes Group and its various sub groups and patient group activity at a local level. Whilst the mechanisms for complaints and feedback are important, the emphasis needs to be on developing mutuality between service users and the NHS. The framework for patients’ rights should reflect on best practice in this area in order to engender a positive culture.

Patient Advice Service and Patient Rights Officers
This is possibly the most contentious set of proposals in the Bill. Although feedback from our survey had just over half of respondents saying yes to the new service, just under a third rejected the idea and it was also the area where there was a larger share of direct comment.

Patient views:

“Just sounds like more waste of NHS funding, if this is an administrative job, if it is a role that will help people, then OK but if it is just a job that fills a limited role and is for show purposes, rather than substance, then it is pointless”

“I suppose hardly anyone would say no to this. However it sounds expensive to run properly, could be swamped, and therefore ultimately of little practical use”

“Better to have more medical staff than bureaucracy”

“Information/guidance should be given from the relevant healthcare agency, GP, clinic, etc rather than have specific jobs created. The creation of a new service and related jobs to support this bill is excessive for an already overstretched NHS service. The only requirement for an Officer would be to deal with complaints which people may not feel comfortable approaching their own healthcare team to deal with”

“Many patients are not aware of the support they are entitled to and it would be a good thing to have someone who knows what to ask for and what we are entitled to”

“This will create a new management post and I think the money would be better spent on front line services”

“This is going to create more admin, more forms, how accessible will these P.R.Os be – how quickly will they be able to resolve any problems?”

“This is going to create more admin, more forms, how accessible will these P.R.Os be – how quickly will they be able to resolve any problems?”

“Do we need another level of Administration? Is the Health Service not already top heavy with non essential groups and not enough actual carers, ie Doctors and nurses etc”
Careful consideration needs to be given to the balance of the proposals in the Bill. As drafted, the role of Patient Rights Officers may be predominantly focused on processing complaints rather than enabling the vital cultural change in the NHS which will deliver real patient rights. Of course, the Bill only outlines in very broad terms the proposed new service. However, a community development model, prioritising the skilling up of groups and communities of patients and healthcare staff, could offer a more effective basis of any new service, whether based within the health service or, possibly, in the voluntary sector. This section of the Bill needs in-depth investigation and consideration with a particular focus on the balance of compliance, advocacy, advice and information and how these are best delivered.

**Access for Marginalised Communities**

People on the lowest incomes are around twice as likely as those on the highest incomes to develop Type 2 diabetes. The prevalence of diabetes in the most deprived areas is over two thirds higher than the most affluent. Black and Minority Ethnic (BME) groups are at least five times more likely to develop diabetes than their Caucasian counterparts and BME groups are more likely to live in more deprived areas. Taking account of equality, diversity, economic and geographical issues is, therefore, essential. Patient and community organisations have the knowledge and expertise to help deliver the conditions for marginalised groups to access services. Consideration should therefore be given to specific measures being included in the Bill which match up to the needs of black and minority ethnic and other marginalised communities.

Alan McGinley
Policy & Public Affairs Manager
Diabetes UK Scotland
13 May 2010

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5 The impairments most commonly reported by adults with long-term health conditions were related to heart, blood pressure or circulation problems and to arthritis. The figures suggest that both heart problems and diabetes (especially the latter) have increased over time. For example in 2001-2002, 30% of adults with long-term health conditions reported that their condition was related to heart problems, while 8% were related to diabetes. The comparable figures for 2005-2006 were 35.5% for heart problems and 12.2% for diabetes. The Scottish Government Social Research, Characteristics of Adults in Scotland with Long-Term Health Conditions. 2007.
7 Scottish Diabetes Framework 2002. NHS Scotland
8 Scottish Diabetes Action Plan 2006
Patient Rights (Scotland) Bill

Faculty of Sports & Exercise Medicine

The Patient Rights (Scotland) Bill has been introduced to the Scottish Parliament and currently is open for consultation. One of the main principles of the bill is that patients will have the right to receive medical treatment within twelve weeks, eg, seen by a consultant or equivalent at a specialised out patient clinic following referral from primary care and to undergo the initial stages of treatment – the treatment time guarantee.

This is an admirable and commendable goal. Patients should expect a high standard of care within the Scottish Health Service and all policy and legislation aimed at improving the patient journey and standard of clinical care should be supported.

Standards or guarantees are however a double edged sword. They can be used to improve services and provide the information that these standards are being driven successfully. But they also highlight areas where clinical care is deficient and requires improvement.

Our remit with this response is to make comment upon the scope and standards of clinical care within the field of the newly recognised specialty of Sport & Exercise Medicine (SEM), which has the role of specialising in all non-surgical musculoskeletal injury and exercise related health issues.

Currently there is no provision within the Scottish Health Service for Sport & Exercise Medicine. There are no consultants practising SEM in substantive posts in Scotland. There are substantive consultant posts within NHS England & Wales and in the armed services. There are two recently appointed SEM Specialty Registrars in training within Scotland, both due to complete their training in 2012. Funding has been made available by the Scottish Government for the appointment of a further four registrars, two in 2010 and two in 2011. At this present time there is no defined commitment for these trainees to be employed within the Scottish Health Service to provide SEM services to the general public. Therefore employment within the private sector may be the only option for these registrars when their training is complete and they are recognised by the General Medical Council as specialists within this field.

If a patient presents to the general practitioner with a sporting injury, acute or chronic, or a chronic medical condition which would respond to an exercise programme (eg, obesity, cardiac disease, hypertension, osteoarthritis, diabetes, depression, to name a small few) then the only option is to refer to the existing secondary care structure. These are often inappropriate referrals and referred to the nearest related specialty. This would include orthopaedics, physiotherapy, rheumatology, cardiology, endocrinology, etc, resulting in a situation which is not ideal for the patient, is more costly and less effective in the quality of care provided. The only other option for a patient is to attend for treatment privately at a private sector hospital or a network of sports injury
clinics, either paying for treatment or claiming through health insurance policies.

These medical specialties already have difficulty in attaining targets for outpatient clinic referrals within the current systems. A treatment time guarantee of 12 weeks will only place these specialities under increasing pressure and the patients with an SEM problem may be placed at a further disadvantage in the clinical appointment pecking order.

In addition, with the drive in a modern health service for preventative medicine, SEM is ideally placed to influence the health of our Nation. Current evidenced-based practice confirms the role of physical activity in the prevention of disease, not least in attempting to influence the adverse effects of the rising levels of obesity and consequent health issues in our young people. No current medical specialty is able to provide this overall expertise. If the aim of a health service is to provide the patient with direct access to specific specialists and the best quality of care available, then all parties in Scotland, inclusive of medical, NHS management and government, have a duty of care to provide this. The introduction of a consultant delivered SEM service within the Scottish Health Service would provide the following benefits:

- The rapid access to definite care for patients with a SEM problem, either acute/chronic musculoskeletal injury or chronic medical disease.
- Provide patients with direct access to quality specialist treatment.
- Ease the burden of time pressure on other medical specialties that currently manage these patients within their own existing framework.
- Facilitate the implementation of the 12 week treatment time proposed by the Patient Rights (Scotland) Bill.

We hope the above comments are of benefit and are happy to provide any other information should this be required.

Dr Stephen Boyce & Dr John MacLean
Scottish Representatives
Faculty of Sport & Exercise Medicine
10 May 2010
Patient Rights (Scotland) Bill

General Dental Council

The General Dental Council (GDC) welcomes the opportunity to respond to the Scottish Parliament’s Health and Sport Committee call for written evidence on the general principles of the Patient Rights (Scotland) Bill. The GDC is the organisation which regulates dentists, dental nurses, dental technicians, clinical dental technicians, orthodontic therapists, dental hygienists and dental therapists in the United Kingdom. As part of this role, we:

- register qualified professionals;
- set standards of dental practice and conduct;
- assure the quality of dental education;
- ensure professionals keep up-to-date;
- help patients with complaints about a dental professional;
- are working to strengthen patient protection.

The GDC support the patient rights and health care principles as set out in the bill. The GDC’s own ethical guidance Standards for Dental Professionals relates well to the Health Care Principles in the Bill, both of which should work together well to increase patient protection as well as raising standards in health care.

Patients, and the standard of care they receive, are at the forefront of the GDC’s work. Timely access to appropriate treatment is important in raising the level of care that patients receive, and the 12 week treatment guarantee in the Bill will be a potential means to achieve this.

The complaints and patient feedback system set out in the Bill will also complement the GDC’s own guidance on complaints handling and professionalism. The need for appropriate and efficient processes to be in place in order that issues can be resolved quickly and at as early a stage as possible are key parts of the GDC’s guidance in this area. The work of Patients Rights Officers and the patient advice system should be a key asset in the assistance of patients in this area. It is important that there is an awareness of the GDC’s work and procedures, among Patient Rights Officers and in the workings of the patient advice system, so that there is a smooth and workable relationship between the two.

The GDC is keen to engage with the patient advice system and Patient Rights Officers through our Director of Scotland.

Ian Jackson
Director for Scotland
General Dental Council
12 May 2010
Patient Rights (Scotland) Bill

Medical Protection Society

The Medical Protection Society is the leading provider of comprehensive professional indemnity and expert advice to doctors, dentists and health professionals around the world.

We are a mutual, not-for-profit organisation offering more than 265,000 members help with legal and ethical problems that arise from their professional practice. This includes clinical negligence claims, complaints, medical council inquiries, legal and ethical dilemmas, disciplinary procedures, inquests and fatal-accident inquiries.

Fairness is at the heart of how we conduct our business. We actively protect and promote the interests of members and the wider profession. Equally, we believe that patients who have suffered harm from negligent treatment should receive fair compensation. We promote safer practice by running risk management and education programmes to reduce avoidable harm. In Scotland, we represent over 700 doctors, dentists and students.

MPS is not an insurance company. The benefits of membership are discretionary - this allows us the flexibility to provide help and support even in unusual circumstances.

General Comments

MPS welcomes the opportunity to comment on the Patient Rights’ (Scotland) Bill which introduces a legal waiting time guarantee and a legal right to complain for users of the NHS in Scotland.

Our comments are set out below:

Treatment Time Guarantees (TTG)

We note that Section 6 (1) and (2) establishes the treatment time guarantee which is intended to insure that patients start to receive treatment within 12 weeks; yet there is no corresponding sanction to ensure that this occurs in practice. Any breach of the treatment time guarantee merely requires the relevant body to apologise and make arrangements to ensure treatment starts at the next available opportunity. Although we very much welcome the government’s focus on improving the patient experience we question how effectively the Bill if implemented as proposed will achieve this in relation to the TTG.

Complaints

We very much agree that in terms of complaints, patients have the right to know what to expect from their healthcare provider and what remedies are
available if they do not receive the level of care that they expect. In our experience, an open and thorough response to a complaint can prevent unnecessary escalation, which is distressing and stressful for patients and doctors alike. We also recognise that patient feedback provides an important means of improving quality.

As we understand it from the explanatory notes to the Bill, the government does not expect that the increase in enquiries about complaints that will follow publication of the Bill will put additional pressures on GP practices or dentists. MPS would expect there to be some increase and would advise the government to encourage practices to contact their respective medical defence organisations for further advice and support.

**Duties to share information**

Section 17 (1) (c) stipulates that a relevant body must supply any information ‘on relevant matters’ requested by the patient advisory and support service. Although we note that Section 17 (3) lays down conditions to protect patient confidentiality we would emphasise that the requirement at Section 17 (1) (c) should not include legal and other advice obtained by doctors from their medical defence organisations.

In conclusion, we will follow the Bill’s progress through parliament with interest and would welcome the opportunity to share with the government our work on advising doctors, dentists and practice managers on all aspects of the complaints process.

**FURTHER INFORMATION**

Please do not hesitate to contact me if you require any further information or clarification on the issues raised in this response.

Rob Hendry  
Head of Medical Services (Edinburgh)  
13 May 2010
Dear Mr & Mrs Committee

It was good to get to the meeting re Patients’ Rights last evening, but I came away with a feeling that there was some need for reference to the way in which folk are not entirely constant and predictable etc. Things can go wrong with even normally able and intelligent and informed people like someone I’ve met who had sudden seizure leaving her sort of stunned and unable to sort out what was really her position in hospital etc... she felt her brain was seriously injured but felt somehow was not getting what she needed to get better and in the end the specialists did change her medication and she was at last able to ‘recover’ And of course many of us can have temporary problems be it memory loss/muddled thinking/ failing to understand what might be easy enough for others difficulties due to hearing/vision etc and so are not able to get clear enough view of what needs to be taken into account etc, Can we not get provision for somehow ensuring what help can be given to those who need it, not formal advocacy or routine practice attention... a sort of contact with whoever can figure out what should be done, be it personal or technical? Aid didn't seem to be clearly included.
Also as I said last night there seemed to be no reference to dying well: I’ve been in touch with not just Margo Macdonald but friends who have similar feelings... they’ve had enough etc. Care in this sense surely we should include also in the proposals being put forward!
Yes, of course, it's right to say it's not a charter for lawyers, but we do need to ensure we're including what we need as patients... I don’t mean as consumers but just human beings!

This is a note I sent to Pat Straw, our Head of Patient & Public Partnership, NHS Lothian University Hospitals Division and now a bit revised for submission to the Scottish Parliament Health and Sport Committee... and I'll send copies to her and the two speakers we had there; James and Sarah, and I'll send a copy to Nurch surgeon who also 'knows' me!

Yours, Ian Melville (known as Melly), member of PPP, City of All ages OF adv. Group, etc, age 91, ex-prof TC Plng. one-time architect, engineer, surveyor, teacher of plng etc, etc.

Mr Ian Melville
2 May 2010
Patient Rights (Scotland) Bill

NHS Highland

Sections 1-5
We support the reinforcement of existing patient rights and healthcare principles, and the general aims to improve patients’ experiences of care and raise the sense of co-ownership of NHS Scotland.

The Bill reflects the desirability of patients accepting greater responsibility for their own health and their use of health services. It also reflects the importance of reciprocal dignity and respect as a fundamental principle in every individual interaction between patients / their carers or families and healthcare staff.

Whilst the Bill states these clearly as patient rights, it does not directly strengthen the associated responsibilities, and we suggest there is a need for further, complementary work to state more clearly the Scottish Government’s position on the responsibilities of NHS service users.

Sections 6-10
The Treatment Time Guarantee represents an understandable aim for patients. However we are concerned that the impacts have not been considered fully, and that this guarantee will act against the best interests of some patients.

Introducing the 12 week TTG within the existing 18 week referral to treatment target will mean that patients with simpler conditions - who have had a relatively straightforward diagnosis and the decision for treatment made early in the 18 week period - will have their treatment completed ahead of those with more a complex diagnosis, and whose clinical needs may be greater. This is in direct conflict with the Scottish Government’s requirement for NHS services to provide healthcare according to clinical need.

We would urge further consideration of the TTG so that patients do receive treatment according to their needs, and so that clinicians maintain some flexibility to balance the needs of their individual patients, within the overall referral to treatment target.

We would support a maximum treatment time guarantee for all patients whose pathway could not be completed within the 18 week referral to treatment target.

Sections 11-17
We support fully the rights of patients to provide feedback on services and to make a complaint, and believe that the shift to a Patient Advice and Support Service is a positive step.

Roger Gibbins
Chief Executive
NHS Highland
11 May 2010
Patient Rights (Scotland) Bill
Office of the Public Guardian

Re Section 1(2)(a)
To be consistent with other legislation e.g. the Adults with Incapacity (Scotland) Act 2000 it is proffered that the “wishes” of the patient, as well as their needs, should be taken into account.

Re Section 1(2)(b)
It should be noted that, on occasions, there may be tension between the “optimum benefit” [to the patient’s health and well being] and the patient’s wishes.

Re Section 1(3)
In the case of an incapable adult who has an appointed proxy (attorney or guardian) does the right to complain extend to their proxy, assuming the proxy has been granted the necessary powers?

Re Section 12(1)
Does the encouragement to raise concerns extend to a proxy on behalf of a patient, where the patient is an incapable adult with a duly appointed proxy?

Sandra McDonald
Public Guardian
Office of the Public Guardian
27 April 2010
Patient Rights (Scotland) Bill

Rarer Cancers Foundation

Introduction

The Rarer Cancers Foundation (RCF) offers advice and information to people with rare or less common cancers and to their families and friends. The charity facilitates supportive networking, raises awareness of rare and less common cancers and works to ensure that people with rarer cancers have access to the best possible services. Although ‘cancer’ is a unifying word, there are as many differences between types of cancer tumour as there are similarities. Between 30% and 50% of all cancers can be classified as ‘rarer’. A cancer may be classed as rare either because it affects an unusual site in the body, or because the cancer itself is of an unusual type, is difficult to diagnose, or requires special treatment.

We have undertaken a great deal of research into the issues that patients with rarer cancers face in gaining access to high quality services. We published Exceptional Scotland? An audit of the policies and processes used by NHS Boards to determine exceptional prescribing requests for cancer treatment in March 2009. This report revealed significant variations in the processes used by NHS Boards in making decisions on the availability of cancer treatments, many of which are relevant to the Patient Rights (Scotland) Bill. Our research has been referenced by the Health Secretary in the Scottish Parliament and has formed the basis of some of the Public Petition Committee’s ongoing work on access to cancer medicines.

Comment on intention of Bill

We welcome the intention of the Patient Rights (Scotland) Bill to establish clearly defined standards of services. We believe the Bill provides a valuable opportunity to provoke a debate on the standards of care that patients should have a right to expect. The Bill also has the potential to stretch the standards of NHS cancer care, ensuring that Scottish cancer patients receive services comparable with the best in Europe. However, the Bill, as currently drafted, misses a number of important opportunities. We would urge the Health and Sport Committee to examine these issues and make recommendations about how the Bill could be improved. Below we set out our response to the sections of the Bill and the healthcare principles it establishes:

Comment on the patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill

We support the inclusion of a set of health care principles and the fact that these principles address the rights and responsibilities of both patients and health professionals. However, we do have concerns that the rights and
principles in the Bill, as currently drafted, do not address some of the issues which cause anxiety for cancer patients:

- The Bill does not establish a principle that all patients should have the right to be diagnosed at the earliest possible opportunity. Establishing such a principle would help focus the attention of NHS Scotland on the importance of encouraging early diagnosis.

- The Bill does not clarify that all patients should be entitled to treatments accepted by the Scottish Medicines Consortium. Our research has found that many NHS boards are not routinely making available cancer treatments which have been accepted by the SMC, creating an unnecessary and time consuming additional for patients. Amending principle 9 (“Health care is based on current recognised clinical guidance”) could address this problem.

- The Bill fails to reinforce the importance of rational, transparent and timely local decision making for those treatments which have not been SMC approved and as such is a missed opportunity to reaffirm the principles set out in the guidance issued to local health boards on the subject. Our research, published in Exceptional Scotland?, found concerning inconsistencies in local processes, many of which have little or no scope for expert clinical input. This needs urgently addressing if the confidence in the NHS of patients with rarer cancers is not to be undermined. Amending principle 15 (“Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures”) to explicitly reflect this guidance would be helpful.

- The Bill does nothing to ensure that patients with particularly rare conditions are not disadvantaged purely on the grounds of the rarity of their disease. For very rare cancers, it may not be possible to secure a licence for medicines. In these circumstances clinicians may opt to use a medicine licensed for a more common form of cancer which has a similar biology of disease to the cancer in question. This is known as ‘near-label’ treatment. Our research has revealed that NHS Boards can find it difficult to make informed decisions about such treatments, which will require specialist input. Establishing a principle on this issue would help motivate NHS Boards to put in place collaborative expert-based processes to assess near-label requests.

Further to these issues, we support principle 16 (“Waste of resources in the provision of health care is avoided”). We believe that introducing more streamlined, rational and transparent processes for local decision making could help to reduce bureaucratic processes. Our research has found that there are almost twice as many exceptional cases requests made per head of population in Scotland (11.5 per 100,000 population, per year) than in England (6.0 per 100,000 population, per year). Although work is needed to understand the reasons for this difference, it will, have a clear impact upon the bureaucratic burden on NHS Boards.
The treatment time guarantee

- The referral to treatment guarantee is not appropriate for the majority of cases of cancer. The 12 week period is too long for patients requiring urgent investigation and/or treatment, including potentially curative interventions such as surgery. The guarantee as currently drafted could actually lead to clinical standards slipping and therefore damage patient outcomes. There is also a danger that such a guarantee could have the perverse consequence of diverting resources to the initial stages of treatment at the expenses of follow up interventions.

Conclusion

We welcome the introduction of the Patient Rights (Scotland) Bill and believe that, with sufficient scrutiny and some amendment, it could become a powerful mechanism for improving the quality of services and bolstering the confidence of patients and the public in the NHS in Scotland. We would welcome the opportunity to provide further evidence if the Committee would find this helpful.

Andrew Wilson
Chief Executive
Rarer Cancer Foundation
8 May 2010

\(^{1}\) RCF, Exceptional Scotland? An audit of the policies and processes used by NHS Boards to determine exceptional prescribing requests for cancer treatment, March 2009

\(^{2}\) RCF, Exceptional Scotland? An audit of the policies and processes used by NHS Boards to determine exceptional prescribing requests for cancer treatment, March 2009

\(^{3}\) RCF, Exceptional Scotland? An audit of the policies and processes used by NHS Boards to determine exceptional prescribing requests for cancer treatment, March 2009

\(^{4}\) RCF, Off limits - An investigation into how NHS organisations determine requests for the use of off-label treatments for cancer patients, August 2010

\(^{5}\) RCF, Exceptional Scotland? An audit of the policies and processes used by NHS Boards to determine exceptional prescribing requests for cancer treatment, March 2009
Patient Rights (Scotland) Bill

Roche Products Ltd

Roche is a leading manufacturer of innovative medicines, including in oncology, rheumatology and virology. We have expertise in a wide range of medical conditions spanning both primary and secondary care. As such we collect a good deal of intelligence on emerging issues and challenges for health service delivery in Scotland, as well as which initiatives are successful in addressing them. We are committed to working in constructive partnership with NHS Scotland, as well as health policymakers and stakeholders.

We welcome the introduction of the Patient Rights (Scotland) Bill as a positive step forward in defining patients’ rights to treatment and care within NHS Scotland. The challenge will be in ensuring that all patients in Scotland are able to avail themselves of their rights, and that sufficient attention is given to the implementation of these rights and responsibilities at a local level. This will need to include adequate monitoring and outcomes measurement to ensure that every NHS organisation offers uniformly high standards of service.

We broadly support the measures contained in the Bill, however we believe that reference should also be made to delivering safe and high quality services, ensuring that these important health themes are at the heart of NHS Scotland.

Below we set out our response to the sections of the Bill and the healthcare principles it establishes:

The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

Health care principles:

We support the inclusion of a set of health care principles and the fact that these principles address the rights and responsibilities of both patients and health professionals; however, we feel that at present the health care principles are disproportionately focussed on secondary care. Consideration should be given to ensuring that patient experience and quality of health services in primary care are also reflected. Primary care is often where patients first access the system and where important early diagnosis and referral occurs. Consequently, the health care principles should include a responsibility on health care professionals to provide access to diagnostic tests, and the results of these, without delay.

We would like to make specific comments about individual principles. We have grouped the health care principles thematically in our response:
1. Anything done in relation to the patient takes into account the patient’s needs
6. The patient’s abilities, characteristics and circumstances are considered

These are crucial principles of health care, which recognise patients as individuals requiring personalised care. Patients’ needs vary according to the type of health problem or disease and one pathway may not suit another patient.

There is some evidence that health care delivery does not take into account patients’ unique needs at present. For example, there is evidence that older people with cancer have a higher mortality rate, lower survival rate and are less likely to be offered the latest treatments\(^1\). It is important, therefore, that information is captured to ensure that treatment is provided in accordance with the provisions of the Patient Rights (Scotland) Bill. In this example, providers should be required to report that they are providing care to patients according to an assessment of their physical fitness – rather than determining care solely on the basis of chronological age.

2. Patients are treated with dignity and respect
3. Privacy and confidentiality are respected
4. Health care is provided in a caring and compassionate manner

We support the inclusion of these principles in the Bill.

5. Support necessary to receive or access health care is available

We have two points to make in relation to supporting patients to receive or access healthcare services in an equitable manner, which we believe is imperative.

- It is important to note that certain groups of patients – for example, injecting drug users – are less likely to access health services and therefore require more support to do so in an equitable manner. We would welcome comments from the Scottish Government as to how they intend to make these principles a reality for vulnerable and hard-to-reach groups of patients, particularly given that conditions affecting injecting drug users, such as hepatitis C, can be serious and communicable – but ultimately treatable.

- Some groups of patients – for example, those with rheumatoid arthritis – can be diagnosed too late for the most effective care to be provided.\(^2\) We believe, therefore, that the “support necessary to receive or access health care” should be extended to take account of when patients should access healthcare – for example, when symptoms develop which might indicate a serious condition. In relation to rheumatoid arthritis for example, an awareness campaign targeted at those aged between 40 and 60 has
recently been recommended by the National Audit Office for the NHS in England. We believe such awareness campaigns could also be covered by the provision of the Bill.

7. **Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing**
8. **The range of options available in the patient’s case is considered**
9. **Health care is based on current recognised clinical guidance**

Roche supports the role of the SMC in recommending medicines for use in the NHS in Scotland. However, it is important to note that no legal right to SMC-approved medicines exists in Scotland, as it does for NICE-approved treatments in England. We believe that the Bill is an important opportunity to legislate to ensure that SMC guidance is made mandatory in the NHS in Scotland – a position entirely consistent with principles #7, #8 and #9.

In addition, we should like to highlight that for some patients - particularly those with rarer diseases such as rare cancers - clinicians can be prevented from prescribing drugs that in their clinical judgment would have a good impact on the patient’s quality of life and even prolong that patient’s life.

In its report *Exceptional Scotland*[^3], the Rarer Cancers Forum identified an average of almost 600 cases each year where patients had to pursue exceptional prescribing requests in order to get access to drugs that were recommended by their clinician. In some cases these requests applied to drugs that were already approved by NICE and the SMC for a different indication.

The Scottish Government’s response to the Public Petitions Committee’s report on exceptional prescribing[^4] committed it to putting in place a system whereby:

- If a patient could derive demonstrable benefit from a drug, it should be available on the NHS; and
- Where a drug is not available on the NHS, it should be because it would not deliver sufficient benefit and not for any other reason

We believe these explicit principles – espoused by the Scottish Government – should be explicitly referred to in this section of the Bill.

10. **Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing**
11. **Patients are provided with such information and support as is necessary to enable them to participate in accordance with paragraph 10 and in relation to any related processes (general or specific)**
13. **Communication about a patient’s health and wellbeing is clear, accessible and understood**
14. Communication about general services and processes and decisions is clear, accessible and understood

Empowering patients through the provision of clear and accessible information is an important feature of a 21st century health service. We believe that there are current gaps in the information which patients should receive about treatment options and treatments, and would welcome the Scottish Government’s thoughts on how these information gaps might be plugged. They include:

- Providing information to patients on clinically-effective treatment options not normally funded by the NHS
- Providing information to patients on the operation of so-called ‘exceptional cases’ processes, which have been shown to operate in an occasionally irrational manner\(^5\) - including in relation to how decisions on individual funding requests are arrived at
- Providing information and support as necessary to access screening programmes, such as breast and bowel cancer screening

12. Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect

15. Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures

We support the inclusion of these health care principles in the Bill.

16. Waste of resources in the provision of health care is avoided

Roche contributes to improvements in Scotland’s health and the efficiency of service delivery through the development of new and more effective treatments in the fields of oncology, rheumatology and virology.

We have two observations to make in relation to the principle:

- Regional variations in the uptake of the most cost-effective medicines across Scotland, lead to variations in the efficiency of services. Uptake of cost-effective medicines should be as uniform as possible
- Medicines need to be delivered to patients at the right time to achieve the greatest cost-effectiveness. A recent National Audit Office report in England – in relation to services for people with rheumatoid arthritis – concluded that productivity gains could be secured by investing in services to diagnose and treat people with rheumatoid arthritis early\(^6\).
Patient rights:

We welcome the patient rights set out in the Bill. However, we believe that they suffer from vagueness, and would suggest that more specific rights are set out in the Bill. The NHS Constitution for England\textsuperscript{7} sets out a number of clear patient rights - including legal rights to treatment with NICE-approved medicines - and this could be a useful template for the enshrinement of similar legal rights in Scotland.

We would urge the Committee to consider developing the patient rights in the Patient Rights (Scotland) Bill so that they include more specific and measurable rights.

As stated above in relation to health care principles, we believe that the main areas on which specific rights could be included are:

- The right to immediate access to treatments that have been approved by the SMC/ NICE
- The right to be supported in accessing healthcare services in an equitable manner
- The right to information on accessing healthcare services
- The right to support to participate in national screening programmes

It will be important that rights established in the Patient Rights (Scotland) Bill are communicated effectively to patients and the general public. Specifically, plans should be put in place to work with different patient groups to interpret what the rights mean in practice to people with different conditions. We believe, therefore, that the Scottish Government should set out a clear statement for communicating the impact of the Bill to the public.

The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (sections 6 to 10):

We support the inclusion of a treatment time guarantee (TTG) in the Bill as a step towards reducing the time from referral to treatment for all conditions. However, we urge the Committee to review the TTG to take account of diseases and conditions where time is crucial to the success of treatment, quality of life and ultimately survival. For example, we support the two-week target from referral to treatment for cancer in England and the one-week target for diagnostic results. There is a strong relationship between early diagnosis and improved survival rates. Patients in Scotland should not have to wait longer than those across the border for the same crucial interventions.

For many non-cancerous conditions, good clinical practice (including NICE clinical guidelines) suggests referral times far shorter than 18 weeks. For example, in rheumatoid arthritis, the National Audit Office found that early diagnosis, referral and treatment significantly improves outcomes, often
halting the disease in its tracks before irreparable damage to joints occurs. Given this, we suggest that the Bill should make clear that patients who require treatment more rapidly than 12 weeks should not be disadvantaged as a result of the TTG.

The complaints and patient feedback system set out in the Bill (Section 11):

We do not have any comments to make on this section.

The patient advice system and the role of Patients Rights Officers (Sections 14-17)

We welcome the establishment of a Patient Advice and Support Service staffed by Patient Rights Officers (PROs). Some patients need more support than others in accessing the health care system including vulnerable patients such as injecting drug users. The Bill should include the expectation that PROs work with other professionals eg drug support workers to improve access to primary and secondary care for these people.

It is important that PROs are tasked with proactively communicating patient rights to the general public as well as responding to enquiries or working with current patients in order that people know, and are empowered to exercise, their rights when they require health care.

We also believe that every NHS professional should regard themselves as a champion of high quality standards in health, and therefore the health care principles set out in the Bill. We suggest that consideration should be given to including this responsibility in future staff contracts.

Mr Greg Stevenson
Senior Strategic Funding and Public Affairs Manager
Roche Products Ltd
12 May 2010

Mr James Woodhouse
Head of Public Affairs
Roche Products Ltd
12 May 2010

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1 Roche Products Ltd, Meeting the needs of older people with cancer: A report assessing what more can be done to tackle cancer in older people, December 2009
2 National Audit Office, Services for People with Rheumatoid Arthritis, July 2009
3 Rarer Cancers Forum, Exceptional Scotland?, March 2009
4 Scottish Government response to the Scottish Parliament’s Public Petitions Committee inquiry into the availability on the NHS of cancer treatment drugs, September 2008
5 Rarer Cancers Forum, Exceptional Scotland?, March 2009
6 National Audit Office, Services for People with Rheumatoid Arthritis, July 2009
8 National Audit Office, Services for People with Rheumatoid Arthritis, July 2009
Patient Rights (Scotland) Bill

Royal College of Physicians of Edinburgh

Patient Rights and Healthcare Principles

The College agrees that it is important for all patients to understand their statutory rights to treatment under the NHS. The College has previously expressed concerns about the potential distortion of clinical priorities through waiting time targets and is pleased to note sections 2 (2) (a) and (b) which balance the rights of individuals with the needs of other patients and require the guaranteed delivery of healthcare to be proportionate and appropriate to each case. It will be important that the impact of clinical priorities on all patients is made clear in patient information.

The health care principles listed in the schedule to the Bill are appropriate and consistent with the professional requirements of doctors. The College has concerns that some are aspirational given budget pressures and urges the government to ensure public expectations are managed carefully. The College also assumes that sections 1(2) (c) and (d) will be interpreted appropriately for paediatric patients and those with communication and other difficulties.

The College’s lay advisors, in commenting on the earlier consultation, are fully supportive of the principles but remain anxious about the financial impact of compensation on NHS budgets and the challenge of enforcing statutory rights fairly without introducing a culture of blame. The College notes that the Bill is silent on the question of a no fault compensation scheme at this time.

12 week treatment time guarantee

There are significant specialty differences in the impact of a 12 week treatment guarantee with many of the medical specialities focusing on acute and urgent care rather than elective treatment. The College welcomes the efforts to reduce waiting times for elective patients, providing new resources are available to support these guarantees and not diverted from the acute/emergency services. The College also welcomes the provision in sections 7 (2) and (3) for Scottish Ministers to determine which patients and treatments are eligible for the guarantee and interprets this to mean that the guarantee will not apply automatically to all patients immediately. The College would be keen to contribute to national discussions about prioritisation and any rolling introduction of the 12 week guarantee.

However the College is keen to ensure that medical patients, most of whom access services in an emergency, benefit from compliance with the 4 hour emergency access target. The College believes that service reconfiguration across Scotland may be required to secure high quality services within statutory guarantees and available budgets, and notes the absence of any references in the Bill to a right to care delivered close to home where clinically appropriate.
The College supports strongly the provision in section 8 (3) that prevents Health Boards giving priority to a patient under the treatment guarantee that may be detrimental to the clinical wellbeing of another patient. This protection of clinical priorities is essential. An example from our dermatology colleagues illustrates the importance of clinical priorities well – patients presenting with suspicious skin lesions will always be prioritised for surgical intervention over patients presenting with other (often cosmetic) lesions, which although less urgent clinically are of great importance to individual patients and the statutory 12 week treatment guarantee may raise expectations.

The College understands the importance of accurate measurement of performance against statutory rights and notes that these issues will be handled through regulations. The College would be pleased to contribute to discussions to resolve problems such as linked and inter-disciplinary referrals; again an example from dermatology illustrates the challenge with patients referred from dermatology to plastic surgery being monitored carefully against targets for malignant melanoma but not for other conditions.

Finally, to achieve these targets it will be essential to review workforce levels and maintain medical staffing at full establishment, with no delays over replacement recruitment or the engagement of appropriately experienced locum doctors.

**Complaints and patient feedback system**

The College supports the provision for establishing effective local complaint handling procedures. Patient views, including complaints, are invaluable in terms of quality control and service development and will play a role in supporting the revalidation of doctors.

**Patient Advice System**

The College approves the establishment of a patient advice and advocacy service that is independent of the Health Boards in Scotland but seeks reassurance that the funding of this service will be proportionate given public sector pressures.

**Role of Patient Rights Officers**

The College agrees that patients will benefit from the support of appropriately trained officers with access to accurate information about local services. The recruitment and training of these officers will be critical to their success. Also innovative networks and communication schemes may be required to ensure all patients have equitable access, particularly in the more remote areas of Scotland.

Elaine Tait  
Chief Executive  
Royal College of Physicians of Edinburgh  
13 May 2010
Scottish Council on Deafness (SCoD)
The Scottish Council on Deafness represents over seventy organisations working with and on behalf of Deaf Sign Language users, Deafblind, Deafened (Acquired Profound Hearing Loss) and Hard of Hearing people in Scotland; and individuals who have an interest in deaf issues or are deaf themselves.

Our membership provides an effective working partnership between the Voluntary Sector, Social Work and Education Departments, NHS Trusts, Health Boards and the Government.

Background to Contribution
One in five of the population in Scotland has a hearing loss. This means there are over one million people in Scotland with a hearing loss, from the profoundly deaf to those who are hard of hearing. They have different communication needs.

There are approximately 6,000 deaf people whose first or preferred language is British Sign Language (BSL).

Many deaf people do not have the same access to health care, treatment and rehabilitation services as their hearing peers. Deaf people do not have equal access to information that enables them to be able to make informed life and health choices. When planning services, the needs of deaf people appear to be included in the term “sensory impairment” as “one-size-fits-all”, rather than people with very different and differing requirements – Deaf Sign Language users need BSL/English Interpreters to ensure appointments with health professionals are fully accessible and information on DVD in BSL, whereas a person who is Deafened will need support from an Electronic Notetaker or a Palantypist to ensure that they fully understand what is happening during appointments and information in written English or their community language.

Contribution

Explanatory Notes: Section 2:

“Subsection (2) describes the way in which that health care should be provided. It should be patient focused, which means regard must be had to the patient’s needs, to the importance of providing the optimum benefit to the patient’s health and wellbeing and the patient should be encouraged to play an active part in decisions relating to their treatment and health care, and they should be provided with appropriate information and support to be able to participate in such decisions. In practice, this might mean:
A deaf patient being provided with a British Sign Language interpreter so that they can discuss their illness and treatment with their doctor, and make an informed decision as to their preferred treatment."

The following are actual patient experiences sent to SCoD by deaf people for inclusion in this response. Names have been changed to protect identities. Thank you to Hearing Concern Link for information.

Lack of interpreter support

On the 23rd April this year (2010), a family were travelling home from holiday and had a car accident in the Midlands. The parents are both Deaf BSL users, as is their daughter who was with them. Their son is hearing. Once they got home to Tayside, the family went to see their GP. Their hearing son had to interpret as the GP could not access a BSL/English interpreter. The mother was told she was just shaken, but her husband, daughter and son had whiplash and should take painkillers. The father had a pain in his mouth, so made an emergency appointment to see his dentist. Again no interpreter was present. The dentist replaced a filling. Three days later, the father’s mouth was extremely painful so he returned to the dentist, who gave him antibiotics.

The father has not been able to eat properly or drink anything hot since the accident. Over the past weekend, the man complained of extreme pain. His wife and son tried to contact NHS 24 for advice but were unsuccessful. He returned to the dentist today (10/05/10). The dentist told him that there is nothing wrong with his teeth and to go see his GP. Again there was no interpreter present. At no time has it been suggested that the man go to Ninewells hospital to have an X-ray taken of his face and skull to rule out facial damage. There are only two qualified and registered BSL/English Interpreters in Tayside to cover all situations where Deaf BSL users required communication support. If there had been an interpreter present at the first GP appointment, this man may have been spared the weight loss and pain he has suffered in the last three weeks. And his family, especially his wife, might not have had the stressful time that she has had.

Access to information and support

“The day I was told that my deafness was permanent the ENT consultant was very rude in that he did not talk to me he spoke to my wife.

His attitude was very abrupt and condescending. The way he told me was "yes Mr Smith you’re deaf, it is permanent; there is nothing we can do for you, goodbye" But as I have said he told my wife, not me as he knew I could not hear him.

My wife then went on to ask him about getting hearing aids and was told that it would take many weeks. We left the hospital that day with absolutely nothing, no information, nowhere to turn for information.
It was as if I had been dumped on the scrapheap of life. “Well, this one’s got no hearing now, get rid of him”. That was how I felt by the time I came out of that hospital.

When I did get hearing aids, I was fitted with them and then left to get on with them. I struggled for the next two years trying to come to terms with the loss of my hearing and the changes that had to be made because of it. But I was never offered any counselling or help at all.”

“Rehab support was never offered nor was I pointed in the direction to find it but had to discover what was available by default. I can still remember my panic when I tried to clean my hearing aid on day one having been told that it had to be taken apart and soaked in warm water (imagine!) and I could not work out which way to put it back together again. I could have destroyed it straight away. The ear mould was not a good fit and hurt me but that was corrected on my excellent first call back which did a lot to help my confidence.”

**Treatment Time Guarantee**

Outside the Central Belt in Scotland, there is a lack of qualified, registered communication support – BSL/English Interpreters, Electronic Notetakers; and there are no Palantypists in Scotland that are available for health appointments. So how will Health Boards ensure that deaf people have the same access to Treatment Time Guarantees as their hearing peers? And what mechanisms will the Scottish Government put in place to specifically monitor Treatment Time Guarantees for deaf people who require appropriate qualified registered communication support to attend for treatment?

**Complaints and Other Feedback**

“I was persuaded by my wife and family to visit my GP to discuss my lack of hearing, mainly speech. I was referred to the Audiology Department at King’s Cross Hospital, Dundee for a hearing test, and recommended for two Digital Hearing Aids.

When these were fitted, I commented that the noise from the pages of forms being turned seemed excessive, but was told that it would take some time to adjust to them.

I persevered, but could not use them if my wife or I were reading a newspaper due to the noise. The hearing aids seemed to amplify higher – pitched sounds such as birds singing, which I could hear clearly without them in. I could not use them outside, for traffic noise, if there was a wind, or when driving, and they made NO difference to speech!

When I visited the department to see what could be done, and listed my comments, I was told that “they hadn’t been fitted properly”. The volume was reduced by 25%, and I was told to try again. This I did, for several weeks, but there was no improvement, so back for another appointment. Another
reduction, of a further 25%, and told that “if that does not make any difference, then you don’t need the aids at all!”

Several more weeks passed and my hearing did not improve with the aids and I could not hear people speaking, I packed them up, enclosed a letter of complaint detailing all that had happened and handed them back to Audiology at King’s Cross Hospital. I have not had any communication at all from the Audiology Department or anybody else at the hospital.

I must now try to improve my lip-reading, but don’t know how, and just ask people to “speak up, please.”

Patient Advice and Support Service

Does the Scottish Government intend to have this service as well as the “Independent Advice & Support Service” funded by local NHS Boards and run by CAB Scotland?

“IASS is available for anyone who uses the NHS and aims to support patients, their carers and families in their dealings with the NHS and in other matters affecting their health. If a patient, their carer or family has any concerns about their care and treatment, they can raise these with the NHS. http://www.cas.org.uk/iass.aspx?NavLinkId=1683”

“What you can complain about
  • Any aspect of NHS treatment or patient care:
    o NHS hospitals and health centres
    o NHS family services (eg GPs, dentists, opticians, community pharmacists)
    o Community services (eg health visitors, community psychiatric nurses (CPNs), physiotherapists, community dieticians)
  • Issues which impact on patient care (eg delays, staff shortage, equipment etc)
  • The provision of NHS funded services (eg catering, cleanliness, transport, etc)
  • Public health issues where complainant her/himself has been directly adversely affected
  • Private hospital or care home where the treatment provided is funded by the NHS. http://www.cas.org.uk/whatyoucancomplainabout.aspx.”

Patient Rights (Scotland) Bill 14 (2) (3): “There may be more than one provider of the patient advice and support service”

What will the Scottish Government do to ensure the needs of deaf people are catered for by all providers of advice and support services?

At the present time, the IASS does not appear to support deaf people, and many deaf people, especially Deaf, Deafblind and Deafened people are unaware that this service exists. Deaf people also have difficulty accessing independent advocacy services in many areas for support in making
complaints/giving feedback about NHS services. Not all NHS Boards produce complaint/ feedback information that is accessible to Deaf and Deafblind people – in BSL and Moon.

Patient Rights

NHS Boards must ensure that services are accessible – this means that they cannot rely on deaf patients having textphones and using TextRelay to contact services, as many deaf people no longer use a textphone, they have a mobile telephone. And it cannot be assumed that deaf people will have access to a computer either. NHS Boards setting up telephone helplines/services must also ensure that they are fully accessible for deaf people. For example, NHS 24 is not at this present time accessible to many, many deaf people; SCoD is working with NHS 24 on this issue at the moment.

Mandy Reid
Policy & Research Officer
Scottish Council on Deafness
10 May 2010
Patient Rights (Scotland) Bill

Scottish Disability Equality Forum (SDEF)

The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland through the removal of barriers and the promotion of equal access for people affected by disability.

It is a membership organisation, representing individuals with any type of impairment, disability organisations and groups who share our values. It aims to ensure the voices of people affected by disability are heard and heeded.

- The patient rights and healthcare principles, and the criteria on which those rights are based, as set out in the Bill.

Equal access to and quality of healthcare

We would like to ensure that the right to equality in relation to healthcare is included in the Bill. While many of the rights and principles contained in the Bill will hopefully contribute to increased equality for all strands, we believe there is a need to include a specific right or principle relating to equality. For instance, one member suggested the Bill contain a principle that healthcare be ‘equally accessible and of equal quality for all members of Scotland’s diverse society.’

We are aware that NHS Scotland has made substantial progress in addressing health inequalities but feel this commitment should be expressed in the Bill, both as a means of cementing the NHS’s and the Scottish Government’s intentions and to ensure that all groups are aware of their right to an equally high standard of care and their right to lay claim to equal treatment.

Furthermore, it should be remembered that even if all the rights and principles contained in the Bill were fulfilled, certain group (such as those with mental health problems, learning difficulties or people from certain ethnic minority groups) may still be receiving a lesser quality of care and attain poorer health outcomes. In many cases members of equalities groups are disadvantaged before they come into contact with the NHS because, for instance, of a failure to raise awareness of services amongst certain groups or the physical inaccessibility of premises. This cannot always be addressed by respecting the individual rights of the patients the NHS comes into contact with. Equality should apply from before the first point of contact to include publicity of a service or health issues as well as staff training to ensure equality of access and awareness. The current inequality of access to healthcare can be illustrated in part by the following statistics.

- People with learning difficulties are less likely to use diagnostic services: women with learning difficulties have fewer mammograms and cervical smears.
People experiencing serious mental health problems are likely to die 10 years earlier than their counterparts who do not have such problems.

Of 866 deaf and hard of hearing people who responded to a survey, 24% said they have missed an appointment because of poor communication such as not being able to hear staff calling out their name. Some 19% have missed more than five appointments.

Nearly half of deafblind people sampled have undergone procedures (operations, injections, drips) that had not been explained.

One of our members also reported that she had been denied treatment at her local dentist, who had refused to get a removable wheelchair ramp for the premises to allow her to enter. The receptionist told her that there was a dentist especially for ‘disabled folk’ in Paisley – miles away from where she lived.

Many of our members also reported that while the treatment they received for the primary condition was good, there was little attendance to, knowledge of or respect for their underlying disabilities, conditions and needs. In some cases members felt this had had a negative impact on their overall health.

Examples from our members and colleagues of their disability not being understood include the following:

- people with conditions such as CP being treated as though they were stupid and being shouted at or ignored
- A man with aphasia being treated rudely because it was assumed that he was drunk
- A blind patient never being given help with using the toilet while the floor is wet and slippery

This illustrates a need for positive, strategic, NHS wide measures to ensure disability awareness and equality of care and treatment. All NHS staff need to be fully equipped to fulfill the rights and principles in relation to the care of people with disabilities and other equalities groups and this cannot be done without strategic action to address training needs, publicity and community engagement. A right to equal access to healthcare would provide a framework to make these improvements.

One member also noted that any right to equality of access to healthcare should include socio-economic inequality given the drastic health inequalities that exist between different socio-economic groups in Scotland.

Another member also commented that geographical equality should be included, noting: “The provision of healthcare treatment must be responsive to individual need and universally accessible regardless of location. The practice of “postcode prescribing” with varying standards applying in different geographical areas is unacceptable.”
One of our members noted that it would be beneficial to refer to ‘health services’ rather than ‘health care’ throughout the Bill. This might help to make it clearer that the rights included in the Bill apply in relation to all contact with the NHS – whether that be secretaries, cleaners, porters or executives.

**Excluded Rights**

There is some concern that the rights and principles set down in the Patient Rights (Scotland) Bill have been chosen over other rights contained in the ECHR, ICCPR and ICESCR, as well as the multitude of other human rights standards which the Scottish Government (and by extension the NHS) is legally obliged to comply with. There is concern that this might lead to these rights being deprioritised and to some extent forgotten by the NHS. Many of these rights are highly relevant in relation to health care. For instance,

- **The Right to Private and Family Life.**
  This might relate to visitation, allowing families to stay together through illness and treatment and the right to equipment (such as wheelchairs) which meet their needs in terms of using their toilets at home

- **Freedom of conscious religion and belief**
  This would be relevant in relation to prayer rooms, staff awareness of religious custom and the right to refuse treatment etc

One option might include a further right in the Bill such as ‘All patients will have their human rights respected’.

**Right Holders**

Many of our members have also stated that there is a need for rights in relation not only to patients but also their carers and family members. They felt that to include this in the Bill would provide an important acknowledgement of the role of carers and the huge emotional investment they often have in the individual they care for. Family members may also be going through a very difficult and upsetting time and they too deserve respect and to have treatment explained to them in terms they understand. Members felt there is a need for NHS staff to listen to and respect their views on the patient’s needs and treatments. They will often have in depth and valuable knowledge of the patient and her/his condition. Carers may also have to deal with the consequences of unsuccessful or unsuitable treatment. While we understand there is a need for patients’ privacy to be respected and that it is essential to ensure the patient’s well-being forms the basis of all decisions affecting them, we believe it might be beneficial to include in the Bill principles such as,

- “Carers and family members are treated with respect”
- “Carers and family members are supported in understanding the information given to them in relation to the patient’s care”
**Clarity of Rights**

There were also calls from our members for more clarity in relation to what the rights and principles would actually mean in practice. One member commented,

“If these rights can’t be enforced in a court what do they mean? Is the NHS in any way accountable for this stuff? It’s just more rubbish.”

If it is to avoid disillusionment and disenfranchisement the NHS and Scottish Government must consider how they can show the rights and principles contained in the Bill are being respected, that they are meaningful and that there has been some improvement – particularly if they are not enforceable by individuals.

One of our members mentioned that there was a need for a clear framework for measuring progress and failure in relation to the Bill. One model might be the human rights framework and its measurement structures in relation to health care. This might act as a starting point for measuring progress and evaluating performance where individual rights cannot be enforced. For instance, under the International Convention on Economic, Social and Cultural Rights (ICESCR) there is a “right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” This right is not generally individually enforced but rather it obliges Governments to meet core minimal standards of health care. It also creates a duty to continually improve the nation’s health against certain indicators. This provision of the ICESCR also guarantees non-discrimination and the equitable distribution of all health facilities, goods and services. It is perhaps a good model for measuring progress in relation to the improvement of care and the realisation of rights in practice.

There were also calls form our members for the Bill to contain more specific rights which could be more easily measured. One member also noted that the consultation on NHS Constitution for England includes a right in relation to treatment that goes beyond what is covered here. It provides “the right to drugs and treatments that have been recommended by NICE for use in the NHS if your doctor says that they are clinically appropriate for you”. This might be seen as a more concrete and measurable standard which would improve the safety and effectiveness of many patients’ care.

**Consultation and Involvement**

Some of our members felt that as well as involving patients in their individual care and treatment there is a need to involve patients, family and carers more widely and in more strategic decisions.

There has been a duty to consult people with disabilities in relation to Disability Equality Schemes under the DDA since 2006. SDEF members know from experience that this duty has not always been meaningfully fulfilled and in some
cases very little effort has been made to ensure the rights and interests of people with disabilities are acknowledged. This Bill might provide the opportunity to publicise and draw together NHS mechanisms for involvement and to make them as accessible as possible to people with disabilities. Eg A duty to make patients aware of avenues for involvement would allow them to raise awareness of PFPI functions, wheelchair user groups, health board elections etc.

- The 12 week treatment guarantee and the provision to deal with breaches of the guarantee

There is a worry amongst some SDEF members that the 12 week waiting time guarantee will lead to excessive focus on newly diagnosed conditions rather than chronic or long-term conditions. For instance, the guarantee will lead to quick treatment for cancer sufferers when they are diagnosed. This is excellent. However, we are concerned about the effect such a guarantee will have on individuals who suffer from chronic pain as a result of a diagnosed condition who already have to wait over a year to access a consultant. There is a real worry that the guarantee will lead to resources being channeled away from individuals with post referral long-term conditions who may have an equal need and equally deserving of rapid and effective treatment.

One of our members who suffers from chronic pain commented that she would like to see a right to have her condition reviewed on an annual basis by a specialist.

Another commented,

“You should know in 3 months how your condition is progressing. As someone who suffers from MS my condition has progressed quicker than I would have thought or wanted but I won't let it win.”

Some members are also concerned that, without an accompanying increase in resources, the 12 week guarantee may remove discretion from clinicians in terms of prioritising urgent cases. If no distinction is made between cases in terms of urgency then waiting time, rather than need, could come to determine the order in which patients are treated.

There is also concern that if there is not an increase in resources to partner the 12 week limit, then this may lead to ‘gaming behaviour’ amongst clinicians. In other words, that in order to meet referral time targets NHS staff will seek alternatives to immediate referral, or where a referral is made, the hospital doctor (if s/he does not see the case as urgent) will perform minimal treatment and then place the patient on another waiting list which is not time limited. This will waste rather than maximise NHS resources.
Another member noted that when making decisions relating to timescales for the treatment of a patient, outside responsibilities and the well-being of dependents and family members should be taken into account. He noted,

“I have a carer and this is never considered in their health treatment. The priority is my carer’s health, but it does have an impact on me too. For example, if my carer has a medical condition and is not treated quickly, then we both end up suffering. There needs to be impact analysis’s made on all carers for this reason and this goes for people with any caring responsibilities.”

Accessibility of the Rights in the Bill
We are aware that most of the rights and principles contained in the Bill are drawn from existing legislation. The purpose of this Bill (to some extent) is to pull existing rights together in order to increase public and NHS awareness.

We fully support this objective. However, the concern amongst our members is how this legislation will be any different from the laws which originally set out these rights. How, in other words, will patients be made aware of their rights and what they mean in practice. One member felt that it should be incumbent on NHS staff to ensure that patients are aware of the Bill and the rights it contains. Patients should also be told how to access support if they do not understand the Bill or feel that their rights have not been respected. They should also be given the opportunity to ask questions.

Another suggestion was that there be a very simple agreement between patients and NHS staff. A very simple document could lay down how the patient could expect to be treated whilst in contact with the NHS (based on the rights and principles detailed in the Bill). The patients specific requirements (whether in relation to communication, diet or an underlying condition) could also be entered into the form at the start of their treatment or initial contact with the NHS. This would not only allow patients to be aware of their rights and feel involved in their care, it would also provide an informal means of holding staff to account if their rights and needs were not respected.

In relation to complaints members were generally pleased with the idea of Patients’ Rights Officers. It was suggested that Patients Rights Officers be enabled to perform outreach work to target those who are most vulnerable but who might, as a result of this, also be the least likely to complain. For instance, the PRO could aim to talk to a certain percentage of inpatients with learning difficulties about their experiences of NHS care.

Johanna McCulloch,
Policy, Information and Parliamentary Officer,
Scottish Disability Equality Forum,
13 May 2010
Patient Rights (Scotland) Bill

Scottish Health Council

The Scottish Health Council was established in April 2005 to promote improvements in the quality and extent of patient focus and public involvement in the NHS in Scotland. It supports and monitors work carried out by NHS Boards to involve patients and the public in the planning and development of health services, and in decisions that affect the operation of those services.

GENERAL COMMENTS

The Scottish Health Council welcomes the introduction of the Patient Rights (Scotland) Bill which is designed to support and strengthen patient participation. We firmly believe that there is merit in consolidating and adding to existing rights as this Bill sets out to do. Including these rights in primary legislation serves to underline their importance.

The Scottish Government’s commitment to raising awareness of these rights with NHS staff and with patients and the public is particularly welcomed by the Scottish Health Council. In order for people to exercise their rights, they must be informed about what these rights are and have access to any support necessary to exercise them. We therefore welcome the Scottish Government’s commitment to make additional investment in support services (independent advocacy and Translation, Interpreting and Communications Support).

NHS staff have a crucial role to play in respecting and promoting patient rights and they must be provided with appropriate training and support to enable them to carry out this role. It is encouraging that this is recognised in the Financial Memorandum with plans for relevant work to be undertaken by NHS Education Scotland.

We are aware that there have been questions raised previously on the need for the Bill and it is possible that some patient and voluntary organisations may feel that the provisions do not go far enough. We hope that these organisations and others representing patient and public interests will take the opportunity to have their say to the Committee. Some issues that have been raised during the earlier consultation may require further consideration such as:

- How some rights will apply to particular services, for example NHS dentistry services;
- Rights of access to services for people in remote and rural communities;
- Whether there should be rights to particular treatments.
Given the importance of patient rights for the people of Scotland and all those working within the NHS, it is essential that the Bill’s impact is monitored and evaluated. We note that it is intended that “…the effects of the Bill will be monitored through the Participation Standard” (Financial Memorandum, paragraph 136). As the Scottish Health Council has lead responsibility for developing the standard and overseeing its use in NHS Scotland, we look forward to further discussions with the Scottish Government, NHS Boards and other stakeholders as to how this might be best achieved.

DETAILED COMMENTS

This section of our submission addresses the points highlighted in the Committee’s call for evidence.

Patient rights, health care principles, criteria

The Scottish Health Council believes that the rights and principles outlined in the Bill are sound and reflect matters which are of obvious importance to patients. We are conscious however, that the language of ‘rights’ can be powerful and may create expectations about entitlement and enforceability that will not be met in practice. It is clear in the Bill that these rights are subject to significant qualifications and limitations. Section 2 specifies that the rights of individuals must: be balanced against those of other patients; be subject to the exercise of clinical judgement; and take account of resources available. Section 18 restricts the potential for legal action relating to the Bill, although it does not affect existing legal remedies such as judicial review or negligence actions.

We fully understand the need for such qualifications and limitations to exist, particularly in the current financial climate. However, it is crucial that in any activity to promote patient rights, these qualifications and limitations are made explicit.

Treatment time guarantee

The importance of treatment being provided to patients within a reasonable time is self-evident. On that basis, we expect that the provisions within the Bill will be very well-received by patients across Scotland.

The use of the term ‘guarantee’ may create expectations that treatment will definitely be provided within the 12 week timescale. However, as acknowledged in the Bill, there will inevitably be occasions when the timescale is not met, and whilst patients will be entitled to an explanation and certain information, they will not be entitled to any compensation. This is understandable, but in order to
manage expectations, it is vital that patients are fully informed about this in any communication or promotional activity about the guarantee.

**Complaints and feedback system**

Effective systems for complaints and feedback are vital for improving the quality of services and patient experience within the NHS. In 2009, the Scottish Health Council published: Making it better: Complaints and feedback from patients and carers about NHS services in Scotland. This research has helped to inform the development of the Bill. We have been working with key stakeholders (including NHS and Independent Advice and Support Service staff, voluntary and community groups and patients) to consider how the recommendations from this research can be implemented across the NHS and will be publishing our findings later this year.

One of the main themes from the Making it better research was that it should be easier for patients to give feedback, as many people wish to give their views but do not wish to make a formal complaint. On that basis, the Scottish Health Council welcomes the provisions in the Bill relating to feedback. It is essential that people are provided with a range of methods and opportunities to provide feedback in recognition of the fact that they may have different preferences regarding how and when they may wish to do this.

**Patient advice system and the role of Patient Rights Officers**

The Bill provides for the establishment of a patient advice and support service which will replace the Independent Advice and Support Service currently delivered by Citizens Advice Bureaux across Scotland. There is no doubt that a free and accessible service promoting and supporting patients to exercise their rights has, at least in theory, the potential to be of significant benefit both to the people of Scotland and to the NHS. However, we note that an evaluation¹ of the existing service identified a number of challenges regarding its delivery, including: developing a national brand; balancing expectations of stakeholders; promoting organisational and service learning; and agreeing suitable reporting arrangements with NHS Boards. It also noted a low level of awareness of the service generally within the NHS.

In order for the new service to deliver on the expectations within the Bill and be supported within the NHS, it is essential that the challenges mentioned above and any other learning points from the existing service are addressed.

Many patient and voluntary organisations already play an invaluable role in providing advice and support to patients about their rights. It is important that there are effective mechanisms by which the NHS can obtain patient feedback via these organisations.

Sandra McDougall
Head of Policy
Scottish Health Council
12th May 2010
1. Introduction

The Scottish Human Rights Commission (the Commission) welcomes the opportunity to comment on the Patients Rights (Scotland) Bill (the Bill) ahead of its consideration by the Health and Sport Committee.

The Commission welcomes the emphasis in the Bill on elements of a human rights based approach, including participation, accountability and empowerment. In this short submission the Commission suggests ways of building on this, to ensure other elements of a human rights based approach are also emphasised appropriately. In particular, we highlight the need to ensure an explicit and consistent connection with binding human rights law, particularly the Human Rights Act 1998. In this light we look forward to supporting the planned package of training, capacity building and awareness raising, to ensure that the Bill is read and understood through the lens of the Human Rights Act, and that its implementation supports the adoption of a comprehensive human rights based approach to health care.

In reference to the issues which the Call for Evidence issued by the Committee, the Commission focuses primarily on the first point – the patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (sections 1 to 5).

2. Legal Framework

- Scotland Act 1998
- Human Rights Act 1998
- European Convention on Human Rights
- European Social Charter
- International Covenant of Economic, Social and Cultural Rights
- Convention on the Rights of Persons with Disabilities
3. Response

The Bill proposes several potentially important initiatives which aim to promote elements of a human rights based approach to health care. For example, the creation of Patients Rights Officers (section 16) and patient advice and support services (sections 14 and 15); as well as mechanisms related to complaints (section 11) and for patient feedback (section 12) have the potential to enhance constructive accountability of public authorities (duty-bearers) and empowerment of patients (rights holders) in the health sector. Likewise, the Health Care Principles (Schedule, introduced by section 4(1) of the Bill) include human rights principles such as dignity, respect, and participation in decision making. In respect of these principles, which are welcomed, the Commission would like to highlight the importance of ensuring they are understood and applied in a manner consistent with public authorities’ duties under the Human Rights Act 1998 (HRA).

The need to read the Bill through the lens of human rights law

The HRA and the Scotland Act 1998 incorporate the Articles of the ECHR into our domestic law. According to the HRA it is unlawful for public authorities to act in a way which is incompatible with a Convention right (section 6). Furthermore, legislation must be read and given effect in a way which is compatible with the Convention rights (section 3). To support public authorities in the health sector to deliver on this duty, it will be important that training, capacity-building and guidance issued following the adoption of the Patients Rights Act, is framed in the context of the binding requirements of the Human Rights Act, and other human rights law and standards.

This will ensure not only that those rights contained in the Bill are understood in the context of the HRA, but also that they are placed in the context of the full range of human rights in health care. For example, references in the Bill to a duty to “have regard to” patients’ rights to participate in decisions related to their care and treatment should be understood in the context of Article 8 of the European Convention on Human Rights, included in the HRA. Article 8 guarantees the right to respect for private and family life, home and correspondence. The scope of this Article is very broad. The European Court of Human Rights (ECtHR) has stated that the element of “private life” alone encompasses, among other things, “aspects of an individual’s physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world.” Or even more broadly “to conduct one’s life in the manner of

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1 While one of the main purposes of the Bill is said to be to “set out the rights of patients receiving health care from the NHS in Scotland” it is not clear that all of the human rights protected in the Human Rights Act are reflected in the Bill. For example, the Bill does not directly refer to the right to life; to freedom from torture, inhuman or degrading treatment or punishment; the right to liberty and security, each of which is clearly relevant in health care settings. See for example Human Rights in Health Care, a short introduction, Department of Health and British Institute of Human Rights, London, October 2008. http://www.slam.nhs.uk/patients/docs/rights/Human%20Rights%20in%20Healthcare%20-%20short%20introduction%20(DoH).pdf

one’s choosing”. It provides protection against non-consensual medical treatment or procedures.

Any interference with this right, including the administration of medical treatment or procedures without free, prior and informed consent, must pass the tests outlined in Article 8(2) of the Convention. In essence it must be according to law, in pursuit of a legitimate aim, and the least interference necessary to achieve that aim (legality, necessity and proportionality). In this respect the reference in the Bill to the “desirability” of proportionality in Section 2(2)(b) of the Bill may lead to confusion with the legal requirement to justify any infringement of Article 8 rights with reference to, inter alia, proportionality.

Guidance and training on this principle should also link to considerations of legal capacity, and the provisions of the Adults with Incapacity (Scotland) Act 2000.

The Convention on the Rights of Persons with Disabilities also contains several protections of the right to participate in decisions (Article 4 on general principles, Article 26 on support for participation, Article 29 on right to participate in public life).

Allied with the right to participate in decisions which affect the exercise of human rights is the right to information. The right to information is a component of the right to autonomy in decision making under Article 8 and access to information is an element of the right to freedom of expression. It is also increasingly recognised as a freestanding right to information in a form and language which enables an individual to participate in decisions which affect their human rights. This includes the right to accessible information for people with disabilities. The Convention on the Rights of Persons with Disabilities requires the provision of, “other appropriate forms of assistance and support to persons with disabilities to ensure their access to information”.

Understanding the rights of everyone

The Commission appreciates the focus provided by the Bill on the rights of patients. However, the experience documented in the Commission’s

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3 Pretty v UK 66 BLMR 147 (2002)
4 See for example Glass v UK (2004) 39 EHHR 15, para 70.
5 The UK has been a party to this convention since 2009. The Scottish Human Rights Commission, together with the Equality and Human Rights Commission, the Northern Ireland Human Rights Commission and the Equality Commission for Northern Ireland, is an independent mechanism named by the UK under the convention to promote, protect and monitor the implementation of the Convention in the UK.
6 Information is referenced in the Bill in section 1(2) as a commitment that “health care is to…(c) have regard to the importance of providing such information and support as is necessary to enable the patient to participate…”
7 See for example Demir and Baykara v. Turkey(2009) 48 EHRR 54 at paras 76, 78, 80, 82-4.
8 For example Article 10, ECHR; article 21 Convention on the Rights of Persons with Disabilities, which includes a specific requirement to take appropriate measures such as: “Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost”.
9 Article 9(2)(f)
independent evaluation of the human rights based approach adopted by The State Hospital\textsuperscript{10} suggests that it is important, in order to ensure the sustainability of a human rights based approach, that the rights of everyone involved are taken into account – patients, staff, carers, families and others – as parts of a common framework of rights, duties and shared responsibilities.

Conclusion

The Commission welcomes the Bill in so far as it:
1. seeks to strengthen awareness of human rights in health care;
2. is based on human rights principles such as dignity, respect and participation;
3. empowers health service users to claim their rights; and
4. strengthens the accountability of public authorities to respect, protect and fulfil those rights.

The Commission considers that the proposed training, awareness raising and guidance noted in the explanatory memorandum is an excellent opportunity to increase understanding of human rights in healthcare. The Commission therefore recommends that the training and awareness raising proposed in paragraphs 62-63 and 67 of the Explanatory Memorandum ensure clear links to the Human Rights Act 1998 and other relevant human rights law, including the right to the highest attainable standard of health, and the Convention on the Rights of Persons with Disabilities.

Duncan Wilson
Head of Strategy and Legal
Scottish Commission for Human Rights
13 May 2010

\textsuperscript{10} Human Rights in a Health Care Setting: making it work for everyone, Scottish Human Rights Commission, Glasgow, December 2009.
http://www.scottishhumanrights.com/research/ourpublications/article/healthcareresearch
Patient Rights (Scotland) Bill
Scottish Independent Advocacy Alliance

The SIAA is a unique organisation delivering the voice of independent advocacy in Scotland. It is a membership organisation that has the overall aim of ensuring that Independent advocacy is available to any vulnerable person in Scotland. The SIAA welcomes the opportunity to contribute to evidence on the Patients’ Rights (Scotland) Bill.

While we welcome the inclusion of signposting to advocacy in the Bill we believe that there is a need for clarification on the difference between the roles of the Patient Rights Officer and of Independent Advocacy. The SIAA occasionally encounters some confusion from certain agencies and some people about what Independent Advocacy is and is not. We believe that without such clarification this confusion will continue. It will be important, when drawing up the service specification for the Patient Advice and Support Service, that this distinction is clearly made.

Provision of Independent Advocacy will fit with the stated aim of supporting people to participate in their health care. Participation is likely to be more meaningful if people feel that they are in control of their own lives, that they are listened to and fully involved in decision making.

While recognising the aim to ensure that everyone is an equal partner in their health care we believe that the Bill needs to make clear the recognition that, for the most vulnerable and marginalised members of our society, it may be more difficult to accept and to act upon their responsibilities in relation to their own health care. We feel that the Bill should include a specific reference to ensure that such individuals do not experience any discrimination because of this.

More generally we believe that the Bill needs to emphasise the importance of issues such as age, ethnicity, gender, social economic background, religion etc. on peoples’ lives, their health and the care and treatment they might receive. We believe that consideration of these issues needs to be at the heart of any care and treatment that a person receives. Also we believe that the process of making a complaint should be simplified and that any potential barriers to a person making a complaint should be removed, for example that complaints do not have to be in writing. We believe that the Bill needs to clearly state that whilst it is important to encourage patients to give feedback or raise their concerns, there should also be the opportunity for the patients’ significant others to also make a complaint or give feedback.

The Scottish Independent Advocacy Alliance is an independent voluntary organisation which receives core funding support from the Scottish Government Health Directorate.

Muriel Mowat,
Research & Quality Officer
Scottish Independent Advocacy Alliance
6 May 2010
Patient Rights (Scotland) Bill

Doreen Sinclair

I wish to ask you, in your role as Convenor of the health committee, if you would take forward my idea for a card that would let anyone who has had an NHS test or examination with an outcome know who to contact if they have not had the results within a specified time. At present, as you may know, the default is 'we will let you know if we need to take this further' which is often taken to mean 'if you don't hear from us you can assume that everything is fine'. Below are my ideas and reasons for the need for this type of card.

I would like to see an NHS nationwide card, perhaps starting in Scotland, which means that anyone getting any sort of test or x-ray, i.e. anything that has an outcome, would get a card or slip of paper which would have something similar to this on it:-

The result of your test/x-ray/investigation (etc) should be available by (date). If you have not received the results within (number of days) of this date please contact (pre-printed with the appropriate information for the area)

There would be several benefits to this:-

- information which has been 'lost in the post', and with the best will in the world some does go astray, would be more likely to be picked up

- it would prevent people from falsely believing that everything is fine because they have not been contacted

- the idea that people should take some responsibility for managing their health, which is something the governments of Britain want to promote, would be present in the fact that patients should make the contact

- it would give permission to those who are reluctant to 'bother' their doctor or surgery

- those who have a difficulty in understanding that the results take time to process would have a date before which they would know that the results would not be available and this would prevent unnecessary phone calls or stress

- carers, parents and partners would know when to expect the results, as well as the patients

- there would be less likelihood of an illness, such as cancer, needing major treatment because results had not come through; conditions
caught early usually are less expensive to treat and have a better outcome

- not everyone is aware of the very good leaflet put out by NHS Scotland It's ok to ask!, which encourages people to ask. How and when will I find out the results of the tests? Who do I contact if I don't get the results of the tests? Most folk I have told had no idea that this leaflet existed

- it is cheap.

Doreen Sinclair
31 March 2010
Finance Committee

Report on the Financial Memorandum for the Patient Rights (Scotland) Bill

Published by the Scottish Parliament on 14 September 2010
Finance Committee

Remit and membership

Remit:

1. The remit of the Finance Committee is to consider and report on-

   (a) any report or other document laid before the Parliament by members of
   the Scottish Executive containing proposals for, or budgets of, public
   expenditure or proposals for the making of a tax-varying resolution, taking
   into account any report or recommendations concerning such documents
   made to them by any other committee with power to consider such
   documents or any part of them;

   (b) any report made by a committee setting out proposals concerning public
   expenditure;

   (c) Budget Bills; and

   (d) any other matter relating to or affecting the expenditure of the Scottish
   Administration or other expenditure payable out of the Scottish
   Consolidated Fund.

2. The Committee may also consider and, where it sees fit, report to the
Parliament on the timetable for the Stages of Budget Bills and on the handling of
financial business.

3. In these Rules, "public expenditure" means expenditure of the Scottish
Administration, other expenditure payable out of the Scottish Consolidated Fund
and any other expenditure met out of taxes, charges and other public revenue.

*(Standing Orders of the Scottish Parliament, Rule 6.6)*

Membership:

Derek Brownlee
Malcolm Chisholm
Linda Fabiani
Joe Fitzpatrick
Tom McCabe (Deputy Convener)
Jeremy Purvis
Andrew Welsh (Convener)
David Whitton

Committee Clerking Team:

Clerk to the Committee
Jim Johnston

Senior Assistant Clerk
Terry Shevlin

Assistant Clerk
Allan Campbell

Committee Assistant
Jennifer Bell
Finance Committee

Report on the Financial Memorandum for the Patient Rights (Scotland) Bill

The Committee reports to the Health and Sport Committee as follows—

INTRODUCTION

1. The Patient Rights (Scotland) Bill (“the Bill”) was introduced in the Parliament on 17 March 2010. The Health and Sport Committee has been designated as the lead committee on the Bill at Stage 1.

2. Under Standing Orders Rule 9.6, the lead committee at Stage 1 is required, among other things, to consider and report on the Bill’s Financial Memorandum (FM). In doing so, it is required to consider any views submitted to it by the Finance Committee (“the Committee”).

3. At its meeting on 27 April 2010, the Committee agreed to adopt level 2 scrutiny in relation to the FM (i.e. that it would take oral evidence from the bill team and seek written evidence from financially affected bodies). The Committee received written submissions from—

- Citizens Advice Scotland;
- National Waiting Times Health Board;
- NHS Ayrshire and Arran;
- NHS Greater Glasgow and Clyde;
- NHS Lanarkshire;
- NHS Lothian;
- NHS Orkney;
- NHS Education for Scotland;
- NHS National Services Scotland;
- NHS 24;
• Royal College of Nursing Scotland;
• Scottish Ambulance Service; and
• State Hospitals Board for Scotland.

4. All submissions can be found as an annexe to this report. At its meeting on 23 March, the Committee took evidence from the Bill team and later received supplementary written evidence and a copy of the Regulatory Impact Assessment. These documents are also annexed to this report.

5. The FM explains that the Bill provides that—

“...the healthcare which patients receive should meet certain criteria. It also establishes a right to make a complaint, legisates for a patient advice and support service and Patient Rights Officers and establishes a 12-week treatment time guarantee.”¹

6. The FM sets out the costs associated with the Bill under three headings—

• principles in provision of services;
• the treatment time guarantee; and
• support and recourse.

7. This report follows the structure of the FM.

SUMMARY OF EVIDENCE

Principles in provision of services

Staff Education and training

8. The significant costs arising from this area of the Bill are non-recurring costs of £800,000 in 2011-12 and 2012-13 in relation to staff education and development.² The FM explains that NHS Education for Scotland (NES) will develop a workforce educational plan, including the recruitment of staff where necessary, commissioning activity, developing educational materials and delivering training in a wide range of settings.³ The financial implications set out in paragraph 64 of the FM are projections based on NES’s experience of similar national programmes of work.

9. In its submission, NES highlighted concerns that NHS boards will have additional resource implications as a result of this area of the Bill.⁴ In addition, NHS Lothian argued that a significant proportion of the funding should be directed to boards because models of education delivery should be local, relevant and

² FM, paragraphs 62 and 64
³ FM, paragraph 64
⁴ NHS Education for Scotland. Written submission to the Finance Committee
accessible to frontline staff.\(^5\) NHS 24 said that the amount suggested within the FM for staff training would only cover the development of training programmes and it fails to acknowledge the additional hours boards are required to cover to give staff the time required for training.\(^6\)

10. During the evidence session, the bill team explained that the costs were based upon NES’s previous experience in delivering similar programmes that were NHS-wide, such as the patient safety programme.\(^7\) In response to concerns raised regarding additional resourcing costs they said that—

   “We are fairly confident that the costings are accurate. We would not necessarily expect any additional costs to health boards if we are building the training into the existing programmes and delivering it through existing training and practice managers and the like. We are quite confident that the networks and infrastructure are in place to deliver the training.”\(^8\)

11. In addition, in relation to comments from health boards about potential additional costs due to covering normal duties, the bill team said—

   “We have been speaking to representatives of NHS Education for Scotland, which delivers all the education materials and so on for the NHS. We are getting involved in pre-registration training, induction training, other training, rather than taking some people out every day to do a whole day away from their normal duties.”\(^9\)

12. The Committee notes the comments from the health boards and the response from the Scottish Government and would encourage the lead committee to pursue the issues raised with the Cabinet Secretary to ensure that the concerns of the health boards have been taken into account.

The treatment time guarantee

13. The FM states that the Scottish Government does not anticipate any direct financial costs in relation to the treatment time guarantee. However, in written submissions some health boards argued that funding for targets has been reduced by £20 million per annum with no additional funding to health boards.\(^10\) In 2009-10 to meet targets NHS Ayrshire and Arran had to invest an extra £3.7 million of its general allocation to supplement funding from the Health Directorate. They estimated the additional funding required for 2010-11 is approximately £4 million.\(^11\) The Bill team clarified that—

   “As far as waiting times are concerned, the bill's treatment time guarantee provisions are what we are discussing, and that guarantee is inextricably linked to the 18-week referral-to-treatment time target. Money that is going

\(^5\) NHS Lothian. Written submission to the Finance Committee  
\(^6\) NHS 24. Written submission to the Finance Committee  
\(^10\) NHS Ayrshire and Arran. Written submission to the Finance Committee.  
\(^11\) NHS Ayrshire and Arran. Written submission to the Finance Committee.
towards meeting that 18-week target, as well as the waiting times, will be covered through recurring funding.”\textsuperscript{12}

14. Nonetheless, the bill team acknowledged that problems exist at individual boards where extra capacity may be required. They confirmed that—

“...issues around the financing of that [the 18 week referral-to-treatment time] and the treatment time guarantee will continue to be discussed in order to ensure delivery.”\textsuperscript{13}

15. They went on to state that—

“...the £70 million has not yet been allocated. We are in discussions with boards on the appropriate allocations.”\textsuperscript{14}

16. The Committee notes the response from the bill team, but again highlights the health boards’ concerns regarding previous funding allocations for the lead committee’s attention

Support and Recourse

Patient Rights Officers and the patient advice and support service

17. The most substantial costs arise from this area of the Bill, including £831,000 being redirected from the current Independent Advice and Support Service (IASS) to supplement an additional £1,250,000 of new funding from the Scottish Administration. This funding is to support the Patient Advice and Support Service (PASS) and the implementation of Patient Rights Officers (PROs).\textsuperscript{15} NHS Lothian argued that this is a considerable level of funding and expense for a service which in large part is currently being delivered by boards and may continue to do so.\textsuperscript{16} In response the Bill team stated—

“Patient Rights Officers are independent and do not work for boards. Case workers who currently provide such a service are employed by Citizens Advice Bureaux. Under the new system, the contract will be open—we do not know who the supplier will be. In response to the consultation, patients and stakeholders said clearly that they wanted an independent advice service and that they wanted to approach somebody who was not employed by the health service.

The contract for the service will not be funded at the expense of nurses. The Scottish Government is keen to emphasise that helping people through their health care journey—especially those people who need a bit more help; not everyone needs a bit of help, but some do—produces a better outcome. The service will assist people to access front-line services.”\textsuperscript{17}

\begin{footnotes}
\footnotetext[15]{Patient Rights (Scotland) Bill. FM, paragraph 104.}
\footnotetext[16]{NHS Lothian. Written submission to the Finance Committee.}
\end{footnotes}
18. In its submission, NHS Greater Glasgow and Clyde stated that, in their view, the £831,000 for patient advice and support services may be an underestimate, and that—

“NHSGGC might actually incur as much as £249,000. This would be substantially higher than the current IASS contract.”\(^\text{18}\)

19. In response, the bill team explained the figure of £831,000 is the sum of what all the boards said they were paying for contracts in the current year.\(^\text{19}\) They go on to comment that going national should provide more consistency of service. The bill team state—

“For the patient rights officers, the additional money from the centre will be spread out across the boards, based partly on how the national resource allocation committee allocates funding but more on how contract works and on the local needs of the different boards. The funding may just continue at the current level.”\(^\text{20}\)

20. There appear to be inconsistencies in the Bill documents in relation to the number of Patient Rights Officers the enacted Bill would implement. The Policy Memorandum states 40 – 50 while the FM states 65 – 80. During the evidence session, the Committee asked the Bill team to explain this difference. They said—

“The 40 to 50 would be the additional ones, with the additional central funding. There are already 30 or so independent advice and support service workers. The 40 to 50 are the additional workers that we could provide with the £1.25 million from central funding.”\(^\text{21}\)

21. The Committee questioned how the Bill team arrived at the figure of 65 – 80 officers. In response, the bill team said—

“Although the service will be different from the current independent advice and support service, we arrived at the figure by looking at current case worker costs and basing our look forward on that. With procurement people in NHS National Services Scotland, we are looking at the specification of a national contract for the future.”\(^\text{22}\)

22. They went on to say—

“We have looked at the numbers and, as the contract is worked through and we discuss local needs with boards, we are trying not to be too specific by saying that we need X number of patient rights officers in every board. We are allowing for a bit of leeway, which includes how much the

\(^{18}\) NHS Greater Glasgow and Clyde. Written submission to the Finance Committee.


organisation that will get the contract wants to spend on marketing, central support and so on. That is why we have tried to cover a range of figures.”

23. The Committee acknowledges the clarification from the Scottish Government. However, the Committee remains concerned that different figures were provided in the two documents, and that additional explanation may have been helpful in the accompanying documents.

24. In its submission, NHS Ayrshire and Arran is of the view that half the number of proposed PROs would be more appropriate because investing in these posts would be at the expense of frontline services. In response to this the bill team said—

“…we ask boards only to continue to provide their current funding level for the independent advice and support service. We will fund centrally the additional costs.”

25. In its written submission, Citizens Advice Scotland (CAS) expressed concerns there was no provision for inflation or salary uplifts over a three year period. In response to this the Bill team explained that—

"On inflation and salaries, we have produced a package with an amount that we think will take us forward. Obviously, though, we are still in discussion about the exact specifications of the contract; costs may be slightly less in the first year, which would allow a bit for an increase for inflation in future years. However, we are still working our way through that.”

26. The written evidence received from CAS shows concern that the FM does not show any marketing budget for the new organisation. The Bill team stated that—

“On marketing, other things are going on. For example, we will look at patient-facing information for people who might not go through a patient rights officer but who still want information. In addition, NHS Inform will come on stream with a national strategy to inform people of everything about their health care, including rights, patient advice and support. Again, we are going through the contract specification with the boards, and the procurement people have been speaking to Citizens Advice Scotland about what it does, so we will build in something for how we market the service locally and nationally.”

Advocacy
27. The FM shows the Scottish Government will provide a non-recurring £500,000 in 2010-11 to allow health boards to assess the provisions for advocacy

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24 NHS Ayrshire and Arran. Written submission to the Finance Committee.
26 Citizens Advice Scotland. Written submission to the Finance Committee.
services required in their area. The Scottish Government will then provide £500,000 per annum of recurring new money from 2011-12 to support advocacy services.\textsuperscript{29} Health boards explained that they may need to provide more services than the £500,000 would fund.\textsuperscript{30} In response to this the bill team stated that the £500,000 allocated to boards in 2010-11 is to assess what the current situation is across each board and whether there are any gaps,\textsuperscript{31} and that—

“The money will then go towards addressing these gaps, which might not be the same across all boards.”\textsuperscript{32}

Translation, Interpreting and Communication Support

28. The FM explains that PROs will direct patients to relevant support services. It is anticipated that one of the main services patients will be directed to is Translation, Interpreting and Communication Support (TICS). The Scottish Government is providing additional funding of £250,000 per annum of non-recurring funds from 2010-2011 to 2012-2013 to NHS Scotland.\textsuperscript{33} In its written submission NHS Lothian said—

“…there needs to be an accurate costing of the implementation implications for NHS Boards. NHS Boards will continue to deliver the bulk of a “patient rights service” but with no new money to assist them. The only financial support is to national organisations. For example, the requirements for interpretation, translation and communication support cannot be underestimated. Yet there is no funding for NHS Boards to meet this increasing need, which is extremely necessary to address not only in respect of informed consent and good person – centred care, but also the legal duties under Equality and Human Rights legislation.”\textsuperscript{34}

29. During the evidence session the Bill team agreed that this was a valid point and said—

“Over the next year, a bit of work will be done with health boards to look at how we co-ordinate and ensure better efficiency and effectiveness in the translation of materials centrally.”\textsuperscript{35}

General issues

30. The FM shows that overall the new money being allocated is £784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13 as a result of this Bill.\textsuperscript{36} In light of the likely reductions in future budgets, the Committee questioned whether funds would definitely be available. The bill team stated—
"We do not know what the spending review will provide, but the best that we can say at the moment is that these figures are what we are working to. As with all things, as we work our way through, we will look to see whether we can get the same outcomes for slightly less or get better value for money elsewhere."37

31. **The Committee notes this response from the bill team and that future allocations are dependent on the outcome of the forthcoming spending review.**

32. The Committee also asked why in the recent NHS workforce projections published recently by the Cabinet Secretary,38 NES forecasts a net reduction of six in the number of staff while the FM suggests an increase in the workload of NES.39 The bill team responded in writing that—

> “The development of training is to be commissioned by the Scottish Government from NHS NES. It was noted in the Patient Rights (Scotland) Bill’s FM, at paragraph 64, that recruitment of staff would be “where necessary”. Given their recent workforce projections, NES may decide that it is not necessary to recruit any additional staff, this is a matter for them.”40

33. **The Committee notes the explanation from the Bill team, but encourages the lead committee to pursue the issue of the reduction in the workforce and the suggested increase in the workload of NES with the Cabinet Secretary.**

**CONCLUSION**

34. **The Committee directs the lead committee to the specific comments made throughout this report on certain aspects of the FM.**

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39 Patient Rights (Scotland) Bill. FM, paragraph 64.
Submission from Citizens Advice Scotland

Citizens Advice Scotland and its 83 CAB offices form Scotland’s largest independent advice network. CAB advice services are delivered through 222 service points throughout Scotland, from the islands to city centres.

The CAB service aims: to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities, or of the services available to them, or through an inability to express their need effectively and equally to exercise a responsible influence on the development of social policies and services, both locally and nationally.

The CAB service is independent and provides free, confidential and impartial advice to everybody regardless of race, sex, disability or sexuality

Introduction

1. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland’s network of 83 Citizens Advice Bureau (CAB) offices. These bureaux deliver free, impartial and confidential frontline advice services through more than 200 service points across the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.

2. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities. In 2008/09, the Scottish CAB service dealt with just under one million client issues resulting in 2,677 enquiries handled by bureaux across Scotland each day of the year.

3. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities. Last year the CAB service dealt with 324,800 debt issues, 257,444 benefit issues, 86,897 housing issues and 74,017 employment related issues – together accounting for 76% of all client issues.

4. The Independent Advice and Support Service (IASS) is a part of the CAB service in Scotland. Funded by local NHS boards, IASS offers advice and support to all NHS users, their carers, and their families.

5. IASS assists patients and their families raise any concerns and complaints they may have regarding care received from the NHS. The service also takes a holistic outlook to supporting its clients, and provides advice on a range of issues, including welfare rights, employment and debt. In this way, patients’ health concerns are interlinked with a number of other issues and IASS aims to support them overall.
6. CAS welcomes the ethos and health care principles that underpin the Patient Rights (Scotland) Bill. However, we have concerns with some of the provisions in the financial memorandum of the Bill, including costs associated with the uptake of the new Patient Advice and Support service (PASS) and the transitionary services that may be required of IASS.

Financial Memorandum: Response to Questionnaire

7. CAS welcomes the opportunity to respond to the questionnaire relating to the Financial Memorandum for the Patient Rights (Scotland) Bill

Consultation exercise for the Patient Rights (Scotland) Bill

8. We did take part in the consultation exercise for the Bill, but we did not comment on the financial assumptions made therein.

9. We had sufficient time to contribute to the consultation exercise

Costs associated with the Patient Rights (Scotland) Bill

Financial Implications for Citizens Advice Scotland:

10. We are concerned that the full financial implications of the Bill for the CAB Service in Scotland - in its capacity as the current provider of the Independent Advice and Support Service (IASS) - have not been taken into account.

11. No funding has been allowed for a handover period in the event that the CAB service in Scotland does not tender for the contract or if it fails to obtain the contract. It will take time for a new service to be established and arrangements would need to be put in place to assist existing and new clients seeking assistance and support during the transition period.

12. No provision has been made during the three year life of the Patient Advice and Support Service (PASS) project for inflationary uplifts or salary increases which would mean a reduction in funding, in real terms, over the period of the contract. This could cause significant problems during the tendering process and subsequently in the delivery of the project.

13. We have the following concerns in relation to particular sections of the financial memorandum:

- **Pt 104:** The funds for current IASS services are approximately £500 short of what is required to run the service in this financial year. Whilst this is a small sum, if it is compounded by the lack of inflationary and salary uplifts, the deficit could become significant.
• **Pt 104:** There does not appear to be a marketing budget for PASS, although this has been identified in the Bill as one of the activities to be carried out – the service provider will need to market PASS service as it will be built on the existing IASS service but under a new name. Subsequently, new marketing materials will also be required. We are unsure if this is already included in the overall funding amount.

• **Pt 108:** The current proposal redirects £134,000 presently provided to CAS to the health boards for PASS and Patient Rights Officers (PRO). It is important that some services be delivered by a central authority, including statistical reporting, marketing, and training. We are concerned that no specific provision has been made for this.

• **Pt 108:** It is unclear what the relationship between health boards and the new PASS service will be, given that contracting will be carried out nationally rather than locally. We would like clarity about whether service contracts will be in place in each health board area with the provider(s) in that area or whether there will be a single national contract. The contractual relationships and local versus national funding arrangements need to be made clear for decisions to be made with regard to tendering.

• **Pt 109:** We very much welcome the provision of additional funding of £116,000 from the Scottish Government but have concerns on how this figure was reached and what its intended purpose is.

• **Pt 111:** The salary scales outlined here are appropriate, although we believe that the £5,000 allocated to on-costs seems low when both pension and national insurance contributions are taken into account. We feel that this figure should be nearer 18% to 20% of wages paid out.

• **Pt 113:** This section pre-supposes that all existing IASS paid staff would move into the new service. Depending on which organisation wins the contract and on their existing arrangements, this may not be the case.

• **Pt 117:** There is a possibility that funds will be required to close down services provided by the current provider and/or handed over to an alternative provider.

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**Can Citizens Advice Scotland meet the costs associated with the Bill?**

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11
14. It is likely that CAS would be able to meet the financial costs associated with the Bill, although we are concerned that bureaux may not be funded to provide any temporary service that may be required during set up of the new service.

15. We recommend that consideration be given to the inclusion of funding for a transitional period of a minimum of three months to allow the new PASS to be established and, if relevant, for the IASS to transfer existing clients, systems and so on to the new provider.

16. We are concerned that funding arrangements may not be sufficient to cover inflationary and salary increases over the life of the project.

Financial Memorandum and the Margins of Uncertainty:

17. The financial memorandum does accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise, though we do feel that account should have been taken of year on year cost increases, and that account should also have been taken of the need for transitional arrangements to be put in place when IASS is replaced with PASS.

Wider Issues:

Costs and Wider Policy Initiatives:

18. We believe that the financial memorandum has taken into account costs associated with wider policy initiatives.

Future Costs:

19. It is difficult to comment on future costs associated with the Bill on any subordinate legislation and guidance until we have a clearer picture about what might be included in regulations or until we receive more detailed guidance. We would welcome the opportunity to make additional comments when further information on regulations and details on guidance have been provided.
Submission from National Waiting Times Health Board

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes the National Waiting Times Health Board responded to the consultation exercise.

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Yes

3. Did you have sufficient time to contribute to the consultation exercise?

Yes

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Yes

5. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

Yes

6. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Yes

Wider Issues

7. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

As far as aware yes

8. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?
Not aware of any at the moment.
Submission from NHS Ayrshire and Arran

Consultation

9. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

*NHS Ayrshire and Arran did not comment on the financial assumptions made at the time of consultation.*

10. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

*Not applicable.*

11. Did you have sufficient time to contribute to the consultation exercise?

*Yes.*

Costs

12. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

*Paragraph 80 of the Financial Memorandum indicates no financial impact arising from the treatment time guarantee. Paragraph 84 notes that funding for access targets has been reduced from £90 million per annum to £70 million per annum and there is no additional funding to health boards for the treatment time guarantee. At 31 March 2010, NHS Ayrshire and Arran had 20 orthopaedic patients waiting longer than 12 weeks, but to achieve this NHS Ayrshire and Arran had invested in 2009/10 an extra £3.7 million non-recurrently of its general allocation funding to supplement SGHD money. For 2010/11 the additional funding required locally is around £4 million therefore there are financial implications for NHS Ayrshire and Arran.*

13. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

*NHS Ayrshire and Arran supports the extra investment in advocacy but has concerns about the recurring investment of £1 million. Paragraph 114 estimates 65-80 full time equivalent Patient Rights Officers (PROs) across Scotland and it is felt that half this number would be more appropriate, since investing in these additional posts would be at the expense of frontline services.*

14. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?
Yes.

**Wider Issues**

15. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

Yes

16. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance?

No

If so, is it possible to quantify these costs?

*Not applicable.*
Submission from NHS Greater Glasgow and Clyde

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

   Yes. There was little detail in the consultation paper on the expected costs arising from the proposed bill. Comment was confined to reflecting the concerns of clinical staff and patient representatives that there may be duplication of existing arrangements, as well as potentially increased administrative costs that would have to be deducted from allocations towards patient care.

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

   To a certain extent. It is clear that many of the costs identified thus far will be met by the Scottish Administration directly. However, it is not clear that all costs have necessarily been identified in terms of the NHS Boards and there is insufficient detail in the Financial Memorandum that would allow us to determine this.

3. Did you have sufficient time to contribute to the consultation exercise?

   Yes.

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

   There is insufficient detail in the memorandum to allow us to answer that question. Although the major additional costs will relate to waiting time guarantees enshrined within the Bill, the Memorandum indicates other recurring costs that are, at present, impossible to quantify. Most notably there is the introduction of new staff training modules within existing programmes and the cost of dealing with additional complaints results for publicity and awareness-raising of new systems introduced under the Bill. Without additional detail on the nature of the training and the scale of publicity to be involved, we cannot accurately scope out the implications for NHSGGC.

   Additionally, we note that the indicated recurring cost to all NHS Boards for the introduction of Patients Rights Officers and the Patient Advice and Support Service (PASS) amounts to £831,000 annually. It is further indicated that this represents the current expenditure on contractual arrangements with Citizen’s Advice Bureaux to provide the Independent Advice and Support Service (IASS).
It is suggested that the IASS contract will end in 2011 and will be directly replaced by PASS, and so no additional expenditure would be incurred by NHS Boards. However, we have two concerns:

- NHSGGC’s current IASS contract expenditure per annum amounts to £138,000 – previous experience suggests that NHSGGC as the largest geographical Board, providing both regional and national services, tends to incur 20 – 30% of the costs of any national initiative. Consequently, from an estimated £831,000 national spend on PASS, NHSGGC might actually incur as much as £249,000. This would be substantially higher than the current IASS contract.

- There is no guarantee that £831,000 will represent the actual national cost of PASS – progress towards implementation is at too early a stage to be able to offer a realistic estimate.

5. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

If any additional financial costs are incurred as a result of the Bill, this would cause severe difficulty to the NHS Board in the context of the current financial climate.

6. Does the Financial memorandum accurately reflect the margins of uncertainty associates with the estimates and the timescales over which such costs would be expected to arise?

We do not believe so – there are a number of imponderables as we have indicated above and we do not feel that this is given sufficient recognition in the Financial Memorandum.

Wider Issues

7. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

To a certain extent, given that reference is made to financial allocations linked to reductions in waiting times.

8. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance. If so, is it possible to quantify these costs?

For the reasons stated above, we are unable to quantify these costs.
Submission from NHS Lanarkshire

Consultation

17. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

*NHS Lanarkshire did not comment on the financial assumptions made at the time of consultation.*

18. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

*N/A*

19. Did you have sufficient time to contribute to the consultation exercise?

*N/A*

Costs

20. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

_The financial memorandum appears to recognise all relevant areas of cost. It does not quantify the increased workload on complaints officers from the expected initial increase in complaints nor does it quantify the opportunity cost or backfill cost in staff training. It makes the assumption that these can be absorbed. These are likely to have an impact, at least in terms of opportunity costs of time that would have been spent progressing other work, but it is unlikely the financial cost of these unquantified elements would be material._

21. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

_Most of the costs associated with the introduction of the bill are to be met by the redirection of existing funding or by additional central funding (£784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13)._  
_A general concern is that, at a time when the full extent of the reduction in public sector finances is unknown committing to new developments with no invest to save potential identified could exacerbate an already difficult situation._  
_Although the Bill makes a reasonable assessment that meeting the 12 week treatment time should be no more financially onerous than delivering the existing 18 week RTT it should be recognised that many Boards will require_
to divert resource from elsewhere to supplement the national funding to deliver this target. Based on current assumptions, NHS Lanarkshire will have to generate additional savings of around £1m from other service areas to enhance dedicated access target funding to meet the 18 week RTT. While this pressure exists independent of the Bill it is important to recognise that the Bill reinforces a target which cannot be met locally within the current level of ringfenced funding.

22. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Other than the comments in 5 above, NHS Lanarkshire has no better information with which to estimate the likely costs although the estimates do appear reasonable.
Submission from NHS Lothian

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes, a response was submitted on behalf of NHS Lothian to the consultation exercise which took place between November 2008 and January 2009. The consultation exercise did not set out any financial information or make any financial assumptions. The consultation paper set out proposals in broad terms for what might be in a Bill of Rights. The only financial comment made in our response was to question the proposal of the Bill being legally enforceable and therefore what sanctions, including financial, might apply. In the event that there were financial implications, it was pointed out that this could prove very costly for the NHS.

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Yes, in that the right to financial compensation is not included.

3. Did you have sufficient time to contribute to the consultation exercise?

Yes, in the 2008-2009 consultation. With regard to the time line for written submissions for evidence on the Bill to the Health and Sport Committee, the letter requesting evidence was emailed on 26 March 2010 with a closing date of 13 May. While we have submitted comments it would have been helpful to have had a little longer e.g. eight weeks, particularly as it was over the Easter holiday. The request for a response to the Finance Committee was emailed to NHS Boards on 11 May 2010. This questionnaire was not attached to the emailed letter from the Healthcare Policy and Strategy Directorate. It would have been helpful to have had longer to reply to the Finance Committee.

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

4.1 No. There is no recognition in the Bill of the financial implications for NHS Boards for the reasons set out in the following paragraphs. In addition there will be implications for NHS Boards in respect of the number of staff needed by NHS Boards to deliver this agenda, while 65-80 independent patients rights officers will be funded.

4.2 The Patient Rights Bill is a small proportion of the totality of existing legal duties and rights for patients and the public. There is a mixture of routes for raising awareness and support for individuals who wish to seek redress or question the application of rights. For the majority of existing patients’
rights people access local services or Health Boards as the first port of call for enquiries or complaints. Where formal recording is in place, NHS Lothian handles approximately 1,150 complaints. This figure excludes enquiries where receptionists, healthcare professions, complaints staff and other staff signpost and inform people about their rights. In contrast, NHS Lothian Independent Advice and Support Service (IASS) service formally recorded 58 cases in 2009-2010. As well as that, NHS Lothian produces patient information for the public, Health News for each Local Authority area, regularly updates its webpage and has a number of specific information leaflets about patient rights.

4.3 All Health Rights Information (HRIS) leaflets are printed and distributed by NHS Lothian. Documentation including the HRIS leaflets must also be locally relevant, produced and locally distributed. These costs are currently met by NHS Boards. It is difficult to calculate the costs to NHS Lothian to support and uphold patient rights in NHS Scotland – it is however not an insubstantial amount.

4.4 It is disappointing that the financial memorandum contains no new funding to geographic or service provision boards. Nor is it evident that there has been any detailed dialogue with Boards on what their costs base for the implementation of new patient rights. An example might be the implementation of the Carer Information Strategy to support carers’ rights, which the government funded to the sum of £9m for 3 years.

4.5 The financial memorandum sets out in paragraph 58 considerable investment, all of which is national for the next 3 years. At a time when there will be serious and significant pressures on NHS Board budgets, the case for legislation is debatable. There is however evidence that if such legislation is enacted then Boards will be involved in the service delivery and potential additional cost.

4.6 Paragraph 59 details £1.6m to NHS Education Scotland to develop materials and a workforce educational development plan. This investment, if focused on the totality of patient rights awareness and cultural competence, is to be welcomed. However if focused on only the parameters of the bill then a significant proportion of the money should be directed to Boards. Models of education delivery must be local and relevant and accessible to frontline staff.

4.7 Translations of leaflets should be produced and paid for nationally, which is not currently the case.

4.8 The current funding for Independent Advice and Support Service (IASS) would appear to have benefited a very small proportion of people who complain, comment or raise a concern or enquiry – see para 4.1 above and para 4.9 below. The vast majority of patient rights issues are dealt with by Boards. Independence becomes – and can be seen to be – an issue for a small proportion of complainants. Our complaints, patient liaison and other staff currently deliver advice and support to a high standard. Being in the
‘business’ supports effective, fast communication and more importantly
resolution.

4.9 The Policy Memorandum states that there will be at least one Patient Rights
Officer per Health Board, yet the Financial Memorandum in para 111 refers
to the provision of around 40-50 new full-time equivalent Patient Rights
Officers across Scotland. In para 114 however it states that total funding is
expected to provide for 65-80 full time equivalents, when the current
funding by Boards to the Independent Advice Service (IASS) provided by
Citizens Advice Bureaux, is added to the proposed Scottish Administration
funding of over £1,000,000 per year. It is not clear how the leap has been
made in numbers of rights officers from the Policy Memorandum to the
numbers proposed in the Financial Memorandum. This seems a
considerable number of staff without any evidence as to how the number
was arrived at.

4.10 NHS Lothian funds the Independent Advice and Support Service (IASS) to
the sum of £78,702, which currently supports people making complaints.
This funds the 10 Citizen Advice Bureaux in the Lothians for initial advice
on the complaints process before referral to an advice worker in more
complex cases (approximately 15 per quarter). The Board is expected to
make this sum available for the new service. This assumes that the current
funding is value for money and given the current and future financial
pressures that NHS services are facing it cannot be assumed that such
sums available in the current year will continue. This support by 14 Boards
together with funding from the Scottish Administration amounts to almost £2
million per annum. This seems a considerable expenditure for a service
which in large part will actually be delivered by Boards (as explained in
paragraphs 4.1 and 4.2 above).

4.11 Paragraph 112 talks of the 14 territorial Health Boards having
commissioned IASS. NHS 24, Scottish Ambulance Service, the State
Hospital, the Golden Jubilee all provide services to patients. It is not clear
why these Boards were excluded.

4.12 It would also be helpful to know what the outputs were from the investment
of £60,000 detailed in paragraph 115 to NSS Scotland.

4.13 Paragraphs 119 and 128 refer to funding to national organisations (for
advocacy and interpretation, translation and communication support), which
do not provide frontline services. If the Bill is enacted the pressures,
already considerable on both these budget areas will be added to with
increased demand, but with no additional financial support to Boards.
Already advocacy services, jointly commissioned with Local Authorities are
being reviewed to ensure compliance with legal duties and national
guidance.

4.14 For face to face interpretation services national contracts are unlikely to
demonstrate cost benefits, but national translation procurement may. This
therefore is to be welcomed as is a move to reducing costs for phone
interpretation and other “e” or IT enabled solutions. The Translation Interpretation Communication Support strategy mentioned in the memorandum has not formally been adopted nor agreed by all Boards in Scotland.

4.15 Further investment to Boards for service provision to meet growing need would be preferred to additional national funding.

5 Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

No, for the reasons set out in answer to question 4. As set out in answer to that question, there needs to be an accurate costing of the implementation implications for NHS Boards. NHS Boards will continue to deliver the bulk of a “patient rights service” but with no new money to assist them. The only financial support is to national organisations. For example, the requirements for interpretation, translation and communication support cannot be underestimated. Yet there is no funding for NHS Boards to meet this increasing need, which is extremely necessary to address not only in respect of informed consent and good person – centred care, but also the legal duties under Equality and Human Rights legislation.

6 Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

No.

6.1 In view of the current financial situation facing both NHS Boards and the Scottish Administration, there is a substantial degree of uncertainty. At a time when there will be serious and significant pressures on NHS Board budgets, the case for legislation is debatable. This is particularly relevant in respect of the proposed Patient Advice and Support Service (PASS) as commented upon in paragraphs 4.9 and 4.10.

6.3 The estimates in the memorandum for redirected and new funding are largely going to be related to costs provided by Scottish Government administration. As such, the estimates for provision of the related services will largely rest on their perspectives on how much these services will cost to provide.

6.4 It is open to NSS/NES to commission provision of such services (such as Patients Rights Officers) from other organisations. Should that be the case, it may result in limited cost savings. However territorial boards will have to ensure that such savings do not arise from additional use of their resources under information sharing arrangements required by the Bill.

Wider Issues
7 If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

7.1 In parallel there is a working group looking at proposals for a “no-fault” compensation scheme to provide restorative justice for patients and relatives who have a grievance against a provider Board or GP. This group reports to the Cabinet Secretary for Health with recommendations in autumn 2010.

7.2 Dependent on the model for such a scheme recommended or adopted, this could have an impact on the existing resources Boards use for settling and administering complaints and claims. This issue is not reflected in the Financial Memorandum.

8 Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

8.1 There may be but unable to quantify these costs, however, a concern would be that as with the consultation on the Bill costs may emerge which are not anticipated at present.

8.2 However, see answer to question 7 above. At present it is not possible to quantify such costs as they are dependent on the model of restorative justice and complaints resolution adopted. Some schemes adopt a fixed tariff and include / exclude specific events (such as acquired infections) so the potential variation in costs is wide. In many ways such differing systems reflect the historic or developing culture towards litigation on medical matters over the last 35-40 years in different parts of the world such as in Scandinavia and the Antipodes.

Melanie Hornett
NHS Lothian
24 May 2010
Submission from NHS Orkney

Consultation

23. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

*NHS Orkney did not participate in the consultation exercise*

24. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

25. Did you have sufficient time to contribute to the consultation exercise?

Costs

26. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

*We note that current funding for the Independent Advice and Support Service (amounting to £8,000 in NHS Orkney) will be redirected to the new patient advice and support service, including Patient Rights Officer, from 2011/12. However, recent experience suggests that there may be increasing costs associated with provision of communication support and advocacy services.*

27. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

*NHS Orkney will expect to support the new patient advice and support service at the current level of financial support to the Independent and Support Service. We note the additional funding in paragraphs 109 and 110 of the Financial Memorandum which Scottish Government will make available.*

28. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

*We anticipate that costs directly associated with the Bill would be incurred from 2011/12 onwards*

Wider Issues

29. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

*As part of the wider policy initiative which has more emphasis on public involvement in service provision and with increasing public awareness of*
patients’ rights, we would anticipate potential additional costs from 2011 onwards.

30. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

Yes, we anticipate additional future costs for communication support and advocacy services which we are unable to quantify at this stage.
Submission from NHS Education for Scotland

Consultation

31. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes we did respond to the consultation for the Patient Rights (Scotland) Bill. We made no comment on the financial assumptions made. However, we did reiterate the issue of training, education and development for staff in order to implement the Bill and this has implications for NHS Boards resource allocation.

32. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Not applicable.

33. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

34. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

NES has been commissioned to deliver educational support for the implementation of the Bill. The funding for this will be met from our existing central funding and significant additional funding from Scottish Government, as per the Financial Memorandum. The additional funding fully reflects the cost implications that we have calculated in order to make the implementation of the Bill meaningful and effective.

35. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

With regards our mainstream education, training and development it is important that we are able to embed the healthcare principles and take account of the rights of patients in all work that we undertake. This will involve careful consideration of the ways that we deliver our core business but any financial implications will be absorbed by each of our Directorates current budgets.

36. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?
We will only be able to deliver the educational programme to support the implementation of the Bill if the identified additional funds, as per the Financial Memorandum, are received by NES from Scottish Government. Otherwise, we would have very limited ability to impact NHS services through our core business. Any reduction in these funds would mean that we would have to reassess our specific plans developed to support implementation of the Bill.

**Wider Issues**

37. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

Developing a mutual NHS where the patient is a partner in their own healthcare, is underpinned by the rights and healthcare principles set out in the Bill. However, delivering this policy does mean a real culture shift for the NHS. This will not necessarily imply additional costs but could change the way NHS staff work and may mean additional training needs for staff. It is this training that has resource implications not just financial but also staff, ie: releasing staff time to attend training. NES has a responsibility to look at how we deliver our training programmes. We must harness and maximise the use of blended learning approaches and new technologies to ensure that all staff have the opportunity to benefit from any training, education or development available from NES.

38. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

Most NHS Boards will have additional resource implications as already mentioned. However, it is difficult to quantify these costs at this stage as we are just in the early stages of looking at educational needs to support implementation of the Bill. However, we will maximise opportunities to embed the healthcare principles and take account of patient rights in all of our core business.
Submission from NHS 24

Consultation

39. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Answer: NHS 24 took part in the consultation exercise for the Bill. NHS 24 commented on the financial implications of:

- An increased use of telephone interpretation services for the public
- Information materials available in different formats and languages.

40. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Answer: Additional funding is being made available for TICS for patients (Financial Memorandum, page 23) to research and communicate with patients and the public. Any potential increase in frontline service provision, for example, through the increase in the British Sign Language or web chat services for deaf and hard of hearing people, do not appear to be covered by this funding.

41. Did you have sufficient time to contribute to the consultation exercise?

Answer: Yes.

Costs

42. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Answer: NHS 24 is developing its services for deaf and hard of hearing people. The Financial Memorandum does not appear to address the need to further develop frontline services for people with specific communication needs.

The amount suggested for staff training would only cover the development of training packages and would not cover the additional hours Boards would require to cover to allow staff the time that they require to be trained.

The costs outlined for public awareness-raising appear to be low in relation to the requirement to publicise this national initiative to the public of Scotland.

43. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?
**Answer:** At this point the scale of the demand that will be generated by the Patient Rights Bill is unknown and therefore it is not possible to calculate exactly the associated financial costs.

It is unlikely that NHS 24 will be able to meet the full financial cost of the technological changes required to make the service fully accessible to deaf and hard of hearing people. There may also be other groups of people for whom additional support may be required and NHS 24 would be unable to fund any major change to technology and service delivery processes.

We would also need to say that most of our cost will be a technology cost and NHS Health Scotland would be unable to support this.

44. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

**Answer:** The Financial Memorandum sets out a programme of evaluation and monitoring in relation to costs and compliance. It is this process which will highlight the margins of uncertainty with estimates and timescales.

**Wider Issues**

45. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

**Answer:** There is recognition of the wider policy initiative in the Financial Memorandum. More information is required on the detail of the costs however in order to assess whether the associated costs are accurately reflected in the document.

46. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

**Answer:** The future costs associated with the Bill may be in the provision of additional information materials, translation/support for patients and technical and service delivery changes. The intention of the Bill is to open up a more equal dialogue with patients and the public about their health. This may lead to an increase in demand for more information in a wide range of formats which will require to be funded. The level of funding required is unknown at this time.
Submission from Royal College of Nursing Scotland

The Royal College of Nursing (RCN) Scotland welcomes the opportunity to submit evidence to the Finance Committee on this key issue for health care. RCN Scotland is committed to promoting the rights of the people of Scotland to person-centred care, providing optimum benefit to health and wellbeing. We are fully supportive of patient rights and the principle of mutuality; a health service owned and supported by patients and staff together. However, RCN Scotland is concerned about the use of primary legislation to achieve this, as we do not believe this to be the most effective approach.

Consultation

47. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

RCN Scotland did take part in the consultation exercise, but did not make comment on the financial assumptions at that stage.

48. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

N/a.

49. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

50. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

In order to support nurses and other health care professionals in their understanding of the implications of the Bill, there is work to be done by the professional bodies, in association with patient groups and the Scottish Government in arriving at a common understanding as to how the health care principles are to be understood, applied and disseminated.

In the face of ongoing financial pressure on numbers of adequately trained staff, equipment and treatment measures, and recognising that things do go wrong, RCN Scotland is concerned at the extent to which health care professionals will increasingly become the subject of complaints relative to alleged breaches of the health care principles and the treatment time guarantee.
The financial implications for the RCN, and the other unions, are significant in terms of increased need for support and representation of members. However, it is difficult to quantify these implications at this stage.

51. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

RCN Scotland would like resources to be made available by the Scottish Government to enable professional bodies and trade unions representing health care staff to engage and collaborate with NHS bodies and organisations representing key interested patient groups. These groups are likely to include AVMA (Action Against Medical Accidents), GDA (Glasgow Disability Alliance), SAMH (Scottish Association of Mental Health), GARA (Glasgow Anti Racist Alliance) and the Scottish Voluntary Sector Health Network.

52. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

RCN Scotland is particularly concerned that whilst there are always margins of uncertainty, the lessons from the Patients’ Charter are that the amount of work in terms of patients’ and staff education is huge. Our reading of the figures is that this has been significantly underestimated. The alternative consequences of this are either: a) no more patients are aware of their rights under the Bill than are currently aware of the excellent information contained within the booklet ‘Your NHS’, which sets out current entitlements, or b) that costs will spiral.

The explanatory notes also make clear the Government’s intention to emphasise responsibilities alongside rights in the implementation of the Bill. This is another huge piece of work which needs significant funding and extensive public engagement.

Wider Issues

53. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

The RCN has the following concerns about the figures in the financial memorandum:

(a) the extent to which the budget will enable patient rights officers to receive the training, skills and competencies to direct patients to the full range of legal remedies available to them in the light of a breach of any of their rights, including the rights under the Bill;
(b) the extent to which the budget will really enable patients and the public to be fully informed as to the principles, the treatment time guarantee and other legal rights and remedies to which they are entitled when receiving health care to achieve participation, accountability, non-discrimination, empowerment and legality;

(c) the extent to which the budget will give health care professionals time to receive training and updates on the health care principles and the treatment time guarantee, as well as other legal rights and remedies available to patients, so they are fully informed as to what is expected of them and where the responsibilities lie.

Whilst we recognise the significant budget provided for NHS Education for Scotland we are concerned that in the current climate, frontline staff will not be given the time to engage in training and development opportunities. The costs on the NHS in Scotland for staff time are far greater than the costs on NES for developing learning materials.

54. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

This Bill is linked to the NHS Scotland Quality Strategy, which describes a mutual NHS where patients are active participants in their care. As mentioned above, an emphasis on responsibilities as well as rights will require a great deal of carefully developed guidance and there is no indication in paragraphs 67-73 that this has been considered.

RCN Scotland would like to emphasise support for a mutual NHS, enhanced through clear, meaningful, and equitable patient rights and responsibilities which sit alongside those rights and responsibilities of staff. However, the cost of effective implementation of this Bill serves to reinforce our belief that legislation is not the most effective way to achieve this.
Submission from Scottish Ambulance Service

I have responded to your call for evidence in relation to the Financial Memorandum of the Patients Rights Bill on behalf of the Scottish Ambulance Service. Whilst I appreciate the aims of the bill in terms of:

- providing more information to the public relating to their healthcare provision
- providing them with guarantees in relation to treatment waiting time
- the provision of patients rights officers

I would ask that within a backdrop of tightening financial resources within the public sector generally and specifically in health, should the financial consequences and requirements of the bill not be re-examined such that a redesigned complaints system within the NHS that delivers an efficient and effective mechanism for the public to ensure their access to healthcare is appropriate is constructed.

I would be grateful if these comments could be fed into the deliberations around the Financial Memorandum of the bill.

1. Yes, the Scottish Ambulance Service participated in the consultation exercise. We did not comment on the financial assumptions made.

2. No comments made, therefore not reflected.

3. Yes, we had sufficient time to contribute to the consultation exercise.

4. If the Scottish Ambulance Service is expected to have a patient rights officer I would hope that this funding is included in the overall funding package and that this person would be able to cover the entire geography of Scotland. The ancillary costs of the post should also be included.

5. The costs of promotional material we assume will be funded by NHS Education. Anything in addition would require to be funded by SGHD. We already have a complaint’s system in place which is able to respond to the current level of activity. However, should there be a significant increase due to the patient rights officers activity. This would require to be funded by the Scottish Government as there is no financial capacity within the Scottish Ambulance Service to add to existing resources.

6. There should be an element of contingency within the costs which does not appear to be currently in place. The timescales appear appropriate.

7. In terms of patient guarantees for waiting times and perhaps more wider access to specialist services. This may create expectations in the public that are not able to be resourced by individual Health Boards.

8. The associated costs that would come from heightened public awareness and increased expectations of the Health Service through the Patients Rights bill should be factored in. This would be extremely difficult to quantify.
Submission from State Hospitals Board for Scotland

Consultation

55. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

No did not take part

56. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

See answer to question one

57. Did you have sufficient time to contribute to the consultation exercise?

n/a

Costs

58. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Para 121 £500k is to be made available to NHS Boards using NRAC formula from 2011-12 to increase support for advocacy to help patients understand the Patients Bill. This will result in a potential 10% increase. The State Hospital would not receive funding due to the NRAC formula being used but would wish to access additional funding if possible. The State Hospital advocacy contract is approximately £130k and 10% would equal £13,000.

Para 129 No specific figures are mentioned but the paragraph refers to increases in finances being made available to support translation, interpreting, and communication support. There may be a knock on effect to the State Hospital but we can accommodate this within our existing budget.

59. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

See answer to question 4

60. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Yes

Wider Issues

61. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?
Yes

62. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

No
Supplementary submission from the Scottish Government

At the Finance Committee evidence giving session by officials on the Patient Rights Bill, on 15 June 2010, Jeremy Purvis, MSP, asked why there was not consistency between the workforce planning exercise and NHS workforce projections published recently by the Cabinet Secretary and the financial memorandum [of the Patient Rights (Scotland) Bill]. The Convenor asked that we respond in writing.

The development of training is to be commissioned by the Scottish Government from NHS NES. It was noted in the Patient Rights (Scotland) Bill’s Financial Memorandum, at paragraph 64, that recruitment of staff by NES would be “where necessary”. Given their recent workforce projections, NES may decide that it is not necessary to recruit any additional staff, however, this is a matter for them.

The Convenor also asked that we submit in writing the Regulatory Impact Assessment. 41

Lauren Murdoch
Bill Team Leader

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41 The RIA was published as part of the papers for the Committee’s 18th meeting 2010, can be viewed at http://www.scottish.parliament.uk/s3/committees/finance/papers-10/fip10-18.pdf
Patient Rights (Scotland) Bill: The Committee took evidence on the Financial Memorandum of the Patient Rights (Scotland) Bill from—

Margaret Duncan, Policy Lead for the Treatment Time Guarantee, Fiona Montgomery, Head of Patient Support and Participation Division, Lauren Murdoch, Patient Rights Bill Team Leader, and Alastair Pringle, Head of Patient Focus and Equalities, Scottish Government.
14:49

On resuming—

Patient Rights (Scotland) Bill: Financial Memorandum

The Convener: Item 3 is evidence from the Scottish Government’s bill team on the financial memorandum to the Patient Rights (Scotland) Bill. I welcome Lauren Murdoch, bill team leader; Margaret Duncan, policy lead for the patient support and participation division; and Alastair Pringle, head of patient focus and equalities. I invite our witnesses to make an opening statement.

Fiona Montgomery (Scottish Government Health Care Policy and Strategy Directorate): The Patient Rights (Scotland) Bill establishes in primary legislation key provisions to put patients at the heart of the national health service in Scotland, including person-centred principles, support services and a treatment time guarantee. To support staff and to help them to understand the rights of patients better, the Scottish Government is funding training and education materials and awareness raising through induction and continuous professional development that is costed at £94,000 this year and £800,000 in each of the next two years. The patient advice and support service, which will be staffed by patient rights officers, will build on the work of the current independent advice and support service, which is provided for health boards through contracts that are negotiated locally with citizens advice bureaux.

To support patients in exercising their rights, to widen access and to ensure consistency of quality, the Scottish Government proposes to commission the service nationally and to provide funding for the patient advice and support service of £1.25 million a year on top of current board funding. That could provide a total of around 65 to 80 full-time equivalent patient rights officers throughout Scotland. Patient rights officers will support people who want to make a complaint, raise concerns or provide feedback on the health care that they have received. The right to do that is established in the bill.

The consultation on the bill and the equality impact assessment highlighted the fact that communication support and advocacy are key to ensuring that more vulnerable people are able to exercise their patient rights. Advocacy services should be available where they are needed, but more work is required to establish what is available and what is needed. That is why, this year, the Scottish Government is providing funding of £500,000 to help boards to undertake an assessment of need and to draw up advocacy plans. From 2011, the Government will provide boards with an additional £500,000 a year to provide additional advocacy services. Translation, interpreting and communication support is funded by boards from their general allocation. To support NHS Scotland’s action plan to improve support and ensure greater uniformity of approach and provision throughout Scotland, the Scottish Government is providing £250,000 per annum for three years.

The bill introduces a treatment time guarantee for eligible patients to start treatment within 12 weeks of their treatment being agreed. That guarantee is part of wider work on driving down waiting times, for which substantial funding has already been provided. Delivery of the 12-week treatment time guarantee is an integral part of the 18-week referral-to-treatment time target.

The money that has been allocated to the bill shows a commitment to supporting patients in the exercising of their rights.

The Convener: Thank you. I invite questions from members.

Malcolm Chisholm: I think that people would definitely support the objectives of the bill. However, having read the evidence from health boards, you will be aware that they are concerned that the costs may be greater than has been stated. Obviously, the context of that is more difficult budgets than the boards have known for a few years.

Three areas of concern have been highlighted, one of which is the training. Boards are saying that the full costs of that training have not been taken into account, as they must in-fill if people go on training courses. You mentioned advocacy and said that the funding would go to services. There seems to have been some ambiguity about whether it would go to the national organisation or to services, and boards are anxious that they may need to provide more services than the £500,000 would fund.

The third area, which is the most interesting, is the waiting time target—the flagship policy in the bill when it was first drafted. The target has now been modified and people will ask what difference the bill will make, but that is a policy question rather than a financial question. The financial question is whether recurring costs will be involved in achieving the waiting time targets. I am aware that some money has been provided this year. I would like to hear some response to the boards’ concerns on that. Is the money that has been provided for waiting times this year recurring, and will it be sufficient to maintain the waiting time right in the bill?

Fiona Montgomery: On training, we have been speaking to representatives of NHS Education for
Scotland, which delivers all the education materials and so on for the NHS. We are getting involved in pre-registration training, induction training and other training, rather than taking some people out every day to do a whole day away from their normal duties.

Alastair Pringle (Scottish Government Health Care Policy and Strategy Directorate): Given the 150,000 staff in the NHS, it would cost a lot more to offer any coherent programme of work around person-centred care than is set out in the bill. NHS Education for Scotland provides an opportunity to develop a national set of principles and training, with a consistent quality of materials and provision throughout the NHS, including in remote and rural areas.

The focus needs to be on the development of a range of materials, on e-learning and on building the principles of person-centred care into the knowledge skills framework, for instance. Working across continuous professional development and existing packages offers by far the most effective mechanism.

There is also an opportunity, through working with NHS Education for Scotland, to deliver some of the training to front-line staff. There has perhaps been a slight misunderstanding over what the money will be used for—it is not just to go to a national board; it is intended to build patient rights training and person-centred care training into existing packages.

Fiona Montgomery: Your second point was on advocacy. We are spending some money this year to find out what is actually happening on the ground and to ascertain whether there are any gaps. The money will then go towards addressing those gaps, which might not be the same across all boards.

As far as waiting times are concerned, the bill’s treatment time guarantee provisions are what we are discussing, and that guarantee is inextricably linked to the 18-week referral-to-treatment time target. Money that is going towards meeting that 18-week target, as well as the waiting times, will be covered through recurring funding.

Margaret Duncan (Scottish Government Health Delivery Directorate): This year’s funding is £70 million, and that is recurring funding—that will go forward next year.

Malcolm Chisholm: I suppose that that covers most of the matter. NHS Ayrshire and Arran has had to put in some non-recurring funding, but I do not know how typical that is of other health boards. NHS Ayrshire and Arran, at any rate, says that it will face an additional cost each year. What is your comment on that?

Margaret Duncan: There are problems at individual boards, which might need to put in some extra capacity. However, we will continue to deal with that through the support and delivery of the 18-week referral-to-treatment time. The issues around the financing of that and the treatment time guarantee will continue to be discussed in order to ensure delivery.

Malcolm Chisholm: So the requirements could be a bit more and, if so, you will just have to cover that, as the target is so important.

Margaret Duncan: Yes, although the £70 million has not yet been allocated. We are in discussions with boards on the appropriate allocations.

Malcolm Chisholm: As you have clarified, there has been some ambiguity about how many patient rights officers would be required. There was a discrepancy between the policy memorandum and the financial memorandum in that regard. You quoted the figure of 65 to 80 officers; I think that that is from the financial memorandum. I suppose that the boards are concerned about that, too—perhaps it is the biggest area of concern, in some ways.

The question is how you arrived at that figure, and whether there is any flexibility for the boards given that some of them are saying that that is not necessarily the right number. I am just reflecting the anxiety of boards, which will face tough budgetary decisions—they are already having to make them. To what extent is that figure for the number of officers an indicative one? Is there some flexibility with it?

15:00

Fiona Montgomery: Although the service will be different from the current independent advice and support service, we arrived at the figure by looking at current case worker costs and basing our look forward on that. With procurement people in NHS National Services Scotland, we are looking at the specification of a national contract for the future. That is partly because there have been inconsistencies in the quality and amount of service across boards. We are trying to make that more consistent. We have looked at the numbers and, as the contract is worked through and we discuss local needs with boards, we are trying not to be too specific by saying that we need X number of patient rights officers in every board. We are allowing for a bit of leeway, which includes how much the organisation that will get the contract wants to spend on marketing, central support and so on. That is why we have tried to cover a range of figures.

Tom McCabe: A number of organisations have expressed concerns about the financial
memorandum. For example, Citizens Advice Scotland has indicated that it cannot see any provision for inflation or salary uplifts over a three-year period. Clearly, if that was the case, that would be a pretty substantial real-terms decrease in the money available over three years. Secondly, CAS said that there does not appear to be any marketing budget for the new organisation. Given the nature of the work that the organisation will do, one would think that marketing would be pretty important in bringing the service to the public’s attention and making people aware that this is a route that they can take.

Lastly, you touched on the national contracts. What will the relationship be between the new organisation and each individual board? Will service-level agreements be set to accommodate local circumstances, or will a national approach be taken through the contract?

**Fiona Montgomery:** On inflation and salaries, we have produced a package with an amount that we think will take us forward. Obviously, though, we are still in discussion about the exact specifications of the contract; costs may be slightly less in the first year, which would allow a bit for an increase for inflation in future years. However, we are still working our way through that.

On marketing, other things are going on. For example, we will look at patient-facing information for people who might not go through a patient rights officer but who still want information. In addition, NHS Inform will come on stream with a national strategy to inform people of everything about their health care, including rights, patient advice and support. Again, we are going through the contract specification with the boards, and the procurement people have been speaking to Citizens Advice Scotland about what it does, so we will build in something for how we market the service locally and nationally.

On the national contract, it has been quite clear that individual boards’ relationships with their local CABs are an important part of taking that forward. We want a national contract to ensure that there is equality of service, but we will still have some sort of local arrangement so that relationships between complaints officers, patient rights officers and so on can be built up.

**The Convener:** How can you ensure value for money and how would you measure it?

**Fiona Montgomery:** It is very difficult to measure value for money in this area. There is quite a lot of evidence about improving a patient’s experience and about information that has an impact on a patient’s health care and health outcomes. We tried to quantify the amount in our work on the regulatory impact assessment. We can do qualitative work and talk about a case study in which we can see that, if somebody is better informed about their health care, they may be better at, for example, taking their medication and attending consultations.

If people get a better health outcome, they might not come in and out of the service so much. However, that is difficult to quantify. We did not put too much about savings in the financial memorandum because we could not justify that with the evidence, but we definitely think that savings will be achieved.

**David Whitton:** I am pleased to hear that you think that savings might be made, but most major health boards that have given evidence expect not savings but increased costs. What consultation have you had with boards about the bill’s financial implications and particularly about the concerns in their submissions?

**Fiona Montgomery:** We have consulted boards all the way through the bill process. The bill was introduced in March, but consultation took place for some time before then. We have talked to national boards such as NHS Education for Scotland about contracts to do pieces of work—that board has given us its estimate for the work. We have spoken to the territorial boards—the local boards—throughout the process and we continue to speak to them and a range of stakeholders.

**Lauren Murdoch (Scottish Government Health Care Policy and Strategy Directorate):** We have spoken to several chief executives at their regular meetings with the Government. We have also met patient focus and public involvement representatives as part of general work on patient support and participation.

**David Whitton:** I will quote just the submission from NHS Lothian, for example. It was asked the standard question:

“If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.”

The board’s answer was “No.” It gave details of why the memorandum did not reflect the costs.

The other point that is made is that, at a time when boards such as NHS Greater Glasgow and Clyde and NHS Lothian have announced staff cuts—including cuts in nurses—you ask them to recruit patient relationship officers. I understand that boards must strike a balance between what is in the bill and what they are asked to do with their finances, but how much has that been taken into account?

**Fiona Montgomery:** On patient rights officers and the patient advice and support service, we ask boards only to continue to provide their current funding level for the independent advice and
support service. We will fund centrally the additional costs.

**David Whitton:** So somebody might just change their job title. Do most health boards not have somebody who deals with complaints?

**Fiona Montgomery:** Patient rights officers are independent and do not work for boards. Case workers who currently provide such a service are employed by citizens advice bureaux. Under the new system, the contract will be open—we do not know who the supplier will be. In response to the consultation, patients and stakeholders said clearly that they wanted an independent advice service and that they wanted to approach somebody who was not employed by the health service. No matter how good and helpful a complaints officer might be, some people wanted independence at some point.

The contract for the service will not be funded at the expense of nurses. The Scottish Government is keen to emphasise that helping people through their health care journey—especially those people who need a bit more help; not everyone needs a bit of help, but some do—produces a better outcome. The service will assist people to access front-line services.

**David Whitton:** Are you confident that enough is being allocated to help with the staff training that Mr Pringle mentioned and that boards will not have to carry an extra burden in the end?

**Fiona Montgomery:** We are packaging that training with a range of other training on the NHS quality strategy that was launched recently, on equalities and on human rights. NHS Education for Scotland has told us that it can deliver the package of materials, which we can embed in staff training.

**Alastair Pringle:** The costs were based on the previous experience of NHS Education for Scotland in delivering similar NHS-wide programmes of work, such as the patient safety programme. We are fairly confident that the costings are accurate. We would not necessarily expect any additional cost to health boards if we are building the training into the existing programmes and delivering it through existing training and practice managers networks and the like. We are quite confident that the networks and infrastructure are in place to deliver the training.

**David Whitton:** I want to pin down exactly how many patient rights officers there will be. Is it 40 to 50, or 60 to 80?

**Fiona Montgomery:** The 40 to 50 would be the additional ones, with the additional central funding. There are already 30 or so independent advice and support service workers. The 40 to 50 are the additional workers that we could provide with the £1.25 million from central funding.

**David Whitton:** On central funding, NHS Lothian said:

“Translations of leaflets should be produced and paid for nationally”

rather than locally. Have you any sympathy with that view?

**Fiona Montgomery:** Perhaps Alastair Pringle could say something about NHS inform.

**Alastair Pringle:** I thought that the point was valid. We are doing some work on national quality assurance and the accessibility of information through NHS inform, which is the new national patient information service. Over the next year, a bit of work will be done with health boards to look at how we co-ordinate and ensure better efficiency and effectiveness in the translation of materials centrally. That work is under way.

**Jeremy Purvis:** I see that there will be quite a bit of money for the bill in 2011-12 and 2012-13. How do you know that you will have that money?

**Fiona Montgomery:** We put this forward at the end of March. We recognised that within the health care strategy and policy directorate we would be able to find the money by reprioritising work because certain things will be coming to an end and so on. Obviously the budget situation gets tighter as we look forward. We still think that we will be able to deliver, but we will have to consider it if things change in the overall budget for health. I would not like to say that the amount of money involved is modest, but it is quite small in the scheme of the health budget. Assisting patients to access front-line services is seen as a priority area.

**Jeremy Purvis:** So, whatever happens in the spending review period, this spending is set. You have been told by ministers that it is an absolute priority to have 40 to 50 additional PROs, rather than nurses, for example.

**Fiona Montgomery:** We do not know what the spending review will provide, but the best that we can say at the moment is that these figures are what we are working to. As with all things, as we work our way through, we will look to see whether we can get the same outcomes for slightly less or get better value for money elsewhere.

**Jeremy Purvis:** Previously, when the committee scrutinised the health boards elections pilot, the Health Boards (Membership and Elections) (Scotland) Bill team told us that they could not give us any indication of expenditure post-2011, because that is in the spending review period and it is out of their hands. Here, the
expenditure seems to be quite set. I do not know which is—

Fiona Montgomery: The figures are the current projections. On the financial memorandum, we are usually asked to look three years ahead. This was the best that we could do with the information available to us.

Jeremy Purvis: I turn to some of the bill’s other impacts. One of the big elements is the impact on Citizens Advice Scotland, given the services that it currently provides. Forgive me, because this might be in the papers, but I could not see it: has a regulatory impact assessment been carried out and, if so, what was its conclusion with regard to the impact on an existing body operating under contract?

Fiona Montgomery: A regulatory impact assessment has been carried out. I cannot give the exact figure for that, but we can certainly pass on any information that we have.

The Convener: Perhaps the information can be submitted in writing to us afterwards.

Fiona Montgomery: Certainly.

Jeremy Purvis: Does the financial memorandum or policy memorandum mention that a regulatory impact assessment has been carried out?

Fiona Montgomery: Possibly not, but a regulatory impact assessment has been carried out.

Jeremy Purvis: Why is that not mentioned?

Fiona Montgomery: I am not sure.

Lauren Murdoch: The financial memorandum makes a brief mention of the regulatory impact assessment.

15:15

Jeremy Purvis: What did the regulatory impact assessment conclude about the proposal to remove the contract from the organisations that currently deliver those services?

Lauren Murdoch: The regulatory impact assessment primarily looked at the impact on patients. It did not look at the impact on the contracts with citizens advice bureaux, which are due to come to an end anyway.

Fiona Montgomery: NHS National Services Scotland is looking into the contract, including whether arrangements under the transfer of undertakings and protection of employment regulations will be required. As Lauren Murdoch has referred to, some of the contracts started in 2006 and some of them started in 2008 but we have extended them all to the end of March 2011. That is the specific timescale.

Jeremy Purvis: I see that paragraph 64 in the financial memorandum states:

“NES will undertake this work including the recruitment of staff where necessary.”

However, in the NHS workforce projections that the cabinet secretary published recently, NHS Education for Scotland forecasts a net reduction of six in the number of its staff. Why is there not consistency between the workforce planning exercise and the financial memorandum, which suggests that the extra work will be incorporated within NHS Education for Scotland? I cannot see how those projections match.

Fiona Montgomery: I would need to go back to look at the NES workforce plan, which I am not familiar with. We can certainly provide that information later.

The Convener: Yes, those are very detailed questions. It would be helpful if the committee could be given that evidence in writing.

Jeremy Purvis: Thank you, convener. In essence, the point is that every health board is projecting reductions in staff numbers, including in the number of clinical staff posts, whereas the bill will require that further investment is made in additional PROs. Indeed, NHS Greater Glasgow and Clyde—I refer to paragraph 4 of its written submission—suggests that the £831,000 for patient advice and support services is an underestimate. The submission states that, of the £831,000 recurring cost,

“NHSGGC might actually incur as much as £249,000. This would be substantially higher than the current IASS contract.”

What is your view on that?

Fiona Montgomery: The £831,000 is what all the boards told us they are paying for their contracts in the current year. If NHS Greater Glasgow and Clyde is paying slightly less than what might be expected from its population average, perhaps that shows why we are moving to a national contract, which should provide a bit more consistency of service.

Jeremy Purvis: NHS Greater Glasgow and Clyde’s concern is that, because of the size of the health board area,

“NHSGGC ... tends to incur 20-30% of the costs of any national initiative.”

Therefore, it estimates that its actual share of those costs will be £249,000. Are you saying that no health board will be asked to contribute any additional expenditure as a result of the bill?

Fiona Montgomery: For the patient rights officers, the additional money from the centre will
be spread out across the boards, based partly on how the national resource allocation committee allocates funding but more on how the contract works and on the local needs of the different boards. The funding may just continue at the current level.

The Convener: We have reached the end of our questions. As you have no final comments to make, I thank you for your attendance and for the evidence that you have given us, which will be helpful to the committee.
Subordinate Legislation Committee

Remit and membership

Remit:

1. The remit of the Subordinate Legislation Committee is to consider and report on-

   (a) any-

   (i) subordinate legislation laid before the Parliament;

   (ii) Scottish Statutory Instrument not laid before the Parliament but classified as general according to its subject matter;

   (iii) Pension or grants motion as described in Rule 8.11A.1;

   and, in particular, to determine whether the attention of the Parliament should be drawn to any of the matters mentioned in Rule 10.3.1;

   (b) proposed powers to make subordinate legislation in particular Bills or other proposed legislation;

   (c) general questions relating to powers to make subordinate legislation; and

   (d) whether any proposed delegated powers in particular Bills or other legislation should be expressed as a power to make subordinate legislation.

*(Standing Orders of the Scottish Parliament, Rule 6.11)*

Membership:

Jackson Carlaw
Margaret Curran
Bob Doris
Helen Eadie
Rhoda Grant
Ian McKee (Deputy Convener)
Jamie Stone (Convener)
Committee Clerking Team:

Clerk to the Committee
David McGill

Assistant Clerk
Jake Thomas

Support Manager
Stephen Fricker
Subordinate Legislation Committee

29th Report, 2010 (Session 3)

Patient Rights (Scotland) Bill

The Committee reports to the Parliament as follows—

INTRODUCTION

1. At its meetings on 27 April and 11 May 2010, the Subordinate Legislation Committee considered the delegated powers provisions in the Patient Rights (Scotland) Bill at Stage 1. The Committee submits this report to the Health and Sport Committee as the lead committee for the Bill under Rule 9.6.2 of Standing Orders.

OVERVIEW OF THE BILL

2. The Patient Rights (Scotland) Bill ("the Bill") was introduced in the Parliament on 17 March 2010 by the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP.

3. The Scottish Government provided the Parliament with a memorandum on the delegated powers provisions in the Bill ("the DPM").¹

4. Correspondence between the Committee and the Scottish Government is reproduced in the Annexe.

5. The Committee determined that it did not need to draw the attention of the Parliament to the delegated powers in sections: 1(4), 4(2), 11(4)(a), 14(2), 15(6), 20(1) and 22(3).

6. The Committee considered that it did not need to draw the attention of the Parliament to the powers of direction in sections: 5(3), 9(2), 11(4)(b), 12(5) and 14(2).

¹ Patient Rights Delegated Powers Memorandum
Delegated powers provisions

Section 5(1) – Guidance in relation to the practical application of the health care principles

Power conferred on: Scottish Ministers
Power exercisable by: guidance
Parliamentary procedure: none

7. Section 5(1) provides that a relevant NHS body must, for the purposes of section 3 (duty to have regard to certain rights and principles), have regard to any guidance issued by the Scottish Ministers in relation to the practical application of the health care principles. The Committee sought further information from the Scottish Government as to the function of the guidance. The Committee notes that the Scottish Government intends that the guidance would provide “best practice” to relevant NHS bodies with respect to the operational application of the health care principles. Unlike directions under section 5(3), the guidance will not be mandatory although the bodies will have to have regard to it.

8. The Committee is satisfied that this delegated power is appropriate to be exercised in the form of guidance.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

9. The power under section 7(1) relates to the descriptions of patients which are eligible for the guarantee and to how the waiting time is to be calculated. The exercise of the power will determine which patients will or will not be eligible to benefit from the guarantee. These are not specified on the face of the Bill, nor are criteria specified on the basis of which the descriptions of eligible patients are to be determined.

10. The Committee considers that the description of patients who are eligible (or, by default, not eligible) for the guarantee is fundamental to that guarantee, which is itself a central provision in the Bill. The Committee appreciates that flexibility may be required to allow for amendment of how the guarantee should apply, in response to different circumstances now and in the future. However, the Committee considers that a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible or of criteria on the basis of which such descriptions are to be determined. The Committee acknowledges that this is ultimately a policy issue for consideration by the lead committee and is content to refer this matter to it for further consideration.

11. Similarly, the Committee considers that the method of calculation of the waiting time may also be of significance. While at first sight this may appear to be
an administrative matter, the exclusion of certain circumstances from the calculation could considerably extend the practical effect of the guarantee.

12. Given the significance of the guarantee, and the significance and effect on the operation of the guarantee of the designation of eligible patients and the calculation of the waiting time, the Committee considers that affirmative rather than negative procedure would be more appropriate.

13. The Committee draws to the attention of the lead committee its view that the power to exclude patients from eligibility for the treatment time guarantee is significant. In its view, a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible which could be amended or of criteria on the basis of which such descriptions are to be determined.

14. The Committee recommends that the power in section 7(1) be subject to affirmative rather than negative procedure because of the significance of the guarantee and the significance and effect on the operation of that guarantee of designation of eligible patients and the method of calculating the waiting time.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

15. Regulations made in exercise of this power may address matters of detail relating to the operation of the guarantee or be of an administrative or technical nature. However, regulations made under this power may also exclude specified treatments and services from the guarantee. The Committee considers that the exclusion of specified treatments and services from the guarantee was an important decision in which the Parliament may wish to play an active role. The Committee therefore asked the Scottish Government to consider whether affirmative procedure would be more appropriate.

16. The Committee acknowledges that treatments and services may be changing all the time and that flexibility will be required to respond to progress on waiting times and on specific treatments and services. However, the Committee does not agree with the statement in the Scottish Government response that this is largely an issue of a medical and technical nature. The Committee is of the view that the exclusion of specified treatments and services from the guarantee is an important issue of significance to patients and to the public generally (as potential patients) and that accordingly affirmative rather than negative procedure is more appropriate.

17. The Committee recommends that this power be subject to affirmative, rather than negative procedure because of the significance, through the
exercise of the power, of the exclusion of specified treatments and services from the guarantee.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

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<td>Power exercisable by:</td>
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<td>Parliamentary procedure:</td>
<td>negative resolution of the Scottish Parliament</td>
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18. The practical effect of this power is to enable the Scottish Ministers to change the maximum waiting time of 12 weeks set out in section 10 to a different time period and to allow the maximum waiting time to be different for different categories of treatment or service. The Committee accepts that maximum waiting times may have to be altered from time to time and in respect of particular treatments and services and that flexibility in this respect will be required. However, the Committee is concerned at the width of the power in that it allows the maximum waiting time to be extended (as well as reduced) and no limit is set on how far the maximum waiting time may be extended. The Committee considers that this could have a significant impact on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The Committee was also concerned at the choice of negative procedure, given that the maximum waiting time is a central policy issue, and sought clarification on the choice of negative rather than affirmative procedure.

19. The Committee does not consider that the first element of the Scottish Government’s response, on its own, adequately addresses the Committee’s concerns with respect to the nature and width of the power. However, the Committee is pleased to note the Scottish Government’s commitment, in the second element of its response, to consider further whether an amendment should be brought forward to apply draft affirmative procedure. An amendment to this effect would address the Committee’s concerns with respect to this power since it would provide an enhanced role for the Parliament in determining any alteration of the maximum waiting time.

20. The Committee recommends that the power should be made subject to affirmative procedure given the significant impact the exercise of the power may have on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The Committee notes the Scottish Government’s commitment to consider further whether an amendment should be brought forward to apply draft affirmative procedure.

Section 9(1) – Guidance in relation to the treatment time guarantee

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21. Section 9(1) provides that health boards must, when taking steps to start the treatment of eligible patients, have regard to any guidance issued by the Scottish
Ministers which relates to the treatment time guarantee, and, in particular, health boards’ compliance with it. The Committee sought further information from the Scottish Government as to the function of the guidance.

22. The Committee notes that the Scottish Government intends that the guidance issued under section 9(1) will relate to detailed operational and practical application. The guidance will not be mandatory but health boards will have to have regard to it.

23. The Committee is satisfied that this delegated power is appropriate to be exercised in the form of guidance.

Section 21(1)(c) – Power when making orders or regulations to make consequential, supplementary, incidental, transitional, transitory or saving provision within those orders or regulations.

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<td>Power exercisable by:</td>
<td>Order</td>
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<td>Parliamentary procedure:</td>
<td>Affirmative / Negative / None</td>
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24. Section 21(1)(c) provides that any power of the Scottish Ministers to make orders or regulations under the Bill includes power to make such consequential, supplementary, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient. This is not a separate stand-alone power. It attaches to and applies to all powers to make orders or regulations. It is therefore subject to the procedure which relates to the order or regulation making power to which it is attached. Given the separate free-standing power in section 20(1) to make ancillary provision by order, the Committee sought justification for the need for the power under section 21(1)(c).

25. The Committee accepts the Scottish Government’s view that, without the power in section 21(1)(c), related provisions may have to be in different instruments, as the power in section 20(1) is restricted to orders and could not be combined with regulations. The Committee accepts also the Government’s explanation that, without the power in section 21(1)(c), there could be potential for conflict with respect to procedure between substantive and connected provisions.

26. However, the Committee does not consider that it is appropriate to make ancillary provision of substance in commencement orders which are subject to no procedure. It therefore asked the Scottish Government for justification of this. The Committee is pleased to note the Scottish Government agrees with the Committee that the power in section 21(1)(c) should not apply to commencement orders and that the Government undertakes to bring forward an amendment to this effect. This addresses the Committee’s concerns in this respect.

27. The Committee is satisfied with the Scottish Government’s justification for the power in section 21(1)(c) in addition to that under section 20(1). The Committee does not consider it is appropriate to provide for substantive provision to be made in commencement orders subject to no procedure. It therefore recommends that section 21(1)(c) should be amended to this effect and notes the Scottish Government’s undertaking to do so.
Other proposed delegated powers

Section 9(3) – suspension of the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: directions

28. Section 9(3) provides that the Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such periods as they consider necessary. The Committee acknowledges that it may be necessary or otherwise appropriate to suspend the guarantee in exceptional circumstances, but it was not clear to the Committee why subordinate legislation could not or should not be used for this purpose given the significance of the matter on the rights conferred by the Bill. It was also not clear to the Committee whether the suspension of the guarantee would be specific (in the sense that it would apply to a specified health board or to a specified hospital) or whether it would be of general application.

29. The Committee accepts that the Scottish Government would intend to suspend the treatment time guarantee only in exceptional circumstances. Section 9(3) makes clear that it is only in exceptional circumstances that the power may be exercised. However, the Committee notes that emergency subordinate legislation is used to address exceptional circumstances in other contexts e.g. the making of prohibition orders with respect to the use of food on public health grounds. The Committee is particularly concerned by the use of directions to suspend the guarantee given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The Committee is accordingly not satisfied from the Scottish Government’s response that directions are appropriate for this purpose.

30. The Committee notes that the suspension of the treatment time guarantee could be specific (in the sense that it would apply to a specified health board or health boards or to a specified hospital or hospitals) or could be of general application, and that the position as to when powers of direction may be used is made clear by section 21(5).

31. The Committee is satisfied that the position as to when powers of direction may be used is made clear in the Bill.

32. However, the Committee is not satisfied that directions are appropriate for the purpose of suspending the treatment time guarantee in exceptional circumstances given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The Committee recommends that the power under section 9(3) should be expressed as a power to make subordinate legislation. If it is necessary for policy reasons to be able to bring that legislation into force immediately subject to subsequent endorsement by Parliament for it to continue in force, then it is possible to provide for such procedure.
Correspondence with the Scottish Government

Patient Rights (Scotland) Bill at Stage 1

Section 5(1) – Guidance in relation to the practical application of the health care principles

Section 9(1) – Guidance in relation to the treatment time guarantee

The Committee asked the Scottish Government—

- Why does the Scottish Government not consider that the guidance is not more appropriately expressed in the form of subordinate legislation?

The Scottish Government responded that the health care principles are general principles to which relevant NHS bodies must have regard. They are not detailed or prescriptive. In practice, they will be implemented having regard to professional and clinical judgement and standards, which will vary according to the facts and circumstances of each case.

Section 5(1) has to be read together with Section 5(3) of the Bill which states that “Scottish Ministers may give a relevant NHS body directions as to the practical application of the health care principles; and a relevant NHS body must comply with any such direction.” Section 5(3) accordingly provides a power for Scottish Ministers to make legal requirements which are binding on a relevant NHS body regarding the practical application of the health care principles in directions. Directions are a more appropriate mechanism than regulations for imposing these requirements, as they allow more flexibility to respond to changing circumstances.

Section 5(1) provides that a relevant NHS body must have regard to any guidance issued by Scottish Ministers in relation to the practical application of the health care principles. The intention is that this guidance would provide “best practice” which would be recommended to such bodies. Unlike directions, however, such guidance would not be mandatory. The bodies would not have a legal obligation to comply with it, but they would have a legal obligation to have regard to it. The intention is that the guidance would relate to the operational application of the principles.

Section 9(1) should be read together with sections 7(1), 7(3) and 9(2), as these provide for regulations and directions in regard to the treatment time guarantee. It is intended that the guidance issued under section 9(1) will relate to detailed operational and practical application, which is more appropriate to be issued in guidance than in regulations or directions.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

The Committee asked the Scottish Government—
• Why does the Scottish Government not consider that the descriptions of patients which are eligible for the treatment time guarantee could be specified on the face of the Bill, or, alternatively that criteria on the basis of which the descriptions of eligible patients are to be determined could be specified on the face of the Bill?

The Scottish Government responds that the intention is for the Bill to establish a treatment time guarantee of 12 weeks. The Policy Memorandum to the Bill explains the intention for which patients will be eligible. As explained in the Delegated Powers Memorandum, placing eligibility in primary legislation would not allow for the appropriate level of flexibility to amend how that treatment time guarantee should apply, in response to different circumstances, now and in the future, given the level of detail which needs to be provided.

• Given the significance and effect of the exercise of the power, why does the Scottish Government not consider that affirmative rather than negative procedure is more appropriate?

The Scottish Government anticipates that the bulk of the provisions in these regulations will relate to the detailed operation of the guarantee, together with administrative and procedural matters which will be technical in nature, and therefore that negative procedure is more appropriate.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

The Committee asked the Scottish Government—

• Given that the exercise of the power may exclude specified treatments and services from the treatment time guarantee, why does the Scottish Government not consider that affirmative rather than negative procedure is more appropriate?

As explored in the Policy Memorandum to the Bill, the intention is that the treatment time guarantee will apply to planned or elective care undertaken as an inpatient or day case; it is intended that there will be a limited number of exceptions, also explored in the Memorandum. Treatments and services are changing all the time; flexibility is required to respond to progress on waiting times and specific treatments and services, such that treatments and services which are initially excluded may become included in the guarantee in the future. Given the largely medical and technical nature of this, negative procedure seems a more appropriate use of Parliamentary time.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

The Committee asked the Scottish Government—
Why does the Scottish Government consider it necessary to take the power to substitute any maximum waiting time for the 12 week maximum specified in the Bill and could the power not be drawn more narrowly in this respect?

As this waiting time is a central provision, should the maximum not be set in primary legislation and only shorter periods specified by order?

Section 10 places the period of maximum waiting time of 12 weeks in primary legislation. Whilst the current policy is pushing waiting times down circumstances for future governments may change over time such that it would not be appropriate to restrict amendments to any maximum waiting times only to less than that specified in the primary legislation. In addition, it may be appropriate in the future to expand eligibility criteria and to include different or new types of treatments or services in a treatment time guarantee where a period longer than 12 weeks is the appropriate maximum waiting time for that particular treatment or service. The provisions at 7(4)(a) and (b) allow for this.

Given that this is a power to amend the definition of ‘maximum waiting time’ in section 10 of the Bill, a central policy matter, what is the justification for the choice of negative rather than affirmative procedure?

The Scottish Government notes that negative procedure would allow for Parliamentary scrutiny whilst also allowing an appropriate level of speed and flexibility to change maximum waiting times in response to specific circumstances and changes in capacity. Whilst the general drive has been towards lowering waiting times, the Scottish Government appreciates the points the Committee have raised and will consider further whether an amendment should be brought forward to apply draft affirmative procedure.

Section 21(1)(c) – Power when making orders or regulations to make consequential, supplementary, incidental, transitional, transitory or saving provision within those orders or regulations.

The Committee asked the Scottish Government—

Given the existence of power in section 20(1) to make ancillary provision by order, what is the justification for the need for the power in section 21(1)(c)?

The Scottish Government notes that section 21(1)(c) is needed because section 20(1) is an order making power and could not be combined with a power to make regulations (e.g. section 7(1)). Without it, related provisions might be forced to be in different instruments.

There may also be cases of a procedural clash: where the substantive order is subject to draft affirmative procedure but a connected incidental provision (under the order making power in section 20(1)) would be subject to negative procedure: this would mean that they would not be able to be combined in the same instrument with the consequence that related provisions would be spread over different instruments.
• Given that the exercise of the “bolt on” power in section 21(1)(c) when attached to a commencement order will not be subject to Parliamentary scrutiny, the Scottish Government is asked whether it considers it would be appropriate to make an amendment to the effect either that section 21(1)(c) should not apply to commencement orders or, alternatively, that where section 21(1)(c) is applied to a commencement order it should be subject to negative procedure?

The Scottish Government agrees with the Committee and will undertake to bring forward an amendment to section 21(1)(c) so that it does not apply to commencement orders.

Section 9(3) – suspension of the treatment time guarantee

The Committee asked the Scottish Government—

• Given that the treatment time guarantee is a key part of the Bill and given that directions do not allow any degree of parliamentary scrutiny, what is the justification for the suspension of the treatment time guarantee by directions, rather than by statutory instrument?

The Scottish Government notes that it would intend to suspend the treatment time guarantee only in exceptional circumstances. An example of this might be a major transport incident such as a plane or train crash with a high number of seriously injured casualties who will require to remain in hospital for a significant period of time or some other unpredictable but critical event that would have a direct impact on a Board’s ability to deliver. Given the unforeseen nature of exceptional circumstances, and the need to be able to respond quickly, directions allow for speed of response. This would mean that the Government is doing what it can as quickly as it can to ensure that Boards are not showing as being in breach of the guarantee through circumstances about which they can do little. As regulations should be laid before Parliament for a minimum of 21 days the exceptional circumstance that required the suspension may then have passed within that time.

• Does the Scottish Government intend that suspension of the treatment time guarantee would be specific (in the sense that it would apply to a specified health board or health boards or to a specified hospital or hospitals) or would be of general application, and could this not be made clear on the face of the Bill?

The Scottish Government intends that the suspension could be made for any or all of the circumstances that the Committee lists. Given that the Bill only provides for the suspension to be made in exceptional circumstances, and that these circumstances are very likely to be unforeseen, their impact on different aspects of the service, boards or hospitals is also difficult to predict and specify. This is why application of the suspension is not detailed in the Bill.

The position as to when powers of direction may be used is made clear on the face of the Bill – see section 21(5)(a).
EXTRACT FROM THE MINUTES OF PROCEEDINGS

Vol. 4, No. 33 Session 3

Meeting of the Parliament

Wednesday 17 November 2010

Note: (DT) signifies a decision taken at Decision Time.

**Patient Rights (Scotland) Bill:** The Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon) moved S3M-7400—That the Parliament agrees to the general principles of the Patient Rights (Scotland) Bill.

After debate, the motion was agreed to (DT) by division: For 84, Against 32, Abstentions 2).

**Patient Rights (Scotland) Bill: Financial Resolution:** The Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon) moved S3M-7391—That the Parliament, for the purpose of any Act of the Scottish Parliament resulting from the Patient Rights (Scotland) Bill, agrees to any increase in expenditure of a kind referred to in Rule 9.12.3(b)(iii) of the Parliament’s Standing Orders arising in consequence of the Act.

After debate, the motion was agreed to (DT) by division: For 99, Against 16, Abstentions 2).
Patient Rights (Scotland) Bill: Stage 1

The Deputy Presiding Officer (Trish Godman): The next item of business is a debate on motion S3M-7400, in the name of Nicola Sturgeon, on the Patient Rights (Scotland) Bill.

15:20

The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): I am pleased to speak in favour of the Patient Rights (Scotland) Bill, which is extremely important. It gives life and meaning to a principle that I hold very dear: the principle of a patient-focused, mutual national health service. It is deliberately about raising the status and focus of patients’ rights, and clarifying those rights and the duties of health boards with regard to the manner in which patients are treated. In short, it seeks to change the culture of the health service and the dynamics of the relationship between the patient and the health service in a way that levels the playing field. I believe that that is why it has strong support in a range of groups that represent the users of the NHS.

The Health and Sport Committee said in its report on the bill:

“there is overwhelming support for the rights and principles which the Bill sets out to enshrine. There is a general acceptance of the need to ensure that the rights of patients are respected and clearly understood”.

The committee acknowledged that the current framework for the promotion and communication of patients’ rights is not effective and that changes need to be made.

The committee’s main criticism of the bill seemed to be that legislation is not necessary to improve patient rights. It recommended that, instead of primary legislation, the measures in the bill, along with all the other rights that patients have in reserved legislation and common law, should be put into a patient charter and issued using my powers under the National Health Service (Scotland) Act 1978.

With the greatest respect to the committee’s report, which is, as usual, a thorough piece of work, I do not agree with that approach. I believe that primary legislation is the right and best way to secure and enhance the rights of Scotland’s patients. Primary legislation raises the importance and meaning of patient rights as a matter of fact and law, and sends a strong and powerful message to the health service, professionals, patients and carers. It will give priority and prominence to the rights of patients, and will help to focus the actions of health boards. I do not believe that a charter would be an effective way to
make real and lasting change in the NHS. We should not forget that that approach was tried before, by the Conservative Government back in 1991, and that it did not work. It did not lead to the changes that people wanted. A patient charter would not have the same authority or status that the bill will have, and it could more easily be ignored or sidelined by future Governments.

If members vote for the Patient Rights (Scotland) Bill, we will be taking a bold step in setting out the foundation for a statutory framework of patient rights that will last way beyond this parliamentary session and even the next. The Parliament would leave a significant legacy if it was the first in the United Kingdom to legislate for patient rights and create an NHS that truly and meaningfully put patients at its heart.

I want to talk about some other points that the committee raised in its report. There has been criticism that the bill contains no new rights and no mechanisms for redress, but that is not the case. The bill will create, for the first time, the legal right to complain and will establish the treatment time guarantee. It is true, of course, that a variety of other rights already exists, but they come from disparate sources, are not always clearly understood, and often relate to very specific matters such as access to records rather than to the very essence of the relationship between the NHS and patients.

On the issue of redress, the only thing that the bill does not do is create a new, additional right to go to court. That does not add up to there being no right of redress. The bill clearly sets out the duties on health boards to respond to and learn from complaints and the steps that they need to take to deliver the treatment time guarantee.

It is also the case that the bill does not remove any existing rights of redress, whether through the courts or to the ombudsman. More fundamentally, the debate about redress is in danger of missing the point of the bill, which is not about adding to existing rights of redress for patients when things go wrong, although as I have said, it strengthens them. After all, as members have pointed out before, most patients do not want to pursue litigation claims against the NHS; no one wants a lawyer by every bedside.

What the bill is about, as I have said, is changing the culture of the health service and the dynamics of the relationship between NHS and patient in order to raise patient satisfaction levels and minimise the chances of things going wrong. However, there was one recommendation in the committee report about redress that I think merits further work. It recommended that the Government consider introducing a method of alternative dispute resolution. I welcome the suggestion and have asked my officials to explore it further.

I turn to the treatment time guarantee. Some committee members thought that the guarantee could distort clinical priorities. If that were the case, it would be a legitimate source of concern, but I assure members that that is not the case. The provision at section 18(1)(a) provides that "Nothing in this Act prejudices ... the exercise of clinical judgement". That means that boards must still take account of clinical priority. Section 8(3)(a) also makes that clear in relation to the treatment time guarantee. However, when I appeared at the committee, I said that I would consider an amendment to the bill to include a similar provision in an earlier section on the treatment time guarantee. I confirm that the Government will lodge that amendment at stage 2, and that clinical priority must also operate within the treatment time guarantee.

The committee was also concerned about the small number of exclusions from the treatment time guarantee; I stress that the list of exclusions is short and that it mainly includes services that, for obvious reasons, it is not possible to deliver within 12 weeks, such as obstetrics and organ donation.

Mary Scanlon (Highlands and Islands) (Con): I remind the minister that although the list is short, there are thousands of mental health patients who are not covered by the treatment time guarantee.

Nicola Sturgeon: Mary Scanlon makes a timely intervention—I was coming on to that very point about mental health. With the greatest of respect, the area has caused some confusion. Where a treatment or service meets the eligibility criteria of planned or elective care delivered on an in-patient or day-case basis, it is covered. That is as true for mental health services as it is for all services.

I know that many in this chamber, including me, are concerned about waiting times for mental health services that will not come within the treatment time guarantee because they are not delivered on a day-case or in-patient basis, such as access to psychological therapies. I have made it clear before, as has the Minister for Public Health and Sport, that we are determined to take action in that respect and are currently working on the development of a health, efficiency, access and treatment target for access to psychological therapy, to be introduced in 2011-12. Mary Scanlon raised an important point, but I hope that I have cleared up the confusion about what is covered in the bill. The rights and principles in the bill apply to all patients; it is not discriminatory.

The committee suggested that the bill should be amended so that compliance with the 18-week referral-to-treatment target is reported in the annual report of general practitioners. The
Government is happy to consider that recommendation.

I move to the final section of the bill, which introduces a legal right to complain and a patient advice and support service. The committee’s report asked what practical difference the complaints procedure in the bill would have. At the moment, no right to complain is set out in primary legislation. Research shows that patients can be reluctant to make complaints. In some cases, that is because of the fear of repercussions—hopefully always unfounded—or of the effect that the complaint might have on patients’ relationship with the NHS and their future treatment. The statutory right that is included in the bill is intended to give patients the confidence that it is okay to exercise that right.

The patient advice and support service will enhance and replace the existing independent advice and support service. It will be staffed by patient rights officers who will provide support and advice to patients about their health and the health service. In particular, they will help patients to give feedback or make a complaint. The committee agreed in its report that there is a need to improve the existing service. It recognised “the current variation” and welcomed

“the commitment of the Scottish Government to address these issues.”

The committee suggested that that should be done by developing the existing structure through a national contract. I agree that a national contract is necessary, but the arrangement would benefit by being underpinned in legislation, to ensure a consistent and enduring value-for-money service.

Ross Finnie (West of Scotland) (LD): I would be grateful for clarification. If no right to complain exists, why are powers being taken to repeal the current legislation on the complaints procedure?

Nicola Sturgeon: I am happy to get the specific answer to that question so that I can give it, but no statutory right to complain exists. The bill introduces the right to complain. If Ross Finnie wants me to address his point when I sum up, I will be happy to do so.

The bill is of course about patients. It introduces measures that patients want on how they are treated, on being involved in decisions about their care and on the support that they get to use health services. However, the bill does more than that. It legislates for support to patients, it establishes the legal right to make a complaint, to raise concerns and to give feedback and it puts in legislation a guarantee on treatment times.

I said to the committee, and I repeat, that my passion for the bill stems directly from my experience in the past three and a half years. I know that everyone in the chamber shares my commitment to and belief in the health service, even if we sometimes disagree on the detail of policy. Ironically, the passion that everybody has for the health service makes me think that the bill is needed.

I am often struck by the fact that patients’ loyalty to and regard for the NHS sometimes make them accept things that should not be accepted. I often speak to patients who feel that making a complaint is somehow disloyal to the health service, that it might affect their care or that it will not make a difference. Some feel that, because they receive world-class clinical care, they should not speak out about issues such as not being properly communicated with, the standard of food in hospitals or the dignity with which they are treated. The bill says clearly that speaking about all such issues is not just okay but is in fact the right of patients.

Yes—the bill is about immediate legal rights, and we are keen to work with members to strengthen the bill further in that regard at stage 2. However, the bill is also about changing the culture and the dynamics—it is about levelling the playing field between the patient and the big organisation that is the health service. For those reasons, I urge members to vote for the bill’s general principles.

I move,

That the Parliament agrees to the general principles of the Patient Rights (Scotland) Bill.

The Deputy Presiding Officer: I call Christine Grahame to speak on the Health and Sport Committee’s behalf.

15:32

Christine Grahame (South of Scotland) (SNP): I remind the Parliament that, as the Presiding Officer was right to say, I speak as the Health and Sport Committee’s convener, so I am—properly—constrained in my remarks.

Here we go—another week, another day and another Health and Sport Committee debate. I tell the team that we should get an award for stamina. I thank the entire Health and Sport Committee team—clerks, the official report and Scottish Parliament information centre staff—for such dedication to duty. I also thank all those who gave written and oral evidence. Enough of gratitude—to business.

The Patient Rights (Scotland) Bill was introduced in the Parliament on 17 March this year. The committee held a seven-week call for written evidence between 25 March and 13 May that resulted in 41 written submissions being
promote the rights of patients but, notwithstanding the cabinet secretary’s comments, we considered that there is an “inherent contradiction between, on the one hand, setting out patient rights in primary legislation giving the impression of enforceable rights and, on the other, making express provision in the Bill to limit the legal enforceability of these rights.”

The committee went on to state that the bill “may raise unrealistic expectations amongst patients regarding their rights due to the limitations on legal enforcement under section 18 of the Bill.”

I heard what the cabinet secretary said and I think that we accept the point, but we are creating a right without a remedy.

Members of the committee differed in their views on the use of primary legislation to promote patient rights. The report states:

“Some Members of the Committee believe the Government’s objective would be more effectively achieved by bringing up to date a revised and comprehensive patient rights charter. This should be in plain English, enshrining the healthcare principles set out in the Schedule to the Bill, all of the rights available to patients (existing rights, new rights provided for in the Bill, including”, as the cabinet secretary said, “an alternative dispute resolution mechanism),”— such as mediation—

“to be published by the Cabinet Secretary using the powers of direction under the NHS (Scotland) Act 1978.”

On the treatment time guarantee, which the cabinet secretary also dealt with, the 12-week treatment time guarantee is for elective/in-patient treatments for patients and there are a number of exclusions—the cabinet secretary referred to some of them. Some that she did not refer to are assisted conception; diagnostic tests; outpatient treatments; and alcohol and drug misuse services, although I think that there may be reasons why it would be difficult in some circumstances to provide those within a treatment time guarantee.

Members of the committee again differed in their views regarding the introduction of the treatment time guarantee and the decision to place it in primary legislation. The report states:

“Some Members consider that the treatment time guarantee will be beneficial to patients by providing reassurance about the maximum time they may have to wait for treatment following diagnosis. Other Members consider that the proposed guarantee would add little to the existing 18 week referral to treatment target and are concerned by evidence that a new target could have unintended consequences including the potential for distortion of clinical priorities. In addition, these Members question the value of a statutory ‘guarantee’ which cannot be enforced.”

The report continues:
“The Committee also noted the concerns raised about the proposed exclusion of a number of services”—
I have mentioned two or three—
“most notably mental health services.”
I again note the cabinet secretary’s remarks. The report goes on:

“While the Committee accepts that it would be illogical to set targets for the treatment of patients accessing mental health services in response to a crisis, it is disappointed that access to services such as cognitive behavioural therapy are deemed to be outside the scope of the 12 week guarantee”.

On complaints and feedback, the committee fully supported the aim of the Government in seeking to develop a more open and accessible system of patient feedback within the NHS. However, we were not clear what practical difference the provisions of the bill would make for patients who want to “give feedback, raise concerns or complain about the health care they have received. Patients already have a ‘right to complain’”—
notwithstanding that it is not enshrined in statute—
“and the provisions of the Bill will not alter that right in any way.”

On PASS and patient rights officers, the committee considered the proposed structure and the costs for the establishment of a new patient advice and support service and noted the variations that have developed in the level of service delivered by the current independent advice and support service, which is operated by citizens advice bureaux. We accepted that the service is not uniform throughout the country. Many of the issues relate to the current contractual and funding basis for the IASS, which varies from one health board area to another.

The committee believed that the role of PASS and patient rights officers “are not sufficiently clearly defined in the Bill”.

The committee went on to note that the role of a PRO will be to act as a “signpost” for patients, assisting them with feedback, providing them with advice and supporting them in making complaints. However, PROs will be prevented from carrying out any advocacy role on behalf of patients. That seemed a bit clutched and, given that, the committee failed to see how PASS and the PROs will be an improvement on the current service provided by the IASS—forgive me for using all these acronyms. In the committee’s view,

“a more effective and efficient approach could be to build on the current IASS structure by developing it through a new national contract. Such an approach would retain the best elements of the present system whilst addressing the concerns regarding the inconsistencies in the level of service and funding between health board areas.”

That would ensure that we do not throw out the baby with the bathwater.

I turn to our overall conclusion. The good news for the cabinet secretary is that we were unanimous in our support for the promotion of patient rights and the Government’s aim of placing patients at the centre of the NHS in Scotland. The bad news is that the committee was divided on whether primary legislation is the most appropriate means of achieving that goal. The report states:

“Some Members feel that the Bill has the potential to offer a renewed focus on patient rights, including a new treatment time guarantee and an enhanced patient advice and support service. These Members consider that the Bill will provide the necessary impetus to help overcome any organisational or cultural obstacles to change which may exist within NHS Scotland.”

However, it continues:

“a majority of the Committee is not persuaded by the evidence which has been advanced to date, that primary legislation is the most appropriate means of promoting patient rights.”

Some members went on to recommend, as an alternative, that the Scottish Government publish a comprehensive patient rights charter, to be enforced in the way that I have described.

The report states:

“Some Members consider that the Bill, as introduced, will not contribute significantly to the goal of achieving a patient-focused health service and, contrary to the Government’s policy intentions, may potentially cause confusion regarding the legal rights of patients.”

It concludes:

“Consequently, the Committee is unable to make a recommendation to the Parliament on the general principles of the Patient Rights (Scotland) Bill.”

We agreed to disagree.

15:41

Jackie Baillie (Dumbarton) (Lab): I welcome the stage 1 debate on the Patient Rights (Scotland) Bill. I thank the Scottish Government for introducing the bill, the Health and Sport Committee for scrutinising it and all those who contributed to the consultation. Although I am pleased to indicate that Labour supports the general principles of the bill, we acknowledge many of the committee’s concerns and intend to lodge a number of amendments at stage 2 to improve the bill’s provisions.

First, there is the fundamental question of whether legislation is required to achieve the outcome that all of us desire. I am glad that the cabinet secretary addressed that point. I know that the Scottish National Party had a manifesto pledge to give every patient a legally binding waiting time guarantee and I recognise that the bill falls short of that commitment; indeed, many of those who gave
evidence to the committee suggested that the lack of sanctions and of a means of enforcement are a potential weakness. I note that section 18 restricts the potential for legal action. I agree with that, because we do not want to foster a compensation culture or to create a bonanza for lawyers. Therefore, one must question why a legislative approach is needed.

Rather than simply legislating that simply declares or asserts something, we need legislation that sensibly advances patients’ rights within a framework that recognises the mutuality of the NHS and the balance between rights and responsibilities of patients and of staff. The bill as drafted does not reflect that balance; as I understand it, it does not even reflect all of patients’ existing rights.

We favour an approach that enables the cabinet secretary to introduce a comprehensive charter of rights and that begins to get the balance right by reflecting responsibilities, too. However, she is right to say that we need to ensure that provisions are properly implemented. Any action of Government requires monitoring, reporting and assessment of whether it is working. There are many things in the health service that are not conditioned by legislation, but health boards are in no doubt about the importance of those issues.

Secondly, the treatment time guarantee covers only in-patient procedures. I understand why it excludes people who require mental health treatment, for example, but it may have the effect of skewing clinical priorities. I note the cabinet secretary’s comments, but I wonder whether the treatment time guarantee is not too blunt an instrument. Surely it would be better to have a more encompassing patient guarantee—a more sophisticated approach that covers different aspects of the patient journey, but with sufficient flexibility to allow for clinical priorities to be considered. That is not necessarily for legislation; rather, we want to enable ministers to take forward the matter in dialogue with patients and clinicians.

Thirdly, and as Christine Grahame has mentioned, the role of patient rights officers lacks clarity and seems only to signpost, so it is not as wide in scope as the existing provision for the independent advice and support service. Surely it would be more cost effective to work with that model and to develop a national contract. We do not need legislation to secure best value.

We agree with establishing the legal right to complain, which we think is important. We agree that we need to improve the NHS complaints system—and I am sure that many members who have worked with the system will testify to that. Again, one wonders whether that should be set out in legislation, but we are willing to consider that point further.

Most people who come to us to describe an unhelpful experience in the NHS do not really want to complain. In many cases, they want the NHS to apologise, and we should never underestimate the power of just saying sorry. Importantly, they also want the NHS to learn from the mistake, so that no one else goes through their experience.

I have been told about the complaints system at the State Hospitals Board for Scotland, which is described as being based on the four Cs. The first of those is complimenting people. That does not happen often enough. We should be telling people that they have got something right—positive endorsement. Secondly, comments are taken on board. That is often enough to resolve a situation and to stop it escalating further. Thirdly, concerns are addressed. Thereafter, and only when necessary, are complaints considered. That system is very much about early resolution and it is important that we learn from that example.

I agree with the suggestions that have been made about an alternative dispute resolution system. We have discussed no-fault compensation and mediation, and I am hopeful that the cabinet secretary will lodge amendments in that regard.

We welcome the bill for the opportunity that it provides to raise patient rights up the agenda. I share the cabinet secretary’s passion for the NHS, its staff and all the hard work that is done in treating our constituents, our families and our friends. We believe in a mutual NHS that is absolutely patient centred. On that basis, we will support the general principles of the bill.

Mary Scanlon (Highlands and Islands) (Con):
In scrutinising any piece of proposed legislation, it is right and proper that parliamentarians look for the benefit that it will bring—in this case, to patient rights. At the end of the stage 1 process, I am still looking for those benefits in the Patient Rights (Scotland) Bill.

Section 1 states:
“Health care is to ... be patient focused ... anything done in relation to the patient must take into account the patient’s needs”.

It goes on to say that health care should provide “optimum benefit to the patient’s health and wellbeing ... and encourage the patient to participate as fully as possible”.

Do we need to legislate for that? Is that not happening? Surely NHS staff do not do things to patients that are not patient focused, that do not provide benefit and that do not involve the participation of the patient. If they do, there are
disciplinary procedures to address such unacceptable behaviour.

Sections 6 to 10 cover the treatment time guarantee. What happens if it is breached?

“The Health Board must ... make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity ... provide an explanation ... give the patient details of ... advice and support”

and tell them

“how to complain.”

Is that not happening at present? As the Health and Sport Committee confirms in its report,

“there is an inherent contradiction between ... setting out patient rights in primary legislation”

and having no legal enforceability for those rights.

The treatment time guarantee does not apply to the majority of patients with mental health problems—they will still have to wait months, and sometimes years, to see a psychiatrist or psychologist or to get cognitive behavioural therapy; neither does the guarantee apply to patients who are waiting for physiotherapy. It does not apply to treatments that are undertaken in hospital out-patient departments, and it does not apply to diagnostic tests. It is a fact that someone can get a hip replacement or heart bypass in 18 weeks—or, in future, in 12 weeks—but people can wait months or years to talk to someone about their depression.

I agree with the Scottish Association for Mental Health that this bill perpetuates the division between mental health and other NHS services. I asked the Law Society of Scotland whether that was considered discrimination against mental health patients and its response was:

“the provision clearly appears to be discriminatory under the normal meaning of the word.”—[Official Report, Health and Sport Committee, 29 September 2010; c 3430.]

The fact is that in mental health there is absolutely no doubt that early diagnosis and early intervention can save NHS spend on treating severe, chronic and enduring mental health problems in the long term, allow people to enjoy a quality of life and allow many to remain in work.

The cabinet secretary spoke of the support for the bill. I attended every minute of every evidence session and I can tell her that the support was minuscule. The Law Society, the British Medical Association, the General Medical Council and many others highlighted the point that nothing in the bill is enforceable by legal action.

The Scottish Public Services Ombudsman, who I think knows something about NHS complaints, stated:

“the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist.”

He went on to say that the bill

“carries the risk of an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS.”

As Jackie Baillie said, there is no provision for patients who wish to give feedback, raise concerns or complain. They will all be channelled to patient rights officers.

I commend the convener of the Health and Sport Committee, who managed to get us all to agree on a final conclusion, which was:

“the Committee is unable to make a recommendation to the Parliament on the general principles of the Patient Rights (Scotland) Bill.”

For all those reasons—and because of the Scottish Conservatives’ commitment to patient rights and responsibilities—I ask the cabinet secretary to examine and produce a revised patient rights charter under the power available to her under the National Health Service (Scotland) Act 1978. The Conservatives produced the first patient charter in Scotland in 1990. It was revised—and rightly so—and enhanced by the Liberal-Labour Scottish Executive in 2000. A further 10 years on, it is appropriate and justified for the Scottish Government to review it. In doing so, it would have our full support.

Ross Finnie (West of Scotland) (LD): For a moment there we saw Jackie Baillie sitting next to the cabinet secretary. Given her change of stance, we can see why.

Patient rights derive from a variety of sources, as the cabinet secretary pointed out—from legislation, case law and common law and convention. Patient rights are undoubtedly not easy to find. Indeed, sometimes it is difficult for the patient to ascertain precisely what their rights are. So, there is no real difficulty; in fact, there is unanimous agreement that if we are fostering a patient-focused, mutual health service, we need to make patient rights more capable of being easily understood and promote them. The disagreement is about how best that can be achieved.

The Liberal Democrats are clear that if we are to have resort to statute, it ought to have a legal purpose and effect. We are not satisfied that it should just be a status symbol or something that gives people a sense of importance. Across the range of Government policy—I mean not necessarily the SNP Government but Governments of any colour—the danger is that very serious policy statements will be diminished because the public will begin to believe that unless
something is in a piece of primary legislation, it is not worth the paper that it is printed on. That would be a dangerous precedent.

Despite the fact that the Government's consultation told it that people did not want a lawyers' charter, it still proceeded with the bill, which is a legal instrument by definition. However, realising that that could be difficult, it drafted section 18(2), which effectively emasculated its own bill by stating:

"Nothing in this Act gives rise to—
(a) any liability to pay damages,
(b) any right of action for specific implement,
(c) any right of action for interdict,
(d) any right of action for suspension".

That left a general right to seek a declaratory judicial review, all of which left one asking oneself why on earth we were creating an act of Parliament if it was to have such little force and effect.

Perhaps members were left with the view that the bill would bring all the patient rights together in one place. Then, we would know clearly and understand what it was about. However, if members read the bill, they will find that at least 17 existing rights are not referred to. The right of access to medical records, the issuing of medical reports for insurance purposes, the right to advocacy services for mental health service users, the right to appoint a welfare attorney, the right to life—for instance, in connection with treatment rationing—the right to a GP and the right to a second opinion are not referred to, and so it goes on.

The bill does not cover all our existing rights and creates only two new rights. One is the treatment time guarantee, which does not necessarily need to have a statutory backing. The other relates to complaints. The bill repeals the Hospital Complaints Procedure Act 1985 and, in section 11, reinstates in effect what that act says.

We are left with a difficult situation and begin to ask why we need a bill. Others have supported us in that. I will quote one or two examples:

"I want to return to the question of exclusions. We are being asked to consider a bill that entrenches discriminatory rights in law. That is one of our main concerns."—[Official Report, Health and Sport Committee, 29 September 2010; c 3436.]

Those are the words of Dr Richard Simpson at committee.

"Human rights legislation is not mentioned in the bill, which just says that it is necessary to 'have regard to' the need to treat a patient with dignity and respect".

Again, those are the words of Dr Richard Simpson in committee.

"My concern is not only that the bill does not help, but that it does not encompass all the rights that patients have."

Those, too, are the words of Dr Richard Simpson.

Presiding Officer,

"the fact is that substantial numbers of rights are not referred to in the bill. The implication is therefore that the rights in the bill are greater than other rights."—[Official Report, Health and Sport Committee, 6 October 2010; c 3563.]

Those, too, are the words of Dr Richard Simpson.

but, despite his trenchant opposition to the bill, he now supports it whole-heartedly. Apparently, he is going to amend it. Perhaps he is going to introduce even more legal powers, although I doubt it. Perhaps he is going to try to bring all the rights, with their different legal remedies, into a single act. What an appalling mess that would be.

As the Health and Sport Committee report makes clear, there is a better alternative, which has been adopted in Australia and south of the border in England: we can achieve the same aims through a patient rights charter. It would not be for the selected few rights that are in the bill, but would embrace all the rights that we have. We believe—just as the cabinet secretary does—that it is vital to promote our rights, but it is equally important that we do so in a way that shows what all our rights are. The cabinet secretary should publish those rights using the power that she has under the 1978 act.

We concede that one of the best things in the bill is the bit to which the cabinet secretary should have regard: schedule 1, which is not concerned with rights but sets out principles with which we are in total agreement.

I leave members with these words:

"In no way do I doubt your good intentions"—

I presume that that was directed at the cabinet secretary—

"in introducing the bill but I feel that it will not help patients in the way you expect it to. A constitution or charter for patients that has the force of direction from your office, and the energy behind it to make sure that patient rights are properly promoted, will achieve what you are seeking to achieve."—[Official Report, Health and Sport Committee, 6 October 2010; c 3576-3577.]

Once again, those are the words of Dr Richard Simpson.

The Deputy Presiding Officer: We move to the debate. Speeches will have to be a tight six minutes.

16:00

Michael Matheson (Falkirk West) (SNP): I have no intention of quoting Richard Simpson in
the course of my speech, even if Ross Finnie chose to do that this afternoon.

The tenor of this health debate is a little healthier than was last Wednesday’s, but yet again we are not unanimous in our position on the bill that is before us. From the debate thus far, there is clear agreement on the importance of patient rights and the need for those rights to be upheld. Our NHS should always ensure that it acts in the best interests of patients wherever possible. Unfortunately, that is not always the case. As we clearly demonstrate in our stage 1 report, the committee was unable to come to an agreed position on whether legislation is the best option to improve patient rights in our health service in Scotland. I am mindful of the sharp divide between those who support and those who oppose the bill. Broadly, those who represent patient interest groups and other interest groups in the NHS favour legislation, and those in the professional bodies that represent those who work in the NHS appear to be strongly opposed to it. That may, in itself, suggest that we have the balance somewhat correct.

I recognise that some members believe that setting out a list of rights in a bill that has limited legal enforceability is not the appropriate way to go. As Christine Grahame said, some committee members see the contradiction in that. Over the course of the evidence that we received at committee, I was not persuaded that, if greater legal enforceability were introduced into the bill, there would be a desire out there to rush to the courts to enforce the legal provisions. The suggestion that including greater legal enforceability in the bill would somehow create a charter for lawyers is well off the mark and somewhat unfounded, on the basis of the evidence that we received as a committee. The cabinet secretary has indicated that she is prepared to look at how the provisions of the bill could be improved at stage 2 to give greater enforceability. I welcome that.

I often deal with complaints from constituents about our health service, but no one has ever come into one of my surgeries and said, “I am here because I want to take our health service to court.” Even if the bill were to provide greater legal enforceability, I suspect that no more of my constituents would rush into my office to say, “I want to take the NHS to court.” In most instances where the NHS has got it wrong, it holds up its hands and says so. Unfortunately, at times there are cases where the NHS is not prepared to do so, which is to be regretted. I believe that that is influenced in part by the fact that at times there is a culture of fear in our NHS; a culture that says admitting to mistakes leaves the NHS open to potential legal challenge. One of the benefits from the bill could be that we start to address that unhealthy culture, which can exist in some parts of our NHS.

In preparing for the debate, I thought about our experience in the lead-up to the coming into force of the Freedom of Information (Scotland) Act 2002. I remember when the Information Commissioner of Canada came to the Parliament to share his experience of the introduction of freedom of information in his country. He was clear that the issue and challenge was not the coming into force of the legislation but changing the cultural mindset of the public agencies affected by it.

I have no doubt that since the Freedom of Information (Scotland) Act 2002 came into force, many of our public bodies have changed their mindset and their attitude to making information available, and that there has been a significant cultural shift in the way in which they do that. I believe that one of the bill’s potential benefits is that it could help to make the cultural shift that is necessary in the NHS, thereby ensuring that patients’ rights are much more central to the decision making of clinicians and management and the way in which they plan and manage their services.

Jim Elder-Woodward summed up the bill’s importance fairly well when he gave evidence to our committee. In talking about the need to ensure that we have an NHS that is truly mutual, he said:

“If we are to work on the basis of mutuality, each person around the table needs to bring a resource with them. For patients, the resource will be the Patient Rights (Scotland) Bill”.—[Official Report, Health and Sport Committee, 29 September 2010; c 3456.]

That can be provided by passing the bill.

16:06

Rhoda Grant (Highlands and Islands) (Lab): The only honest way to describe the bill is as a disappointment. It does not do what it says on the tin.

I am certain that everyone in the Parliament is signed up to the concept of improving patients’ rights, so this bill, of all bills, should have been given a fair wind. It is a sign of how short it falls of that aim that the committee could not recommend to the Parliament that its general principles be agreed to at stage 1.

I am deeply disappointed that the cabinet secretary appears not to have taken seriously the committee’s concerns. The real dilemma is whether the bill can be amended so radically at stage 2 that it will improve the situation of patients. I for one am willing to try. If we cannot do that, the bill will need to be voted down at stage 3, because in its present form it would be detrimental to patients. As others have said, the bill as it stands...
enshrines some current rights but leaves out others. We fear that it would create a hierarchy of rights. Are the ones that are identified in the bill more important than those that are the subject of ministerial directions?

The bill would not provide a remedy for patients whose rights have not been met. No one wants American-style litigation in our health service, but if people are to be provided with a right they must have a remedy in the event that they cannot access it. In its report, the committee suggested something along the lines of mediation, but I am not so sure. If a patient’s waiting time guarantee has been breached, they need action, not discussion.

There are other issues that the bill does not cover. Some of the hardest cases that I have to deal with involve people whose health has suffered or who have lost loved ones because of the actions of clinicians. The current complaints procedure is wholly inadequate in dealing with such cases, because boards and professionals tend to close ranks for fear of litigation or of a doctor being struck off. They do not deal with the issues or respond satisfactorily. The Scottish Public Services Ombudsman cannot help, because it looks just at the process rather than the substance of the complaint.

The only option that patients are left with is to go to law. They are not experts, so they need to find a professional who is willing to review the case, which comes at a cost. They have limited resources to take on the full force of a health board and its insurer in the court system. Needless to say, people are reluctant to do that, not just because of the cost but because they do not know where to start. Such people often come to MSPs to ask them to right the wrong, in the belief that if the state has let them down, it is for the state to right that wrong, but we have no tools to use on their behalf other than mediation, which, frankly, does not work in such cases. I am hugely frustrated by that. It is wrong when all that we can do is offer sympathy. The Stafford hospital inquiry is a pretty sobering example of what happens when complaints are not dealt with properly.

I do not have all the answers, but we need to examine the issue further. One option might be to consider setting up a body along the lines of the Independent Police Complaints Commission, which provides independent scrutiny. That would obviously have a cost, but it might be a better use of the money that has been put aside for a new complaints service.

On the proposed patient advice and support service, the evidence was strong that the current independent advice and support service works well when health boards pay for that service for their patients. The current service is provided by citizens advice bureaux, and it works well by ensuring that patients receive advice on health care and any other issues that might concern them, such as benefits. There is real concern that a new service would stop that joined-up approach and cause patients to have to deal with myriad people when they are possibly not best placed to do so. It is clear that all patients need to be able to access the service, regardless of their health board. Perhaps that should be done on a national basis, with the Government top-slicing the funding rather than leaving the decision to the health boards. When money is tight, health boards obviously will look for savings, and that kind of service becomes vulnerable if it is not protected.

As I said, not all rights are enshrined in the bill. It is clear that legislating for some rights and setting them in stone would be problematic. For example, the waiting time guarantee might change. Services that have no guarantee will not be included. Also, of course, legislation cannot be amended day and daily when patients’ rights change.

Some members are keen on a patient charter, which has merit. An accessible statement of rights and responsibilities for patients would be helpful, but that does not need legislation. Indeed, to make it accessible, we should really avoid enshrining it in legal mumbo-jumbo. The bill could place a duty on the Government to produce a charter that gives patients a clear statement of their rights and responsibilities and the remedies when they are denied.

The only part of the bill that got unanimous support was the health care principles in the schedule. They provide a statement of intent about how patients should be treated when they engage with the health service, and they should be the basis of a new ethos for health care.

We need more than warm words. For the bill to work, it must do something, and if it is to progress into law, it will have to be changed radically. I hope that those changes can be made.

16:11

Nanette Milne (North East Scotland) (Con):
The NHS with which I grew up was a paternalistic organisation in which patients were the passive recipients of treatment that was meted out to them by those who thought that they knew best what was good for them. In hospital, they were talked over by a retinue of people in white coats who assumed that the patient would have no understanding of their medical condition. That approach is clearly unacceptable in the 21st century, and thankfully things have moved on, with patients having rights, including that of being fully involved with the management of their health
issues. However, the system is not perfect and patients can feel let down by it. The Scottish Government's intention to create a fully patient-centred and genuinely mutual NHS is laudable and has widespread support.

The point at issue is whether legislation, as outlined in the bill, is necessary to achieve that goal. From the evidence that was given to the Health and Sport Committee, it is clear that many witnesses believe that it is not. Consumer Focus Scotland noted that patients have rights already, but they are not mentioned in the bill, and as we have heard, the SPSO pointed out that the bill does not extend significantly patient rights in relation to the quality of NHS services that are provided for them in Scotland, and fears that to enshrine them in primary legislation could lead to "an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS."

The Law Society articulates a common concern of witnesses, that the bill lacks teeth because it does not include the provisions that are necessary to enforce the principles and guarantees that it contains. The RCN is "unconvincingly that legislation is more useful than a review of how rights and responsibilities are promoted and implemented"

and the GMC is not clear about how those rights that are included in the bill would be implemented, measured and enforced.

It is unusual to have such a weighty body of opinion questioning the need for a bill and doubting the effectiveness of the proposals within it. Mary Scanlon has pointed out that the treatment time guarantee that is set out in the bill is not legally enforceable, and that many people who have conditions that are not included in that guarantee, such as mental health problems and deafness, stand to lose out under the proposed legislation. The list of conditions might be small, but that is no comfort to the patients who are affected. The BMA has serious concerns, which I share, that to place treatment time guarantees into statute will skew clinical priorities, and although I do not always agree with the BMA, I certainly agree that targets should always be based on clinical evidence and not on political imperative.

Finally, there is doubt about the accuracy of the projected costs that are associated with the bill. A number of concerns have been raised about that by organisations, including NHS boards and Citizens Advice Scotland. I worry about added bureaucracy developing around an unspecified number of patient rights officers.

I am not a member of the Health and Sport Committee but, from what I have read about the bill, I cannot see that it is necessary, or even that it would produce the cultural change that the cabinet secretary seeks. Of course, I believe in a patient-centred health service and that patients should have the right to quality treatment whenever they need it within an NHS that has their best interests as its foremost consideration. I also believe that patients should be supported and helped if and when they feel let down by the service.

We need a more open and accessible system of patient feedback in the NHS. Many patients would like to give constructive feedback following a health care experience, but they do not want to do that through a formal complaint. There should be a mechanism to cope with that. However, to set in new legislation what the NHS has been striving to do throughout its existence—namely, to ensure that anything done in relation to a patient takes into account the patient's needs and that regard is given to the importance of providing optimum benefit to the patient's health and wellbeing—does not seem necessary to me or to many of the people and organisations that have taken an interest in the bill.

Surely a much better option would be to look again at the patient charter, which was devised by John Major's Government in 1990 and revised 10 years later by Labour. A strengthened patient charter would be every bit as effective as the bill in improving the promotion and implementation of existing rights and responsibilities for those who use and work in the NHS. Its efficacy across Scotland could readily be judged by Government ministers during their annual review of health boards' performance. We all want the best deal possible for patients but, along with many others, my party feels that the bill is not the best way in which to achieve that. However, as Mary Scanlon said, we are willing to co-operate fully with the cabinet secretary should she be willing to go down the road of producing a more effective patient charter.

16:17

Jamie Stone (Caithness, Sutherland and Easter Ross) (LD): To me, the question is, "What are patient rights?" My constituents are patients, I am a patient and the cabinet secretary is a patient—we are all patients, if not now, then sooner or later. So in talking about a truly national health service, with patients requiring diagnosis, receiving treatment and, we hope, being made well, I take a first-principles approach. Accordingly, we should consider what my constituents—the people who live the length and breadth of my vast and remote constituency—approach me about in relation to the health service.

Let me look back over my time as a member of the Scottish Parliament. My first example is maternity services in the far north. I and other Highland MSPs witnessed what was probably the
biggest demonstration that Caithness has ever seen when there was a proposal to downgrade the consultant-led maternity service based in Caithness general hospital in Wick. When faced with an increase in the number of mothers having to travel a 200-mile round-trip to Inverness to have their babies, the people of the far north were not having it, and they told us so loud and clear.

A second example is dental services in my constituency. How many times have I raised that in the Parliament? More times than I and, I dare say, the cabinet secretary would care to remember. Sadly, the lack of available NHS dental services for my constituents has been a huge issue for years, and it continues to be one. Going private and paying for a dental insurance scheme is simply not an option for those who are unemployed, the elderly or those on lower incomes. What do they do if no NHS dental service is available? Do they go private or do they go without? Alas, we know the answer. If people do not get treatment, far worse dental problems and associated health problems are stored up for a much more frightening future day.

A third issue that my constituents have contacted me and other members about and asked us to raise in the Parliament is the Scottish Ambulance Service. There are issues such as single manning; ambulances having to be parked up so that two single crew members can double up; and even doctors having to leave their practice area to accompany a patient in an ambulance, sometimes for more than 100 miles to hospital in Inverness.

A fourth example is the patient transport service. There is a lack of availability of the service. Also, as I have argued for long enough, the remuneration system and the associated tax regime—which is not the cabinet secretary’s problem, although in a way it is and very directly so—lead to drivers in remote and far-flung locations pulling out. Those are real problems for patients.

Those are four examples of things that are important to my constituents: access to a maternity service; access to an NHS dental service that will not have X thousands on the waiting list; access to a speedy, properly manned ambulance service when one is needed; and a patient transport service that is not only a one-way service and that does not lead to patients sometimes missing appointments, which is no good for their health and recovery and wastes the time and precious resources of our health professionals.

I am sure that other members could give many more examples of what patient rights are about. They are about a right to diagnosis, a right to treatment, a right to recovery, a right to genuinely local NHS services and a right not to be disadvantaged because of where one lives. I make no apology for the fact that, for more than 11 years, that has been the central theme of all that I have said in this chamber on health matters. In focusing on such issues, I believe, like members from all parties, that I am genuinely reflecting constituents’ rights.

Do constituents come to me and say, “I want my legal rights”? No, they do not. What they very often say—too often—is that they want help and treatment for them, for their loved one or for their neighbour, or they say, “I know that doctors, nurses and health professionals already do their best; I just want to be able to access their services.” As other members have said, if someone has a complaint about the treatment that they are receiving or the lack of it—we all get the occasional complaint—they, I and other MSPs know that we have recourse to the ombudsman, to our local NHS board, to the chair of that board and, indeed, to the cabinet secretary herself. I put on record the helpful and constructive attitude that ministers have taken. By and large, the present complaints procedure works. Yes, as others have said, more advice and a charter could help, but that would be a very different beast from the bill.

I have described the very real expectations of my constituents, which are all about local service delivery and availability, and about not being disadvantaged for reasons of geography and distance. Alas, however well intentioned the bill might seem at first, at this stage it misses the mark and addresses precious little to my constituents.

The Deputy Presiding Officer (Alasdair Morgan): I can give the next two members only four minutes each.

16:22

Irene Oldfather (Cunninghame South) (Lab):

My comments concern issues around people who lack capacity, some of which were discussed at the recent meeting of the cross-party group on Alzheimer’s. I associate myself with Mary Scanlon’s comments on the importance of early diagnosis and treatment for those with mental health problems, and I raise the possibility of further, unintended consequences, particularly in relation to those who lack capacity.

There is insufficient recognition that there is a difference between normal best practice in relation to the rights of competent patients and best practice in relation to the rights of patients who lack capacity or who are unable to consent to medical treatment or health care due to a mental disorder, of whom people with dementia are the largest group. I understand the rationale behind rights being enshrined in the Adults with Incapacity
whether it is required at all. However, there can be
assisting matters.
incorporating the charter of rights for people with
address those priorities, but I feel that
remains to be done to show that the bill can
and equity in the system. A great deal of work
those who lack capacity that we ensure fairness
they are and how to claim them. It is essential for
documented procedures.
Scotland reports that that is not happening, and
Evidence from the Mental Welfare Commission for
based on information, treatment must be lawfully
patients. Dr Toft therefore also recommends that
doctor issues, patients are on the wrong levels of thyroxine or are on thyroxine but not converting from T4 to T3, and they need advocacy.

Thyroid disorders are a gender issue, as women are five times more likely to suffer from them than men are, and 17 per cent of women over 60 will suffer from some form of hypothyroidism. In its submission to the Health and Sport Committee, Breast Cancer Care suggested that health care should be based on clinical and patient-specific need that excludes all strands of discrimination. Any discussion of rights should, therefore, not ignore the gender imbalance that exists in many areas of health care, such as thyroid disorders. Many very ill people with thyroid dysfunction are not being diagnosed by general practitioners, are on the wrong levels of thyroxine or are on thyroxine but not converting from T4 to T3, and they need advocacy.

Dr Anthony Toft, a world-renowned and highly respected Scottish endocrinologist, believes that it is of prime importance that GPs consider how patients present, rather than simply accepting the results of blood tests. He suggests that doctors should take a whole-picture approach that takes into consideration all the patient’s symptoms and does not rely totally on tests. That is important in the case of a lack of T3. In such a circumstance, the tests show that the T4 is fine, and the GP will insist that there is nothing wrong with the patient’s thyroid function when, in fact, they are gravely ill and getting progressively worse.

Another issue that the proposed patient advice and support service could assist with is generic prescribing. Obviously, we are looking to save money in the health service, but a drug such as thyroxine can vary in strength and quality, depending on the source, and that variation can have a detrimental impact on the health of thyroid patients. Dr Toft therefore also recommends that the same make of thyroxine should be dispensed to a patient, but GPs and pharmacists do not seem to be aware of that. Advocacy is needed in that regard.

In addition, particularly for that vulnerable group, where there is a significant crossover between health and social care it must be recognised that rights do not stop when someone leaves the general practitioner’s surgery or the acute ward. A one-door approach is essential if we are to avoid confusion among carers and patients about where to go with which part of their complaint. To that end, I ask that, in reshaping the proposals, we consider the inclusion of the charter of rights for people with dementia that the Government has already endorsed.

Connected to that, Alzheimer Scotland has expressed concern that, in limiting the duties of patient rights officers to raising awareness and understanding of the rights of patients only in relation to the rights that patients have under the bill, there is an implication that they will be under no obligation to have knowledge of or to promote and support the rights of patients under the Adults with Incapacity (Scotland) Act 2000 or the Mental Health (Care and Treatment) (Scotland) Act 2003. That could be extremely confusing for carers of people with dementia or other disorders who need to know where to take their complaints about general acute medical care and treatment.

If the patient lacks capacity to make decisions based on information, treatment must be lawfully authorised by a relevant enactment or rule of law. Evidence from the Mental Welfare Commission for Scotland reports that that is not happening, and on-going work continues to lack properly documented procedures.

Rights are meaningful only if one knows what they are and how to claim them. It is essential for those who lack capacity that we ensure fairness and equity in the system. A great deal of work remains to be done to show that the bill can address those priorities, but I feel that incorporating the charter of rights for people with dementia within it would go some way towards assisting matters.

Elaine Smith (Coatbridge and Chryston) (Lab): The main problem with the bill seems to be whether it is required at all. However, there can be little doubt that the underlying ethos should be

supported and encouraged, and the Scottish Government has rightly recognised the need for the provision of better information for patients, as well as a guaranteed standard of care and reasonable treatment throughout the NHS in Scotland. Making patients aware of not only their responsibilities, which we are often reminded of, but their rights is a positive step forward that ought to be welcomed across the chamber.

It is vital that health care professionals listen to the patients’ cares and concerns, with patients being treated as partners, whose knowledge of their own body and symptoms is respected, rather than as subjects who are just dictated to. I will focus on the example of thyroid disorders in order to highlight the importance of patient advocacy and a need for a change of ethos, as outlined by the cabinet secretary earlier.

Thyroid disorders are a gender issue, as women are five times more likely to suffer from them than men are, and 17 per cent of women over 60 will suffer from some form of hypothyroidism. In its submission to the Health and Sport Committee, Breast Cancer Care suggested that health care should be based on clinical and patient-specific need that excludes all strands of discrimination. Any discussion of rights should, therefore, not ignore the gender imbalance that exists in many areas of health care, such as thyroid disorders. Many very ill people with thyroid dysfunction are not being diagnosed by general practitioners, are on the wrong levels of thyroxine or are on thyroxine but not converting from T4 to T3, and they need advocacy.

Dr Anthony Toft, a world-renowned and highly respected Scottish endocrinologist, believes that it is of prime importance that GPs consider how patients present, rather than simply accepting the results of blood tests. He suggests that doctors should take a whole-picture approach that takes into consideration all the patient’s symptoms and does not rely totally on tests. That is important in the case of a lack of T3. In such a circumstance, the tests show that the T4 is fine, and the GP will insist that there is nothing wrong with the patient’s thyroid function when, in fact, they are gravely ill and getting progressively worse.
The health of many thyroid patients could be much improved if GPs and others listened to them rather than simply depending on tests. That is an area that requires more attention, research and advocacy for patients in Scotland.

Whether or not the bill progresses to the end of stage 3, a patients rights officer could promote the interests of the patient in cases in which they are not being listened to or are too ill to advocate on their own behalf. With or without the bill, we need to start viewing patients as equal partners in our system of health care. As well as ensuring that their views are respected, that could prevent more serious conditions from arising or stop there being lengthy periods of misdiagnosis, which would save the NHS money in the long run.

As others have said, the area of complaints needs to be updated and modernised. Patients not only need clear procedures in order to make complaints; they need evidence that their complaints are dealt with and that effective changes are made and systems modified as necessary. It is vital that feedback be given. As the constituency member for Coatbridge and Chryston, I have heard numerous instances over the years of constituents who are dissatisfied with NHS services but worried that, if they complain, they may receive less favourable treatment.

Overall, our NHS is an excellent service that operates on the principle that people are treated on the basis of health need and not their ability to pay. Any change must be an improvement and in no way detrimental to that ethos, and it must work better for the patients of Scotland.

16:30

Iain Smith (North East Fife) (LD): I make it clear from the outset that the Liberal Democrats believe that the rights of patients are of utmost importance. They should be clearly set out, and NHS boards must be held responsible for upholding them. However, the issue before us today is whether primary legislation is the right way to go about that.

It is important that the Parliament remembers that primary legislation is not about sending messages but about changing the law of Scotland. It involves establishing legal rights and responsibilities for the people of Scotland and the legal duties and responsibilities of those bodies that serve them. The problem with the bill is that it does not do anything new. It does not extend or improve the rights and responsibilities of the people of Scotland, or the duties and responsibilities of the bodies that serve them.

When we consider primary legislation, we must ask the following questions. First, is there a problem that needs to be addressed? There are certainly issues in relation to improving patient rights and the existing complaints procedures. Is primary legislation the best way to deal with those issues, or can alternative methods be used? Is the existing legislation properly implemented and enforced, or does it need to be amended?

The case has not been made for new primary legislation in this area. Other options are available to the Government and to the Parliament to address those matters.

Let us take the complaints system, for example. The cabinet secretary made much in her opening remarks of the fact that the bill introduces a new legal right of complaint. However, as Ross Finnie pointed out, that right already exists.

Nicola Sturgeon: Will the member give way?

Iain Smith: I will finish the point, but I will let the minister in if I have time.

Complaints about the NHS are dealt with by the service at two levels. Level 1 is an informal stage, at which local resolution is sought, and level 2 is a formal complaint that involves an NHS internal review. There is then the option of referral to the SPSO. That is covered by key legislation in the Hospital Complaints Procedure Act 1985, which—most significantly—is complemented by directions and procedural guidance from the Scottish Executive that were last updated in 2005. The Government has the power to change the complaints procedure through direction and guidance if it feels the need to do so, which is an important point.

Nicola Sturgeon: I want to clarify the point that Ross Finnie made earlier. Will Iain Smith and Ross Finnie accept that the 1985 act does not give patients a legal right to complain? It makes provision for the complaints procedure arrangements that must be in place, but it does not give the legal right to complain that the bill would give.

Iain Smith: Well, 11,000 people make complaints every year under the Crown system and, of those complaints, 27 per cent are completely upheld and 33 per cent are partially upheld. There are a lot of people out there who are quite able to use the existing complaints procedure. Some people do not use it, but that is not because they think that there is no legal right to complain; that is myth. It is because they are concerned about the process, they are frightened that it might affect their future relationship with their health professionals or they have other reasons for not doing so.

I will address a couple of other issues that came up in the debate. On the treatment time guarantee, we should remember a bit of the history. The 2007 Scottish National Party manifesto stated:
“Individuals sometimes need to be treated more quickly than the national waiting time guarantees. To ensure this happens we will introduce a Patients Rights Bill to give every patient a legally binding waiting time guarantee appropriate for their condition.”

That was slightly watered down by September 2007, when the SNP introduced its programme for government, which stated:

“We will consult on our proposals for a Patients’ Rights Bill which will bring greater accountability to our health service, give patients more rights and give legal effect to waiting time guarantees”.

The bill before us today states that if a health board does not meet the treatment time guarantee, it must

“make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity”

—in other words, the patient will be put on a waiting list. The board must also

“provide an explanation to the patient as to why the treatment did not start within the maximum waiting time”

—it was because there were too many people ahead of them on the waiting list. The bill does not really extend the existing rights of patients under the current waiting time provisions.

Patient rights are important, but there is always a danger that we will start to pass bills because of what they say on the cover rather than what they say inside. The Patient Rights (Scotland) Bill would be a good thing if it extended patient rights but, as has already been hinted at, there are some serious questions about whether it in fact diminishes those rights. For example, there are existing common-law rights to consent to or refuse treatment; to have adequate information about treatment, side effects and risks, or informed consent; and to appoint a welfare attorney. However, the bill states only that health care is to

“allow and encourage the patient to participate as fully as possible”

and to “have regard to” the need to provide information, and it contains no right to appoint a welfare attorney.

There is a legal right to confidentiality under the common law and the data protection legislation, but the bill states only that health professionals must “have regard to” confidentiality. On human rights, there is an absolute right to freedom from degrading treatment and an absolute right to privacy, but the bill states only that health professionals must “have regard to” the need to provide patients with dignity and respect and the need to respect privacy and confidentiality. It strikes me that, in those areas, the bill diminishes the existing rights rather than improving them. For that reason, we cannot support the bill.

I cannot understand the Labour Party’s position on the bill. In every single speech that Labour members have made, they have argued against the use of primary legislation, yet they are going to vote for it at stage 1. That does not make sense. I hope that they will see sense between now and decision time.

16:36

Murdo Fraser (Mid Scotland and Fife) (Con): This afternoon’s debate has been helpful in setting out the different positions that people take on the Patient Rights (Scotland) Bill. The position that is taken by the cabinet secretary and her colleagues on the SNP benches is clearly that the bill is appropriate and necessary. The position that has been set out by my Conservative colleagues and the Liberal Democrats is that the bill is inappropriate and unnecessary. The Labour Party’s position is drowning in a sea of fudge.

There is a philosophical question at the heart of the debate: when is legislation necessary? The view that my party and I take is that we should legislate only when necessary and as a last resort. We should not legislate as a gesture or, as Iain Smith said, to send a message. That is what the cabinet secretary said earlier that the bill would do. Ross Finnie made the point very fairly in his opening speech. I find myself increasingly in agreement with Mr Finnie in health debates. Some have observed that, indeed, I am increasingly coming to resemble Mr Finnie. However, I reassure him that that is only a temporary arrangement on my part. I will be as delighted as he will be when St Andrew’s day comes along and I can get the razor out.

It seems to me that legislation should be put through only when it is necessary, when it is required as a last resort, and when we have exhausted all the other possibilities. I do not believe that the bill meets those tests, because what is required by the bill should be happening already in the NHS. The bill will make no difference.

What is singular about the reaction to the bill and the evidence on it from the health bodies is that, as Michael Matheson said, it has been extremely negative. The Royal College of Nursing said:

“There is a need to enshrine patient rights, but we do not believe that legislation is the way forward.”

BMA Scotland said:

“We could do it by publishing a charter, so that patients feel more empowered to address patient rights issues within the context of an on-going episode of care.”

Dr Bill Mathewson from the Royal College of General Practitioners Scotland said:
“I agree with my colleagues.”—[Official Report, Health and Sport Committee; 29 September 2010; c 3439, 3440.]

Others to whom Mary Scanlon referred took the same view. Does the cabinet secretary see the irony that, just a week after we were lectured to on minimum unit pricing of alcohol and told that we should listen to the medical establishment when it comes to health issues, she is now disregarding its opinions on the important issue of patient rights? The Government is taking a pick-and-choose approach.

There has been a lot of discussion about the treatment time guarantee. We have always been nervous about enshrining time limits and targets in legislation. On this occasion, we agree with the BMA, which has expressed concern that the measure would have unintended consequences, distort clinical care and harm patients. Nanette Milne, speaking from medical experience, agreed with the BMA and confirmed what it had to say. We need to be cautious. We are not convinced that there is a need to enshrine the guarantee in legislation. In any event, there is no sanction. What is the point of having a legal right in the bill if the recipient cannot enforce it?

The provision will, of course, come at a cost, as we will need an army of patient rights officers—potentially between 65 and 80 full-time equivalents throughout Scotland—who will take money out of the health budget. We believe that that money could be better spent on front-line services.

There are other flaws in the bill. Mary Scanlon quite properly referred to the lack of mention of those with mental health issues who face extremely long waiting times to be seen. They will not be helped at all by the bill. Other patients, such as those who are waiting for physiotherapy, are in the same boat. Therefore, we have deep concerns about the approach that the cabinet secretary has proposed.

What should be done instead?

Elaine Smith: Are patients’ rights not such an important issue that the cabinet secretary should be given the opportunity to amend the bill at stage 2? If it is not amendable, members of Murdo Fraser’s party could then decide not to support it.

Murdo Fraser: I hear that point but, to be honest, I have difficulty seeing how the bill could be amended in a way that would make it acceptable to us. It seems to us that there is a better way to approach the matter, through enhancing the patients charter. Mary Scanlon set out that approach. Notwithstanding the cabinet secretary’s rather dismissive words, the patients charter was an improvement in the NHS. It improved the way in which patients were dealt with and their rights to complain. There was a culture change in the NHS at that time, and it was improved by the previous Administration. We think that that is the right way forward.

There is an issue with NHS complaints more generally. Jamie Stone drew attention to that in a fine speech. Last week, I met the Scottish Public Services Ombudsman, Jim Martin, to discuss some issues. The problem in the NHS is that, if people feel that they or a member of their family has had bad treatment, they will want some redress. Those people will not be looking for money or compensation; they will probably be looking for an apology. They will want somebody to say, “We’re sorry. We got this wrong and lessons have been learned.” However, the current system does not allow that to happen and, in frustration, many people end up going to lawyers and seeking redress through the courts. That is extremely expensive, stressful and time consuming, and they are not looking for that. They want a proper complaints system. That is what we should get, but the bill will not give us that, which is why we will not support it.

I am sorry that poor Richard Simpson, who is a robust opponent in committee, has now been exposed as Jackie Baillie’s poodle, and that he will meekly vote for the bill. We and Rhoda Grant say that it does not do what it says on the tin. There is a better way, so members should reject the bill.

16:42

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I am flattered by Ross Finnie’s repeated quotes from my attempts to ask questions about the bill in the committee.

I think that we all agree that the bill has good intentions, and that we need to improve patients’ rights and how they are managed. Most of the witnesses who gave evidence to the committee thought that drawing together patients’ rights would be valuable. I do not often agree with Michael Matheson, but I agree with him that there was a clear divide between the approach of the health professionals, whom Murdo Fraser quoted at length, and the approach of the patient groups. Those groups clearly indicated a desire to legislate. We should take account of that.

Almost all the witnesses indicated that there are serious problems with the bill as drafted.

Ross Finnie: Does the member agree that it is more accurate to say that there was a clear desire to have expressions as set out in the schedule? There was little evidence of anybody wanting a law to go to court with.

Dr Simpson: I will come back to that.

A number of members have referred to the Law Society, which pointed out that there are 17 other rights that patients already have that are not set
out in the bill. Ten of those are listed in paragraph 43 of the committee’s report. Some of those rights are fundamental and some of them are very complex. Irene Oldfather was eloquent, as usual, when she said that impaired capacity is an important issue that needs to be addressed. Other members have referred to the GMC’s concern that a patient’s right to refuse treatment was not made clear. The Scottish health council and Consumer Focus have expressed doubts about the bill, and we have considerable doubts about it. That is not surprising in view of what Ross Finnie quoted.

The committee clearly enunciated the central paradox of the bill. We want patients to have clearly laid out rights, but section 18 effectively precludes any significant legal action. However, once again, we all agree on that because we do not want lawyers at the foot of the bed.

The lawyers describe those provisions in the bill as not being meaningful. When is a right not a right? If it is enforceable, it is a right; if it is not enforceable, perhaps it is not a right.

Jackie Baillie and others have made clear our preference for powers to be developed and published in a charter of rights. However, perhaps that should be dealt with in a bill that has the enabling powers to produce it. It should also contain provisions on patients’ rights and responsibilities as well as those of staff.

Later sections of the bill deal with the treatment time guarantee. We have considerable difficulties with the guarantee and will seek to amend it. Sections 6 to 10, which introduce the guarantee, present another conundrum. In committee, Ian McKee questioned witnesses repeatedly about the trade-off between clinical priorities and guarantees. When we first debated the subject, I was attacked by the cabinet secretary because I said that clinical priorities must always come first. Her reply was that if a guarantee is not binding, it is not a guarantee, and if it is not binding, will patients not find it meaningless? There is therefore a second conundrum in the bill that we need to address. I say to my Liberal Democrat and Tory colleagues that, although we might not be successful, we will seek to address the conundrum by taking a much more flexible approach to patient guarantees, rather than giving the precise guarantees that the cabinet secretary seeks to embody in primary legislation, which might change.

Others have said that the treatment time guarantee, as it is laid out in the bill, is highly discriminatory. SAMH and others indicated their serious concerns about mental health being almost totally excluded from the bill in relation to treatments such as CBT. However, that is not the only area that faces a problem. Why is the national scoliosis service excluded? Assisted conception, which is a source of considerable delay and problems, is a worry to many patients, so why is it excluded? We need a much more flexible approach in the TTG sections of the bill and we will seek to amend them.

Elaine Smith spoke about issues in primary care. Primary care is not covered by the bill, yet many of the delays in cancer diagnosis relate to the primary care sector, about which there are no guarantees in the bill.

There are many targets in the NHS that are not just for in-patient procedures. NHS Lothian indicated that procedures that are in-patient today might be out-patient procedures tomorrow and therefore subject to a TTG. The situation will be different in different health boards, so there are real problems in not making the TTG provision more flexible.

Turning to the complaints section of the bill, I note that the SNP undertook to introduce no-fault compensation and I know that it is still working on that. That is important in relation to where we are going. It is a pity that it cannot be included in the total package at this point, but I understand the difficulties. We would welcome a much more formal mediation process because, as many speakers have said, patients do not want to enter into a formal complaints procedure; they want something else.

In paragraph 136 of our report, we refer to the example of the complaints system in the Equality and Human Rights Commission’s evidence. It is known as the four Cs and was developed by the state hospital, as my colleague Jackie Baillie explained. That system encompasses and embodies the approach that we all want to see. It includes compliments, which are about positive feedback. It includes comments, which are simply something in passing such as, “The doctor is wearing a wrist watch,” which is against health care-acquired infection regulations; someone in that situation does not want to complain, but they might want to say, “Doctor, you might want to take your wrist watch off,” or to say to the nurse, “You know, the doctor was wearing his wrist watch.” If they see a commode with blood fluids on it—we have lots of HAI reports—they do not want to complain because it might be just about to be cleaned, but they should be able to make a comment. The system also deals with concerns, which are short of a complaint. The four Cs system has changed the culture, which is what we all want to do, and we can try to embody it in legislation, which would give greater formality to the complaints procedure than there is under the 1985 act.

Finally, the bill introduces PASS and PROs. PROs will be expensive and will be a backwards step from the current IASS. However, we heard
evidence that the IASS is flawed, is not uniform and has no national contract. That involves many issues that might be worth being embodied in primary legislation. We need to see what we can do on that. I urge the cabinet secretary to suspend the retendering process that is going on, which is damaging the system that is in place. Staff are leaving, and we will lose the volunteers who are associated with the system.

Despite many reservations, Labour will support the bill at stage 1. We offer the Government the opportunity to work together to amend the bill significantly at stage 2. If the bill can be amended to the degree that we want, we hope to support it at stage 3. However, we reserve our position until we see whether the bill can be amended and can meet the serious objections to it in its present form.

We need a charter of rights that apply from the bill and other legislation. We need to consider treatment time guarantees. Huge issues are involved. We are prepared to work with the Government in a serious attempt to make the bill practicable.

16:51

Nicola Sturgeon: I thank all members for their speeches, the Health and Sport Committee for its work at stage 1 and Christine Grahame for her opening speech. He will not thank me for supporting him, but I thank Richard Simpson for displaying open-mindedness. I remind Ross Finnie, who is normally a stickler for procedure, that part of the job of all Health and Sport Committee members—they do it well—is to scrutinise and ask questions at stage 1. It is rather unfair to quote people’s questions against them in debate.

It is extremely encouraging that everybody has agreed with the principles of strengthening patients’ rights. I think that it is agreed that something needs to be done to improve the current framework. I believe that that should be done through primary legislation. Mary Scanlon said that the bill had no support and she mentioned the BMA, the RCN and the GMC. They are all respected organisations, but they represent providers of health services. She omitted to mention organisations such as Inclusion Scotland, the Rarer Cancers Forum and the RNIB, all of which—as Richard Simpson said—support the bill, as do organisations that represent people who use health services, as Michael Matheson said.

Many members have said that we should achieve the aim by a patients charter. My issue with that—with which Labour agreed to an extent—is that, without legislation, any rights that are in a patients charter can be easily eroded or forgotten. Whether the Tories and their new-found friends in the Liberal Democrats like it or not, that is what happened to the previous patients charter. I remind members that that charter existed when patients routinely waited a year or 18 months for hospital treatment.

Murdo Fraser: I am genuinely interested in the cabinet secretary’s argument, but the problem with her proposal is that the bill contains no legal remedies to enforce the rights that she is supposed to be giving. How is what she suggests better than the patients charter?

Nicola Sturgeon: I am coming to that point. If Murdo Fraser has patience, he will hear the answer to his question.

I was about to say that it is perhaps not surprising that the Tories—and, to a lesser extent, the Liberals—oppose the bill, because the coalition Government south of the border is removing or at least diluting many guarantees that patients had.

Mary Scanlon said that all that the bill covers should be happening. She is right, but we all know—and, as the Cabinet Secretary for Health and Wellbeing, I am prepared to admit—that although the NHS delivers to those standards in the overwhelming majority of cases, to be frank, it does not do so in some cases. The bill is intended to raise standards for all patients.

The issue has been raised that the bill is not enforceable. We deliberately took on board people’s response to the consultation that they did not want the system of the lawyer by the bedside. I make no apology for that—that is the sign of a listening Government—but it is not true to say that the bill contains no rights of redress. The bill contains the right to complain and to give feedback. There are existing rights to go to the ombudsman, to initiate judicial review and to take action for clinical negligence, if that is appropriate. The bill also legislates for support to help patients to raise standards and to ensure that their rights are met. I think that that is particularly important when it comes to helping more vulnerable patients.

Jackie Baillie made the important point that what patients want when something goes wrong is for the NHS to acknowledge it and to learn lessons. That is why the duty that the bill puts on health boards to respond to and learn from complaints is, in my view, as important as the right to complain itself.

It is absolutely not the case that the bill somehow diminishes rights for patients and removes existing rights. Patients will still have other rights that are set out in other legislation or in common law—the rights in the bill will be additional to those. Some members have mentioned the list of rights identified by the Law
Society. Patients will still have all those rights and they will have additional rights. As is always the case, information for patients and staff will include information about all the rights available to patients.

I am not sure whether Irene Oldfather is still in the chamber, but she raised some important issues about patients who lack capacity, which I will certainly reflect on further.

Jackie Baillie said that the treatment time guarantee covers only in-patient and day-case treatment and Richard Simpson made a valid point about procedures moving between the different categories of treatment, but I know that they would both accept that the treatment time guarantee sits within, or would sit within, the overall treatment guarantees that we have in the health service, which, of course, cover all stages of the patient journey.

Rhoda Grant said that people whose treatment time guarantee is not met do not want dispute resolution. She is absolutely right about that, which is why the bill expressly sets out the steps that boards must take in those circumstances.

Elaine Smith raised important equality issues. I tell her that the bill was developed after consultation with and consideration of the impact on equality groups. We will continue to have equality at the forefront of our minds.

**Mary Scanlon:** Can the minister tell me who does not have a right to complain at present? Who will have a new right to complain if the bill is passed?

**Nicola Sturgeon:** The answers to those questions are easy. Right now, nobody has a statutory right to complain and, if the bill is passed, everybody will have a statutory right to complain. That is probably one of the easiest questions that I have been asked in the chamber for some time.

On the treatment time guarantee, I say again that the eligibility criteria of planned or elective care on an in-patient or day-case basis applies to all services, including mental health services, so it is wrong to say that mental health patients will lose out as a result of the bill, but it is right to say that on-going work is required to reduce waiting times for access to mental health services that do not fall within those criteria.

The last area that I will address is the patient advice and support service. I believe that patients need access to support to help them use the health service and to help them complain when things do not go as they expect. The bill builds on the current service but makes some important improvements to the way that that service is run. I believe that it is important to legislate for PASS so that there is no risk of the erosion of such a service. Citizens Advice Scotland said in its evidence to the committee that the bill would make PASS statutory, so health boards would have to fund it.”—[Official Report, Health and Sport Committee, 8 September 2010; c 3259.]

Rhoda Grant, Jackie Baillie and others said that PASS could be more restrictive than the current service. I should point out that the current service is funded only to provide health information; it is the fact that citizens advice bureaux provide the service that allows it to provide access to a more holistic service. Of course, potential providers in the future would be able to do the same.

In conclusion, I welcome the debate and I am very open—as I always am—to working with members to bring forward sensible amendments at stage 2 that will strengthen what is currently in the bill. For the purposes of today, however, I ask members to support the Patient Rights (Scotland) Bill and its general principles.
Patient Rights (Scotland) Bill: Financial Resolution

16:59

The Presiding Officer (Alex Fergusson): The next item of business is consideration of motion S3M-7391, in the name of John Swinney, on the financial resolution for the Patient Rights (Scotland) Bill.

Motion moved,

That the Parliament, for the purposes of any Act of the Scottish Parliament resulting from the Patient Rights (Scotland) Bill, agrees to any increase in expenditure of a kind referred to in Rule 9.12.3(b)(iii) of the Parliament’s Standing Orders arising in consequence of the Act—[Nicola Sturgeon.]

The Presiding Officer: The question on the motion will be put at decision time.
Decision Time

17:01

The Presiding Officer (Alex Fergusson):

There are four questions to be put as a result of today’s business. The first question is, that motion S3M-7400, in the name of Nicola Sturgeon, on the Patient Rights (Scotland) Bill at stage 1, be agreed to. Are we agreed?

Members: No.

The Presiding Officer: There will be a division.

For

Adam, Brian (Aberdeen North) (SNP)
Allan, Alasdair (Western Isles) (SNP)
Baillie, Jackie (Dumbarton) (Lab)
Baker, Claire (Mid Scotland and Fife) (Lab)
Baker, Richard (North East Scotland) (Lab)
Boyack, Sarah (Edinburgh Central) (Lab)
Brown, Keith (Ochil) (SNP)
Butler, Bill (Glasgow Anniesland) (Lab)
Campbell, Aileen (South of Scotland) (SNP)
Chisholm, Malcolm (Edinburgh North and Leith) (Lab)
Coffey, Willie (Kilmarnock and Loudoun) (SNP)
Constance, Angela (Livingston) (SNP)
Craigie, Cathie (Cumbernauld and Kilsyth) (Lab)
Crawford, Bruce (Stirling) (SNP)
Cunningham, Roseanna (Perth) (SNP)
Don, Bob (Glasgow) (SNP)
Eadie, Helen (Dunfermline East) (Lab)
Ewing, Fergus (Inverness East, Nairn and Lochaber) (SNP)
Fabian, Linda (Central Scotland) (SNP)
Ferguson, Patricia (Glasgow Maryhill) (Lab)
FitzPatrick, Joe (Dundee West) (SNP)
Foulkes, George (Lothians) (Lab)
Gibson, Kenneth (Cunninghame North) (SNP)
Gibson, Rob (Highlands and Islands) (SNP)
Glen, Martin (North East Scotland) (Lab)
Godman, Trish (West Renfrewshire) (Lab)
Gordon, Charlie (Glasgow Cathcart) (Lab)
Grahame, Christine (South of Scotland) (SNP)
Grant, Rhoda (Highlands and Islands) (Lab)
Gray, Iain (East Lothian) (Lab)
Harvie, Christopher (Mid Scotland and Fife) (SNP)
Henry, Hugh (Paisley South) (Lab)
Hyslop, Fiona (Lothians) (SNP)
Ingram, Adam (South of Scotland) (SNP)
Kelly, James (Glasgow Rutherglen) (Lab)
Kerr, Andy (East Kilbride) (Lab)
Kidd, Bill (Glasgow) (SNP)
Lamont, Johann (Glasgow Pollok) (Lab)
Lochhead, Richard (Moray) (SNP)
MacAskill, Kenny (Edinburgh East and Musselburgh) (SNP)
Macdonald, Lewis (Aberdeen Central) (Lab)
Macintosh, Ken (Eastwood) (Lab)
Martin, Paul (Glasgow Springburn) (Lab)
Marwick, Tricia (Central Fife) (SNP)
Mather, Jim (Argyll and Bute) (SNP)
Matheson, Michael (Falkirk West) (SNP)
Maxwell, Stewart (West of Scotland) (SNP)
McAveety, Mr Frank (Glasgow Shettleston) (Lab)
McCabe, Tom (Hamilton South) (Lab)
McKee, Ian (Lothians) (SNP)
McKelvie, Christina (Central Scotland) (SNP)
McLaughlin, Anne (Glasgow) (SNP)
McMahon, Michael (Hamilton North and Bellshill) (Lab)

Against

Aitken, Bill (Glasgow) (Con)
Brocklebank, Ted (Mid Scotland and Fife) (Con)
Brown, Gavin (Lothians) (Con)
Brown, Robert (Glasgow) (LD)
Brownlee, Derek (South of Scotland) (Con)
Carlaw, Jackson (West of Scotland) (Con)
Finnie, Ross (West of Scotland) (LD)
Fraser, Murdo (Mid Scotland and Fife) (Con)
Goldie, Annabel (West of Scotland) (Con)
Hume, Jim (South of Scotland) (LD)
Johnstone, Alex (North East Scotland) (Con)
Lamont, John (Roxburgh and Berwickshire) (Con)
McArthur, Liam (Orkney) (LD)
McGrigor, Jamie (Highlands and Islands) (Con)
McInnes, Alison (North East Scotland) (LD)
McLetchie, David (Edinburgh Pentlands) (Con)
Milne, Nanette (North East Scotland) (Con)
Mitchell, Margaret (Central Scotland) (Con)
Munro, John Farquhar (Ross, Skye and Inverness West) (LD)
O’Donnell, Hugh (Central Scotland) (LD)
Pringle, Mike (Edinburgh South) (LD)
Purvis, Jeremy (Tweeddale, Ettrick and Lauderdale) (LD)
Rumbles, Mike (West Aberdeenshire and Kincardine) (LD)
Scanlon, Mary (Highlands and Islands) (Con)
Scott, John (Ayr) (Con)
Scott, Tavish (Shetland) (LD)
Smith, Elizabeth (Mid Scotland and Fife) (Con)
Smith, Iain (North East Fife) (LD)
Smith, Margaret (Edinburgh West) (LD)
Stephen, Nicol (Aberdeen South) (LD)
Stone, Jamie (Caithness, Sutherland and Easter Ross) (LD)
Tolson, Jim (Dunfermline West) (LD)

Abstentions

Harper, Robin (Lothians) (Green)
Harvie, Patrick (Glasgow) (Green)

The Presiding Officer: The result of the
division is: For 84, Against 32, Abstentions 2.

Motion agreed to,

That the Parliament agrees to the general principles of the Patient Rights (Scotland) Bill.

The Presiding Officer: The next question is, that motion S3M-7391, in the name of John Swinney, on the financial resolution to the Patient Rights (Scotland) Bill, be agreed to. Are we agreed?

Members: No.

The Presiding Officer: There will be a division.

For
Adam, Brian (Aberdeen North) (SNP)
Aitken, Bill (Glasgow) (Con)
Alian, Alasdair (Western Isles) (SNP)
Bailie, Jackie (Dumfarton) (Lab)
Baker, Claire (Mid Scotland and Fife) (Lab)
Baker, Richard (North East Scotland) (Lab)
Boyack, Sarah (Edinburgh Central) (Lab)
Brocklebank, Ted (Mid Scotland and Fife) (Con)
Brown, Gavin (Lothians) (Con)
Brown, Keith (Ochil) (SNP)
Brownlee, Derek (South of Scotland) (Con)
Butler, Bill (Glasgow Anniesland) (Lab)
Campbell, Aileen (South of Scotland) (SNP)
Carlaw, Jackson (West of Scotland) (Con)
Chisholm, Malcolm (Edinburgh North and Leith) (Lab)
Coffey, Willie (Kilmarnock and Loudoun) (SNP)
Constance, Angela (Livingston) (Lab)
Craige, Cathie (Cumbernauld and Kilsyth) (Lab)
Crawford, Bruce (Stirling) (SNIRING) (SNP)
Cunningham, Roseanna (Perth) (SNP)
Don, Nigel (North East Scotland) (SNP)
Doris, Bob (Glasgow) (SNP)
Eadie, Helen (Dunfermline East) (Lab)
Ewing, Fergus (Inverness East, Nairn and Lochaber) (SNP)
Fabiani, Linda (Central Scotland) (SNP)
Ferguson, Patricia (Glasgow Maryhill) (Lab)
FitzPatrick, Joe (Dundee West) (SNP)
Foulkes, George (Lothians) (Lab)
Fraser, Murdo (Mid Scotland and Fife) (Con)
Gibson, Kenneth (Cunninghame North) (SNP)
Gibson, Rob (Highlands and Islands) (SNP)
Glen, Marilyn (North East Scotland) (SNP)
Godman, Trish (West Renfrewshire) (Lab)
Goldie, Annabel (West of Scotland) (Con)
Gordon, Charlie (Glasgow Cathcart) (Lab)
Grahame, Christine (South of Scotland) (SNP)
Grant, Rhoda (Highlands and Islands) (Lab)
Gray, Iain (East Lothian) (Lab)
Harvie, Christopher (Mid Scotland and Fife) (SNP)
Henry, Hugh (Paisley South) (Lab)
Hyslop, Fiona (Lothians) (SNP)
Ingram, Adam (South of Scotland) (SNP)
Johnstone, Alex (North East Scotland) (Con)
Kelly, James (Glasgow Rutherglen) (Lab)
Kerr, Andy (East Kilbride) (Lab)
Kidd, Bill (Glasgow) (SNP)
Lamont, Johann (Glasgow Pollok) (Lab)
Lamont, John (Roxburgh and Berwickshire) (Con)
Lochhead, Richard (Moray) (SNP)
MacAskill, Kenny (Edinburgh East and Musselburgh) (SNP)
Macdonald, Lewis (Aberdeen Central) (Lab)
Macintosh, Ken (Eastwood) (Lab)
Martin, Paul (Glasgow Springburn) (Lab)
Marwick, Tricia (Central Fife) (SNP)
Mather, Jim (Argyll and Bute) (SNP)
Matheson, Michael (Falkirk West) (SNP)
Maxwell, Stewart (West of Scotland) (SNP)
Mcaveety, Mr Frank (Glasgow Shettleston) (Lab)
McCabe, Tom (Hamilton South) (Lab)
McGrigor, Jamie (Highlands and Islands) (Con)
McKee, Ian (Lothians) (SNP)
McKelvie, Christina (Central Scotland) (SNP)
McLaughlin, Anne (Glasgow) (SNP)
McMahon, Michael (Hamilton North and Bellshill) (Lab)
McMillan, Stuart (West of Scotland) (SNP)
McNeill, Duncan (Greenock and Inverclyde) (Lab)
McNeill, Pauline (Glasgow Kelvin) (Lab)
McNutty, Des (Clydebank and Milngavie) (Lab)
Mlne, Nanette (North East Scotland) (Con)
Mitchell, Margaret (Central Scotland) (Con)
Morgan, Alasdair (South of Scotland) (SNP)
Mulligan, Mary (Linlithgow) (Lab)
Murray, Elaine (Dumfries) (Lab)
Neill, Alex (Central Scotland) (SNP)
Oldfather, Irene (Cunninghame South) (Lab)
Park, John (Mid Scotland and Fife) (Lab)
Paterson, Gil (West of Scotland) (SNP)
Peacock, Peter (Highlands and Islands) (Lab)
Peattie, Cathy (Falkirk East) (Lab)
Robison, Shona (Dundee East) (SNP)
Russell, Michael (South of Scotland) (SNP)
Saldmond, Alex (Gordon) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)
Scott, John (Ayr) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)
Smith, Elaine (Coatbridge and Chryston) (Lab)
Smith, Elizabeth (Mid Scotland and Fife) (Con)
Stevenson, Stewart (Banff and Buchan) (SNP)
Stewart, David (Highlands and Islands) (Lab)
Sturgeon, Nicola (Glasgow Govan) (SNP)
Swinney, John (North Tayside) (SNP)
Thompson, Dave (Highlands and Islands) (SNP)
Watt, Maureen (North East Scotland) (SNP)
Welsh, Andrew (Angus) (SNP)
White, Sandra (Glasgow) (SNP)
Whitefield, Karen (Airdrie and Shotts) (Lab)
Whitton, David (Strathkelvin and Bearsden) (Lab)
Wilson, Bill (West of Scotland) (SNP)
Wilson, John (Central Scotland) (SNP)

Against
Brown, Robert (Glasgow) (LD)
Finnie, Ross (West of Scotland) (LD)
Hume, Jim (South of Scotland) (LD)
McArthur, Liam (Orkney) (LD)
McInnes, Alison (North East Scotland) (LD)
Munro, John Farquhar (Ross, Skye and Inverness West) (LD)
O'Donnell, Hugh (Central Scotland) (LD)
Pringle, Mike (Edinburgh South) (LD)
Purvis, Jeremy (Tweeddale, Ettrick and Lauderdale) (LD)
Rumbles, Mike (West Aberdeenshire and Kincardine) (LD)
Scott, Tavish (Shetland) (LD)
Smith, lain (North East Fife) (LD)
Smith, Margaret (Edinburgh West) (LD)
Stephen, Nicol (Aberdeen South) (LD)
Stone, Jamie (Caithness, Sutherland and Easter Ross) (LD)
Tolson, Jim (Dunfermline West) (LD)

Abstentions
Harper, Robin (Lothians) (Green)
Harvie, Patrick (Glasgow) (Green)

The Presiding Officer: The result of the division is: For 99, Against 16, Abstentions 2.
Motion agreed to,

That the Parliament, for the purposes of any Act of the Scottish Parliament resulting from the Patient Rights (Scotland) Bill, agrees to any increase in expenditure of a kind referred to in Rule 9.12.3(b)(iii) of the Parliament’s Standing Orders arising in consequence of the Act.
SCOTTISH GOVERNMENT RESPONSE TO THE HEALTH AND SPORT COMMITTEE’S STAGE 1 REPORT ON THE PATIENT RIGHTS (SCOTLAND) BILL

1. The Government welcomes the Committee’s commitment to promote the rights of patients and foster a patient-centred culture within NHS Scotland.

**Use of primary legislation to promote patient rights and alternatives to primary legislation**

2. It is the Government’s view that primary legislation is the most appropriate method of ensuring the delivery of patient rights.

3. Putting patients’ rights into primary legislation raises their status as a matter of fact and law, as well as through the message it sends and the effect it will have on focusing the actions of the NHS. Patients’ representative organisations alluded to primary legislation giving patients a resource to use to engage with the NHS on a mutual basis.

4. The Government does not believe that a patient rights charter alone is an effective or robust way to strengthen and improve the rights of patients in Scotland.

**What constitutes a right and rights not contained in the Bill**

5. The report acknowledged that the definition of a right is a complex issue and that there was near unanimous consensus that legislation should avoid establishing a ‘lawyer’s charter’.

6. The Government has aimed to strike a careful balance between establishing rights for patients and not providing additional channels to sue the NHS, as this was a clear concern for many in the consultation and in the evidence presented to the Committee. The Bill establishes patient rights and allows for legal recourse via a declaratory judicial review. It does not remove the right of patients to take legal action on the basis of other rights or concerns, such as medical negligence claims.

7. There was concern that the Bill does not mention every right that patients have in their use of the health care service. Some of these rights exist in reserved legislation and in the common law. The Government does not think it is necessary or desirable to duplicate existing legislation and common law by laying out these rights in the Patient Rights (Scotland) Bill. Nevertheless, the Government acknowledges the concerns raised. The information and publicity to implement the Bill will include not only the rights in this Bill but also additional rights that exist in other legislation and common law. The Scottish Government is also considering Guidance for Health Boards that will draw together the range of rights that apply to patients.

**Support for the aims of the Bill**

8. A number of patient representatives groups welcomed the Bill and believed that it would contribute to creating a mutual NHS. The Scottish Government intends that
the Bill will help to bring about a culture change towards a truly patient-focussed NHS.

The enforceability of rights

9. The Bill focuses on deliverability and action for patients, not on mechanisms to sue the NHS; instead, this Bill is about achieving a culture change and setting out the way in which care should be delivered, with the availability of independent support for those who want to complain or raise concerns.

10. The Committee has said that they support the desire of the Scottish Government not to introduce a ‘charter for lawyers’, yet it also says that it thinks limiting the rights for legal redress may raise unrealistic expectations. The Scottish Government welcomes the Committee’s suggestion of a remedy such as alternative dispute resolution and will explore this further.

Potential distortion of clinical priorities

11. The Cabinet Secretary for Health and Wellbeing has noted that targets are intended not to skew clinical priorities but to ensure that patients are treated timeously. Section 18 of the Bill states that nothing in the Bill prejudices the exercise of clinical judgement and Section 2 notes that the rights of other patients must be taken into account. In the Treatment Time Guarantee, Section 8(3) refers to the clinical need of others when a Health Board is taking action following a breach of the guarantee. Nevertheless, the Government notes the suggestion that clinical priority should be stated earlier in the Treatment Time Guarantee sections and intends to put forward an amendment to this effect. This will operate within the guarantee, and is not intended to allow exceptions from it.

Exemptions from the 12 week Treatment Time Guarantee

12. The Government notes the Committee’s concerns with regard to those services that do not meet the eligibility criteria of the Treatment Time Guarantee. Where a treatment or service meets the eligibility criteria of planned or elective care on an inpatient or day case basis, then it is covered. That is the same for mental health services and for all services, unless specifically excluded. Work is ongoing to reduce waiting times in access to mental health services and is seeking to address waiting times in those mental health services that do not come within the TTG eligibility criteria, such as access to psychological therapies.

Monitoring of primary care services

13. The Government notes the Committee’s concerns about the monitoring of the Treatment Time Guarantee in relation to those eligible services that are delivered via primary care. The Government is considering the Committee’s recommendation that compliance should be reported in the annual report of a GP practice.

14. The Committee was concerned that the Guarantee has potential to make for confusion rather than clarity. The Treatment Time Guarantee in its implementation will emphasise partnership and communication between clinician and patient. The
clinician will take into account relevant factors and determine for each patient whether treatment should be as an inpatient or day case or in an outpatient setting or even in primary care and, therefore, the eligibility for the Guarantee.

15. The Committee reported that it “noted the unequivocal statement by the Cabinet Secretary that the 12 week Treatment Time Guarantee only applies to elective in-patient treatment”. To use the word “only” is not an accurate interpretation of what the Cabinet Secretary said during the evidence session; she noted that it applied “to elective planned treatment, whether that be in-patient treatment or day-case treatment”.

16. The Committee was also concerned that the Treatment Time Guarantee could not be enforced. The Bill lays out steps that Boards must take where a Treatment Time Guarantee is breached: this should not be about a patient having to go to court in order to have a Treatment Time Guarantee met. The Bill also provides for powers for Ministers to direct a Health Board to take specified action in relation to a Board’s compliance with the Treatment Time Guarantee.

**Patient complaints and feedback**

17. The Scottish Government agrees with the Committee that a more open and accessible system of patient feedback within the NHS is to be encouraged.

18. The Scottish Government recognises the importance of patient feedback and has specified in the Bill that Health Boards must consider all concerns and feedback raised in order to learn from them and make improvements to patient care.

19. The Bill provides for a legal right to make a complaint; the detail of which will be in Regulations and Directions. The intention is for the provision of appropriate and supportive arrangements, such as additional independent support provided by the Patient Advice and Support Service, as well as the existing support provided by NHS Complaints Officers.

20. The existing ‘right to complain’ is not currently set out in primary legislation. Research shows that people are reluctant to make a complaint in some cases because of fear of repercussions or the effect this may have on their relationship with the NHS and their future treatment. The ‘statutory right’ included in the Bill will help to give patients the confidence that it is okay to exercise this right.

**Patient Advice and Support Service and Patient Rights Officers**

21. The Scottish Government believes that it is important to underpin the advice and support service through legislation and is committed to ensuring that patients have access to good quality consistent advice and support.

22. In order to achieve this consistency, enhance the current service and ensure best value for money, the Bill proposes that the new Patient Advice and Support Service is contracted nationally by the Common Services Agency of the NHS. The procurement process will ensure that in commissioning the service public funds and resources are used effectively.
Financial implications of the Bill

23. The Committee noted that it was uncertain whether the projected costs in the Bill’s Financial Memorandum are reliable and accurate. It also suggested that different figures were provided for the numbers of Patient Rights Officers with 40-50 in the Policy Memorandum and 65-80 in the Financial Memorandum.

24. Given the current financial pressures, the Government notes the Committee’s concerns. The Financial Memorandum was based on information available and projections made at the beginning of 2010 and, as noted in the oral evidence “we will look to see whether we can get the same outcomes for slightly less or get better value for money elsewhere”. The Government set out funding for specific projects and provision with the intention that the bodies delivering those do so within the funding allocated: it does not expect costs to escalate following Bill enactment.

Subordinate Legislation Committee findings and recommendations

25. The Government accepts the Committee’s recommendations that affirmative rather than negative procedure would be more appropriate for Sections 7(1), 7(3) and 7(4), and intends to bring forward amendments. The Government does not agree that a power to make subordinate legislation is more appropriate than directions under Section 9(3) in order to suspend the Treatment Time Guarantee as it believes that directions are an appropriate measure to respond speedily to unforeseen exceptional circumstances.

26. The Government has written separately to the Subordinate Legislation Committee.

Equalities


Overall conclusion

28. It is disappointing that the Committee did not recommend that Parliament should support the general principles of a Bill that seeks to strengthen patients’ rights. The Bill was supported during Stage 1 by many groups representing users of the NHS. The Bill is fundamental to this Government’s vision of creating an NHS which is patient-focused. The Government has always been clear that patients’ rights are of paramount importance and they should be given the prominence and priority that primary legislation affords.

Scottish Government
24 November 2010
SUBORDINATE LEGISLATION COMMITTEE

33rd Meeting, 2010 (Session 3)

Tuesday 30 November 2010

Paper by the Clerk

Patient Rights (Scotland) Bill – Response to SLC Stage 1 Report

Background

1. Under Rule 9.6.2 of Standing Orders, the Subordinate Legislation Committee submitted its report on the delegated powers provisions in the Patient Rights (Scotland) Bill to the Health and Sport Committee, as lead committee for the Bill, on 11 May 2010.

2. On 24 November 2010, Lauren Murdoch, Patient Rights Bill Team Leader, wrote to the Clerk to the Subordinate Legislation Committee responding to the Committee’s Stage 1 report.

Scottish Government Response

3. The response indicates that the Scottish Government intends to seek to amend the Bill in line with the Subordinate Legislation Committee’s recommendations on the delegated powers contained in sections 7(1), 7(3), 7(4) and 21(1)(c).

4. In its stage 1 report, the Committee recommended that the power under section 9(3) should be expressed as a power to make subordinate legislation. The Government has noted this but contends that it may not be appropriate for all circumstances.

5. The Government believes that directions are an appropriate measure to respond speedily to unforeseen exceptional circumstances and does not intend to bring forward an amendment to this section.

Progress of the Bill

6. The Bill passed Stage 1 on 17 November 2010. Stage 2 will start on Tuesday 7 December.

7. The Subordinate Legislation Committee will give further consideration to the delegated powers contained in the Bill after Stage 2.

Recommendation

8. Members are invited to note the Scottish Government’s response to the Subordinate Legislation Committee’s report on the Patient Rights (Scotland) Bill at Stage 1.

Irene Fleming
Clerk to the Committee
Correspondence from the Scottish Government dated 24 November 2010

PATIENT RIGHTS (SCOTLAND) BILL at Stage 1: Subordinate Legislation Committee Report

In your letter of 11 May 2010 to the Scottish Government’s Elspeth MacDonald, Head of Constitution and Parliamentary Secretariat, you attached a copy of the Subordinate Legislation Committee’s report on the Bill and asked for a response prior to the commencement of Stage 2 proceedings.

Thank you for your consideration of the Bill and its delegated powers. We note that the Committee determined that it did not need to draw the attention of the Parliament to the delegated powers in sections: 1(4), 4(2), 11(4)(a), 14(2), 15(6), 20(1) and 22(3), and that it considered that it did not need to draw the attention of the Parliament to the powers of direction in sections: 5(3), 9(2), 11(4)(b), 12(5) and 14(2).

I will deal with the other issues raised in sequence, and the Scottish Government response.

Section 5(1) – Guidance in relation to the practical application of the health care principles

Power conferred on: Scottish Ministers
Power exercisable by: guidance
Parliamentary procedure: none

The Committee sought further information from the Government on the function of the guidance. The Committee was satisfied that this delegated power is appropriate to be exercised in the form of guidance.

Scottish Government: the Government notes the Committee’s response.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

The Committee drew to the attention of the lead committee its view that the power to exclude patients from eligibility for the treatment time guarantee is significant. In its view, a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who
are to be eligible which could be amended or of criteria on the basis of which such descriptions are to be determined.

**Scottish Government**: the Government believes that eligibility criteria are most appropriately expressed in secondary legislation, for the reasons stated in previous correspondence.

The Committee recommended that the power in section 7(1) be subject to affirmative rather than negative procedure because of the significance of the guarantee and the significance and effect on the operation of that guarantee of designation of eligible patients and the method of calculating the waiting time.

**Scottish Government**: the Government anticipates that the bulk of the provisions in these regulations will relate to the detailed operation of the guarantee, together with administrative and procedural matters which will be technical in nature; this would suggest that negative procedure would be appropriate but the Government has considered the Committee’s comments further and the Health and Sport Committee’s endorsement of the comments and intends to bring forward an amendment to apply draft affirmative procedure to these regulations.

**Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee**

**Power conferred on:** Scottish Ministers  
**Power exercisable by:** regulations made by statutory instrument  
**Parliamentary procedure:** negative resolution of the Scottish Parliament

The Committee recommended that this power be subject to affirmative, rather than negative procedure because of the significance, through the exercise of the power, of the exclusion of specified treatments and services from the guarantee.

**Scottish Government**: the Government noted that this is largely an issue of a medical and technical nature but has considered the comments in the report that the exclusion of specified treatments and services from the guarantee is an important issue of significance to patients and to the public generally (as potential patients), and the Health and Sport Committee’s endorsement of the comments and intends to bring forward an amendment to apply draft affirmative procedure to these regulations.

**Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time**

**Power conferred on:** Scottish Ministers  
**Power exercisable by:** order made by statutory instrument  
**Parliamentary procedure:** negative resolution of the Scottish Parliament

The Committee recommended that the power should be made subject to affirmative procedure given the significant impact the exercise of the power may have on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The Committee noted the Scottish Government’s commitment to consider
further whether an amendment should be brought forward to apply draft affirmative procedure.

Scottish Government: the Government intends to bring forward an amendment to apply draft affirmative procedure to this section of the Bill.

Section 9(1) – Guidance in relation to the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: guidance
Parliamentary procedure: none

The Committee was satisfied that this delegated power is appropriate to be exercised in the form of guidance.

Scottish Government: the Government notes the Committee’s response.

Section 21(1)(c) – Power when making orders or regulations to make consequential, supplementary, incidental, transitional, transitory or saving provision within those orders or regulations.

Power conferred on: Scottish Ministers
Power exercisable by: Order
Parliamentary procedure: Affirmative / Negative / None

The Committee is satisfied with the Scottish Government’s justification for the power in section 21(1)(c) in addition to that under section 20(1). The Committee does not consider it is appropriate to provide for substantive provision to be made in commencement orders subject to no procedure. It therefore recommends that section 21(1)(c) should be amended to this effect and notes the Scottish Government’s undertaking to do so.

Scottish Government: the Committee’s response is noted. The Government will bring forward an amendment to section 21(1)(c) so that it does not apply to commencement orders.

Other proposed delegated powers

Section 9(3) – suspension of the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: directions

The Committee was satisfied that the position as to when powers of direction may be used is made clear in the Bill. However, the Committee was not satisfied that directions are appropriate for the purpose of suspending the treatment time guarantee in exceptional circumstances given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The Committee recommended that the power under section 9(3) should be expressed as a power to make subordinate legislation. If it is necessary for policy reasons to be
able to bring that legislation into force immediately subject to subsequent endorsement by Parliament for it to continue in force, then it is possible to provide for such procedure.

Scottish Government: The Government notes the Committee’s point of view and the lead Committee’s endorsement of that. It would be possible to do as the Subordinate Legislation Committee suggests, however this may not be appropriate for all circumstances. For example, if the suspension was for a few days for one Health Board area, then directions are an appropriate measure: making subordinate legislation might not in that instance be an appropriate use of Parliament’s time. If the exceptional circumstances were to have a much broader impact then it is possible that subordinate legislation would be more appropriate. The Government believes that, on balance, directions are an appropriate measure to respond speedily to unforeseen exceptional circumstances and thus does not intend to bring forward an amendment to this section.
PATIENT RIGHTS (SCOTLAND) BILL: DRAFT REGULATIONS AND DIRECTIONS

1. The Scottish Government noted its intention to share early drafts of secondary legislation with the Health and Sport Committee, to aid the Committee’s consideration of the Bill, at stage 2 of the Parliamentary process. The secondary legislation will then be consulted on more fully at a later stage.

2. With this in mind, the following draft documents are attached for the Committee’s consideration:

- Directions on the health care principles;
- Regulations and Directions on the treatment time guarantee;
- Regulations on complaints and Directions on complaints and patient feedback; and
- A copy of the information on the Patient Advice and Support Service, already submitted in August 2010. Paragraphs 16 – 18 of this cover note explain why Regulations have not yet been drafted on this topic.

To a large extent the draft Regulations and Directions are self-explanatory, but we have provided a brief background and summary of the relevant powers below to assist the Committee. We have sought to highlight the issues which may be of particular interest / relevance to the Committee.

Health Care Principles

3. The Scottish Ministers may issue Directions on the practical application of the health care principles, in accordance with section 5(3) of the Patient Rights (Scotland) Bill.

Treatment Time Guarantee

4. The Scottish Ministers must make Regulations relating to the eligibility for and calculation of the treatment time guarantee in accordance with section 7(1) of the Patient Rights (Scotland) Bill. In addition to this, the Scottish Ministers may make further provision about the treatment time guarantee under Regulations in accordance with section 7(3) of the Bill. The Scottish Ministers may also give Directions under section 9(2) of the Bill to direct a Health Board to take specified action in relation to its compliance with the treatment time guarantee.

Regulations

5. The Scottish Government has been closely considering the list of proposed exceptions given in the Policy Memorandum to ensure that this list is a short as possible. There are now only four exceptions to the treatment time guarantee for treatments or services that might otherwise meet the eligibility criteria:

- Assisted reproduction
- Obstetrics services
- Organ and tissue transplantation
- Designated national specialist services for the surgical intervention of spinal scoliosis
6. Obstetric services are excluded because it would not be logical to apply a maximum 12 week waiting time to the process of birth and delivery. Organ and tissue transplantations are excluded because these procedures are dependent on organ/tissue availability. In assisted reproduction, work is ongoing towards introducing a maximum waiting time, as the Government knows that there is inequity in access to this service. The scoliosis service is currently delivered by very few clinicians and is dependent on availability of these staff.

7. The calculation of the waiting time as specified in regulation 3 is modelled on the guidance to the NHS for the management of all waiting times, called ‘New Ways of Defining and Measuring Waiting Times’ (New Ways aims to provide a consistent approach to the management of waiting times).

Consultation

8. These draft Regulation and Directions have been modelled on ‘New Ways of Defining and Measuring Waiting Times’ guidance; that guidance was developed in close consultation with the NHS in Scotland. As with all of the draft directions and regulations, these draft regulations and directions are subject to further stakeholder consultation once the Bill is enacted.

Complaints and Patient Feedback

9. The Scottish Ministers may issue Regulations and Directions relating to the arrangements for dealing with complaints and feedback, in accordance with sections 11(4) and 12(5) of the Patient Rights (Scotland) Bill.

No Fault Compensation Group

10. The initial consultation proposals in 2008/09 for the Patient Rights (Scotland) Bill raised the issue of a scheme of no-fault compensation. A group was established in June 2009 to consider the introduction of a no-fault compensation scheme for injuries as a result of medical treatment. This group has recently submitted its report and this is currently being considered.

11. Although this work is outwith the Bill, the draft regulations and directions on NHS complaints will be reviewed following a ministerial decision on this matter.

SPSO Complaints Handling Principles

12. The SPSO submitted a draft of their first statement of complaints handling principles (CHPs) to Parliament on 1 November 2010. Scottish Government officials have developed the attached draft regulations and directions taking account of this work and will review these regulations and directions following a decision by Parliament on the CHPs. Officials are aware that the SPSO intends to publish revised guidance later this year which will also be taken into consideration.
Alternative Dispute Resolution

13. In their stage 1 report, the Health and Sport Committee recommended that ‘a remedy such as alternative dispute resolution should be explored further at Stage 2’ (para 79). Cabinet Secretary, Nicola Sturgeon, has asked officials to explore this further.

14. The existing 2005 Directions on complaints set out the use of conciliation to resolve complaints about primary care providers.

15. In light of the comments made by Committee members, officials are reviewing the use of mediation in primary care and considering, with interest, its role with regards to complaints made to relevant NHS bodies.

Patient Advice and Support Service (PASS)

16. The Scottish Ministers may make Regulations about the Patient Advice and Support Service, in particular about the service it is to provide, under section 15(6) of the Patient Rights (Scotland) Bill.

17. Since submission of the information sheet (see attached) on the Patient Advice and Support Service (PASS) to the Health and Sport Committee in August, Scottish Government officials have been considering what should be set out in Regulations and what will be set out in the contract specification between the NHS’s Common Services Agency (CSA) and the PASS provider.

18. Through development of the service contract (which is on-going) it has been decided that it is not necessary at this stage to draft Regulations on PASS. The functions of PASS are clearly set out in the Bill and the detail of its operations will be addressed in the service contract, including details about the requirement on the PASS to report on its activities, such as timing, method and format of the report.
The Scottish Ministers give the following Directions in exercise of the powers conferred by section 5(3) of the Patient Rights (Scotland) Act 2011 and all other powers enabling them to do so.

Citation, commencement and application
1.—(1) These directions may be cited as the Patient Rights (Health Care Principles) (Scotland) Directions 2011 and come into force on [        ].

Interpretation
2. In these “directions”—
   “the Act” means the Patient Rights (Scotland) Act 2011;
   “carer” means a person, other than a care worker, who provides, or intends to provide, a substantial amount of care on a regular basis for another person;
   “care worker” means a person who provides care to another person under a contract;
   “designated representative” means any person nominated by the patient to be the patient’s representative;
   “relevant staff” means any member of staff who provides medical treatment to patients, assists in the provision of such treatment or assists patients to access medical treatment;
   “staff” means any person employed by a relevant NHS body, or otherwise engaged to provide services to such a body (whether under a contract, agreement or other arrangement or as a volunteer);
   “support” means support provided by a third party to assist a patient to receive or access health care and to participate in decisions relating to their health and well-being;
   “support needs” means the patient requires support to access health care or to participate in decisions about their health;

Publication of health care principles
3. Each relevant NHS Body must publicise the health care principles to patients and staff.

Patient Focus
4.—(1) Each relevant NHS Body must ensure that when delivering health care to patients that anything done in relation to the patient takes into account the concerns, opinions and preferences of:-
   (a) the patient; and
   (b) where appropriate, any partner, family member, carer, care worker, or other designated representative of the patient.

(2) Each relevant NHS Body must publicise to patients the support that is available for patients and how to request this support.
(3) Each relevant NHS Body must provide appropriate training to ensure all relevant staff are aware of the support that is available to patients and how to access these services for patients.

(4) Where a patient has requested support from a relevant NHS Body, that relevant NHS Body must where reasonably practicable and appropriate:-
   
   (a) ensure the support is provided;
   
   (b) ensure the support needs of the patient are recorded by, and communicated between, relevant staff; and
   
   (c) ensure the support is arranged in advance of any future appointment which the patient has, or may have.

(5) Without prejudice to the generality of the definition in direction 2, unless the context otherwise requires, “support” for the purpose of these Directions includes:
   
   (a) a friend, relative, partner, carer, care worker or other supporter being present with the patient at his or her appointment;
   
   (b) translation, interpreting or other communication support (TICS) services;
   
   (c) advocacy
   
   (d) the Patient Advice and Support Service.

(6) Each relevant NHS Body must provide training to ensure all staff are clear about their role in the delivery of patient-focused care. This training must provide guidance to staff in how to identify, respect and, where possible, address the needs of patients.

(7) Each relevant NHS Body must, so far as reasonably practicable, ensure health care is provided in a private and safe environment.

**Quality Care and Treatment**

5.—(1) Each relevant NHS Body must ensure that health care is provided in a clean environment and that the risks to patients of hospital acquired infections are minimised.

**Patient Participation**

6.—(1) Each relevant NHS Body must publicise to patients the behaviour that is expected of patients when interacting with staff.

(2) Each relevant NHS Body must publicise to patients and staff the importance of patient participation in decisions relating to the patient’s health.

(3) Each relevant NHS Body must give patients information on and the opportunity to discuss their medical condition and treatment options with their health care professional.

**Communication**

7.—(1) Information and advice, either verbal or written, must be given to a patient in a way the patient can understand.

(2) General information and publicity materials must be provided with consideration given to their accessibility for all patients.

(3) Each relevant NHS Body must provide training for all staff in communication skills.
The Scottish Ministers make the following Regulations in exercise of the powers conferred by section 7(1) and (3) of the Patient Rights (Scotland) Act 2011(1) and all other powers enabling them to do so.

Citation, commencement and interpretation

1.—(1) These regulations may be cited as the Patient Rights (Treatment Time Guarantee) (Scotland) Regulations 2011 and come into force on [        ].

(2) In these regulations—
“the Act” means the Patient Rights (Scotland) Act 2011;
“agreed treatment” means a specific treatment agreed between an eligible patient and the Health Board;
“assisted reproduction” means a treatment designed to lead to conception by means other than sexual intercourse;
“authorised provider” means a provider of medical services in an EEA state(2) or Switzerland other than the United Kingdom who is lawfully providing such services in the territory of that state;
“day case basis” means that the treatment has been assessed as requiring the patient to remain in the place of treatment for a period of time following the treatment for the purposes of that patient’s supervised recovery and which does not require an overnight stay;
“designated national specialist services” means services which are commissioned by National Services Division, which is a division within the Common Services Agency;
“eligible patient” means a patient of a description specified in regulation 2;
“general medical practitioner” means a medical practitioner whose name is included in the General Practitioner Register kept by the General Medical Council;
“Health Board” includes the National Waiting Times Centre Board;
“inpatient basis” means the treatment requires the patient to be admitted to and remain in the place of treatment overnight;
“maximum waiting time” is the period of 12 weeks beginning with the date on which the patient agrees to the agreed treatment;
“planned or elective treatment” means treatment which is pre-arranged and non-emergency;

(1) 2011 c.[    ].
(2) See Schedule 1 to the Interpretation Act 1978 (c.30) for the definition of the “EEA State” which was inserted by section 26(1) of the Legislative and Regulatory Reform Act 2006 (c.51).
“treatment” means a surgical or medical intervention ordinarily provided by the Health Board (other than such treatments or services specified in regulation 4);
“treatment time guarantee” has the meaning given in section 6(2) of the Act.

Patients eligible for the treatment time guarantee

2. For the purposes of section 7(2)(a) of the Act (treatment time guarantee: further provision) patients which are eligible for the treatment time guarantee are those patients due to receive planned or elective treatment on an inpatient or day case basis.

Calculation of waiting time

3.—(1) For the purposes of section 7(2)(b) of the Act the calculation of waiting time starts from the date on which the treatment is agreed between the patient and the Health Board (the Health Board which agrees the treatment is the “responsible Health Board”).

(2) Notwithstanding paragraph (1), waiting time will not start in circumstances when a patient is unavailable for treatment, and there is no known end date to that unavailability.

(3) Notwithstanding paragraph (1), the following periods of time are not to be counted towards a maximum waiting time—

(a) periods of time when the patient is unavailable for the agreed treatment—
   (i) because the relevant medical clinician has advised that the patient has another medical condition which prevents the agreed treatment from going ahead for that period of time; or
   (ii) because the patient has advised the Health Board that that patient is or will be unavailable for treatment for that period of time;

(b) periods of time when the treatment time guarantee is suspended in accordance with directions made under section 9(3) of the Act.

(4) Notwithstanding paragraph (1), where the calculation of waiting time has started, that calculation may be reset to zero in the circumstances described in sub-paragraphs (a), (b) and (c) where it is reasonable and clinically appropriate in all the circumstances—

(a) the patient has contacted the Health Board in advance of an agreed appointment for the agreed treatment to advise that that patient is unable to attend the agreed appointment;

(b) the patient has declined to accept two offers of an appointment for the agreed treatment where the dates offered were reasonable;

(c) the responsibility for the agreed treatment has transferred to a different Health Board in accordance with regulation 6.

(5) Notwithstanding paragraph (1), a Health Board may refer a patient back to that patient’s general medical practitioner (and the treatment time guarantee will cease to apply to that patient without prejudice to the applicability of the treatment time guarantee in any future referral) in circumstances described in sub-paragraphs (a), (b) and (c), where it is reasonable and clinically appropriate in all the circumstances—

(a) the patient did not attend an agreed appointment for the agreed treatment and that patient had not contacted the Health Board in advance of the agreed appointment to advise of such inability to attend;

(b) the patient has declined to accept two offers of an appointment where the dates offered for the appointment were reasonable;

(c) the patient has for the third time contacted the Health Board in advance of an agreed appointment for the agreed treatment to advise that that patient is unable to attend the agreed appointment.

(6) A Health Board must ensure that its patients are made aware of the consequences if they—

(a) do not advise the Health Board if they are unable to attend an agreed appointment;

(b) decline to accept offers of appointment made by a Health Board.
Exceptions to the treatment time guarantee

4. For the purposes of section 7(3)(a) of the Act, the treatment time guarantee does not apply to the following treatments and services—

(a) assisted reproduction;
(b) obstetrics services;
(c) organ and tissue transplantation; and
(d) designated national specialist services for the surgical intervention of spinal scoliosis.

Health Board compliance with Treatment Time Guarantee

5.—(1) For the purposes of section 7(3)(b) of the Act, a Health Board must take all reasonably practicable steps to ensure that the patient’s treatment starts in accordance with the treatment time guarantee.

(2) Without prejudice to the generality of subsection (1), and notwithstanding any agreements which may be in place with another Health Board, where a Health Board is unable to meet the treatment time guarantee within its own area, it must use all reasonable endeavours to—

(a) arrange for the provision of the agreed treatment through another Health Board;
(b) arrange for the provision of the agreed treatment through the National Health Service in England, Wales or Northern Ireland;
(c) arrange for the provision of the agreed treatment in an EEA state or Switzerland other than the United Kingdom from an authorised provider; or
(d) arrange for the provision of the agreed treatment through the independent health care sector within the United Kingdom.

(3) For the purposes of paragraph (2), a Health Board in deciding whether to pursue option (a), (b), (c) or (d) must have regard to the importance of securing the effective and efficient use of the health service organisation and resources.

(4) Where a patient is treated outside the area of the responsible Health Board in accordance with an arrangement made under paragraph (2), without prejudice to the National Health Service (Travelling Expenses and Remission of Charges) (Scotland) (No. 2) Regulations 2003(\textsuperscript{3}) or any agreement which may exist between Health Boards, the responsible Health Board is responsible for the cost of any transport and accommodation arrangements necessarily and reasonably incurred as a result of any such arrangement.

Transfer to a different Health Board

6. For the purposes of section 7(3)(d) of the Act the responsibility for a treatment time guarantee transfers to a different Health Board in circumstances when a patient’s usual residence changes to a different Health Board area and that patient has requested to be treated in the new Health Board area.

Provision of information to patients

7.—(1) For the purposes of section 7(3)(e) of the Act, Health Boards must provide patients with clear and accurate information about—

(a) how maximum waiting time is calculated; and
(b) the circumstances in which the maximum waiting time may be extended, recalculated or suspended.

\textsuperscript{3} S.S.I. 2003/460, as amended by the National Health Service (Travelling Expenses and Remission of Charges) (Scotland) Amendment (No. 2) Regulations 2006 No. 183.
EXPLANATORY NOTE

(This note is not part of the Regulations)
The Scottish Ministers give the following Directions in exercise of the powers conferred by section 9(2) of the Patient Rights (Scotland) Act 2011 and all other powers enabling them to do so.

Citation, commencement and interpretation

1. (1) These directions may be cited as the Patient Rights (Treatment Time Guarantee) (Scotland) Directions 2011 and come into force on [        ].

Interpretation

(2) In these Directions-

“the 2011 Regulations” means the Patient Rights (Treatment Time Guarantee) (Scotland) Regulations 2011;

“the Act” means the Patient Rights (Scotland) Act 2011;

“the agreed treatment” means a specific treatment agreed between an eligible patient and the Health Board;

“eligible patient” means a patient of a description specified in regulation 2 of the 2011 Regulations;

“general medical practitioner” means a medical practitioner whose name is included in the General Practitioner Register kept by the General Medical Council;

“Health Board” includes the National Waiting Times Centre Board;

“treatment” means a surgical or medical intervention ordinarily provided by the Health Board (other than such treatments or services specified in regulation 4 of the 2011 Regulations);

Monitoring and recording the treatment time guarantee

2. (1) In pursuance of section 6(4)(a) of the Act, a Health Board must record the following:-

(a) the date on which the treatment is agreed between the patient and the Health Board;

(b) the date on which the patient’s agreed treatment starts;

(c) the dates when a patient is unavailable for treatment and the reason for that unavailability;

(d) when the treatment time guarantee is suspended in accordance with directions made under section 9(3) of the Act;
(e) the date on which a patient has contacted the Health Board in advance of an agreed appointment for the agreed treatment to advise that he or she is unable to attend the agreed appointment, and the reason for that unavailability;

(f) the date on which a patient has not attended an agreed appointment for the agreed treatment and has not advised the Health Board of this in advance of the appointment;

(g) when a patient declines to accept an offer of an appointment for the agreed treatment;

(h) when the responsibility for the agreed treatment has transferred to a different Health Board in accordance with regulation 6 of the 2011 Regulations.

(2) In circumstances where the treatment has been agreed between the patient and the Health Board, but the patient is unavailable for treatment, and there is no known end date to that unavailability, a Health Board must-

(i) record that information; and

(ii) ensure that the availability of the patient for the agreed treatment is reviewed within 13 weeks from when the treatment was agreed; and

(iii) record the outcome of that review.

Communications with patients

3. (1) In circumstances when-

(a) a patient has not attended an agreed appointment for the agreed treatment and has not advised the Health Board in advance of that appointment; and

(b) pursuant to regulation 3(5) of the 2011 Regulations, the Health Board has accordingly decided to refer the patient back to his or her general medical practitioner,

the Health Board must as soon as reasonably practicable notify in writing the relevant patient, that patient’s general medical practitioner and, where appropriate, that patient’s carer of that decision, and of the consequences of that decision for the calculation of that patient’s treatment time guarantee.

(2) Where a Health Board realises it is unable to meet the treatment time guarantee within its own area, it must as soon as reasonably practicable:-

(a) notify in writing the relevant patient and, where appropriate the patient’s carer; and

(b) seek the patient’s agreement for such treatment to be undertaken in another Health Board area, or where appropriate outwith the National Health Service in Scotland in pursuance of regulation 5(2) of the 2011 Regulations.

Form of communication

4. (1) Any communication which is required by these Directions to be made to a patient may be sent to the patient electronically where the patient-

(a) has consented to this in writing; and

(b) has not withdrawn such consent in writing.

Suspension of the treatment time guarantee: form of application

5. In the event that a Health Board considers that the treatment time guarantee should be suspended in its area in accordance with section 9(3) of the Act, the Health Board’s Chief Executive, or a person authorised by the Health Board to act on his or her behalf, must send a request in writing to the Scottish Ministers.
The Scottish Ministers make the following Regulations in exercise of the powers conferred by section 11(4)(a) of the Patient Rights (Scotland) Act 2011(1) and all other powers enabling them to do so.

PART 1

COMMENCEMENT AND INTERPRETATION

Citation, commencement and interpretation

1.—(1) These regulations may be cited as the Patient Rights (Complaints Procedure) (Scotland) Regulations 2011 and come into force on [ ].

(2) In these regulations—

“the Act” means the Patient Rights (Scotland) Act 2011;

“the 1978 Act” means the National Health Service (Scotland) Act 1978;

“the 2005 Directions” means the Directions to Health Boards, Special Health Boards and the Agency on Complaints Procedure which came into force on 1st April 2005;

“arrangements” means, unless the context otherwise requires, arrangements that are required and made under section 11 of the Act;

“child” means an individual who has not attained the age of 16;

“disciplinary proceedings” means—

(a) any procedure for disciplining employees adopted by any relevant NHS body;

(b) the investigation of matters relating to primary care services under the National Health Service (Tribunal) (Scotland) Regulations 2004(2) and the National Health Service (Discipline Committees) (Scotland) Regulations 2006(3);

“feedback and complaints manager” means the person appointed in accordance with regulation 2(3);

“feedback and complaints officer” means the person appointed under regulation 2(1);

“Healthcare Improvement Scotland” means the body established under section 10A of the 1978 Act;

(1) [footnote to be inserted].

(2) S.S.I. 2004/38.

(3) S.S.I. 2006/330.
“the PASS” means the patient advice and support service secured by the Agency under section 10ZA of the 1978 Act;

“relevant complaints procedure” means—

(a) any complaints procedure that may at any time be or have been required respectively by any of the following provisions—

(i) paragraphs 12 and 13 of Schedule 1 to the National Health Service (Pharmaceutical Services) (Scotland) Regulations 2009(1);

(ii) part 6 of Schedule 5 to the National Health Service (General Medical Services Contracts) (Scotland) Regulations 2004(2);

(iii) part 6 of Schedule 1 to the National Health Service (Primary Medical Services Section 17C Agreements) (Scotland) Regulations 2004(3);

(iv) paragraph 11 of Schedule 1 to the National Health Service (General Ophthalmic Services) (Scotland) Regulations 2006(4);

(v) paragraph 36 of Schedule 1 to the National Health Service (General Dental Services) (Scotland) Regulations 2010(5);

“responsible body” means a relevant NHS body and service provider;

“service provider” means any person who provides health services for the purposes of the health service under a contract, agreement or arrangements made under or by virtue of the 1978 Act;

“writing” includes any communication sent by electronic means if it is received in a form which is legible and capable of being used for subsequent reference.

PART 2

GENERAL

Feedback and Complaints Officer and Manager

2.—(1) For the purposes of the arrangements, each responsible body must appoint a feedback and complaints officer to manage the handling of complaints under the arrangements.

(2) The functions of the feedback and complaints officer may be performed personally or by a person authorised by the relevant responsible body to act on the feedback and complaints officer’s behalf.

(3) Each relevant NHS body must appoint a person, in these Regulations referred to as a feedback and complaints manager, to be responsible for ensuring compliance with the arrangements, and in particular ensuring that action is taken if necessary in the light of the outcome of a complaint.

(4) The functions of the feedback and complaints manager may be performed by the Chief Executive of the relevant NHS body or by a person authorised by the relevant NHS body to act on the Chief Executive’s behalf.

(1) S.S.I. 2009/183. Relevant amendments are made by paragraph 1 of the Schedule to these Regulations.

(2) S.S.I. 2004/115.


(4) S.S.I. 2006/135.

(5) S.S.I. 2010/208.
Persons who may make a complaint

3.—(1) A complaint may be made by—
   (a) a patient or former patient; or
   (b) any person who is affected or likely to be affected by the action, omission or decision of the responsible body which is the subject of the complaint.

(2) A complaint may be made by a person (in this regulation referred to as a representative) on behalf of a person mentioned in paragraph (1)—
   (a) with the consent of the person mentioned in paragraph (1);
   (b) where the person mentioned in paragraph (1) is a child and the responsible body is satisfied that there are reasonable grounds for the complaint being made by a representative instead of the child;
   (c) where the person is incapable of making a complaint.

(3) A representative of a child must be—
   (a) either parent, or in the absence of both parents, the guardian or other adult person who has care of the child;
   (b) a person duly authorised by the local authority, where the child is in the care of that local authority under the Children (Scotland) Act 1995(12);
   (c) a person duly authorised by a voluntary organisation by which the child is being accommodated under the provisions of that Act.

(4) For the purposes of regulation 2(b), where a responsible body is not satisfied that there are reasonable grounds for the complaint being made by a representative instead of the child, it must notify the representative in writing, and state the reason for its decision.

(5) Where a complaint is made by a representative, the views of the person on whose behalf the complaint is made, must be taken into account at all stages of the complaints process, in so far as it is reasonable and practicable to do so.

(6) This paragraph applies where—
   (a) a representative makes a complaint on behalf of—
      (i) a child;
      (ii) an adult who is incapable of making the complaint; and
   (b) the responsible body to which the complaint is made is satisfied that the representative is not conducting the complaint in the best interests of the person on whose behalf the complaint is made.

(7) Where paragraph (6) applies—
   (a) the complaint must not be considered or further considered under these Regulations;
   (b) the responsible body must notify the representative in writing, and state the reason for its decision.

(8) Where a person mentioned in paragraph (1) has died, a complaint may be made by a relative or other person who had an interest in their welfare or, where the person was as described in paragraph (3)(b) or (c), by the authority or voluntary organisation.

(9) In these Regulations any reference to a complainant includes a reference to a representative.

(12) 1995 (c.36).
Matters excluded from consideration under the arrangements

4.—(1) The following complaints are excluded from the scope of the arrangements—
   (a) a complaint made by a relevant NHS body which relates to any matter connected with the exercise by another relevant NHS body of its functions;
   (b) a complaint made by a service provider which relates either to any matter connected with the exercise of a relevant NHS body’s functions, or to the contract or arrangements under which the service provider provides health services;
   (c) a complaint made by an employee of a responsible body about any matter relating to the employee’s contract of employment;
   (d) a complaint which is being or has been investigated by the Scottish Public Services Ombudsman;
   (e) a complaint arising out of an alleged failure to comply with a request for information under the Freedom of Information (Scotland) Act 2002;\(^{(1)}\);
   (f) a complaint about which the complainant has stated in writing that the complainant intends to take legal proceedings; and
   (g) a complaint about which a relevant NHS body is taking or proposing to take disciplinary proceedings in relation to the substance of the complaint against the person who is the subject of the complaint;
   (h) a complaint which—
      (i) is made orally; and
      (ii) is resolved to the complainant’s satisfaction not later than the end of the next working day after the day on which the complaint is made;
   (i) a complaint the subject matter of which has previously been investigated under—
      (i) these Regulations;
      (ii) the 2005 Directions, in relation to a complaint made under those Directions prior to [ ]; or
      (iii) a relevant complaints procedure, in relation to a complaint made under such a procedure prior to [ ].

(2) Subject to paragraph (3), where a person makes or wants to make a complaint, which is or becomes a complaint excluded from the arrangements in terms of paragraph (1) and a responsible body makes a decision to that effect, the responsible body must as soon as reasonably practicable notify the complainant in writing—
   (a) that such a complaint is excluded from the scope of the arrangements; and
   (b) of the appropriate alternative procedures for making such a complaint.

(3) Paragraph (2) does not apply to a complaint specified in sub-paragraph (h) of paragraph (1).

(4) Where a complaint which is a complaint excluded from the arrangements in terms of paragraph (1) is part of, or is connected with, another complaint which is not so excluded, nothing in this regulation prevents that other complaint being handled in accordance with the arrangements.

PART 3
DEALING WITH COMPLAINTS

Requirement to deal with complaints

5.—(1) Subject to regulation 4, a complaint must be dealt with in accordance with the arrangements if it is made—
   (a) orally or in writing to the responsible body;
   (b) within the period specified in regulation 6; and

\(^{(1)}\) 2002 asp 13.
(c) by a person specified in regulation 3.

(2) Where a complaint is made in accordance with paragraph (1), the responsible body must—

(a) make a written record of the complaint;

(b) provide the complainant with a written acknowledgement of the complaint, within 3 working days of the date on which the complaint was made.

(3) In the case of a complaint made to a service provider in accordance with paragraph (1), the service provider must inform the appropriate Health Board of the complaint within 10 working days of receipt of the complaint.

Period for making a complaint

6.—(1) Subject to paragraph (2) the period for making a complaint is—

(a) six months from the date on which the matter which is the subject of the complaint occurred; or

(b) six months from the date on which the matter which is the subject of the complaint comes to the complainants notice, provided that the complaint is made no later than twelve months after the date on which the matter which is the subject of the complaint occurred.

(2) Where the complaint is not made during the period specified in paragraph (1) it is to be referred to the feedback and complaints officer and if that officer is of the opinion that—

(a) having regard to all the circumstances of the case, it would have been unreasonable to expect the complainant to make the complaint within that period; and

(b) notwithstanding that time has elapsed since the date on which the matter which is the subject of the complaint occurred, it is still possible to investigate the complaint properly,

the complaint must be treated as though it had been received during the period specified in paragraph (1).

Investigation and result of a complaint

7.—(1) A responsible body to which a complaint is made must—

(a) investigate the complaint in a manner appropriate to resolve it timeously and efficiently;

(b) where appropriate ensure that those persons who were involved in the matter which is the subject of the complaint are given the opportunity to comment on the complaint; and

(c) during the investigation, keep the complainant and persons who were involved in the matter which is the subject of the complaint informed, as far as is appropriate and reasonably practicable, as to the progress of the investigation.

(2) A report of the investigation must be sent to the complainant in writing within 20 working days of the date on which the complaint was made or, where that is not possible, as soon as reasonably practicable.

Form of communications

8. Any communication which is required by these Regulations to be made to a complainant may be sent to the complainant electronically where the complainant—

(a) has consented to this in writing; and

(b) has not withdrawn such consent in writing.

PART 4

TRANSITIONAL, SAVING OR CONSEQUENTIAL PROVISIONS

Transitional provision in respect of former complaints

9.—(1) Where prior to [   ], a complaint has been made in accordance with any former complaints legislation, it must be investigated, or in an appropriate case continue to be investigated, in accordance with those provisions.
(2) Where, following [   ], a complainant requests a review of a complaint which was dealt with before that date, it must be investigated in accordance with former complaints legislation.

(3) In this regulation, “former complaints legislation” means the Hospital Complaints Procedure Act 1985 and the 2005 Directions.

(4) The Schedule (consequential provisions) has effect.

[   ],
[   ]
2010
SCHEDULE 1

CONSEQUENTIAL PROVISIONS

10. Amendment of the National Health Service (General Medical Services Contracts) (Scotland) Regulations 2004.

[     ]

11. Amendment of the National Health Service (Primary Medical Services Section 17C Agreements) (Scotland) Regulations 2004.

[     ]

12. Amendment of the National Health Service (General Ophthalmic Services) (Scotland) Regulations 2006.

[     ]

13. Amendment of the National Health Service (Discipline Committees) (Scotland) Regulations 2006.

[     ]

14. Amendment of the National Health Service (Pharmaceutical Services) (Scotland) Regulations 2009.

[     ]

15. Amendment of the National Health Service (General Dental Services) (Scotland) Regulations 2010.

[     ]
EXPLANATORY NOTE
(This note is not part of the Regulations)
The Scottish Ministers give the following Directions in exercise of the powers conferred on them by sections 11(4)(b) and 12(5) of the Patient Rights (Scotland) Act 2011 and all other powers enabling them to do so.

PART 1

COMMENCEMENT AND INTERPRETATION

Commencement

1. These Directions come into force on XXXXX.

Interpretation

2. In these Directions –

“the Act” means the Patient Rights (Scotland) Act 2011;

“the 1978 Act” means the National Health Service (Scotland) Act 1978;

‘the Agency’ means the Common Services Agency for the Scottish Health Service;

“arrangements” means, unless the context otherwise requires, arrangements that are required to be made by section 11 of the Act;

“complainant” means a person who makes a complaint under the arrangements;

“feedback and complaints officer” means the person appointed under regulation 2(1) of the Regulations

“Healthcare Improvement Scotland” means the body established under section 10A of the 1978 Act;

“relevant NHS body” means a Health Board, Special Health Board and the Agency;

“person who is the subject of the complaint” means any person who –

(a) is identified in the complaint as the person against whom the complaint is brought;
(b) where the complaint does not identify a named person against whom the complaint is brought, a person who, in the opinion of the feedback and complaints officer is best able to deal with the matter that is the subject of the complaint; or

(c) in the case of a complaint about the provision of services by a service provider, the service provider;

“the Regulations” means the Patient Rights (Complaints Procedure) (Scotland) Regulations 2011;

“the PASS” means the patient advice and support service secured by the Agency under section 10ZA of the 1978 Act;

“responsible body” means a relevant NHS body and service provider;

“service provider” means any person who provides health services for the purposes of the health service under a contract, agreement or arrangements made under or by virtue of the 1978 Act;

“SPSO” means the Scottish Public Services Ombudsman;

“writing” includes any communication sent by electronic means if it is received in a form which is legible and capable of being used for subsequent reference.

PART 2

GENERAL

Arrangements in writing

3. Each relevant NHS body must make information available in writing as to the arrangements for dealing with complaints to any person who requests such information.

Objectives of the arrangements

4. Each relevant NHS body must ensure that when a complaint is made under the arrangements, the complainant is treated in a courteous and sympathetic manner by any person dealing with complaints.

Encouraging patients to raise concerns or give feedback

5.- (1) Each relevant NHS body must encourage patients to raise concerns or give feedback on the healthcare they have received.

(2) Where appropriate, each relevant NHS body must have regard to other sources of patient feedback, other than those identified in section 12(2) of the Act.

Staff training and empowerment

6. Each relevant NHS body must ensure that staff who deal with feedback and complaints under the arrangements:

(a) receive training to deal with such feedback and complaints;
(b) are issued with guidance on how to deal effectively with such feedback and complaints;
(c) are aware of the advice and support available to patients or their representatives, specifically
the feedback and complaints officer and the PASS.

PART 3

DEALING WITH COMPLAINTS

Requirement to deal with complaints

7. Pursuant to regulation 5(2) of the Regulations-

(a) a written record of the complaint must specify –

   (i) the patient’s name and where known the patient’s Community Health Index number;
   (ii) the name of the complainant and the relationship to the patient where they are not the
       same person;
   (iii) the date when the complaint was made;
   (iv) the date on which the matter which is the subject of the complaint occurred;
   (v) the subject matter of the complaint,

(b) a written acknowledgement of the complaint must include the following information-

   (i) details of the advice and support available to the complainant including the PASS;
   (ii) a statement confirming that the complainant will-
       (a) be informed of the results of the investigation within 20 working days of the date
           on which the complaint was made; and
       (b) in the event that the timescale in paragraph (a) cannot be met, be notified and
           provided with a revised timetable and an explanation as to why there is a delay.

Investigation and result of a complaint

8.- (1) The report of the investigation referred to in regulation 7(2) of the Regulations must

   (a) an explanation of how the complaint has been considered;
   (b) the conclusions of the investigation, including any areas of disagreement;
   (c) the contact details of the SPSO
   (d) the contact details of the feedback ad complaints officer;
   (e) the contact details of the relevant PASS;
   (f) confirmation as to whether the responsible body considers that any remedial action is
       needed in consequence of the complaint;
   (g) an explanation of any remedial action which has or will be taken.

(2) Where a complaint is made to a relevant NHS body, the report referred to in regulation 7(2)
of the Regulations must be signed by the Chief Executive of the relevant NHS body, or where that
is not possible, by a person authorised by the relevant NHS body to act on the Chief Executive’s
behalf.
(3) The responsible body must provide any person who is the subject of the complaint with feedback following resolution of the complaint.

Form of communication

9.- (1) When investigating a complaint pursuant to the arrangements, each relevant NHS body must ascertain the complainant’s preferred method of communication and where reasonably practicable and in keeping with patient confidentiality, communicate with the patient by this means.

(2) Any communication which is required by these Directions to be made to a complainant may be sent to the complainant electronically where the complainant –

(a) has consented to this in writing; and
(b) has not withdrawn such consent in writing.

PART 4

MONITORING AND PUBLICITY

Monitoring

10.- (1) Each relevant NHS body must:-

(a) prepare reports every 3 months;
(b) ensure that each of its service providers prepare reports every 3 months,

for the purposes of monitoring the arrangements.

(2) The reports referred to in paragraph (1) must specify –

(a) each complaint received;
(b) the subject matter and outcome of each complaint;
(c) the number of complaints where mediation services were used;
(d) whether the response period specified in regulation 7(2) of the regulations was complied with;
(e) the remedial action which has been taken as a result of the complaint.

(3) In the case of a report prepared pursuant to direction 10(1)(b), the relevant Health Board must ensure that the service provider sends the report to the Health Board with whom the service provider has a contract, agreement or arrangements to provide health services (“the relevant Health Board”), as soon as reasonably practicable after the end of the three month period to which the report relates.

(4) After having received a report referred to in paragraph (3), the relevant Health Board must –

(a) review the report and identify any area of concern;
(b) as part of its annual report referred to at 11(1) of these Directions, summarise the reports received throughout the year by virtue of paragraph (3).

Annual reports
11.- (1) Each relevant NHS body must publish an annual report for each year which must-

(a) specify the number of complaints which the relevant NHS body has received;
(b) specify the number of complaints where mediation services were used;
(c) specify whether the response period specified in regulation 7(2) of the Regulations has been complied with;
(d) summarise –
   (i) the subject matter of complaints that the relevant NHS body has received;
   (ii) the way in which complaints were handled;
   (iii) any matters of general importance arising out of those complaints;
   (iv) what action has been or is to be taken to improve services as a consequence of the complaints.

(2) In paragraph (1), ‘year’ means a period of 12 months ending with 31st March.

(3) Each relevant NHS body must ensure that its annual report is available to any person on request.

(4) The annual report referred to in paragraph (1) must be sent to –

(a) the Scottish Ministers;
(b) the relevant PASS: and
(c) Healthcare Improvement Scotland,
as soon as is reasonably practicable after the end of the year to which the report relates.

Publicity

12.- (1) Each relevant NHS body must ensure that the persons listed in paragraph (2) are informed of –

(a) the arrangements;
(b) the name of the feedback and complaints officer;
(c) the postal and email address for the feedback and complaints officer;
(d) the details of the advice and support which is available to patients, including the PASS.

(2) The persons referred to in paragraph (1) are –

(a) patients and carers;
(b) staff of the responsible body;
(c) persons exercising functions of the responsible body under a contract or other arrangement with it;
(d) in the case of a Health Board –
   (i) service providers with whom they have made contracts or arrangements for the provision of health services;
   (ii) the relevant PASS for the Health Board area;
(e) in the case of a service provider –
   (i) the Health Board whose area includes any part of the area of the service provider;
(ii) the relevant PASS for the area of the service provider

Consideration by senior management

13. Senior management of the relevant NHS body must review, at least twice a year, with a view to identifying areas of concern, agreeing remedial action and improving the exercise of the relevant NHS body’s functions:

(a) the reports referred to at 10(1) and 11(1) of these Directions;
(b) feedback received from patients, carers or members of the public; and
(c) recommendations made by the SPSO where appropriate.

PART 5

MEDIATION

[Under consideration]

PART 6

REVOCATIONS

The Patient Rights (Scotland) Bill - The Patient Advice and Support Service (PASS)  
(Submitted August 2010)

The Scottish Government may issue Regulations about the Patient Advice and Support Service, in particular about the service it is to provide, in accordance with Section 15(6) of the Patient Rights (Scotland) Bill. The Government is considering what should be set out in Regulations and what will be set out in the contract specification between the NHS’s Common Services Agency and PASS. The information below therefore sets out how it is anticipated the PASS will operate.

Who can use Patient Advice and Support Service (PASS) – that the service is available to patients, carers, users of NHS services and members of the public (including children).

Geographic coverage – that the service is to be accessible across Scotland including to those living in remote and rural areas.

Cost – that the PASS will be provided free at the point of delivery.

Function of PASS – the Patient Rights (Scotland) Bill states that PASS will help patients and members of the public raise concerns, make a complaint or raise feedback about their healthcare. PASS will also make patients and members of the public aware of their rights and responsibilities when using the NHS. The PASS will not give legal or clinical advice on healthcare issues, investigate complaints, assist with complaints about private healthcare services (except where these have been purchased by the NHS but are provided by an independent sector organisation) or support a patient/ carer/ relative to attend a Fatal Accident Inquiry.

Patient Rights Officers (PRO) – there must be at least one PRO per health Board and they will provide support and advice to any member of the public (see ‘Who can use PASS’) regardless of which Health Board they reside in or are receiving care in.

Staff Training – that PROs should be suitably trained in order to carry out their functions effectively, that training should take account of the needs of the service users and the support and advice they might require e.g. mental health, gender, sexual orientation, and long-term care.

Monitoring and Evaluation – that there will be monitoring and evaluation of the PASS.

Reporting to Health Boards – that the PASS will report on its activities.

Role of responsible bodies – that Health Boards and service providers will make service users aware of the PASS.
Marshalled List of Amendments for Stage 2

The Bill will be considered in the following order—

Sections 1 to 4  Schedule
Sections 5 to 22  Long Title

Amendments marked * are new (including manuscript amendments) or have been altered.

Before section 1

Dr Richard Simpson

19  Before section 1, insert—

<Patient Rights Charter

(Patient Rights Charter

(1) The Scottish Ministers must make an order containing a charter of rights and responsibilities to be conferred upon patients, to be known as the Patient Rights Charter, (“the Charter”).

(2) The Charter, as contained within an order under subsection (1), must, subject to subsection (3), include all existing statutory rights and responsibilities conferred upon patients and may also confer new rights and responsibilities upon patients.

(3) The Charter must not include rights and responsibilities in relation to specific treatments or medicines and subsection (1) does not enable the Scottish Ministers to confer such rights and responsibilities upon patients.

(4) The rights and responsibilities contained within the Charter are to apply to all patients of relevant NHS bodies, but may also include rights and responsibilities to apply to specific groups of patients only.

(5) The Scottish Ministers must—
   (a) from time to time review the Charter, and
   (b) when they consider it appropriate to do so, make an order containing revisions to the Charter or a revised Charter.

(6) Before making an order under subsection (1) or subsection (5)(b), the Scottish Ministers must consult such persons as they consider appropriate.>

Section 1

Dr Richard Simpson

20  In section 1, page 1, line 16, at end insert <, taking all reasonable steps to ensure that the patient is supplied with information and support in a form that is appropriate to the patient’s needs.>
Dr Richard Simpson

21 In section 1, page 1, line 16, at end insert—

<have regard to and respect for the rights and responsibilities conferred on patients by the Charter to be made by the Scottish Ministers under section (Patient rights charter)(1).>

Dr Richard Simpson

22 In section 1, page 1, line 17, leave out from <make> to <feedback> in line 18 and insert <give feedback or comments, or raises concerns or complaints>

Section 3

Mary Scanlon

23 In section 3, page 2, line 5, leave out <have regard to> and insert <uphold>

Dr Richard Simpson

24 In section 3, page 2, line 5, after <principles> insert <and the charter>

Mary Scanlon

25 In section 3, page 2, line 8, leave out <has regard to> and insert <upholds>

Dr Richard Simpson

26 In section 3, page 2, line 8, after <principles> insert <and the charter>

Mary Scanlon

27 In section 3, page 2, line 19, leave out <have regard to> and insert <uphold>

Schedule

Dr Richard Simpson

28 In the schedule, page 10, line 15, at end insert—

<Health care is provided in such a way as to avoid unnecessary harm or injury to the patient.>

Patients are cared for in an appropriate, clean and safe environment at all times.>

Dr Richard Simpson

29 In the schedule, page 10, line 18, after <wellbeing> insert <, including sharing accurate information and agreeing actions required from joint decisions>

Dr Richard Simpson

30 In the schedule, page 10, line 20, after <participate> insert <and take action>
Dr Richard Simpson

31 In the schedule, page 10, line 22, leave out <encouraged> and insert <expected>

Dr Richard Simpson

32 In the schedule, page 10, line 23, after <respect> insert <and to engage with the health bodies in a responsible manner>

Dr Richard Simpson

33 In the schedule, page 10, line 31, at end insert—

<Systems are in place for patients to provide feedback, make a comment, raise a concern or make a complaint about their experience of health care in order to improve quality. Patients are provided with feedback in response to any comment, concern or complaint they make.>

Section 5

Dr Richard Simpson

34 In section 5, page 2, line 21, after <principles> insert <and the charter>

Dr Richard Simpson

35 In section 5, page 2, line 22, after <principles> insert <and the charter>

Dr Richard Simpson

36 In section 5, page 2, line 25, after <principles> insert <and the charter>

Section 6

Nicola Sturgeon

1 In section 6, page 2, line 36, at end insert—

<( ) appropriately prioritising the start of the patient’s agreed treatment taking account of the patient’s clinical needs and the clinical needs of other eligible patients awaiting agreed treatments in accordance with the treatment time guarantee,>

Dr Richard Simpson

37 Leave out section 6 and insert—

<Patient guarantee>

(1) In pursuance of the right conferred by section 1(1), a patient is to—

(a) be offered a first appointment of the kind requested by the patient’s general practitioner in accordance with subsection (2),
be offered such appointments as are necessary for the carrying out of diagnostic tests in accordance with subsection (2), and
(c) start to receive treatment within the maximum waiting time specified for the purposes of this paragraph.

(2) An appointment is offered in accordance with this subsection if the date of the appointment falls within the maximum waiting time specified for the purposes of subsection (1)(a) or, as the case may be, (b).

(3) A maximum waiting time specified for the purposes of subsection (1)(c) must be expressed as a maximum waiting time from the time of referral by the patient’s general practitioner.

(4) A guarantee described in subsection (1) is to be known as a patient guarantee.

(5) A Health Board must take all reasonably practicable steps to ensure that it complies with a patient guarantee.

(6) Those steps include in particular, steps for—
(a) monitoring each patient guarantee,
(b) making such arrangements as are necessary to enable a patient guarantee to be met either—
(i) within its own area, or
(ii) if it is unable (or anticipates that it will be unable) to make those arrangements in its own area, through another Health Board or a suitable alternative provider of treatment.

(7) Before making an order under this section, the Scottish Ministers must consult such persons as they consider appropriate.

(8) A Health Board may offer a patient a guarantee—
(a) of a shorter waiting time in relation to the matters mentioned in subsection (1) than the maximum waiting time specified by virtue of subsections (1) and (2),
(b) in relation to a waiting time in connection with matters other than those mentioned in subsection (1).

(9) In this section, “specified” means specified in an order made by the Scottish Ministers.

Section 7

Dr Richard Simpson
38 In section 7, page 3, line 9, leave out <treatment time> and insert <patient>

Dr Richard Simpson
39 In section 7, page 3, leave out lines 11 and 12

Dr Richard Simpson
40 In section 7, page 3, line 17, leave out <treatment time> and insert <patient>
Dr Richard Simpson
41 In section 7, page 3, line 22, leave out <treatment time> and insert <patient>

Dr Richard Simpson
42 In section 7, page 3, line 24, leave out <treatment time> and insert <patient>

Dr Richard Simpson
43 In section 7, page 3, leave out subsection (4)

Section 8

Dr Richard Simpson
44 In section 8, page 3, line 36, leave out <treatment time> and insert <patient>

Dr Richard Simpson
45 In section 8, page 3, line 39, leave out from <agreed> to end of line 40 and insert <patient guarantee is met as soon as is reasonably practicable.>

Dr Richard Simpson
46 In section 8, page 4, line 1, leave out from <treatment> to end of line 2 and insert <patient guarantee was not met,>

Dr Richard Simpson
47 In section 8, page 4, leave out line 6 and insert—

<( ) how to give feedback or comments or raise concerns or complaints.>

Dr Richard Simpson
48 In section 8, page 4, line 8, leave out <the start of any treatment> and insert <a patient guarantee>

Dr Richard Simpson
49 In section 8, page 4, line 10, leave out <for treatment>

Dr Richard Simpson
50 In section 8, page 4, line 11, leave out from <and> to end of line 12

Section 9

Dr Richard Simpson
51 In section 9, page 4, line 14, leave out from <when> to <time> in line 16 and insert <in meeting a patient guarantee, have regard to any guidance issued by the Scottish Ministers which relates to the guarantee.>
Mary Scanlon
52 In section 9, page 4, line 14, leave out <have regard to> and insert <comply with>

Dr Richard Simpson
53 In section 9, page 4, line 18, leave out <treatment time> and insert <patient>

Dr Richard Simpson
54 In section 9, page 4, line 20, leave out <treatment time> and insert <patient>

Section 10

Dr Richard Simpson
55 In section 10, page 4, leave out lines 24 to 28

Dr Richard Simpson
56 In section 10, page 4, leave out lines 30 and 31

Dr Richard Simpson
57 In section 10, page 4, line 31, at end insert—
   <“patient guarantee” has the meaning given in section (Patient guarantee)(1)>;

Dr Richard Simpson
58 In section 10, page 4, leave out line 35

Section 11

Dr Richard Simpson
59 In section 11, page 5, line 4, leave out <complaints> and insert <and responding to feedback, comments, concerns or complaints on health care>

Dr Richard Simpson
60 In section 11, page 5, line 7, at end insert—
   <( ) identifying best practice,>

Dr Richard Simpson
61 In section 11, page 5, line 8, after <how> insert <feedback and comments are to be given, or concerns and>

Dr Richard Simpson
62 In section 11, page 5, line 9, leave out <makes a complaint> insert <gives feedback or comments, or raises concerns or complaints>
Dr Richard Simpson
63 In section 11, page 5, line 13, after <the> insert <feedback, comments, concerns or>

Nicola Sturgeon
2 In section 11, page 5, line 20, at end insert—

<( ) Directions under subsection (4)(b) may, in particular, include provision for the resolution of complaints by conciliation or mediation.>

Dr Richard Simpson
64 Move section 11 to after section 12

Section 12

Dr Richard Simpson
65 In section 12, page 5, line 29, leave out <raise any concerns or give feedback> and insert <provide feedback, comments, concerns or complaints>

Dr Richard Simpson
66 In section 12, page 5, line 31, leave out from <raise> to end of line 33 and insert <provide such feedback, comments, concerns or complaints to—

(a) the relevant NHS body,

(b) a member of the relevant NHS body as nominated by that body, or

(c) the patient advice and support service.>

Dr Richard Simpson
67 In section 12, page 5, line 34, leave out from first <a> to <feedback> in line 35 and insert <feedback, comments, concerns or complaints are given to a member of staff of the relevant NHS body as nominated by that body or the patient advice and support service, the member of staff or patient advice and support service may pass the information>

Dr Richard Simpson
68 In section 12, page 5, line 37, leave out <all concerns raised and feedback> and insert <feedback, comments, concerns or complaints>

Dr Richard Simpson
69 In section 12, page 5, line 38, at end insert—

<( ) Where feedback, comments, concerns or complaints are given to a member of staff of the relevant NHS body as nominated by that body or the patient advice and support service, the member of staff or patient advice and support service must report back to the relevant NHS body and the patient concerned.>
Dr Richard Simpson
70 In section 12, page 5, line 38, at end insert—

<( ) The Scottish Ministers may require a relevant NHS body to provide them with information regarding the performance of the duties under subsections (1) and (4).>

Section 14

Dr Richard Simpson
71 In section 14, page 6, leave out line 17 and insert—

<( ) The patient advice and support service may be provided by Citizens Advice Bureaux or any other such source of independent advice and information.>

Section 15

Dr Richard Simpson
72 In section 15, page 7, line 7, leave out subsection (3)

Section 16

Dr Richard Simpson
73 Leave out section 16

Section 17

Nicola Sturgeon
3 In section 17, page 8, line 1, after <as> insert <providers of>

Nicola Sturgeon
4 In section 17, page 8, line 3, leave out from beginning to <body> and insert <The Agency must secure that providers of the patient advice and support service give relevant bodies>

Nicola Sturgeon
5 In section 17, page 8, line 5, leave out <it provides> and insert <providers of the patient advice and support service provide>

Nicola Sturgeon
6 In section 17, page 8, line 6, leave out <the relevant body> and insert <relevant bodies>
After section 17

Dr Richard Simpson

74 After section 17, insert—

<No-fault compensation scheme in relation to patient rights

No-fault compensation scheme in relation to patient rights

(1) The Scottish Ministers must by regulations establish a scheme for the purpose of enabling compensation to be provided to patients of NHS bodies, where such patients consider that their rights under this Act have not been met or have been breached, without recourse to civil proceedings.

(2) Regulations under subsection (1) must include—

(a) the circumstances in which the scheme would apply,
(b) the grounds on which patients would be eligible for the scheme,
(c) the grounds for membership of the scheme on the part of any body or other person to whose liability the scheme applies,
(d) the form proceedings under the scheme would take,
(e) the forms of compensation to be made available,
(f) where financial compensation is to be given to a patient, the upper limit for that compensation, and
(g) the assistance to be made available to patients seeking compensation under the scheme.

(3) The scheme applies only in relation to patient rights under this Act and does not extend to other matters in which a patient considers that there has been negligence on the part of an NHS body.>

Section 18

Nicola Sturgeon

7 In section 18, page 8, line 15, at end insert—

<(1A) Subject to subsection (2), nothing in this Act prejudices>

Dr Richard Simpson

75 In section 18, page 8, line 17, after <Act> insert <, with the exception of section (No-fault compensation scheme in relation to patient rights).>

Nicola Sturgeon

8 In section 18, page 8, line 19, at end insert—

<( ) any right of action for specific performance of a statutory duty,>
Nicola Sturgeon
9 In section 18, page 8, line 21, at end insert—

<(3) The rights conferred on a patient by this Act are in addition to, and do not affect, any other rights in relation to health care that a patient has, or may acquire, under any other enactment or rule of law.

(4) Subsection (3) does not affect the generality of subsection (1A).>

After section 18

Nicola Sturgeon
10 After section 18, insert—

<Inquiries and default and emergency powers

Powers of the Scottish Ministers

(1) In sections 76, 77, 78 and 78A of the 1978 Act (inquiries and default and emergency powers) references to that Act include references to this Act.

(2) Section 77 of the 1978 Act applies to a Special Health Board in relation to the functions conferred or imposed on it by or under this Act.>

Section 19

Dr Richard Simpson
76 In section 19, page 8, line 26, at end insert—

<“feedback” means appreciation by the patient of the service provided by the relevant NHS body,>

Dr Richard Simpson
77 In section 19, page 8, line 32, at end insert—

<“patient” means a patient who is in receipt of treatment provided by the relevant NHS body,>

Section 21

Nicola Sturgeon
11 In section 21, page 9, line 13, at beginning insert <except an order under section 22(3),>

Nicola Sturgeon
12 In section 21, page 9, line 16, leave out <order is to be made under>

Nicola Sturgeon
13 In section 21, page 9, line 17, at beginning insert <order is to be made under>
Dr Richard Simpson

78* In section 21, page 9, line 17, leave out <or 4(2)> and insert <, (Patient rights charter)(1) and (4)(b), 4(2) or (Patient guarantee)(1)>

Nicola Sturgeon

14 In section 21, page 9, line 17, leave out from first <or> to end and insert <, 4(2) or 7(4).>

Nicola Sturgeon

15 In section 21, page 9, line 17, at end insert—

<(  ) regulations are to be made under section 7(1) or (3), or>

Dr Richard Simpson

15A As an amendment to amendment 15, line 2, leave out <section> and insert <sections (No-fault compensation scheme in relation to patient rights)(1),>

Nicola Sturgeon

16 In section 21, page 9, line 18, at beginning insert <order is to be made under>

Nicola Sturgeon

17 In section 21, page 9, line 20, leave out <order> and insert <statutory instrument containing the order or regulations>

Section 22

Nicola Sturgeon

18 In section 22, page 9, line 36, leave out from <and> to end of line 37
Correction Slip to the Marshalled List of Amendments for Stage 2

The text of the following amendment is incorrect in the Marshalled List of Amendments for Stage 2. The wording of the amendment should be as below, which is the same as the text of the amendment which appeared on the Daily List of Amendments to Bills lodged on 1 December (published in the Business Bulletin for Thursday 2 December). The amendment appears on page 5 of the Marshalled List of Amendments for Stage 2.

Section 9

Dr Richard Simpson

51 In section 9, page 4, line 14, leave out from <when> to <time> in line 16 and insert <in meeting a patient guarantee, have regard to any guidance issued by the Scottish Ministers which relates to the>
Groupings of Amendments for Stage 2

This document provides procedural information which will assist in preparing for and following proceedings on the above Bill. The information provided is as follows:

- the list of groupings (that is, the order in which amendments will be debated). Any procedural points relevant to each group are noted;
- the text of amendments to be debated during stage 2, set out in the order in which they will be debated. THIS LIST DOES NOT REPLACE THE MARSHALLED LIST, WHICH SETS OUT THE AMENDMENTS IN THE ORDER IN WHICH THEY WILL BE DISPOSED OF.

Groupings of amendments

**Patient Rights Charter**
19, 21, 24, 26, 34, 35, 36

**Health care: provision of information and support in an accessible form**
20

**Rights of patients to give feedback or comments, or raise concerns and complaints and the handling of them**
22, 47, 59, 60, 61, 62, 63, 2, 64, 65, 66, 67, 68, 69, 70, 76

**Duties on relevant NHS bodies**
23, 25, 27, 52

**Health care principles**
28, 29, 30, 31, 32, 33

**Treatment time guarantee**
1

**Patient guarantee**
37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 48, 49, 50, 51, 53, 54, 55, 56, 57, 58, 77

*Notes on amendments in this group*
Amendment 51 pre-empts amendment 52 in group *Duties on relevant NHS bodies*

**Patient advice and support service**
71, 72, 73

**Duties to share information with the providers of the patient advice and support service**
3, 4, 5, 6

**No-fault compensation scheme**
74, 75, 15A

SP Bill 42-G  Session 3 (2010)
Protections and limitations
7, 8, 9

Inquiries and default and emergency powers
10

Orders, regulations and directions
11, 12, 13, 78, 14, 15, 16, 17, 18
HEALTH AND SPORT COMMITTEE

EXTRACT FROM THE MINUTES

37th Meeting, 2011 (Session 3)

Tuesday 14 December 2010

Present:

Helen Eadie
Christine Grahame (Convener)
Mr Frank McAveety (Committee Substitute)
Mary Scanlon

Ross Finnie (Deputy Convener)
Michael Matheson
Ian McKee
Dr Richard Simpson

Also present: Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP

Apologies were received from Rhoda Grant.

Patient Rights (Scotland) Bill: The Committee considered the Bill at Stage 2.

The following amendments were agreed to (without division): 20, 22, 23, 25, 1, 47, 59, 60, 61, 62, 63, 2, 64, 65, 68, 70, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17 and 18.

The following amendments were agreed to (by division)—

19 (For 5; Against 3; Abstentions 0);
21 (For 5; Against 3; Abstentions 0);
24 (For 5; Against 3; Abstentions 0);
26 (For 5; Against 3; Abstentions 0);
28 (For 5; Against 3; Abstentions 0);
34 (For 5; Against 3; Abstentions 0);
35 (For 5; Against 3; Abstentions 0);
36 (For 5; Against 3; Abstentions 0);
72 (For 5; Against 3; Abstentions 0);
73 (For 5; Against 3; Abstentions 0).

The following amendments were disagreed to (by division)—

31 (For 3, Against 5, Abstentions 0);
66 (For 4, Against 4, Abstentions 0; amendment disagreed to on casting vote);
67 (For 4, Against 4, Abstentions 0; amendment disagreed to on casting vote);
69 (For 4, Against 4, Abstentions 0; amendment disagreed to on casting vote);
76 (For 4, Against 4, Abstentions 0; amendment disagreed to on casting vote).
The following amendments were moved and, with the agreement of the Committee, withdrawn: 37, 71 and 74.

The following amendments were not moved: 27, 29, 30, 32, 33, 38, 39, 40, 41, 42, 43, 44, 45, 46, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 75, 77, 78 and 15A.

Sections 2, 4, 7, 9, 10, 13, 14, 19 and 20, and the long title were agreed to without amendment.

Sections 1 and 3, the schedule, sections 5, 6, 8, 11, 12, 15, 17, 18, 21 and 22 were agreed to as amended.

The Committee completed Stage 2 consideration of the Bill.
Scottish Parliament

Health and Sport Committee

Tuesday 14 December 2010

[The Convener opened the meeting at 15:02]

Patient Rights (Scotland) Bill:
Stage 2

The Convener (Christine Grahame): Welcome to the 37th meeting this session of the Health and Sport Committee. I remind everyone to switch off mobile phones and electronic equipment. Apologies have been received from Rhoda Grant. I welcome Frank McAveety, who is substituting for her today.

We have only one item on the agenda: day 1 of stage 2 of the Patient Rights (Scotland) Bill. Members have before them the marshalled list of amendments and the groupings of amendments for debate. I welcome the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon.

Before we move on to consider the amendments, I state that it is my intention to get through all the groups of amendments and to complete stage 2 today. Brevity and succinct submissions would be welcome; I know that members are all up for that. If we do not complete stage 2 today, we will have to have a double sitting at a later date. That is the stick; you have had the carrot.

Before section 1

The Convener: Amendment 19, in the name of Richard Simpson, is grouped with amendments 21, 24, 26 and 34 to 36.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): A paradox that emerged both in the responses to the Government’s consultation and in the evidence that was given to the committee was that, although, like the committee, all the respondents concurred in the belief that patient rights are of great importance, many questioned the need for primary legislation. Those who questioned the need for primary legislation came close to opposing it—on the ground that it is unnecessary. Patient organisations, on the other hand, were more supportive but were concerned that the bill is inflexible and exclusive—for example, the lack of any mention of mental ill health was a particular concern.

Other organisations, such as the Law Society of Scotland and the General Medical Council, expressed concerns about the possibility that omitting many of the rights that patients currently enjoy through existing legislation in statute or common law, or through common practice in the national health service, would mean that the rights that are specified in the bill would, in some way, have primacy. Paragraphs 42 to 44 of the committee’s stage 1 report referred to some of the 17 such rights that were evidenced to us by the Law Society.

As my colleague Ross Finnie has quoted at some length, I was frequently critical of the bill in my questioning of witnesses. Indeed, I remain sceptical of the Government’s suggestion that primary legislation is needed to raise awareness or, as the Royal National Institute of Blind People Scotland said to us, to change practice. However, I share the Government’s desire to attempt to place in law patients’ rights, and this first amendment is one of a large number that attempt to build on the Government’s initial work in the bill.

Amendments 19, 21, 24, 26, 34, 35 and 36 will, if passed, make it a requirement for the minister to publish a charter of rights. That would parallel the English approach and it would benefit from some read-across to that charter. Such a charter would build on the work that was done initially by the Conservative party and subsequently by the Labour and Lib-Dem Administration in its charter. It would be flexible and should be inclusive of other conferred rights. If it is backed by political leadership, it should help to raise awareness and change the culture.

I move amendment 19.

Ross Finnie (West of Scotland) (LD): I made it clear at stage 1 that I was unpersuaded of the need for primary legislation, and I suppose that remains my view. However, the Parliament has passed the bill to stage 2, so it is incumbent upon us to look constructively at suggestions that are being made. Although I am not sure of the need for primary legislation, if the view remains that we require it, I believe that the lot of patients would be hugely improved by a document that set out their rights clearly and concisely. I therefore support amendment 19.

Nicola Sturgeon (Deputy First Minister and Cabinet Secretary for Health and Wellbeing): The way patients are treated when they receive health care—being involved in decisions about their care and receiving appropriate support—is extremely important. That is why we introduced the bill and why it sets out how patients should be treated when they receive health care. As Richard Simpson has outlined, amendment 19 would introduce the power for ministers to issue an order putting into statute a patient charter, which would
set out all existing statutory rights and responsibilities that apply to patients.

I listened carefully to the stage 1 debates at committee and in the chamber, and I accept that some members feel that setting out rights and responsibilities in a patient charter would have benefit for patients and for staff. For those reasons I am happy to agree with amendment 19 in principle. However, the Scottish Government is not able to accept the group of amendments as they are currently drafted. I ask Richard Simpson to consider not pressing them today, with an assurance that we will work with him to produce amendments that will have the desired effect without the difficulties that I believe the amendments would lead to as currently drafted.

The difficulties include, for example, the stipulation that the charter would be contained in an order that was subject to affirmative procedure. That could make the process of updating the charter—which may need to be done regularly and often—cumbersome and time consuming, because its altered form would always have to come back to the Parliament to be approved. In addition, if the charter is to be contained in an order and is to list reserved as well as devolved legislation, as would be the case if all existing statutory rights were to be listed in it, then there may be some legislative competence issues. There are also issues about the length and usability of the charter as proposed.

All in all, although I support the amendments in principle, I think that they require further detailed consideration and development. An alternative could be the bill making provision for ministers to publish a patient charter, which could be updated quickly and easily without its taking up parliamentary time every time updating was necessary, and could be more flexible in the information that it contained—I note that Richard Simpson rightly used the word “flexibility” in connection with the proposed patient charter. It would therefore be more useful for patients and for staff.

Although I agree with the introduction of a patient charter in principle, the detail of how it would work in practice needs to be given further consideration. I ask Richard Simpson to withdraw amendment 19 and not to press the others in the group, and I commit to working with him on mutually acceptable amendments on a patient charter for him to lodge at stage 3.

Dr Simpson: I think that we will have the same discussion about several of my amendments.

On amendment 19, I do not acknowledge that the argument about regular updating and members having the opportunity to debate the charter has any validity. The matter is so important that it is crucial that members have the opportunity to debate rights, and that they are seen by the public to be debating them. If we have to do so regularly, members should not consider their time doing so to be ill spent.

I understand the need to list reserved legislation—it is clear that an order would have to be drawn up in a way that would address the reservations that the cabinet secretary has expressed. I accept that there is an additional problem in that reserved legislation may from time to time require to be updated, but the strength of the arguments that were put to us on ensuring that all patient rights be included in a single charter leads me to say that I want to press amendment 19, although I am happy to look at any further amendments that the Government might want to lodge to increase flexibility. The cabinet secretary’s argument on that is the one argument she made that I would accept.

The Convener: The question is, that amendment 19 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Graha me, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 19 agreed to.

Section 1—Patient rights

The Convener: Amendment 20, in the name of Richard Simpson, is the only amendment in the group.

Dr Simpson: I will be very interested to hear what the cabinet secretary has to say about amendment 20.

Amendment 20 reflects one of the main concerns that people have expressed to me over a number of years, particularly people with a disability that might impair their ability to deal with information on a number of different matters that they are presented with. I accept that it appears that considerable progress has been made over the past decade in providing information in forms that meet patients’ needs, and that that information should be made available to people in a form in which they can use it under existing
reserved legislation, but progress is still patchy, and I believe that including the provision in the bill will indicate that the right in question is as important as the other rights that may be contained in the charter.

I move amendment 20.

Nicola Sturgeon: Amendment 20 is a logical extension of many provisions that are already in the bill. Evidence from the consultation on the bill and the equality impact assessment as well as evidence that the committee has received suggest that the form in which information is provided is of real importance to patients, particularly groups of patients with particular needs. I hope that Richard Simpson is not too surprised that I am happy to support amendment 20.

Amendment 20 agreed to.

Amendment 21 moved—[Dr Simpson].

The Convener: The question is, that amendment 21 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 21 agreed to.

The Convener: Amendment 22, in the name of Richard Simpson, is grouped with amendments 47, 59 to 63, 2, 64 to 70 and 76.

Dr Simpson: The Government and the Parliament have made an important commitment to the development of the mutuality aspect of the NHS. The days in which any form of autocracy or paternalism in the delivery of care was seen as acceptable should be past. In parallel with that growing mutuality, a robust and modern complaints system is needed. It is not a matter of there having been no complaints system, but it has been under the direction of the minister under the National Health Service (Scotland) Act 1978 and not in statute. I understand that that is the reason for the Government's including the matter in the bill.

15:15
There are multiple deficiencies in the current system and there is no opportunity for genuine partnership. There is, really, only a complaints system and many patients do not want to complain. That may be because the issue is not of great moment, or because to start a complaint is too formal, or because it is felt by patients, families or carers that to do so would risk the relationship with health professionals during treatment. For the health team, a complaint implies blame, fault or even negligence and—again—smacks of there being little mutuality.

In its evidence to the committee, the Scottish Human Rights Commission referred to a system that has been developed at the state hospital at Carstairs. It arose in part from a whole-systems approach to care and management in the hospital, based on a human rights approach. When I visited Carstairs, I was impressed by the benefits of the system, which is referred to as the four Cs. They are: compliments, or positive feedback when good practice is appreciated by patients or families, which might help to spread such practice; comments, which would apply to minor observations, such as on a clinician wearing regulation short sleeves but still wearing a wrist watch or bracelet; and concerns, which would be more serious or might be on a frequent minor example of good practice not being followed or a comment not being acted upon. From looking at health care environment inspectorate reports, there must be many occasions when a comment or concern that has been expressed by a patient, visitor or carer could have led to action. The last of the four Cs is complaints.

The effect of introducing the four Cs system was to increase mutuality and improve practice in what I think members would accept is the fairly difficult setting of the state hospital. The system there reduced the number of complaints and significantly improved the ethos and atmosphere in the hospital. The committee, along with the Scottish Human Rights Commission, commended the approach.

Amendments 22, 47, 59 and 63 would introduce that approach in the bill. Amendment 64 would move a positive feedback section ahead of the complaints section, and so is a simple reordering of the bill. Amendments 66 and 69 would tackle a concern of Consumer Focus Scotland, patients and the independent advice and support service by ensuring that there was feedback on any action that was taken by a national health service body. Such feedback would go beyond a simple report to the patient; I have often found in dealing with such issues as an MSP that patients get a fairly full report of their cases, but it does not say what action the board has taken to amend the
underlying problems. Most of us want to know when we complain, comment or have concerns, that our action has resulted in changes in practice.

Amendment 70 would introduce a power to require feedback to the health department so that it may, in turn, relay to other boards actions that may be pertinent to the NHS in Scotland as a whole, just as alerts on patient safety are currently disseminated.

In conclusion, I say that I also support the Government’s amendment 2, which will introduce mediation and conciliation.

I move amendment 22.

Nicola Sturgeon: I am happy to speak to amendment 2 and other amendments in the group. In its report, the committee recommended that a remedy such as alternative dispute resolution be explored further at stage 2. As I confirmed in the stage 1 debate, I asked my officials to do that, so amendment 2 will specifically enable Scottish ministers to issue directions to a relevant NHS body about the use of conciliation or mediation as part of the complaints process. I am committed to ensuring that patients have access to a complaints system that is easy to navigate, that is responsive to their concerns and which—crucially—results in improvements in how care is delivered. I urge members to support amendment 2.

I turn to the other amendments in the group. I support amendments 60, 64 and 70 and I welcome the references to “feedback, comments, concerns or complaints” in other amendments. I intend at stage 3 to lodge a few tidy-up amendments to ensure consistency of language throughout the bill. Nevertheless, I support the amendments.

I have a concern that amendment 76, which would insert a definition of feedback, does not recognise, in using the word “appreciation”, that feedback can be negative as well as positive. I therefore ask Richard Simpson to reflect on that point and perhaps not press the amendment so that we can find more appropriate wording before stage 3.

Ross Finnie: When the bill was introduced, the cabinet secretary pointed out that we do not have a statutory right to complain. I am bound to say that I have never come across anyone who has had a letter of complaint returned to them in an envelope with a covering note that said, “You don’t have a right to complain, so we’re sending your complaint back.” However, I have had a host of complaints that have demonstrated beyond peradventure that the system for dealing with complaints in the health service is unsatisfactory in many cases.

I welcome the cabinet secretary’s support for the principles behind Richard Simpson’s amendments. Those principles are not exclusively but are certainly more often used in Carstairs than anywhere else. I, too, have looked at the system there, which appears to bring substantive changes. If it can improve for patients’ benefit the way in which complaints are dealt with, that is very much in patients’ interests. We will support Richard Simpson’s amendments.

Dr Simpson: I will press amendment 22 and I will move the other amendments in the group. I intend to move amendment 76 on feedback because, in the system that I propose, “feedback” means only positive feedback. Comments, concerns and complaints are the other three areas, which we deal with in other amendments on the looped feedback system that we suggest. I am happy to work with the Government on what amendments 66, 67 and 69 propose, although I will move them—I would rather have them in the bill before stage 3 and then work with the Government to develop further amendments and seek clarification.

Amendment 22 agreed to.

Section 1, as amended, agreed to.

Section 2 agreed to.

Section 3—Duty to have regard to certain rights and principles

The Convener: Amendment 23, in Mary Scanlon’s name, is grouped with amendments 25, 27 and 52.

Mary Scanlon (Highlands and Islands) (Con): The bill says that health boards and other relevant NHS bodies must “have regard to the health care principles”
and the treatment time guarantee. The intention behind the amendments in the group is to strengthen the bill and to ensure that health boards place patients’ rights firmly at the heart of patient care rather than simply consider them by having regard to them. Several committee members have raised that issue, because the exact meaning of “have regard to” is uncertain and ambiguous.

The bill does not place a specific duty on NHS Scotland to comply with patients’ rights. The duty of having regard to the rights and principles extends to any person with whom a relevant NHS body “enters into a contract, agreement or arrangements to provide health care”, in so far as those rights and principles “are relevant to the service being provided.”

I understand that contractors who deliver services, such as general practitioner practices or cleaning and catering services in a hospital, will be covered by the bill—in so far as those services are covered by the bill. Given that the bill sets out patients’ rights, it seems reasonable to give those rights priority and to uphold them.

Another criticism of the current wording is the lack of accountability: it would be impossible to verify whether a health board or other NHS body had actually regarded the patient’s rights. It might be demonstrable that the patient’s rights had been disregarded, but the opposite would not necessarily be the case. To change the wording of the bill to “uphold” would send a message to the NHS body and to Health Scotland and the Scottish Government, which will, I presume, hold NHS bodies to account.

As the Health and Sport Committee confirms in its report, there is an inherent contradiction between setting out patient rights in primary legislation—that has, perhaps, changed, as of today—and there being no legal enforceability in terms of those rights. I certainly do not want a lawyer’s charter, but I want something that promotes the rights of patients. Perhaps “uphold” is too strong a word, however. I am interested in hearing what the cabinet secretary has to say on the matter. I should also say that the matter has been raised with the Scottish Association for Mental Health, which believes that people with mental health issues are particularly vulnerable in relation to bodies having regard to their rights.

I move amendment 23.

Nicola Sturgeon: The Government is happy to support amendments 23 and 25. Amendment 27 is technically incompetent, because it refers to the wrong section, so I invite Mary Scanlon not to press it. She might want to lodge a replacement at stage 3.

Although I understand what Mary Scanlon is trying to do with amendment 52, I suggest that it is not technically appropriate. Mary Scanlon might want to reflect on it in advance of moving it. The treatment time guarantee is contained in statute and the intention is to issue guidance to health boards on how they can implement and abide by the treatment time guarantee. However, guidance is just that—it is guidelines that set out best practice but which are not, in themselves, statutory obligations. To use the term “comply with” in statute would not be technically appropriate.

The reason for setting out in guidance how the treatment time guarantee is to be met is to provide health boards with the flexibility that members have said in previous discussions is important. For example, the health board might have regard to the guidance, but decide—because of the individual circumstances of the patient—not to comply in exact terms with that guidance in meeting its statutory obligations.

The wording of amendment 52 is not technically appropriate. I would be happy to have further discussions with Mary Scanlon after stage 2, but I ask her not to move it today.

Mary Scanlon: I am delighted with that response. I think that I will press amendments 23 and 25 and withdraw amendments 27 and 52.

The Convener: You cannot withdraw those amendments yet. Are you pressing amendment 23?

Mary Scanlon: Yes.

Amendment 23 agreed to.

Amendment 24 moved—[Dr Simpson].

The Convener: The question is, that amendment 24 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 24 agreed to.
Amendment 25 moved—[Mary Scanlon]—and agreed to.

Amendment 26 moved—[Dr Simpson].

The Convener: The question is, that amendment 26 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 26 agreed to.

Amendment 27 not moved.

Section 3, as amended, agreed to.

Section 4 agreed to.

Schedule

15:30

The Convener: Amendment 28, in the name of Richard Simpson, is grouped with amendments 29 to 33.

Dr Simpson: These amendments to the schedule contain some of the principles on which any charter should be based. The principles are intended not to be fully inclusive but to provide a basis for the charter. The amendments build on the schedule and endeavour to include a number of items that the Royal College of Nursing and the British Medical Association regard as important. Amendments 28 and 29 were suggested by the Royal College of Nursing. Amendments 30 to 32 are about responsibility as well as rights. Amendment 31, in particular, strengthens respect for staff by substituting “expected” for the somewhat weaker word “encouraged” in the bill as drafted. Amendment 33 inserts in the schedule a reference to the new complaints system.

I move amendment 28.

Nicola Sturgeon: I support the principle and intention behind amendment 28, which seeks to address an issue that everyone accepts has been a top priority for the Government: namely, the reduction of health care associated infection and the promotion and enhancement of patient safety.

However, there are issues with the amendment as drafted. For example, it talks about patients having to be treated

“in an appropriate, clean and safe environment at all times.”

When reading the amendment for the first time, most people would think that there was nothing wrong with it. However, if someone is in a road traffic accident and requires to be treated at the roadside, it is not immediately clear whether that would satisfy the definition of a “clean and safe environment”, although it is the most appropriate environment in which to treat the person at the time. I am slightly concerned that the scope of the amendment is a bit too wide. The amendment needs some work to ensure that the intention behind it can be fulfilled without unintended consequences. I invite the member to work with us on that.

Amendments 29 to 32 seek to use the health care principles to place responsibilities on patients. I agree that patient responsibility is important. It is perennially difficult to define, but we all accept that it is desirable for patients to be encouraged to take on greater responsibility. However, it is not appropriate to use the health care principles to place responsibilities on patients, as the purpose of the principles is to place duties on health boards. It would be better to use the proposed patient charter to confer responsibilities on patients. I invite Richard Simpson to reflect on that point.

Amendment 33 repeats provisions on complaints and feedback that are already set out in section 11. The provisions in section 11 place statutory duties on relevant NHS bodies so, strictly speaking, it is unnecessary to include them in the health care principles. For that reason, I invite the member not to move amendment 33. However, given that the provisions are already included in the bill in principle and in practice, it will not be the end of the world if the amendment is agreed to.

Dr Simpson: I hope that the committee will agree to amendment 28. I look forward to working with the Government to correct the phrase

“clean and safe environment at all times”,

as I accept the Government’s argument that there are occasions when emergency interventions are absolutely necessary. We may be able to include in the provision some wording that covers emergency situations.

If we do not include in the schedule the wording that amendments 29 to 32 would insert, the bill will be left unbalanced. Unless the Government’s intention is to introduce the responsibilities elsewhere in the bill, which is not evident from any of the amendments that it has lodged, I am inclined to pursue them. Amendment 31, which
strengthens respect for staff by changing the word “encouraged” to “expected”, is especially vital. In my view, it is not sufficient for us only to encourage people to treat staff with respect. I must declare an interest, as I was assaulted by a patient in a clinic. Because of that particularly unpleasant experience, I lean towards the use of rather stronger language to make the point clearly.

All the items will be included in the charter, but there should also be some balance in the schedule. I will press amendment 28 in my name.

Ross Finnie: I am not entirely clear whether, in the event that amendments 29 to 32 were either withdrawn or disagreed to, the cabinet secretary intends to lodge amendments to place those obligations in the charter instead of seeking to locate them in the principal legislation.

Nicola Sturgeon: Yes, that is the intention.

The Convener: The question is, that amendment 28 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 28 agreed to.

Amendments 29 and 30 not moved.

Amendment 31 moved—[Dr Simpson].

The Convener: The question is, that amendment 31 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 31 agreed to.

Amendment 34 moved—[Dr Simpson].

The Convener: The question is, that amendment 34 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 34 agreed to.

Amendment 35 moved—[Dr Simpson].

The Convener: The question is, that amendment 35 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 35 agreed to.

Amendment 36 moved—[Dr Simpson].

The Convener: The question is, that amendment 36 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scallon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahaeme, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 36 agreed to.

Section 5, as amended, agreed to.

Section 6—Treatment time guarantee

The Convener: Amendment 1, in the name of the cabinet secretary, is in a group on its own.

Nicola Sturgeon: I will be brief, convener. I listened to members’ concerns about the possibility of the treatment time guarantee distorting clinical priorities and, as that is clearly not the intention behind the provision, have lodged amendment 1 to reinforce the importance of boards prioritising the start of patients’ treatment according to clinical need. Prioritisation must take place within the delivery of the treatment time guarantee for all eligible patients, which means that patients should not be left to languish on a waiting list. I urge members to support this amendment.

I move amendment 1.

Amendment 1 agreed to.

The Convener: Amendment 37, in the name of Richard Simpson, is grouped with amendments 38 to 46, 48 to 51, 53 to 58 and 77. I draw members’ attention to the fact that if agreed to amendment 51 will pre-empt amendment 52.

Dr Simpson: Our objection to the proposed treatment time guarantee is that it is too prescriptive. The cabinet secretary made it clear in evidence that “where a service is not delivered as planned or elective care on an inpatient or day-case basis, it will not be covered by ... the” treatment time guarantee. One problem with the current proposal, as I understand it, is that for a single given procedure there would be a guarantee for only in-patient treatment; however, as NHS Lothian set out in evidence, the procedure itself might be carried out as a day-case or even as an out-patient procedure. Indeed, the procedure might be carried out more and more in general practice under a section 17C agreement or local enhanced service contract.

The policy memorandum listed exclusions, some of which were understandable, but others were less so, such as direct access to x-rays, diagnostic tests, out-patient treatment, some national services, and so on.

There are other issues of concern, such as those stated by the Royal National Institute for the Deaf: waiting as a child might be far more damaging than waiting as an adult, because an 18-week wait for a deaf child would result in the loss of half a year’s education. Other concerns were expressed by SAMH about talking treatments or possible guarantees for children with mental health problems, who, despite efforts by successive Governments, are unfortunately still being admitted to adult wards.

We must find a way of balancing realistic guarantees, reflecting the finite resources of the NHS and the clinical priorities that are paramount in the Government’s determination to ensure as speedy a service as is practicable, and ensuring that any discrimination, other than on the grounds of clinical priority, is minimised.

The amendments seek to allow future ministers to introduce a suite of guarantees that will address some of those concerns and reflect the priority in waiting times that the Government is seeking to emphasise, some with related health improvement, efficiency, access and treatment targets. That is not easy, and this is my first attempt, with a lot of help from the Parliament’s bill team. The amendment might not be perfect; indeed, it might still be too prescriptive, but I do not believe that the Government has got it right either. If the cabinet secretary says today that she is prepared to work with us and the committee to find a form of words that will be flexible, provide the clarity that we need and meet the concerns that have been expressed, I will not press my amendments. For the moment, I await the committee’s comments and the cabinet secretary’s response.

I move amendment 37.

Mary Scanlon: Amendment 37 is an amendment after my own heart. Throughout our deliberations on the bill, I have raised mental health treatment issues.

I seek some clarity from the cabinet secretary. I am aware that the Government is proposing a referral-to-treatment target for psychological therapies—I have submitted some written questions on the subject—but I would like to hear something to assure me that the cabinet secretary is taking the matter seriously, given that the largest percentage of mental health patients fall outwith the treatment time guarantee because few have in-patient or elective treatment. Although the cabinet secretary is thinking about psychological therapies, while mental health patients receive less than equal treatment under the bill I would like some clarity on her approach to the waiting time
target. Will it fit in with the treatment time guarantee for psychological therapies?

Nicola Sturgeon: I will start with a brief response to Mary Scanlon’s point about psychological therapies and mental health treatment more generally. I hope that it is obvious that the Government is committed to improving services for mental health patients, including reducing the horrific waiting times that people who are waiting for mental health services traditionally had to endure. We intend, over time, and as long as it is possible and sustainable, to bring groups of patients who are waiting for particular types of treatment that have not traditionally been included in the waiting time guarantee into the ambit of the 18-week referral-to-treatment guarantee. I will talk about that again in a second.

As the bill is framed, people who require in-patient, planned treatment will be covered by the treatment time guarantee, but those who require other types of treatment are, nevertheless, still covered by the 18-week referral-to-treatment guarantee. As I said, we want to bring additional groups of patients within that guarantee.

I turn to Richard Simpson’s comments, and assure him that I am happy to work with him and the committee to see whether we can find common ground around the provisions in the bill and his amendments. I ask him not to press his amendments, but to give us the time to work together to come up with a better set of amendments. It would be preferable to get to a set of provisions that are right, rather than amending the bill now and trying to improve the amendments later, which could end up being a bit messy.

15:45

I take Richard Simpson’s point about being less prescriptive, although I am not convinced that his amendments achieve that objective in all respects. They appear to be trying to put the whole patient journey, including its different stages, into statute. On the face of it, that might seem a perfectly reasonable thing to do, because, as I have just said to Mary Scanlon, we have the whole-journey, 18-week referral-to-treatment guarantee, and the treatment time guarantee in the bill is intended to sit within that.

However, any whole-journey, referral-to-treatment time target, by its very nature, requires to have what we call tolerances. For example, we would say that 90 or 95 per cent of patients have to be treated within the time. The reason is that, as everybody knows, there is a degree of uncertainty attached to the diagnosis part of the patient journey, which can take a long time. It might take several diagnostic tests to find out what is wrong with the patient before we can determine the treatment that is appropriate for them, and it might not always be possible to do that within the maximum waiting time.

We therefore need flexibility, and it is difficult to provide adequately for tolerances in legislation that confers individual rights. The Government has chosen to put that part of the patient journey about which there can be certainty—that is, the part from diagnosis and the decision to treat, to treatment taking place—into statute. In the vast majority of cases, patients will be treated both within the 12-week treatment guarantee and the overall 18-week referral-to-treatment guarantee but, in a small number of cases where diagnosis may take longer than 18 weeks, the flexibility will still be there.

The approach also means that, if it takes more than 18 weeks to diagnose a patient and they are already out of the guarantee period by the time treatment is agreed, they will not be in no man’s land, because they will still have as a long stop the 12-week guarantee for the period between the decision to treat and treatment taking place.

A secondary concern about how the amendments are framed is that specifying in the bill different guarantees for different stages of the journey ignores, to some extent, some substantial redesign work that has already taken place. These days, not all patients will go through all the set stages of the patient journey. One example is the one-stop shop systems that many boards have put in place for cataract treatment, under which patients do not get an out-patient appointment at all. They are pre-assessed on the day of the operation and everything happens on the same day. A patient might be assessed and treated on the same day within the 18-week referral-to-treatment guarantee. Say that happened within 16 weeks. Under the system that is proposed in the amendments, there might have been a breach of the outpatient appointment bit of the patient journey. We must be careful that we do not provide perverse incentives and encourage boards to go back to old ways of delivering treatment.

There is another subsidiary concern. Amendment 77 defines “patient”, and that definition is applied to the whole of the bill, but it seems to include only patients who are currently receiving treatment. It excludes those who have had treatment, those who are in recovery, and those who are waiting for treatment.

Those are my key concerns about the amendments. I am happy to see whether we can come to common ground between now and stage 3. If that does not prove possible, Richard Simpson will still be free to lodge amendments at stage 3 and I will be free to argue against them, but there is an opportunity for us to try to design something that suits all our purposes and gets us
something in the bill that is workable and goes with the grain of service redesign rather than counter to it.

**Dr Simpson:** The discussion has been helpful. I thank the cabinet secretary for her comments. I welcome the Government’s intention to give patients some clarity on what can and cannot be guaranteed. The conundrum is that, if the Government gives guarantees that are too strict, it might interfere with clinical priorities. That is a concern of clinicians, and of course we do not want that to happen. On the other hand, however, we do not want patients to be left hanging for ever, or for prolonged periods of time.

The amendments were an attempt to give future ministers the flexibility to be able to introduce such guarantees as they believed to be appropriate but, on reflection, I am not sure that they do that. The cabinet secretary has been helpful in setting that out.

I entirely accept her view that there is a considerable need for tolerances in the period from referral to diagnosis. For some conditions—such as prostate cancer, which is an area in which I was very much involved—there is a need for repeated observations and tests. It is crucial not to go ahead with treatment too quickly; if one proceeded with treatment because one was required to do so, it might be inappropriate for that particular patient.

I accept many of the cabinet secretary’s arguments, but I am not comfortable with the current treatment time guarantee, although I acknowledge the intention to provide clarity in the text of the bill for that particular aspect of the journey. I welcome her undertaking to work with the committee and with me to see whether we can get something that is a little broader but also flexible and, for that reason, I will not press amendment 37.

Amendment 37, by agreement, withdrawn.

**Section 6,** as amended, agreed to.

**Section 7—Treatment time guarantee: further provision**

Amendments 38 to 43 not moved.

Section 7 agreed to.

**Section 8—Breach of the treatment time guarantee**

Amendments 44 to 46 not moved.

Amendment 47 moved—[Dr Simpson]—and agreed to.

Amendments 48 to 50 not moved.

Section 8, as amended, agreed to.

**Section 9—Treatment time guarantee: guidance and directions**

**The Convener:** We are wondering when we might have a little break. Members should let me know when they feel that they could do with one.

Amendments 51 to 54 not moved.

Section 9 agreed to.

**Section 10—Treatment time guarantee: key terms**

Amendments 55 to 58 not moved.

Section 10 agreed to.

**Section 11—Complaints**

Amendments 59 to 63 moved—[Dr Simpson]—and agreed to.

Amendment 2 moved—[Nicola Sturgeon]—and agreed to.

Section 11, as amended, agreed to.

Amendment 64 moved—[Dr Simpson]—and agreed to.

**Section 12—Patient feedback**

Amendment 65 moved—[Dr Simpson]—and agreed to.

Amendment 66 moved—[Dr Simpson].

**The Convener:** The question is, that amendment 66 be agreed to. Are we agreed?

**Members:** No.

**The Convener:** There will be a division.

**For**

Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

**Against**

Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)

**The Convener:** The result of the division is: For 4, Against 4, Abstentions 0. I use my casting vote against the amendment.

Amendment 66 disagreed to.

Amendment 67 moved—[Dr Simpson].

**The Convener:** The question is, that amendment 67 be agreed to. Are we agreed?

**Members:** No.

**The Convener:** There will be a division.

**For**

...
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)

The Convener: The result of the division is: For 4, Against 4, Abstentions 0. I use my casting vote against the amendment.

Amendment 68 disagreed to.

Amendment 68 moved—[Dr Simpson]—and agreed to.

Amendment 69 moved—[Dr Simpson].

The Convener: The question is, that amendment 69 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)

The Convener: The result of the division is: For 4, Against 4, Abstentions 0. I use my casting vote against the amendment.

Amendment 69 disagreed to.

Amendment 70 moved—[Dr Simpson]—and agreed to.

Section 12, as amended, agreed to.

Section 13 agreed to.

The Convener: Do members want a little break, or do you want to press on?

Members: Press on.

Section 14—Patient advice and support service: establishment and funding

The Convener: Amendment 71, in the name of Richard Simpson, is grouped with amendments 72 and 73.

Dr Simpson: The committee was generally of the view that the current system—the independent advice and support service—has been a helpful development. It is a relatively young service, but its association with local citizens advice bureaux is already much appreciated by patients. The ability to manage patients’ concerns in an holistic way, addressing concerns beyond those of the immediate NHS problem, is worth while and should not be lost in any new development.

Amendment 71 seeks a change in name and a presumption that any new service, whether it is provided by the citizens advice bureaux or by another organisation, is independent and continues to take a comprehensive approach. We support the name change to PASS and the move to a consistent national contract.

Amendments 72 and 73 remove the development of the new patient rights officers. Having a new group of officers whose function is simply to signpost is not the way to go. The boards will have to designate those who will be responsible for responding, but the route to go down is to use Citizens Advice Scotland, local citizens advice bureaux or similar independent organisations—which one hopes would use trained volunteers and staff—with advice continuing on a number of issues and people acting as much more than signposts. I would prefer any funds to be used to enhance what already exists, rather than to create a new group of officers.

I move amendment 71.

16:00

Nicola Sturgeon: We all accept that the association of the service with citizens advice bureaux has been one of its strengths. Many of the comments that were made at an earlier stage of the bill on the holistic nature of the service related not to the design of the service but to the fact that the service is provided by citizens advice bureaux, which can signpost patients on to other services that they provide. I do not take issue with the point about the strength of that service. However, I am advised that, in all likelihood, amendment 71 would breach procurement rules, because it appears that its intention is to specify a preferred provider for the patient advice and support service, which should rightly be awarded by competitive tender.

The amendment also seems slightly odd in that it names citizens advice bureaux but also states that the provider could be “any other such source of independent advice and information.”

That begs the question why mention a specific organisation. However, I am most concerned about procurement rules in relation to the amendment. I therefore ask Richard Simpson to seek to withdraw amendment 71 and, if he presses it, I ask the committee to oppose it.
As Richard Simpson said, if amendments 72 and 73 are agreed to, the bill will no longer specify that the PAS service is to be staffed by patient rights officers. Personally, I think that that would be a retrograde step, as patient rights officers would have a useful function to perform. However, it is important to stress that, if the amendments are agreed to, they would not otherwise affect the delivery of the PAS service, which I believe will be an extremely strong and valuable service, with or without patient rights officers.

**Mary Scanlon:** I have a question for the cabinet secretary. We heard a lot of evidence that the complaints system is inconsistent and patchy across Scotland, but I was impressed by some of the services that are provided by citizens advice bureaux. We were told that it is an holistic service. I am minded to support Richard Simpson’s amendments although, obviously, I do not want to support anything that breaches procurement rules. Will the new system be an add-on or a parallel service? What will happen to some of the good practice if we do not pursue amendment 71? What will happen to some of the excellent citizens advice bureaux, such as the one at Raigmore hospital in Inverness, which is highly valued by patients?

**Nicola Sturgeon:** Putting to one side the issue of who provides the services, I point out that the services will continue. The purpose of the bill is not to add to or fundamentally change the service. As we discussed at stage 1, it is about ensuring that there is an obligation to provide the services consistently and that they do not go by the wayside if boards are looking to make savings. It is about entrenching the service firmly in the NHS.

Given my comments on procurement, I need to be careful in what I say about a service that is to be competitively tendered. However, I have heard—and I agree with—many of the comments that have been made about the service that is currently provided. Whether in future that service is provided by CABx or, to use the words in amendment 71, “any other such source of independent advice and information”, we want to ensure that it has the same qualities and holistic nature as at present, so that patients continue to enjoy those benefits.

I am significantly concerned by the procurement implications of amendment 71 but, if it helps, I am more than happy to provide further advice to the committee, within the constraints relating to legal advice that we have discussed at the committee in other contexts. I can perhaps provide a bit more information to the committee to flesh out the concern before we get to stage 3. However, it would be unfortunate if we agreed to something today that raised significant legal issues.

**Helen Eadie (Dunfermline East) (Lab):** I am very pleased that everyone round the table seems to be in agreement with the fundamental principles. That is good, because all of us have had experience of using patient advice and support services. I had to battle hard to get such services established in Fife.

As regards procurement, what strikes me about amendment 71 is its use of the word “may”. It does not say, “The patient advice and support service will be provided by Citizens Advice Bureaux or any other such source of independent advice and information.” I think that it provides sufficient wriggle room for anyone to be able to go to tender, should the procurement rules say that, so I query the minister’s argument.

**Nicola Sturgeon:** As I said, I would be happy to provide further information to the committee. I take Helen Eadie’s point about amendment 71’s use of the word “may” rather than “shall” or “must”. Nevertheless, it seeks to put one provider in a preferential position by naming it and no other potential provider in the bill. It is that, rather than any stipulation around it, that gives rise to those concerns.

Without prejudicing any final decision that might be taken on the matter, I would be happy to provide some further information that could inform members before we get to stage 3.

**Dr Simpson:** May I ask the convener a question? If we sought to agree to an amendment that was against procurement legislation, would the Presiding Officer not rule that out of order?

**The Convener:** No.

**Dr Simpson:** So we could do it.

**The Convener:** Yes. It would be challengeable in court, once the bill was passed.

**Dr Simpson:** I certainly do not wish to press an amendment that might be in contravention of procurement rules, although we were careful to put in the word “may” and not “must” and to add the rider, which the cabinet secretary saw as rather strange, that, although the service is currently provided by the CABx, it could be provided by “any other such source of independent advice and information.”

The intention was partly to ensure that we have an organisation that can provide an holistic approach, because it was quite clear from evidence to us that that was highly valued by the people who use the present service. Therefore, if the Government is prepared to work with us on the basis that we will come back at stage 3 with an amendment that...
spells out those principles, as opposed to specifying the CABx, I am prepared to seek leave to withdraw amendment 71.

Nicola Sturgeon: I am prepared to do that. Richard Simpson may be right—maybe we should try to enunciate the principles rather than name a particular organisation. That might be a better way to go about it.

Amendment 71, by agreement, withdrawn.

Section 14 agreed to.

Section 15—Patient advice and support service

Amendment 72 moved—[Dr Simpson].

The Convener: The question is, that amendment 72 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Graham, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 72 agreed to.

Section 15, as amended, agreed to.

Section 16—Patient Rights Officers

Amendment 73 moved—[Dr Simpson].

The Convener: The question is, that amendment 73 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Scanlon, Mary (Highlands and Islands) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Graham, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)

The Convener: The result of the division is: For 5, Against 3, Abstentions 0.

Amendment 73 agreed to.

Section 17—Duties to share information

The Convener: Amendment 3, in the name of the minister, is grouped with amendments 4 to 6.

Nicola Sturgeon: Amendments 3 to 6 are entirely technical in nature. They seek to amend the bill so that duties are placed on the Common Services Agency rather than being placed directly on the provider of the PASS. That will make section 17 consistent with the rest of the bill.

I move amendment 3.

Amendment 3 agreed to.

Amendments 4 to 6 moved—[Nicola Sturgeon]—and agreed to.

Section 17, as amended, agreed to.

After section 17

The Convener: Amendment 74, in the name of Richard Simpson, is grouped with amendments 75 and 15A.

Dr Simpson: Some parties have had significant objections to the bill and its overall necessity. We will see at stage 3 where we have managed to get to. One of the problems with the bill is that, although it seeks to create rights, it specifically excludes individuals from seeking redress. We have all acknowledged that the Government has listened. Parliament said clearly that it did not want to create a situation where there would be lawyers at the bedside. However, without some redress, the rights are—it is said at least by some people—meaningless.

One of my regrets about the bill is that it has been introduced before the Government could conclude its consideration of a general, no-fault compensation system. I realise that such a scheme and consideration of it will deal primarily with clinical matters, but a system of no-fault compensation could equally be applied to some of the rights and guarantees that the bill will underpin.

Combined with conciliation and mediation provisions, which the Government has itself added today, we could avoid lawyers, while acknowledging when rights are infringed. Amendment 74 seeks to introduce such a system for non-clinical issues.

I await with interest the cabinet secretary’s comments.

I move amendment 74.

Ross Finnie: I have some sympathy with Richard Simpson on this matter, although I appreciate that the Government had been considering it separately—and we have not had any response on that. I am in no doubt that, if we
are to make a fundamental change in addition to the changes that have now been suggested to the provisions on how complaints are dealt with and how boards respond to them, the need for a no-fault compensation scheme is very important.

I have one reservation, to which Richard Simpson could respond when he winds up. In subsection (3) of the new section that amendment 74 would insert, he seeks to restrict the application of such a scheme to the matters that are covered by the bill. That seems to be a recipe for serious confusion. As a matter of principle, I support the introduction of no-fault compensation into the national health service—although one would like to see the detail—but I am very nervous about the idea of simply moving an amendment to effect such provisions under this bill. Given how the bill is constructed, it is difficult to be precise as to where the scheme might or might not apply. We have now helpfully moved towards including a charter within the bill. If that charter makes specific reference to the various rights that patients have and patients are led to believe that they might benefit from no-fault compensation only to find that the way in which subsection (3) is expressed restricts patients to matters under the principal part of the bill rather than those that come under the schedule, that could cause confusion. I would be grateful if Richard Simpson could address that point when winding up.

Mary Scanlon: I have a couple of questions for the member. No-fault compensation is a highly complex issue, and I am aware that we have not taken any evidence on the subject. What sort of consultation has Richard Simpson carried out? What organisations support the amendments in this group? Does he have concerns, as I do, that we have not had an opportunity to discuss the issue at stage 1?

16:15

Nicola Sturgeon: As Richard Simpson has said, amendment 74 proposes the establishment of a no-fault compensation scheme to cover patients’ rights under the bill. Under the proposal, a patient could claim compensation even if they had not suffered any injury, harm, damage or loss.

As members will be aware, I have expressed sympathy with the idea of moving to a no-fault compensation scheme, although Mary Scanlon is correct to point out that the area is highly complex. Because of those complexities, I asked Sheila McLean of the University of Glasgow to convene an expert group to examine no-fault compensation, to look at systems in other parts of the world and to consider all the complexities and costs that would inevitably be associated with the introduction of such a scheme. I have now received Sheila McLean’s report; the Government is considering it and will publish it and our response as soon as possible. Because of the complexities and potential cost implications, we are taking a wee bit of time to consider it, but that is the proper way of proceeding.

Although no-fault compensation has a great deal to commend it, it would, as I have said, inevitably have cost implications. Moreover, my view even since before the bill’s introduction is that the move would represent such a fundamental legal change that it would require separate legislation: I have never been of the view that it was appropriate to make provision for it in this bill, although if we move to the system in future, it could be made to apply to the rights in the bill. Given that such a system would have wider application than to those rights alone, we have to consider the issue in its totality instead of tagging it on to the bill. That is particularly important given that, as Mary Scanlon has rightly pointed out, the committee has taken no evidence on the matter.

I might be wrong, but I suspect that Richard Simpson has lodged these amendments partly as a probing exercise to find out where we are with no-fault compensation. I appreciate members’ interest in the matter, but it is important that we proceed carefully and with due consideration. The publication of Sheila McLean’s report and the Government’s response—which, as I say, will happen as soon as possible—will provide the right environment for a full debate on the pros and cons of such a system and on the way forward, if Parliament thinks that we should move on the issue.

Dr Simpson: I agree with much of what the cabinet secretary said but, instead of the bill as it stands, I still would have preferred to have been presented with a package that was partly on patient rights and partly on a no-fault compensation scheme and which covered clinical and patient rights issues. I make it clear that the point of lodging the amendment was not to address the clinical issues. However, although it was not our intention to make it overly restrictive, I accept Ross Finnie’s point that it might well be, given that it might not cover some of the elements that would be in the charter but not in the bill.

Nevertheless, one of the fundamental criticisms of the bill is that, if a right is to be a right, there must be redress. That conundrum has not yet been solved without the kind of massive participation of lawyers that none of us wants. As the cabinet secretary has suggested, this is undoubtedly a probing amendment, but I have also lodged it to put on record my view that, even if we are able to pass it, the bill will remain fundamentally flawed in its failure to provide redress.
However, I am heartened by the cabinet secretary's comments. I believe that we should introduce a no-fault compensation system for all sorts of reasons, especially the fact that, in the past financial year, £31 million was paid out on negligence claims. Those settlements might well be totally appropriate, but some of those claims go back seven, eight or nine years and the people in question and their families have suffered as a result. Even though the situation has improved substantially, major clinical issues still need to be addressed.

That said, I seek the committee's permission to withdraw amendment 74.

Amendment 74, by agreement, withdrawn.

Section 18—Protection and limitations

The Convener: Amendment 7, in the name of the minister, is grouped with amendments 8 and 9.

Nicola Sturgeon: Amendments 7 and 8 are technical amendments to ensure that the original policy intention of the rights that are set out in the bill do not give rise to additional rights to sue health boards, thereby avoiding the lawyer-by-the-bedside concern that was expressed earlier. Patients' rights to sue under other legislation, such as in cases of medical negligence, continue to be unaffected, as is the option of pursuing a declaratory judicial review with the remedy of reduction; all that is still available.

Amendment 9 seeks to address a specific point that was made at an earlier stage, which is that the bill does not exhaustively narrate all the rights that patients have. The amendment simply intends to draw attention to the fact that the rights in the bill are additional to those that already exist and do not undermine them or suggest that they might no longer exist. Of course, we have moved some way this afternoon in the discussion of a patients charter but, nevertheless, amendment 9 is still important.

I move amendment 7.

Amendment 7 agreed to.

Amendment 75 not moved.

Amendments 8 and 9 moved—[Nicola Sturgeon]—and agreed to.

Section 18, as amended, agreed to.

After section 18

The Convener: Amendment 10, in the name of the minister, is in a group on its own.

Nicola Sturgeon: Amendment 10 is a technical amendment to ensure consistency with the National Health Service (Scotland) Act 1978. It means that the powers that Scottish ministers have under the 1978 act to hold inquiries, to declare a health board or special health board to be in default, to use emergency powers, and to use powers to ensure that services are delivered to a standard that they consider to be acceptable will also apply in the context of the Patient Rights (Scotland) Bill. Of course, as with the 1978 act, those are considered to be powers of last resort.

I move amendment 10.

Amendment 10 agreed to.

Section 19—Interpretation

Amendment 76 moved—[Dr Simpson].

The Convener: The question is, that amendment 76 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For
Eadie, Helen (Dunfermline East) (Lab)
Finnie, Ross (West of Scotland) (LD)
McAveety, Frank (Glasgow Shettleston) (Lab)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)

Against
Grahame, Christine (South of Scotland) (SNP)
Matheson, Michael (Falkirk West) (SNP)
McKee, Ian (Lothians) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)

The Convener: The result of the division is: For 4, Against 4, Abstentions 0. I use my casting vote against the amendment.

Amendment 76 disagreed to.

Amendment 77 not moved.

Section 19 agreed to.

Section 20 agreed to.

Section 21—Orders, regulations and directions

The Convener: Amendment 11, in the name of the minister, is grouped with amendments 12, 13, 78, and 14 to 18.

Nicola Sturgeon: I will move amendment 11 and speak to amendments 11 to 18. The amendments are entirely technical in nature and, with the exception of amendment 18, were all recommended by the Subordinate Legislation Committee. Amendment 18 simply removes a power to appoint different days on which provisions in the act will come into force for different purposes. That will now be covered by section 8 of the Interpretation and Legislative Reform (Scotland) Act 2010.

I will just say a brief word about Richard Simpson's amendment 78.
The Convener: I was just going to point that out to you. I like to point things out occasionally, just to give myself some meaning.

Nicola Sturgeon: You have lots of meaning as far as I am concerned, but I will not butter you up any more.

Amendment 78 intends to apply affirmative procedure to the patients charter and the patient guarantee. The amendment is technically deficient because it refers to the wrong section of the bill, so I invite Richard Simpson not to move that amendment and to rectify it for stage 3.

I move amendment 11.

The Convener: Richard Simpson will speak to that technically wrong amendment.

Dr Simpson: Notwithstanding the technical deficiency, which would have led me not to move the amendment, the patient guarantee sections of the bill have not been passed, so I will not move the amendment for that reason.

Nicola Sturgeon: Well spotted.

Ross Finnie: That was a trick question.

Nicola Sturgeon: It was just a test.

The Convener: I feel as if it is all beginning to fall apart. Let us keep going, as the end is in sight. No other members have indicated that they wish to speak, so the minister will wind up.

Nicola Sturgeon: Richard Simpson is right. Saying that the amendment that I was describing is technically deficient showed my own technical deficiencies in not spotting that the sections to which it refers were not agreed to.

The Convener: I am sure that there is meaning in that answer, but I cannot for the life of me think of it at the moment.

Amendment 11 agreed to.

Amendments 12 and 13 moved—[Nicola Sturgeon]—and agreed to.

Amendment 78 not moved.

Amendment 14 moved—[Nicola Sturgeon]—and agreed to.

Amendment 15 moved—[Nicola Sturgeon].

Amendment 15A not moved.

Amendment 15 agreed to.

Amendments 16 and 17 moved—[Nicola Sturgeon]—and agreed to.

Section 21, as amended, agreed to.

Section 22—Short title and commencement

Amendment 18 moved—[Nicola Sturgeon]—and agreed to.

Section 22, as amended, agreed to.

Long title agreed to.

The Convener: That concludes stage 2 consideration of the Patient Rights (Scotland) Bill an hour earlier than anticipated. We did it at breakneck speed.

I thank the cabinet secretary for her attendance. I remind members that the committee meets again—I know that you are longing for this—tomorrow in committee room 4. We could really stay put.

Michael Matheson (Falkirk West) (SNP): You can, convener.

The Convener: No, I will not.

Meeting closed at 16:27.
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Schedule—Health care principles
Patient Rights (Scotland) Bill

[AS AMENDED AT STAGE 2]

An Act to make provision about the rights of patients when receiving health care; and for connected purposes.

Patient Rights Charter

Z1 Patient Rights Charter

(1) The Scottish Ministers must make an order containing a charter of rights and responsibilities to be conferred upon patients, to be known as the Patient Rights Charter, ("the Charter").

(2) The Charter, as contained within an order under subsection (1), must, subject to subsection (3), include all existing statutory rights and responsibilities conferred upon patients and may also confer new rights and responsibilities upon patients.

(3) The Charter must not include rights and responsibilities in relation to specific treatments or medicines and subsection (1) does not enable the Scottish Ministers to confer such rights and responsibilities upon patients.

(4) The rights and responsibilities contained within the Charter are to apply to all patients of relevant NHS bodies, but may also include rights and responsibilities to apply to specific groups of patients only.

(5) The Scottish Ministers must—

(a) from time to time review the Charter, and

(b) when they consider it appropriate to do so, make an order containing revisions to the Charter or a revised Charter.

(6) Before making an order under subsection (1) or subsection (5)(b), the Scottish Ministers must consult such persons as they consider appropriate.

Patient rights

(1) It is the right of every patient that the health care received by the patient be as described in subsection (2).

(2) Health care is to—
(a) be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs,

(b) have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing,

(c) allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing,

(d) have regard to the importance of providing such information and support as is necessary to enable the patient to participate in accordance with paragraph (c) and in relation to any related processes, taking all reasonable steps to ensure that the patient is supplied with information and support in a form that is appropriate to the patient’s needs,

(e) have regard to and respect for the rights and responsibilities conferred on patients by the Charter to be made by the Scottish Ministers under section (Z1)(1).

(3) It is the right of every patient to give feedback or comments, or raises concerns or complaints about health care received.

(4) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify subsection (2).

2 Patient rights: further provision

(1) In construing the right of a patient under section 1(1), the matters set out in subsection (2) below must be taken into account.

(2) The matters are—

(a) the rights of other patients under section 1(1),

(b) the desirability of action delivering health care being proportionate, and otherwise appropriate, to the circumstances of each case,

(c) those specified in section 18(1)(a) and (b).

Health care principles

3 Duty to uphold certain rights and principles

(1) For the purposes of the rights conferred by section 1, each relevant NHS body must—

(a) in performing its health service functions, uphold the health care principles and the charter in so far as they are relevant to the function being performed, and

(b) ensure that any person with whom it enters into a contract, agreement or arrangements to provide health care upholds the health care principles and the charter in so far as they are relevant to the service being provided.

(2) For the purposes of this Act, a “relevant NHS body” is—

(a) a Health Board,

(b) a Special Health Board,

(c) the Common Services Agency for the Scottish Health Service (“the Agency”).

4 Health care principles

(1) In this Act, “health care principles” are the principles set out in the schedule.
(2) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify the schedule.

5 **Health care principles and Charter: guidance and directions**

(1) A relevant NHS body must, for the purposes of section 3, have regard to any guidance issued by the Scottish Ministers in relation to the practical application of the health care principles and the charter.

(2) Before providing guidance in relation to the health care principles and the charter, the Scottish Ministers must consult such persons as they consider appropriate.

(3) The Scottish Ministers may give a relevant NHS body directions as to the practical application of the health care principles and the charter; and a relevant NHS body must comply with any such direction.

6 **Treatment time guarantee**

(1) In pursuance of the right conferred by section 1(1), an eligible patient is to start to receive an agreed treatment within the maximum waiting time.

(2) The guarantee described in subsection (1) is to be known as the treatment time guarantee.

(3) A Health Board must take all reasonably practicable steps to ensure that it complies with the treatment time guarantee.

(4) Those steps include, in particular, steps for—

   (a) monitoring each treatment time guarantee,

   (aa) appropriately prioritising the start of the patient’s agreed treatment taking account of the patient’s clinical needs and the clinical needs of other eligible patients awaiting agreed treatments in accordance with the treatment time guarantee,

   (b) making the necessary arrangements for the agreed treatment of the patient to start in accordance with the treatment time guarantee either—

      (i) within its area, or

      (ii) if it is unable (or anticipates it will be unable) to treat a patient in its own area, through another Health Board or a suitable alternative provider of the treatment.

7 **Treatment time guarantee: further provision**

(1) The Scottish Ministers must by regulations make the further provision about the treatment time guarantee specified in subsection (2).

(2) The further provision is—

   (a) the descriptions of patients which are eligible for the treatment time guarantee, and

   (b) how waiting time is to be calculated (in particular, specifying the circumstances in which days are not to be counted towards a maximum waiting time).

(3) The Scottish Ministers may by regulations specify—
(a) treatments and services (including categories of treatments and services) in respect of which the treatment time guarantee does not apply,

(b) action that a Health Board is to take to ensure that it complies with a treatment time guarantee,

(c) circumstances in which the maximum waiting time for a patient may be extended or recalculated (and how such extension or recalculation is to be done),

(d) circumstances in which responsibility for a treatment time guarantee may transfer to a different Health Board,

(e) the information that a Health Board is to provide to patients about the treatment time guarantee, including—
   (i) how waiting times are calculated,
   (ii) the circumstances in which the maximum waiting time may be extended, recalculated or suspended,
   (iii) such other information as the Scottish Ministers consider appropriate.

(4) The Scottish Ministers may by order—

(a) amend the duration of the maximum waiting time for the time being specified in section 10,

(b) specify such different period of time to be the maximum waiting time under section 10 in relation to any treatment or services specified in such order.

8 Breach of the treatment time guarantee

(1) This section applies where a Health Board has not complied with a treatment time guarantee.

(2) The Health Board must—

(a) make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity,

(b) provide an explanation to the patient as to why the treatment did not start within the maximum waiting time,

(c) give the patient details of—
   (i) the advice and support available (including in particular the patient advice and support service described in section 15), and
   (ii) how to give feedback or comments or raise concerns or complaints.

(3) In making the arrangements mentioned in subsection (2)(a), the Health Board—

(a) must not give priority to the start of any treatment where such prioritisation would, in the Health Board’s opinion, be detrimental to another patient with a greater clinical need for treatment,

(b) must have regard to the patient’s availability, and

(c) must have regard to other relevant factors.
9 Treatment time guarantee: guidance and directions
(1) Health Boards must, when taking steps to start the treatment of eligible patients, have regard to any guidance issued by the Scottish Ministers which relates to the treatment time guarantee (and in particular, Health Boards’ compliance with it).

(2) The Scottish Ministers may direct a Health Board to take specified action in relation to its compliance with the treatment time guarantee (including, in particular, the steps it must take).

(3) The Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such period as they consider necessary.

10 Treatment time guarantee: key terms
For the purposes of this section and sections 6 to 9—

“agreed treatment” means a specific treatment agreed between an eligible patient and the Health Board;

“eligible patient” means a patient of a description specified in the regulations to be made in pursuance of section 7(2)(a) as being eligible for the treatment time guarantee;

“Health Board” includes the National Waiting Times Centre Board;

“maximum waiting time” is the period of 12 weeks beginning with the date on which the patient agrees to the agreed treatment;

“treatment” means a surgical or medical intervention ordinarily provided by the Health Board (other than such treatments or services as may be specified in regulations made in pursuance of section 7(3)(a));

“treatment time guarantee” has the meaning given in section 6(2).

12 Encouragement of patient feedback etc.
(1) A relevant NHS body is to encourage patients to provide feedback, comments, concerns or complaints on health care.

(2) Patients may raise such concerns with or give such feedback to—

(a) the relevant NHS body, or

(b) a Patient Rights Officer.

(3) Where a concern is raised with or feedback is given to a Patient Rights Officer, the officer may pass such concern or feedback to the relevant NHS body (but may do so only with the consent of the patient).

(4) The relevant NHS body must consider feedback, comments, concerns or complaints received with a view to improving the performance of its functions.

(4A) The Scottish Ministers may require a relevant NHS body to provide them with information regarding the performance of the duties under subsections (1) and (4).

(5) The Scottish Ministers may give a relevant NHS body directions about the performance of the duties under subsections (1) and (4).
11 Arrangements for handling and responding to patient feedback etc.

(1) The Scottish Ministers must ensure that each relevant NHS body has adequate arrangements in place for the matters described in subsection (3).

(2) A relevant NHS body must ensure that each of its service providers has adequate arrangements in place for the matters described in subsection (3).

(3) The matters are—

(a) handling and responding to feedback, comments, concerns or complaints on health care made—

(i) by or on behalf of patients,

(ii) by or on behalf of such other persons as the Scottish Ministers may specify by regulations made under subsection (4)(a), and

(aa) identifying best practice,

(b) publicising how feedback and comments are to be given, or concerns and complaints are to be made and handled,

(c) giving a person who gives feedback or comments, or raises concerns or complaints details of the advice and support available to patients,

(d) publicising the details of the advice and support available to patients (and, in particular, the patient advice and support service serving the relevant NHS body),

(e) monitoring the feedback, comments, concerns or complaints received with a view to—

(i) identifying any areas of concern, and

(ii) improving the performance of its functions.

(4) The Scottish Ministers may—

(a) by regulations make provision about the—

(i) arrangements mentioned in subsections (1) and (2),

(ii) matters described in subsection (3),

(b) give a relevant NHS body directions about such arrangements or matters.

(4A) Directions under subsection (4)(b) may, in particular, include provision for the resolution of complaints by conciliation or mediation.

(5) In this section, a “service provider” is any person who provides health services for the purpose of the health service under a contract, agreement or arrangements made under or by virtue of the 1978 Act.

(6) The powers conferred on the Scottish Ministers by virtue of this section are without prejudice to their powers under the 1978 Act.

(7) Nothing done under or by virtue of this section is to preclude an investigation under the Scottish Public Services Ombudsman Act 2002 (asp 11) in respect of any matter.

13 Repeal of the Hospital Complaints Procedure Act 1985

The Hospital Complaints Procedure Act 1985 (c. 42) is repealed.
Patient advice and support service

14 Patient advice and support service: establishment and funding

(1) In the 1978 Act, in section 10(1) (Common Services Agency), after “section” insert “and section 10ZA”.

(2) After section 10 of that Act insert—

“10ZA Provision of patient advice and support service

(1) The Agency must secure the adequate provision of the patient advice and support service described in section 15 of the Patient Rights (Scotland) Act 2010 (asp 00) in relation to each relevant body.

(2) In exercising its function under subsection (1), the Agency must have regard to the desirability of the service being provided in the most efficient and effective manner possible.

(3) There may be more than one provider of the patient advice and support service.

(4) The patient advice and support service is not to be provided by—

(a) a Health Board,
(b) a Special Health Board,
(c) the Agency.

(5) Each relevant body must make to its provider of the patient advice and support service, in respect of the provider’s expenses (as respects its activities relating to the service), payments of such amounts, and at such times, as the Scottish Ministers may direct.

(6) For the purposes of this section, a “relevant body” is—

(a) a Health Board, and
(b) any other body that the Scottish Ministers may by order specify.”.

15 Patient advice and support service

(1) The patient advice and support service to be secured by the Agency under section 10ZA of the 1978 Act is to provide advice and support services to patients and other members of the public in relation to the health service.

(2) In particular, the patient advice and support service is to—

(a) promote an awareness and understanding of the rights and responsibilities of patients,
(b) advise and support persons who wish to make a complaint, raise concerns or give feedback about health care,
(c) provide information and advice on such matters as it considers likely to be of interest to persons using the health service,
(d) provide such—

(i) other advice or support,
(ii) reports on its activities,

as the Agency may specify.
(4) For the purposes of subsection (2), a reference to the rights of patients is a reference to the rights of patients under this Act.

(5) For the purposes of subsection (2), the responsibilities of a patient include the responsibility of the patient—

(a) for the patient’s own health and wellbeing, and

(b) to behave appropriately in the receipt of health care.

(6) The Scottish Ministers may by regulations make further provision about the patient advice and support service and in particular about the services it is to provide.

17 Duties to share information

(1) A relevant body must (where reasonably practicable and otherwise appropriate) give providers of the patient advice and support service information about—

(a) the relevant body (and the health service generally) including its organisation, procedures and specific services that it provides,

(b) any changes to the information mentioned in paragraph (a), and

(c) such other relevant matters as providers of the patient advice and support service may reasonably request.

(2) The Agency must secure that providers of the patient advice and support service give relevant bodies information about—

(a) the services that providers of the patient advice and support service provide,

(b) such other relevant matters as relevant bodies may reasonably request.

(3) No information is to be given under subsection (1) or (2) which would infringe patient confidentiality.

(4) For the purposes of this section “relevant body” has the same meaning as in section 10ZA(6) of the 1978 Act (provision of patient advice and support service).

18 Protections and limitations

(1) Nothing in this Act prejudices—

(a) the exercise of clinical judgement,

(b) the effective and efficient use of the health service organisation and resources.

(1A) Subject to subsection (2), nothing in this Act prejudices any other enactment or rule of law.

(2) Nothing in this Act gives rise to—

(a) any liability to pay damages,

(b) any right of action for specific implement,

(ba) any right of action for specific performance of a statutory duty,

(c) any right of action for interdict,

(d) any right of action for suspension.
(3) The rights conferred on a patient by this Act are in addition to, and do not affect, any other rights in relation to health care that a patient has, or may acquire, under any other enactment or rule of law.

(4) Subsection (3) does not affect the generality of subsection (1A).

Inquiries and default and emergency powers

18A Powers of the Scottish Ministers

(1) In sections 76, 77, 78 and 78A of the 1978 Act (inquiries and default and emergency powers) references to that Act include references to this Act.

(2) Section 77 of the 1978 Act applies to a Special Health Board in relation to the functions conferred or imposed on it by or under this Act.

General

19 Interpretation

(1) In this Act, unless the contrary intention appears—

“the 1978 Act” means the National Health Service (Scotland) Act 1978 (c. 29);

“the Agency” has the meaning given by section 3(2)(c);

“health care” means services provided under the health service;

“health care principles” has the meaning given by section 4(1);

“the health service” means the health service established in pursuance of section 1 of the National Health Service (Scotland) Act 1947 (c. 27);

“health service function” means any function under or by virtue of the 1978 Act which is a function concerned with, or connected to, the health service;

“patient advice and support service” is to be construed in accordance with section 15(1);

“relevant NHS body” has the meaning given by section 3(2).

(2) In this Act, unless the contrary intention appears, terms used in this Act and the 1978 Act have the same meaning as they have in the 1978 Act.

20 Ancillary provision

(1) The Scottish Ministers may by order make such consequential, supplemental, incidental transitional, transitory or saving provision as they consider necessary or expedient for the purposes of, or in consequence of, or for the purposes of giving full effect to, any provision of this Act.

(2) An order under this section may modify any enactment, instrument or document.

21 Orders, regulations and directions

(1) Any power conferred by this Act on the Scottish Ministers to make an order or regulations—

(a) must be exercised by statutory instrument,
(b) may be exercised so as to make different provision for different purposes (including different areas),

(c) except an order under section 22(3), includes power to make such consequential, supplemental, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient.

(2) No—

(a) order is to be made under section 1(4), 4(2) or 7(4),

(aa) regulations are to be made under section 7(1) or (3), or

(b) order is to be made under section 20 containing provisions which add to, omit or replace any part of the text of an Act,

unless a draft of the statutory instrument containing the order or regulations has been laid before, and approved by resolution of, the Parliament.

(3) Any other statutory instrument containing an order or regulations under this Act (except an order under section 22(3)) is subject to annulment in pursuance of a resolution of the Parliament.

(4) Any power to make directions under this Act includes power to vary or revoke such directions.

(5) Any power to make directions under this Act may be exercised—

(a) generally or to meet the circumstances of a particular area or matter,

(b) either in relation to all cases to which the power extends, or in those cases subject to exceptions, or in relation to any specified cases or classes of case, and

(c) subject to such other exceptions or conditions as the Scottish Ministers think fit.

22  Short title and commencement

(1) This Act may be cited as the Patient Rights (Scotland) Act 2010.

(2) This section and sections 20 and 21 come into force on Royal Assent.

(3) The remaining provisions of this Act come into force on such day as the Scottish Ministers may by order appoint.
SCHEDULE
(introduced by section 4(1))

HEALTH CARE PRINCIPLES

Patient focus

1. Anything done in relation to the patient takes into account the patient’s needs.
2. Patients are treated with dignity and respect.
3. Privacy and confidentiality are respected.
4. Health care is provided in a caring and compassionate manner.
5. Support necessary to receive or access health care is available.
6. The patient’s abilities, characteristics and circumstances are considered.

Quality care and treatment

7. Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.
8. The range of options available in the patient’s case is considered.
9. Health care is based on current recognised clinical guidance.
9A. Health care is provided in such a way as to avoid unnecessary harm or injury to the patient.
9B. Patients are cared for in an appropriate, clean and safe environment at all times.

Patient participation

10. Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing.
11. Patients are provided with such information and support as is necessary to enable them to participate in accordance with paragraph 10 and in relation to any related processes (general or specific).
12. Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect.

Communication

13. Communication about a patient’s health and wellbeing is clear, accessible and understood.
14. Communication about general services and processes and decisions is clear, accessible and understood.

Complaints

15. Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures.
Other

16 Waste of resources in the provision of health care is avoided.
Patient Rights (Scotland) Bill
[AS AMENDED AT STAGE 2]

An Act to make provision about the rights of patients when receiving health care; and for connected purposes.

Introduced by: Nicola Sturgeon
On: 17 March 2010
Bill type: Executive Bill
This document relates to the Patient Rights (Scotland) Bill as amended at Stage 2
(SP Bill 42A)

PATIENT RIGHTS (SCOTLAND) BILL
[AS AMENDED AT STAGE 2]

REVISED EXPLANATORY NOTES

CONTENTS

1. As required under Rule 9.7.8A of the Parliament’s Standing Orders, these revised Explanatory Notes are published to accompany the Patient Rights (Scotland) Bill (introduced in the Scottish Parliament on 17 March 2010) as amended at Stage 2. Text has been added or deleted as necessary to reflect the amendments made to the Bill at Stage 2 and these changes are indicated by sidelining in the right margin.

INTRODUCTION

2. These Explanatory Notes have been prepared by the Scottish Government in order to assist the reader of the Bill and to help inform debate on it. They do not form part of the Bill and have not been endorsed by the Parliament.

3. The Notes should be read in conjunction with the Bill. They are not, and are not meant to be, a comprehensive description of the Bill. So where a section or schedule, or a part of a section or schedule, does not seem to require any explanation or comment, none is given.

SUMMARY OF THE BILL

4. The Patient Rights (Scotland) Bill provides that it is the right of every patient that the health care received is patient-focused, which means that the provision of health care takes into account the patient’s needs. The Bill also provides that the health care received has regard to the importance of providing the optimum benefit to the patient’s health and wellbeing, allows for patient participation in decisions about their healthcare and provides appropriate information and support to allow them to do so.

5. The Bill introduces a guarantee (to be known as the treatment time guarantee) that eligible patients will start to receive treatment within 12 weeks of the treatment being agreed.

6. The Bill also provides for the right of every patient to give feedback or comments or raise concerns or complaints and to have access to support to do so. The Bill provides for the
Common Services Agency of the NHS in Scotland to secure the provision of a patient advice and support service.

**COMMENTARY ON SECTIONS**

**Section Z1: Patient Rights Charter**

7. Subsection (1) places a duty on Ministers to make an order which contains a charter of patients’ rights and responsibilities, which is to be known as the Patient Rights Charter (“the Charter”).

8. Subsection (2) provides that the Charter must contain all existing statutory rights and responsibilities, but may also give patients some new rights and responsibilities.

9. Subsection (3) provides that the Charter must not include any rights or responsibilities in relation to specific treatments or medicines. Also, the duty to make an order containing the Charter does not give Ministers any power to create new rights or responsibilities in relation to specific treatments or medicines.

10. Subsection (4) provides that the rights and responsibilities contained within the Charter apply to all NHS patients, but that some of the rights and responsibilities may apply only to specific groups of patients.

11. Subsection (5) places a duty on Scottish Ministers to review the Charter and update or revise it by order, when they consider it appropriate to do so.

12. Subsection (6) places a duty on Scottish Ministers to consult with those they think appropriate before they make an order containing the Charter or make an order to update the Charter.

**Section 1: Patient rights**

13. Subsection (1) sets out the right for every patient that the health care they receive is to be provided in a certain way, as described in subsection (2).

14. Subsection (2) describes the way in which that health care should be provided. It should be patient focused, which means regard must be had to the patient’s needs; to the importance of providing the optimum benefit to the patient’s health and wellbeing; and the patient should be encouraged to play an active part in decisions relating to their treatment and health care, and they should be provided with appropriate information and support, in a format that is appropriate for their needs, to be able to participate in such decisions. Health care providers must also have regard to and respect for the rights and responsibilities that patients have under the Charter. In practice, this might mean:

- A healthcare professional listening to a patient’s experience of coping with a long-term condition, and taking this into account when considering the best treatment options.
• A patient being encouraged to take their medication regularly or to become more active in order to lose weight and improve their health.
• A deaf patient being provided with a British Sign Language interpreter so that they can discuss their illness and treatment with their doctor, and make an informed decision as to their preferred treatment.

15. Subsection (3) gives patients a right to give feedback or comments, or raise concerns or complaints about the health care they have received.

16. Subsection (4) enables Scottish Ministers to modify subsection (2), following appropriate consultation. For example, bodies that might be consulted could include Health Boards, healthcare workers professional bodies, and members of the public.

Section 2: Patient rights: further provision

17. This section provides that meeting the rights of an individual patient should be balanced with the effect on the rights of other patients in receiving healthcare and should take into account the resources available and should be subject to the exercise of clinical judgement and the effective and efficient use of health service organisation and resources.

Section 3: Duty to uphold certain rights and principles

18. Subsection (1)(a) places a duty on the bodies specified in subsection (2), (which are Health Boards, Special Health Boards and the Common Services Agency for the Scottish Health Service) to uphold the health care principles set out in the schedule and the Charter when providing health care, where relevant to the service being provided. For example, it might be relevant for a hospital consultant to have regard to all of the principles in the schedule when discussing with a patient their diagnosis and treatment. Or, it might be relevant for a healthcare practitioner to check back with a patient that the patient has understood the information they have been given about their medication.

19. Subsection (1)(b) means that bodies specified in the subsection must also ensure that any person they enter into a contract, agreement or arrangement with also upholds the health care principles and the Charter, in so far as they are relevant to the service being provided. For example, this may apply to cleaning and catering services in hospitals, where they have patient contact, and to services provided at a primary care level, such as GP practices that are contracted by Health Boards. For example, it might be relevant for a member of catering staff to treat patients with dignity and respect when serving them food. However, ensuring that health care is based on current clinical guidance would not be relevant to a member of catering staff as they would not provide clinical care.

Section 5: Health care principles and Charter: guidance and directions

20. Subsection (1) provides that any body with a duty under section 3 must have regard to any guidance issued by Scottish Ministers about the practical application of the health care principles and the Charter. Subsection (2) provides that Scottish Ministers must consult relevant people or organisations before giving that guidance. For example, Scottish Ministers
may provide guidance about practical ways to implement Health Care Principle 5 “Support necessary to receive or access health care is available”, which might include ensuring patients are aware that they can have a third party with them to support them, such as a friend, relative or partner etc, or ensuring that patients are aware of translation, interpreting and communication support services and how to access them.

21. Subsection (3) provides that Scottish Ministers may give the bodies directions on how the health care principles and the Charter should be applied in practice.

Section 6: Treatment time guarantee

22. Section 6(1) and (2) establishes a maximum waiting time for eligible patients, known as the treatment time guarantee. The maximum waiting time is set out in section 10. Eligible patients should start to receive that treatment within 12 weeks of the treatment being agreed between the patient and the Health Board.

23. Subsection (3) provides that Health Boards must take all reasonably practicable steps in order to comply with the treatment time guarantee and subsection (4) gives examples of actions a Health Board must take to deliver the treatment time guarantee for its eligible patients. Health Boards must monitor the guarantee, take account of the patient’s clinical needs and the clinical needs of other eligible patients awaiting agreed treatments when arranging the patient’s treatment start date, make arrangements for the agreed treatment to start within its area or if it is unable to treat the patient in its own area, make arrangements either with another Health Board, with the National Waiting Times Centre Board or with another suitable provider such as the NHS in England or a private healthcare provider.

Section 7: Treatment time guarantee: further provisions

24. Subsections (1) and (2) place a duty on Scottish Ministers to, by regulations, provide a description of those patients who are eligible for the treatment time guarantee and show how the waiting time is to be calculated, specifying the circumstances in which days are not to be counted towards the maximum waiting time.

25. Subsection (3) gives Scottish Ministers power to make regulations providing for other matters relating to the treatment time guarantee, including the treatments and services and categories of treatments and services in relation to which the guarantee will not apply.

26. Subsection (4) allows Scottish Ministers to change the length of the treatment time guarantee by order. For example, this could be to make the maximum waiting time shorter, as services become more efficient. Different periods could be specified for different treatments, for example if some treatments should be delivered within a shorter time.

Section 8: Breach of the treatment time guarantee

27. This section sets out what will happen if a Health Board does not deliver the treatment time guarantee. Subsections 8(2)(a) and subsection (3)(a) mean that the Health Board will be required to offer the patient treatment in a way that will ensure the patient is admitted quickly
for treatment but will not distort the clinical priority of patients whose condition requires more urgent treatment. Subsections (3)(b) and (c) provide that the patient’s availability and anything else that is relevant should also be taken into account when making arrangements for the patient to be treated at the next available opportunity. Subsection (2)(c) places a duty on the Health Board to give the patient details of the advice and support that is available to them and information about how to give feedback or comments or raise concerns or complaints.

Section 9: Treatment time guarantee: guidance and directions

28. Section 9(1) provides that that Health Boards must have regard to any guidance issued by Scottish Ministers in terms of the treatment time guarantee.

29. Section 9(2) provides that Scottish Ministers may direct a Health Board to take action specified in the directions in relation to the guarantee.

30. Section 9(3) allows Scottish Ministers by direction to suspend the treatment time guarantee in exceptional circumstances. For example, an exceptional circumstance could be a public health emergency that required the treatment time guarantee to be suspended for a short period, to allow Health Boards to respond to the situation and concentrate all resources on dealing with the emergency, such as in the case of a severe outbreak of pandemic flu.

Section 10: Treatment time guarantee: key terms

31. This section defines the key terms referred to in sections 6 to 9 including specifying that the maximum waiting time for eligible patients for an agreed treatment is 12 weeks. The period of 12 weeks runs from the date on which the patient agrees the treatment to the date on which the treatment begins.

Section 12: Encouragement of patient feedback etc.

32. This section provides for Health Boards, Special Health Boards and the Common Services Agency for the Scottish Health Service to encourage patients to give feedback, comments, concerns or complaints on healthcare, and that patients can provide this to a Patient Rights Officer, or the relevant body. This section is also intended to ensure that when feedback is given to a Patient Rights Officer (PRO) that the PRO must make sure that the feedback is passed back to the relevant body. For example, if a patient felt more comfortable about giving feedback about their health care to a person who sits outwith the Health Board, there is a way for them to do this (via the PRO) and for Health Boards to be informed of that feedback.

33. Subsection (3) establishes that feedback should only be provided to the relevant body with the patient’s consent.

34. Subsection (4) means that NHS bodies must consider all feedback, comments, concerns or complaints to see how they could improve the delivery of their services.
35. Subsection (4A) means that NHS bodies may be required by the Scottish Ministers to provide information to Ministers on their performance in relation to encouraging patients to provide feedback, etc. and how this has been considered.

36. Subsection (5) means that Scottish Ministers may direct NHS bodies in how they should perform their duties in dealing with feedback, comments, concerns or complaints.

**Section 11: Arrangements for handling and responding to patient feedback etc.**

37. Subsection (1) provides that Scottish Ministers must ensure that each Health Board, Special Health Board and the Common Services Agency for the Scottish Health Service has: a suitable process in place for: handling and responding to feedback, comments, concerns or complaints on health care; publicising this process; identifying best practice; telling the complainant about the advice and support available to patients; publicising the advice and support available; and monitoring complaints.

38. Subsection (2) provides that those bodies must also ensure that anyone providing a health service on its behalf (such as GPs) must have suitable processes in place to deal with these matters.

39. Subsection (3) sets out the matters which the processes for handling feedback, complaints, concerns, or comments must deal with.

40. Subsection (4) gives Scottish Ministers power to give directions to NHS bodies and make regulations about the processes which must be in place. This enables Scottish Ministers to direct a Health Board to take appropriate actions. For example, if a particular Health Board had not been publicising its process adequately, Scottish Ministers could direct the Health Board to publicise the process via a series of posters and leaflets situated in hospitals and health centres.

41. Subsection (4A) provides that directions given by Scottish Ministers to NHS bodies may include provision for the resolution of complaints by conciliation or mediation.

42. Subsection (5) sets out what is meant by a “service provider”. For example, a “service provider” could be a GP practice.

43. Subsection (7) provides that nothing done in terms of section 11 excludes the Scottish Public Services Ombudsman’s (SPSO) right to carry out investigations, and the right of a person who has made a complaint to go to the Ombudsman. A complainant will normally still have had to exhaust (or at least invoke) the complaints mechanism provided before seeking a SPSO investigation.
Section 13: Repeal of the Hospital Complaints Procedure Act 1985

44. This section repeals the Hospital Complaints Procedure Act 1985 in full. The provisions of this Act are replaced by the measures around feedback and complaints outlined in the Bill.

Section 14: Patient advice and support service: establishment and funding

45. Section 14 amends the National Health Service (Scotland) Act 1978 by inserting a new section 10ZA. The functions of the Common Services Agency for the Scottish Health Service are extended to its new functions under section 10ZA. This, read with section 10(7) of the National Health Service (Scotland) Act 1978, means that there is a specific provision which states that in carrying out its functions the Agency shall act subject to, and in accordance with, such directions as may by given by the Scottish Ministers.

46. Section 10ZA requires the Common Services Agency for the Scottish Health Service to secure the provision of a patient advice and support service in relation to each Health Board, and any other body that Scottish Ministers specify in an order. In order to do this, the Agency will procure the service from a provider or providers. The service may be supplied by more than one provider, but not by a Health Board, a Special Health Board or the Agency itself.

Section 15: Patient advice and support service

47. Section 15 outlines the services that the patient advice and support service will provide to patients and members of the public.

48. Subsection (2)(a) and (b) place a duty on the patient advice and support service to promote awareness and understanding of the rights and responsibilities of patients and to advise people who want to complain, raise concerns or give feedback about healthcare. In practice, this might mean, for example, advising a patient who wanted to complain about their GP how to do so, and providing guidance to the patient as to whether the complaint is a matter for the GP practice complaints system, or whether it is a regulatory matter that should be referred to the regulatory body.

49. Subsection (2)(c) and (d) provides that the patient advice and support service may also provide other information and advice on subjects that might be of interest to people using the health service.

50. Subsection (5) sets out the patient responsibilities of which the patient advice and support service is to raise awareness and understanding. An example of such a patient responsibility might be to attend an agreed appointment or to cancel if necessary, well in advance, so that an appointment can be offered to another patient.
Section 17: Duties to share information

51. Section 17 subsection (1) places a duty on relevant bodies (such as Health Boards) to share information with the patient advice and support service, and allows the patient advice and support service to ask for any other information that it would find helpful. For example, the patient advice and support service might seek clarification on procedures or services offered in a particular area.

52. Subsection (2) means that the Agency must ensure that providers of the patient advice and support service give information on its services to the relevant bodies. It also means that these bodies can request information from the patient advice and support service. An example might be a Health Board asking its local patient advice and support service for statistical information on the numbers of women and men using the service because it wanted to compare that with the gender profiles of patients in the Health Board area.

53. Subsection (3) requires that when sharing information, patient confidentiality must be respected.

Section 18: Protections and limitations

54. Subsection (1) provides that the Bill does not prejudice the exercise of clinical judgement; the effective and efficient use of the health service organisation or resources or any relevant legislation or rule of law.

55. Subsection (1A) provides that nothing in the Bill affects any other relevant legislation or rule of law. This is, however, subject to the provisions of sub-section (2), which excludes the right to pursue specified legal remedies to enforce the rights in the Bill.

56. Subsection (2)(a) provides that the rights set out in the Bill are not of a nature that will impose any liability on any person to pay damages. This means that a patient could not claim damages from a Health Board for an alleged failure to deliver health care in the manner set out in the Bill.

57. Subsection 2(b), (ba), (c) and (d) provide that no person could enforce the rights set out in the Bill by an action for specific implement, specific performance of a statutory duty, interdict or suspension.

58. The interaction of the provisions in subsections (1A) and (2) do not alter or affect a person’s rights to take action to enforce rights which they have on grounds other than those conferred by this Bill, for example a right to claim damages in the case of medical negligence.

59. Subsections (3) and (4) clarify that patients have other rights when receiving health care (beyond those rights set out in the Bill) and that the Bill does not affect those other rights.
Section 18A: Powers of the Scottish Ministers

60. This section means that the ministerial powers available under sections 76 to 78A of the National Health Service (Scotland) Act 1978 will also be available to the Scottish Ministers in the context of the Bill. Sections 76 to 78A of the National Health Service (Scotland) Act 1978 relate to powers of inquiry, and default and emergency powers which are available to the Scottish Ministers, for example, where they consider that a Health Board (or other relevant body) is not adequately fulfilling its functions.

Section 19: Interpretation

61. This section provides legal definitions for key terms that have been referred to in the Bill.

Section 20: Ancillary provision

62. This section gives Scottish Ministers the power to make consequential, supplemental, incidental, transitional, transitory or saving provisions by order for the purpose of giving full effect to the Bill.

Section 21: Orders, regulations and directions

63. Subsection (1) provides that all regulations and orders under the Bill are to be made in the form of a statutory instrument and that regulations and orders may make different provisions for different purposes.

64. Subsection (2) provides that (i) orders made under sections 1(4), relating to changes in how healthcare is delivered, 4(2) relating to changes in the healthcare principles, 7(4) relating to the maximum length of time a patient should wait for treatment under the treatment time guarantee or section 20, relating to ancillary provision, and (ii) regulations made under section 7(1) or (3), relating to the treatment time guarantee, are to be subject to affirmative procedure.

65. Subsection (3) provides that any other statutory instrument made under the Bill (apart from under section 22(3), relating to the date that the provisions come into force) is to be subject to negative procedure.

66. Subsections (4) and (5) make provision for the way in which Scottish Ministers can exercise their powers of direction under the Bill.

Section 22: Short title and commencement

67. Subsection (2) means that that sections 20, 21 and 22 will come into force on the date of Royal Assent. The remaining provisions will come into force on a date or dates appointed by Scottish Ministers.
Schedule: Health care principles

68. The schedule sets out the health care principles. Section 3 of this Bill places a duty on Health Boards to uphold these principles when delivering healthcare. The principles should ensure that health services are provided in a way that places the patient and their needs and experiences at the centre of an interaction with health services, and which also ensures that patients are encouraged and provided with support to participate in decisions about their treatment and health care.
PATIENT RIGHTS (SCOTLAND) BILL

SUPPLEMENTARY DELEGATED POWERS MEMORANDUM

Purpose

1. This Memorandum has been prepared by the Scottish Government to assist the Subordinate Legislation Committee in its consideration of the Patient Rights (Scotland) Bill. This Memorandum describes provisions in the Bill conferring power to make subordinate legislation which were either introduced to the Bill or amended at Stage 2. The Memorandum supplements the Delegated Powers Memorandum on the Bill as introduced.

PROVISIONS CONFERRING POWER TO MAKE SUBORDINATE LEGISLATION INTRODUCED OR AMENDED AT STAGE 2

Section Z1 – Patient rights charter

Power conferred on: Scottish Ministers
Power exercisable by: Order made by statutory instrument
Parliamentary procedure: Negative resolution of the Scottish Parliament.

Provision

2. Section Z1 places a duty on Scottish Ministers to make an order containing a charter of rights and responsibilities to be conferred upon patients, to be known as the Patient Rights Charter. It is provided that the Charter must include all existing statutory rights and responsibilities conferred upon patients and may also confer new rights and responsibilities upon patients. The Charter must not include rights and responsibilities in relation to specific treatments or medicines and the provision does not enable the Scottish Ministers to confer such rights and responsibilities upon patients. The rights and responsibilities contained within the Charter are to apply to all patients of relevant NHS bodies, but may also include rights and responsibilities to apply to specific groups of patients only. The Scottish Ministers must review the Charter from time to time, and make revisions by order when they consider it appropriate to do so.

3. Prior to making an order either containing or revising the Charter, Scottish Ministers must consult such persons as they consider appropriate.

Reason for taking power

4. This was a non-Government amendment made at Stage 2 of the Bill process.
5. The Scottish Government understands that the intention behind section Z1 is to bring together into a single document the rights and responsibilities which patients have when they receive health care. It appears that section Z1 means that the Scottish Ministers would have to identify all existing legislation that gives rights or responsibilities to patients, and restate or list that legislation in a statutory instrument. It is not clear to the Scottish Government whether the reference to existing statutory rights is intended to pick up statutory rights conferred in the future. It is also not clear whether the provisions seek to, or would require the Scottish Ministers to, list or restate reserved legislation. The Scottish Government has some concerns that this provision may raise issues of legislative competence (albeit that the provisions could possibly be read down to avoid this). It is noted that there is no reference to patients’ common law rights.

6. The Scottish Government is concerned that providing that a Patient Rights Charter is to be set out in secondary legislation is inflexible, and issues as to the length and usability of the Charter for patients could arise. The Scottish Government intends to work together with the relevant Committee member who lodged the amendment at stage 2, in order to amend section Z1 so that its provisions are clearer and more workable.

**Reason for choice of procedure**

7. Due to the relevant amendment being technically deficient, the Committee member opted not to move the amendment which would have resulted in section Z1 being subject to affirmative resolution. By default the Order is therefore subject to negative resolution of the Scottish Parliament.

8. As stated above, the Scottish Government is concerned that it is inappropriate for the Patient Rights Charter to be set out in a statutory instrument. However, it is the Scottish Government’s position that, if the Patient Rights Charter is to be contained within an order, this should be subject to negative resolution, which will allow more flexibility to revise the Charter regularly and to take account of changes to other legislation (reserved and devolved) which may have an impact on the Charter.

**Section 7(1) – Treatment time guarantee: further provision**

**Power conferred on:** Scottish Ministers  
**Power exercisable by:** Regulations made by statutory instrument  
**Parliamentary procedure:** Affirmative resolution of the Scottish Parliament

9. Section 7(1) provides that the Scottish Ministers must, by regulations, make further provision about the treatment time guarantee. Section 7(2) provides that the regulations must set out the descriptions of patients who are eligible for the treatment time guarantee and how the waiting time is to be calculated. This reflects the provisions as drafted in the Bill as introduced.

**Reason for choice of procedure**

10. Section 21(2) of the Bill has been amended at stage 2 so that regulations made under section 7(1) are subject to affirmative procedure. This change was made in response to the recommendation by the Subordinate Legislation Committee and the Health and Sport Committee that the exercise of the power in section 7(1) should be subject to affirmative procedure because
of the significance of the guarantee and the significance and effect on the operation of that guarantee as regards the designation of eligible patients and the method of calculating the waiting time. The Scottish Government was content to follow this recommendation.

Section 7(3) – Treatment time guarantee: further provision

Power conferred on: Scottish Ministers
Power exercisable by: Regulations made by statutory instrument
Parliamentary procedure: Affirmative resolution of the Scottish Parliament

Provision

11. Section 7(3) gives power to Scottish Ministers to specify, by regulations, the treatments and services which will not be covered by the treatment time guarantee, the action a Health Board must take to ensure it complies with the treatment time guarantee, the circumstances in which the maximum waiting time for a patient can be recalculated or extended, or when the responsibility for a treatment time guarantee may transfer to a different Health Board, and the information that a Health Board is to provide to patients about the treatment time guarantee. This reflects the provisions as drafted in the Bill as introduced.

Reason for choice of procedure

12. Section 21(2) of the Bill has been amended at stage 2 so that regulations made under section 7(3) are subject to affirmative procedure. This change was made in response to the recommendation by the Subordinate Legislation Committee and the Health and Sport Committee that the exercise of the power in section 7(3) should be subject to affirmative procedure because of the significance, through the exercise of the power, of the exclusion of specified treatments and services from the guarantee. The Scottish Government was content to follow this recommendation.

Section 7(4) – Treatment time guarantee: further provision

Power conferred on: Scottish Ministers
Power exercisable by: Order made by statutory instrument
Parliamentary procedure: Affirmative resolution of the Scottish Parliament

Provision

13. This provision gives Scottish Ministers the power to change the maximum waiting time of 12 weeks to a different time period, and allow the maximum waiting time to be different for different categories of treatment or service. This reflects the provisions as drafted in the Bill as introduced.

Reason for choice of procedure

14. Section 21(2) of the Bill has been amended at stage 2 so that regulations made under section 7(4) are subject to affirmative procedure. This change was made in response to the recommendation by the Subordinate Legislation Committee and the Health and Sport Committee that the exercise of the power in section 7(4) should be subject to affirmative procedure given the significant impact the exercise of the power may have on the nature of the guarantee and on the
extent of the right afforded by sections 1(1) and 6(1) of the Bill. The Scottish Government was content to follow this recommendation.

Section 11(4) – Arrangements for handling and responding to patient feedback etc.

Power conferred on: Scottish Ministers
Power exercisable by: Regulations made by statutory instrument
Parliamentary procedure: Negative resolution of the Scottish Parliament

Provision

15. Section 11(3)(a)(ii) and (4)(a) provides that the Scottish Ministers may make regulations about the arrangements which relevant NHS bodies and their service providers must have in place to handle feedback, comments, concerns and complaints.

Reason for adjusting power

16. The scope of the power under section 11 was broadened by virtue of amendments at stage 2 so that the Bill now imposes a duty on Scottish Ministers to ensure that each Health Board, Special Health Board and the Common Services Agency has a suitable process in place for handling feedback, comments, concerns and complaints. The amendments also mean that there is specific provision to say that the arrangements for complaints procedure must include identifying best practice. The reason behind these amendments is to recognise that patients may not necessarily want to complain, but may (also) want to provide feedback or comments, or raise a concern. The intention is to ensure that patients and members of the public are able to feed in a range of views and that these will be monitored by relevant NHS bodies to improve the performance of its function.

Reason for choice of procedure

17. As per the Bill as introduced, regulations made under the provision at 11(3)(a)(ii) and (4)(a) will be subject to negative procedure.

Section 21(1)(c) – Orders, regulations and directions

Power conferred on: Scottish Ministers
Power exercisable by: order or regulations made by statutory instrument
Parliamentary procedure: affirmative or negative procedure of the Scottish Parliament

Provision

18. This provision allows Scottish Ministers, when making orders or regulations under this Act, to make such consequential, supplemental, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient.

19. Section 21(1)(c) was amended at stage 2 to ensure that this power does not apply to commencement orders. The Subordinate Legislation Committee said that it did not consider that it was appropriate to make ancillary provisions of substance in commencement orders which are subject to no parliamentary procedure. The Scottish Government was content to follow the
recommendation from the Subordinate Legislation Committee that the power in section 21(1)(c) should not apply to commencement orders.

Section 22(3) – Short title and commencement

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: no procedure

Provision

20. Section 22(3) provides for all sections of the enacted Bill (other than sections 20, 21 and 22) to come into force on such a day as the Scottish Ministers appoint by order.

21. This provision was amended at stage 2 to remove the power in section 22(3) to appoint different days for different purposes, in terms of when the provisions in the Act come into force. This position will now be covered by section 8(2) the Interpretation and Legislative Reform (Scotland) Act 2010.
Subordinate Legislation Committee

Remit and membership

Remit:

1. The remit of the Subordinate Legislation Committee is to consider and report on-

(a) any-

   (i) subordinate legislation laid before the Parliament;

   (ii) Scottish Statutory Instrument not laid before the Parliament but classified as general according to its subject matter;

   (iii) Pension or grants motion as described in Rule 8.11A.1;

and, in particular, to determine whether the attention of the Parliament should be drawn to any of the matters mentioned in Rule 10.3.1;

(b) proposed powers to make subordinate legislation in particular Bills or other proposed legislation;

(c) general questions relating to powers to make subordinate legislation; and

(d) whether any proposed delegated powers in particular Bills or other legislation should be expressed as a power to make subordinate legislation.

*(Standing Orders of the Scottish Parliament, Rule 6.11)*

Membership:

Bob Doris (Deputy Convener)
Helen Eadie
Rhoda Grant
Alex Johnstone
Ian McKee
Elaine Smith
Jamie Stone (Convener)
Committee Clerking Team:

Clerk to the Committee
Irene Fleming

Assistant Clerk
Jake Thomas

Support Manager
Lori Gray
Subordinate Legislation Committee

14th Report, 2011 (Session 3)

Patient Rights (Scotland) Bill as amended at Stage 2

The Committee reports to the Parliament as follows—

1. At its meetings on 1 and 22 February 2011, the Subordinate Legislation Committee considered the delegated powers provisions in the Patient Rights (Scotland) Bill as amended at Stage 2. The Committee submits this report to the Parliament under Rule 9.7.9 of Standing Orders.

2. The Scottish Government provided the Parliament with a supplementary delegated powers memorandum on the provisions in the Bill (“the supplementary DPM”)\(^1\). The Committee took evidence from the Scottish Government on the powers in section Z1 (Patient Rights Charter) and section 9 (suspension of waiting time guarantee) at its meeting on 1 February. On 10 February the Scottish Government wrote to advise the Committee that the Government had tabled amendments in relation to section 9 and that Dr Richard Simpson MSP had tabled further amendments to section Z1. As these amendments are directly relevant to the Committee’s concerns these amendments have been taken into account in this report.

3. The Committee is content with the powers at sections: 7(1), 7(3), 7(4), 11(4)(a), 21(1)(c) and 22(3).

Delegated Powers Provisions

Section Z1 – Patient Rights Charter

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4. This is a new power inserted by an amendment lodged by Dr Richard Simpson. Section Z1 requires the Scottish Ministers to make an order containing a charter of rights and responsibilities to be conferred upon patients, to be known as the Patient Rights Charter. It must contain all existing statutory rights and responsibilities.

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\(^1\) Supplementary Delegated Powers Memorandum
responsibilities conferred upon patients, and it may confer new rights and responsibilities upon patients, but does not enable the Scottish Ministers to confer rights and responsibilities in relation to specific treatments or medicines.

5. The Committee considers that the purpose and scope of this power is unclear. It was not clear to the Committee whether the Charter would simply list rights and responsibilities conferred upon patients by other legislation, or whether those rights and responsibilities would be restated in, and given further legal effect through, the Charter. The Committee notes from the evidence session that the Scottish Government takes the view that the Charter would list rights and responsibilities conferred upon patients which could be found in other legislation, and that the Charter would not be legally enforceable, given the terms of section 18 of the Bill. The Committee does not consider the preparation of such a list which is not intended to be legally enforceable to be an appropriate use of subordinate legislation.

6. The Committee considers that the power to confer new rights and responsibilities on patients in section Z1(2) is an inappropriate delegation of powers, on the basis that it confers a very wide discretion on the Scottish Ministers to alter patients’ rights and to impose responsibilities on them with very limited restrictions. The rights and responsibilities which could be conferred are limited only by section Z1(3), which provides that Ministers may not confer rights and responsibilities in relation to specific treatments or medicines, and by the need for any provision to be within legislative competence. The Committee considers that if the Scottish Ministers intend to confer additional rights or to impose responsibilities on patients then there is no reason why this cannot be done in the Bill itself or through subsequent primary legislation. The proposal that the Charter be used to create new rights and responsibilities also conflicts with the intention that the Charter is not legally enforceable.

7. The Committee notes that the member who introduced section Z1 has tabled amendments at Stage 3 which, if agreed to, will omit that section and replace it with provisions which make it clear that the Charter is to summarise patients’ rights and responsibilities. Through these amendments it is specifically provided that the Charter is not to give rise to new rights or responsibilities, and that it may not alter any existing rights or responsibilities. Instead of the Charter being contained in an order, it is not to take the form of subordinate legislation, although it is to be laid before Parliament before it is published. The Committee considers that these amendments address its concerns in relation to the purpose of the Charter and the appropriateness of it being contained in subordinate legislation.

8. The replacement provisions no longer confer delegated powers on the Scottish Ministers to make subordinate legislation. Instead, they must publish a Charter and lay a copy of it before Parliament. They are also required to review the Charter at least once in every five year period, and must revise it if it does not accurately summarise patients’ rights and responsibilities, or is not sufficiently effective in raising awareness of them. A revised Charter must similarly be laid before Parliament and published.

9. The Committee is of the view that power to make the Charter should not be exercisable by subordinate legislation, on the basis that the Charter is
not intended to have legal effect. It further considers that it is inappropriate to permit the Scottish Ministers to confer new rights and responsibilities on patients by way of inclusion in the Charter, and that it would be preferable for them to be stated on the face of the Bill or in subsequent primary legislation.

10. The Committee welcomes amendment 1 and related amendments which replace section Z1 and require that the Scottish Ministers make, lay before the Parliament and publish the Charter.

Section 9(3) – suspension of the treatment time guarantee

Power conferred on: The Scottish Ministers
Power exercisable by: Directions

11. Section 9(3) provides that the Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such periods as they consider necessary. Such directions are not subject to any parliamentary control or formal scrutiny. In its Stage 1 report the Committee recommended that, given the significance of a suspension of the guarantee the power under section 9(3) should be expressed as a power to make subordinate legislation. It asked the Scottish Government to consider further whether suspension of the treatment time guarantee should be subject to Parliamentary scrutiny, particularly when the suspension would remain in place for a significant period of time.

12. Having taken further evidence from the Scottish Government on the matter the Committee accepts that there may be some circumstances in which the suspension may be very short and therefore the use of subordinate legislation would be disproportionate. However, the Committee remains of the view that there will come a point at which the period of suspension merits investigation by the Parliament.

13. The Committee is pleased to note that the Scottish Government has tabled an amendment which will limit the period for which the treatment time guarantee may be suspended by directions to 30 days. It further provides that if the Ministers wish to extend that suspension they may do so by making an order. Such an order may come into force on being made, but will require to be approved by resolution of the Parliament within 28 days to remain in force.

14. The Committee acknowledges that the period for which the treatment time guarantee may be suspended by directions is ultimately a policy issue for consideration by the Parliament, and is content to refer this matter to it for consideration of whether a period of 30 days is appropriate.

15. The Committee recommends that suspension of the treatment time guarantee for more than a restricted period of time should be exercised through subordinate legislation and subject to Parliamentary approval within 28 days of the suspension taking effect if it is to continue in force. The Committee recommends that section 9(3) should be amended to achieve
this, and welcomes the Scottish Government’s amendments 14 and 15 to this effect.

16. The Committee draws to the attention of the Parliament the proposed maximum period for which the treatment time guarantee may be suspended by directions, which is 30 days, and recommends that the Parliament consider whether this period is the appropriate point at which the Parliament’s approval should be required.
FOR INFORMATION

PATIENT RIGHTS (SCOTLAND) BILL – STAGE 3

Amendments lodged in relation to section Z1 (Charter of Patient Rights and Responsibilities) and section 9 (Treatment time guarantee: suspension)

Section Z1

Dr Richard Simpson

1 Leave out section Z1 and insert—

<Charter of Patient Rights and Responsibilities

(1) The Scottish Ministers must, within 6 months of the coming into force of this section, publish a document to be known as the Charter of Patient Rights and Responsibilities (“the Charter”).

(2) The Charter must set out a summary of the rights and responsibilities (as existing at the date of publication) of patients and relevant persons.

(3) The Charter may also include—

(a) a summary of the duties of relevant NHS bodies,

(b) a summary of the behaviour expected from patients and relevant persons,

(c) such other information as the Scottish Ministers consider relevant in relation to health care or the health service (for example, information relating to targets for the periods of time within which patients are to be treated).

(4) Nothing in the Charter is to—

(a) give rise to any new rights,

(b) impose any new responsibilities, or

(c) alter (in any way) an existing right or responsibility.

(5) For the purposes of this section and section (review and revision of Charter), a “relevant person” is—

(a) a person who has a personal interest in the health care of a patient (for example a member of the patient’s family or a carer),

(b) such other categories of person as the Scottish Ministers consider appropriate.

(6) The Charter is to be published in such form and manner as the Scottish Ministers consider appropriate.

(7) Before publishing the Charter under subsection (1), the Scottish Ministers must—

(a) consult such persons as they consider appropriate,

(b) lay a copy of the Charter before Parliament.

(8) The Scottish Ministers must, as soon as reasonably practicable after publication of the Charter under subsection (1), notify each relevant NHS body of the publication of the Charter.

(9) Each relevant NHS body must make available without charge copies of the Charter to patients, staff and members of the public.
(10) In carrying out the duty under subsection (9), a relevant NHS body must take account of the particular needs of the persons to whom the Charter is to be made available as to the form of the Charter (for example by making it available in different languages or in Braille).

After section Z1

Dr Richard Simpson

2 After section Z1, insert—

<Review and revision of Charter

(1) The Scottish Ministers must carry out a review of the Charter at least once in any period of 5 years.

(2) The purposes of a review under subsection (1) are—

(a) to ensure that the Charter continues to accurately summarise the rights and responsibilities of patients and relevant persons (as existing at the date of review), and

(b) to assess how effective the Charter is in raising awareness of the rights and responsibilities of patients and relevant persons.

(3) When reviewing the Charter under subsection (1), the Scottish Ministers must also review how effective the arrangements for the publication and distribution of the Charter have been in promoting awareness of the Charter and, if they consider it appropriate, take such steps as they consider necessary to improve those arrangements.

(4) In carrying out a review under subsections (1) and (3) the Scottish Ministers must consult such persons as they consider appropriate.

(5) The first review under subsection (1) must be completed not later than 5 years from the date on which the Charter is published under section (Charter of Patient Rights and Responsibilities)(1).

(6) The Scottish Ministers must revise the Charter where, following a review under subsection (1), the Scottish Ministers consider that the Charter—

(a) does not accurately summarise the rights and responsibilities of patients and relevant persons, or

(b) is not sufficiently effective in raising awareness of the rights and responsibilities of patients and relevant persons.

(7) The Scottish Ministers may revise the Charter at any other time if they consider it appropriate to do so (whether following a review under subsection (1) or otherwise).

(8) Where the Scottish Ministers revise the Charter under subsection (6) or (7), they must—

(a) publish it as so revised (in such form and manner as they consider appropriate),

(b) notify each relevant NHS body of the publication of the Charter as so revised.

(9) Before publishing the Charter under subsection (8)(a), the Scottish Ministers must—

(a) consult such persons as they consider appropriate, and

(b) lay a copy of the Charter before Parliament.
(10) In this Act, a reference to the Charter is a reference to the Charter as it may be revised from time to time.

After section 9

Nicola Sturgeon

14 After section 9, insert—

<Treatment time guarantee: suspension>

(1) This section applies where the Scottish Ministers consider that exceptional circumstances exist.

(2) The Scottish Ministers may direct that the treatment time guarantee be suspended for such period as they consider necessary.

(3) But such period of suspension must not exceed 30 days.

(4) The Scottish Ministers may by order—

(a) extend the duration of a period of suspension under subsection (2) beyond the 30 day limit in subsection (3) for such further period as they consider necessary,

(b) suspend the treatment time guarantee for such period in excess of 30 days as they consider necessary.

(5) An order made under subsection (4) (other than one to which subsection (7) applies)—

(a) must be laid before the Scottish Parliament, and

(b) ceases to have effect at the expiry of the period of 28 days beginning with the date on which it was made unless, before the expiry of that period, the order has been approved by resolution of the Parliament.

(6) Subsection (7) applies to an order made under subsection (4) consisting only of—

(a) provision revoking an earlier order under subsection (4), or

(b) such provision and provision made by virtue of section 21(1)(c).

(7) An order to which this subsection applies is subject to annulment in pursuance of a resolution of the Parliament.

(8) In reckoning for the purposes of subsection (5)(b) any period of 28 days, no account is to be taken of any period during which the Scottish Parliament is—

(a) dissolved, or

(b) in recess for more than 4 days.

(9) Subsection (5)(b) is without prejudice to—

(a) anything previously done by reference to—

(i) a direction under subsection (2),

(ii) an order under subsection (4), or

(b) the making of a new order under subsection (4).>
Present:

Bob Doris (Deputy Convener)  Helen Eadie
Alex Johnstone  Ian McKee
Elaine Smith  Jamie Stone (Convener)

Apologies were received from Rhoda Grant

Patient Rights (Scotland) Bill: The Committee took evidence on the Bill after Stage 2 from—


Patient Rights (Scotland) Bill (in private): The Committee considered the evidence heard earlier in the meeting and agreed to seek further information from the Scottish Government.
Patient Rights (Scotland) Bill: After Stage 2

The Convener (Jamie Stone): Welcome to the Subordinate Legislation Committee's third meeting of 2011. We have received apologies from Rhoda Grant. I ask everyone to turn off mobile phones, BlackBerrys and that sort of thing. I heard something ringing earlier, but it was outside the room, I think.

The first agenda item is our old friend the Patient Rights (Scotland) Bill. I extend a warm welcome to the Scottish Government officials who have joined us. They are Ruth Dickinson, bill team officer; Fiona Montgomery, head of patient support and participation; Francesca Rennie, from the legal directorate; and Margaret Duncan, waiting times policy lead. I remind members that stage 3 of the bill will take place on 24 February. I understand that Fiona Montgomery would like to make a short opening statement.

Fiona Montgomery (Scottish Government Directorate for Chief Nursing Officer, Patients, Public and Health Professions): We are here to discuss the bill as amended at stage 2, but I want to give the committee an update on one particular issue. At stage 2, the Cabinet Secretary for Health and Wellbeing advised the Health and Sport Committee that there were difficulties with the amendments on a patient rights charter and with the proposals that now appear as section Z1 of the bill. The section introduces a duty on ministers to make an order that puts into statute a patient rights charter, which is to set out all existing statutory rights and responsibilities that are conferred on patients.

The Scottish Government believes that there are several difficulties with section Z1 as drafted. For example, it appears that such an order, which would be subject to the negative procedure, could require to be updated regularly and brought before the Parliament every time it was altered. In addition, if the charter is to cover reserved as well as devolved legislation, there might be legislative competence issues. As the cabinet secretary advised the Health and Sport Committee, the Government has been considering how section Z1 can be amended at stage 3 in a way that will have the desired effect without the difficulties that are present in the current draft.

The Convener: Without further ado, I move to Elaine Smith to ask questions, given what we have heard.

Elaine Smith (Coatbridge and Chryston) (Lab): The committee understands that the intention behind the new section is to set out patient rights and responsibilities in one document. Do you agree that that is the intention?

Fiona Montgomery: Yes.

Elaine Smith: What is the legal effect of incorporating a right into the charter, in terms of the status of the charter and any existing provisions that are covered by the charter?

Francesca Rennie (Scottish Government Directorate for Legal Services): It is probably for me to answer that. Just to explain, I am here not to provide legal advice for the committee, but to set out the Government's position in relation to the stage 2 amendments in question. As the committee is aware, they were non-Government amendments and the Government spoke against them, as we had concerns about the provisions.

On the status of section Z1, it creates a duty on the Scottish ministers to set out in an order the rights and responsibilities of patients. The order is to “include all existing statutory rights and responsibilities conferred upon patients”.

There are issues around the definition of statutory rights and responsibilities and what that would cover. That would need to be looked into. Some existing statutory rights are set out in reserved legislation, which is another of our concerns.

I do not know whether that answers your question—it might not.

Elaine Smith: Although the Government was not supportive of the amendments, it must now take a view on the practical application of the provisions and on the legal implications. We are trying to tease out a wee bit more of that from you. We are grateful that you are here and trying to assist us with the matter. Perhaps some of my colleagues want to come in on that point.

Ian McKee (Lothians) (SNP): In the bill as amended at stage 2, under the heading “Patient rights”, section 1(2)(e), on page 2, states that health care is to “have regard to and respect for the rights and responsibilities conferred on patients”.

What do you think about having that under the heading “Patient rights”? It seems that people will have a right to have responsibilities, if you see
what I mean. Do you not think that those sit rather uneasily together?

Francesca Rennie: In general, we have concerns about the amendments regarding the patient rights charter. The Government will lodge amendments for stage 3. We will work towards that and we are considering how the provisions can be amended at stage 3. I agree that the Government is concerned about section 1(2)(e).

Helen Eadie (Dunfermline East) (Lab): It is several weeks since we considered the issue in the Health and Sport Committee, and I am concerned that you are still reflecting on it. I hoped that you would have got nearer to clarity in the areas of doubt. I press you to be a little more forthcoming on that.

Francesca Rennie: As the cabinet secretary indicated at stage 2, we are working towards lodging amendments. They are not finalised but, broadly speaking, they would place a duty on the Scottish ministers to publish an information document containing the rights and responsibilities of patients, rather than to set those out in a statutory instrument, which the Government considers would have limitations and would negate what is understood to be the intention behind section Z1.

Helen Eadie: When the issue was debated in the Health and Sport Committee, the thrust of the discussion and debate was that the committee wanted to have legislative teeth behind the charter and thought that anything less would be a step backwards. That was my understanding of the committee’s discussions. If we simply have an information document, we have no better than the document that was referred to in various proceedings by Ross Finnie. If we simply have guidance, that does not have legislative teeth, which is what the committee and the cabinet secretary were keen to have. I am concerned about the direction of travel that the Government seems to be taking.

Fiona Montgomery: One difficulty is about legislating for responsibilities. It is not the Government’s policy to legislate for individual patient responsibilities, because of the difficulties about imposing sanctions on patients. That is one reason why we did not favour a statute.

Helen Eadie: The bill is actually called the Patient Rights (Scotland) Bill. I know that, in the parlance that we all engage in, we can embrace the responsibilities quickly. Every one of us would accept that we have responsibilities in life, but the whole purpose and raison d’être of the bill is to give patients rights. If we are back-pedalling on that, that makes a nonsense of what we have been trying to establish.
the effect of the rights would be maintained. That is the Government’s position.

**The Convener:** At present.

**Francesca Rennie:** Yes.

**The Convener:** Stage 3 is still before us. It will be interesting to see what happens in the meantime.

**Elaine Smith:** How do you envisage the new power being exercised in practice? In your view, is subordinate legislation an appropriate means of achieving the intention?

**Francesca Rennie:** The Government’s position is that subordinate legislation is inappropriate.

**Elaine Smith:** Will you explain that further?

**Francesca Rennie:** I have already explained that the fact that the patient rights charter would be set out in subordinate legislation would affect how usable patients would find the charter, because of how we would be able to describe what their rights are, for example.

**Elaine Smith:** Right—so you are quite clear about that point.

Helen Eadie mentioned the stage 2 debate on the amendment. During that debate, the member who lodged the amendment indicated that his intention in proposing the provisions was to address the concern that the primacy of the bill might affect existing rights that are already set out in legislation, statute or common law, or through the common practice of the national health service. Is that concern valid?

**Francesca Rennie:** Could you repeat that please?

**Elaine Smith:** The primacy of the bill might affect existing rights as set out in legislation, statute or by common law, or through common practice in the national health service. Is that concern valid?

**Francesca Rennie:** Is the concern that the bill will affect existing statute?

**Elaine Smith:** Yes.

**Francesca Rennie:** Section 18 provides that nothing in the legislation will affect existing statute.

**Elaine Smith:** That is fine. There would be no advantage in considering subordinate legislation to address that concern, because you do not see that as a concern because it would be addressed by section 18. Is that what you said?

**Fiona Montgomery:** Yes.

**Ian McKee:** I draw your attention to section Z1(2), which says that in relation to specific treatments or medicines. The power would also be limited by the restraints on the legislative competence of Scottish ministers.

**Ian McKee:** How do you think the provisions would be used in the context of the existing national health service regime?

**Francesca Rennie:** If you are asking whether the Government will be looking to confer new rights and responsibilities when implementing the provision if it survives stage 3, I understand that that is not the current intention. My policy colleagues might want to comment.

**Ian McKee:** You talk about the current intention, but we are talking about the law. If, under the provisions, patients were given new rights and responsibilities that were contradictory to the existing law, which would have primacy? Would it be the new rights and responsibilities that were introduced under the charter, or would it be the existing law, which would have been altered by the new rights and responsibilities?

**Francesca Rennie:** The Government’s position is that there would be no incentive to propose a right or responsibility that would contradict existing law. Primacy would be considered when we were considering conferring the new rights.

**Ian McKee:** I am sure that the Government has no desire to do that, but as a result of the way in which section Z1 is written, new rights and responsibilities could be introduced and, theoretically, they could conflict with rights and responsibilities that are enshrined in existing law.

**Francesca Rennie:** Yes, but it would be within the confines of legislative competence.

**Ian McKee:** Which would take primacy?

**Francesca Rennie:** If I have understood your question correctly, it would be the new rights and responsibilities.
Ian McKee: Do you have a view on how any rights conferred by the charter would be enforced against third parties in practice?

Francesca Rennie: I might veer into giving the committee legal advice if I answered that question.

Ian McKee: So you do not have an official view.

Francesca Rennie: Can you repeat the question, please?

Ian McKee: The charter confers certain rights. Could they be enforced against third parties? Are they enforceable?

Francesca Rennie: It is our understanding that, because section 18 has not been amended, section Z1 does not intend to give legal effect to the charter.

Ian McKee: Do you mean even if there are new rights?

Francesca Rennie: Yes.

Bob Doris (Glasgow) (SNP): For my comprehension of all this, is it the Government’s position that any new rights that are to be extended to patients should be included in the bill because that would maximise scrutiny, and that it is not appropriate for them to be in subordinate legislation?

Francesca Rennie: The Government’s position is that, as drafted, section Z1 does not achieve what is understood to be the aim of section Z1. I do not know that I can say much more.

Ruth Dickinson: It might help if I said a bit more about the amendments that we are considering, just to give the committee a flavour of the Government’s position.

We might lodge amendments to insert a provision that an information document would have to be published that would list existing rights and responsibilities. We are considering that any amendments would mean that the charter could not create new rights and responsibilities, nor could it alter existing ones. The Government’s position is that there are pitfalls in the approach that is taken by section Z1 at the moment.

Bob Doris: So the Government would seek to amend section Z1 in such a way that there could be a charter, but it could not be used to extend patient rights. Is that correct?

Ruth Dickinson: Yes.

Bob Doris: That goes back to my initial question. There are patient rights in the bill. The waiting time guarantee is a patient right and it is on the face of the bill. I ask again: is it the Government’s position that any extension of patient rights—such as the waiting time guarantee—is best placed in the bill rather than in a charter and that, rather than amending the charter to make it work, you are amending the charter to ensure that it does not mess things up?

Fiona Montgomery: The Government has put forward the rights that it thinks are correct at this point, but we do not know what any future Government may think. Putting them on the face of the bill rather than lower down the chain will ensure that they receive the scrutiny that they require.

Bob Doris: I apologise—that is the clarification that I was looking for. The Government favours putting any additional patient rights on the face of the bill rather than in subordinate legislation. That is very helpful, thank you.

Ian McKee: Does the Government intend any new patient right that is in the bill, such as the waiting time guarantee, to be in the charter along with all the other existing rights?

Ruth Dickinson: Yes.

Ian McKee: Thank you.

The Convener: Thank you. It is Helen Eadie’s turn.

Helen Eadie: I am still not content with the answers that have been given, so I will revisit some of the questions. Correct me if I am wrong, but I understand that, in committee, the arguments that members have had at the various stages of the bill have focused on the fact that there will not be a charter—I think that that was Bob Doris’s point. A moment ago, you said that there will be a charter, but my understanding is that there will not be a charter unless section Z1 stands. Is that the case?

Ruth Dickinson: At stage 2, the cabinet secretary committed to the principle of a charter.

Helen Eadie: That is what I thought.

Ruth Dickinson: That is correct. However, she did not necessarily commit to how it will be drafted, for all the reasons that we have been through. We are working to amend the bill so that it may include a charter, which will be set out slightly differently.

Helen Eadie: On the one hand, the phrase “information document” has been used repeatedly today; on the other hand, you are saying that there will be a charter. Which is it to be?

Ruth Dickinson: It will be both. It will be an information document, but it will be called a patients charter, a charter of patients’ rights or something along those lines.

Helen Eadie: But it will be only an information document; it will not contain any legally enforceable rights.
Ruth Dickinson: Yes. The document will be an information document—that is correct.

Helen Eadie: So it will not contain legally enforceable rights. I am happy that that has been clarified. Does anyone want to add anything to that?

Fiona Montgomery: It will refer to a range of rights, some of which will be legally enforceable and some of which will not. It will refer to the whole charter.

Francesca Rennie: The charter itself will be an information document.

The Convener: I can see the tidiness of that.

Bob Doris: I apologise to Helen Eadie, but maybe I have not understood. I thought that the essence of the Government’s issue was not the idea of a charter that would draw existing rights together irrespective of what it was called; I thought that the Government’s issue was that, through the use of subordinate legislation, new rights could be added to the charter that would be legally enforceable, and that is why the Government wants to amend the charter at stage 3. Is that correct?

Ruth Dickinson: Yes. My colleague has given some of the reasons why we do not think that the subordinate legislation route is appropriate. I do not know whether Francesca Rennie wants to say anything more about that.

Francesca Rennie: Yes, that is right. We want to amend the provisions because they lack clarity, for starters. Also, we do not think that it is appropriate to have a charter containing all existing statutory rights in subordinate legislation.

The Convener: The discussion has been helpful to the committee and everything that has been said is now a matter of record in the Official Report. These matters will be examined in much greater detail at stage 3, but that has been a helpful discussion. Let us now return to where we were.

Helen Eadie: That was helpful. We are told that the advantage of subordinate legislation is the fact that it can be amended quickly. You must reflect on that. It is why we, as elected members, choose to use affirmative processes that ensure that the full Parliament scrutinises a statutory instrument or negative processes whereby statutory instruments tend to be nodded through much more quickly.

I can imagine legislation being passed at Westminster that requires the legislation that we enact in Scotland to be updated and amended. I would have thought that the subordinate legislation route would be helpful for a charter of this nature, because the charter could be contained in a single document, and it could be updated to reflect any added legislative requirements from Westminster. I will let that stick to the wall, unless the officials want to comment.

Fiona Montgomery: As Francesca Rennie said earlier, that would mean that we could refer only to the act, whereas in an information-type charter we could explain it.

Helen Eadie: That takes us neatly to the next issue. You have already covered legislative competence, to an extent, but perhaps you want to expand on what you have said, given the debate that we are having. Do you want to add anything about legislative competence and the issues that might arise from the things that we are looking at today?

Francesca Rennie: First, we believe that the provisions in section Z1 are within the competence of the Scottish Parliament, therefore the bill would not be outwith competence if they survived stage 3. However, in drafting any order in accordance with those provisions, we believe that a fine line would need to be observed to ensure that we did not encroach on reserved matters in terms of the legislative competence of the Scottish ministers.

Helen Eadie: Right. The supplementary delegated powers memorandum talks about flexibility, and the length and usability of the charter. You are suggesting that, as the bill is currently drafted, the charter should be subject to negative procedure. Where specifically do your concerns lie regarding the flexibility of that process?

Francesca Rennie: Our concern lies, for instance, in the fact that we may need to update any such charter regularly. Negative procedure would be appropriate, as it would allow us to do that.

Helen Eadie: You would prefer negative procedure to be used to allow that to happen.

Francesca Rennie: Yes, but it is open to others to have a different view on the appropriate parliamentary procedure.

Helen Eadie: You think that that would be the way to address concerns, so that there could be an updated charter.

Francesca Rennie: No. The position of the Government is that we have fundamental concerns about section Z1 and that, if it is to survive stage 3, any order made under it should be subject to negative procedure. Our fundamental position is that we want to amend section Z1.

Helen Eadie: That would enable a quick, speedy response to anything that was happening in either European or Westminster legislation.

Francesca Rennie: Yes.
The Convener: We are grateful to Ruth Dickinson for giving us a taste of an amendment. If you have nothing else to add, we will move on.

Bob Doris: Let us move on to another area of the bill—the power to suspend the treatment time guarantee, under section 9(3). I believe that we raised the matter at stage 1, due to concerns about it, and that correspondence on the issue is on-going.

The bill will allow waiting time guarantees to be suspended by ministerial direction under “exceptional circumstances”, but there is no definition of what would constitute “exceptional circumstances”. In practice, little use may be made of the power. It may be used, for example, when there is an infection control incident and parts of a hospital must be isolated, meaning that waiting time guarantees cannot be met. We would understand that. However, the bill does not determine how long the suspension would last or for what reasons it could be introduced. Therefore, although we accept that, by and large, Governments use such extensive powers sensibly, it is our job as the Subordinate Legislation Committee to ensure that the provision is backed up by the appropriate checks and balances.

Has any thought been given to amending section 9(3) so that the suspension could be activated immediately by ministerial direction but, within a set number of days, the matter would have to return to the Parliament in subordinate legislation to be backed up by the appropriate scrutiny and a decision of the Parliament?

14:45

Francesca Rennie: My colleague Margaret Duncan might have something to say about the power of suspension.

Margaret Duncan (Scottish Government Directorate for Health Workforce): We do not know what the suspension would be for or what the consequences would be for waiting times. There could be an infection control incident that could be sorted within a week, with not a lot of patients infected, but we could have pandemic flu with thousands of people across Scotland using beds. We would have a major issue getting all the patients whose operations were cancelled back into the system to deliver the waiting times. There are different scenarios, which is why we cannot be descriptive.

A few years back, when the plastics factory in Glasgow blew up, as soon as the health board knew that there were casualties, it phoned us and said that it might need to suspend its operations, with a suspension of the waiting time target. However, it did not know the volume at that stage. We were happy for it to go ahead with that, and said that, once we had an idea of the impact, we would be happy to grant a suspension. The next morning, the board told us that, unfortunately, there had mainly been fatalities and very few patients were in hospital for care, so the incident had had no effect. However, we were prepared to act. The board had to cancel operations for the next day just in case and some of those people would have been at the maximum of their wait.

The measure is to allow us to deal with such incidents. It could be a major road accident or train crash, but we cannot predict what it would be. We want to be able to act quickly and to tell boards that they can have a suspension. We can then quickly work up the detail on what the volume is likely to be. We also need a recovery plan to get all the people back in. We do not want to suspend the guarantee and then find that, when we remove the suspension, people whose operations have been suspended wait forever until they are treated because they are back into the normal waiting time route for patients.

Bob Doris: That is a good example. I come from Maryhill, so I know that the plastics factory explosion had quite an impact on the community. I understand the potential knock-on consequences of such a serious and unforeseen incident, as does the committee. The committee cannot second guess how any future Government might use such wide-ranging powers. That is what we had concerns about. We suggested that if, within a set period—whether 30, 60 or 90 days—the suspension was not lifted and the waiting time guarantee was not recommenced, the Government would have to come to the Parliament and have its decision scrutinised. I hope that that would be flexible enough to deal with national emergencies such as those that we have spoken about.

Margaret Duncan: I am happy to give that further consideration and to write to the committee, if that would be appropriate. Obviously, we need to give more thought to the policy.

The Convener: That brings our questions to an end. I thank the witnesses for joining us. The session has been detailed, highly informative and thought provoking, perhaps for both sides.
PATIENTS RIGHTS (SCOTLAND) BILL - CONTAMINATED BLOOD - STAGE 3 AMENDMENT

The Scottish Government Stage 3 amendments to the Patients Rights (Scotland) Bill are due to be lodged with Parliament on 10 February 2011.

I am writing to advise you that I intend, as part of this process, to lodge one further set of amendments which seek to amend the provisions of section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 ('the 2005 Act'). The purpose of these are to introduce additional categories of persons to whom payments may be made by Scottish Ministers under a scheme for persons affected with hepatitis C through NHS treatment with blood/blood products.

Background

As you may be aware, in October 2010, Anne Milton MP, the current Parliamentary Under Secretary of State for Health at the Department of Health (DH) announced that she intended to review the current provisions for those infected by HIV/hepatitis C in this way. On 10 January this year, Rt Hon Andrew Lansley MP published the Review report which included recommendations on the provision of additional support to those patients and others associated with them, particularly those with hepatitis C infection. DH officials have now begun to implement the Review recommendations in England but I wished to hold off making an announcement in Scotland until I had discussed the recommendations with patient representatives here.
I had a meeting with patient representatives on 3 February 2011 who indicated that they wished time to further consider the detail of the DH proposals and agreed to let me have their further thoughts by 17 February. I intend to make a formal announcement regarding plans for Scotland shortly thereafter.

However, in order to have the legislative authority to make payments to a new category of claimant, I need to secure an amendment to s.20 of the 2005 Act. The PRB gives us the only opportunity to do this before dissolution.

Purpose of Amendment

The provisions contained in section 28 of the 2005 Act give Scottish Ministers powers to set up a scheme to make payments to those infected with hepatitis C through NHS treatment with blood/blood products. It also defines the general categories of persons to whom payments can be made under any such scheme, with further eligibility criteria being specified in the terms of the scheme(s) made under that section. Should I wish in due course to make payments to a new category (or categories) of claimants under any existing or new scheme, as they have decided to do in England, section 28 would need to be amended. As a result, to ensure that, if I chose to do so, I can put in place any such new arrangements in Scotland, quickly, following my announcement and thus ensure that any newly eligible claimants can submit applications for support quickly thereafter (and not have to hold off until legislative changes in the new Parliamentary session later in 2011 at the earliest), I am putting forward these amendments, using the Patient Rights Bill as a vehicle.

I hope this is helpful in explaining, in advance, the background and purpose of these particular amendments.

NICOLA STURGEON
Marshalled List of Amendments selected for Stage 3

The Bill will be considered in the following order—

Sections Z1 to 22  Schedule
Long Title

Amendments marked * are new (including manuscript amendments) or have been altered.

Dr Richard Simpson

1  Leave out section Z1 and insert—

<Charter of Patient Rights and Responsibilities

(1) The Scottish Ministers must, within 6 months of the coming into force of this section, publish a document to be known as the Charter of Patient Rights and Responsibilities (“the Charter”).

(2) The Charter must set out a summary of the rights and responsibilities (as existing at the date of publication) of patients and relevant persons.

(3) The Charter may also include—

(a) a summary of the duties of relevant NHS bodies,

(b) a summary of the behaviour expected from patients and relevant persons,

(c) such other information as the Scottish Ministers consider relevant in relation to health care or the health service (for example, information relating to targets for the periods of time within which patients are to be treated).

(4) Nothing in the Charter is to—

(a) give rise to any new rights,

(b) impose any new responsibilities, or

(c) alter (in any way) an existing right or responsibility.

(5) For the purposes of this section and section (Review and revision of Charter), a “relevant person” is—

(a) a person who has a personal interest in the health care of a patient (for example a member of the patient’s family or a carer),

(b) such other categories of person as the Scottish Ministers consider appropriate.

(6) The Charter is to be published in such form and manner as the Scottish Ministers consider appropriate.

(7) Before publishing the Charter under subsection (1), the Scottish Ministers must—

(a) consult such persons as they consider appropriate,

(b) lay a copy of the Charter before Parliament.
(8) The Scottish Ministers must, as soon as reasonably practicable after publication of the Charter under subsection (1), notify each relevant NHS body of the publication of the Charter.

(9) Each relevant NHS body must make available without charge copies of the Charter to patients, staff and members of the public.

(10) In carrying out the duty under subsection (9), a relevant NHS body must take account of the particular needs of the persons to whom the Charter is to be made available as to the form of the Charter (for example by making it available in different languages or in Braille).

Irene Oldfather

1A As an amendment to amendment 1, line 36, after <Braille> insert <or by having regard to the particular needs of adults with incapacity within the meaning of section 1(6) of the Adults with Incapacity (Scotland) Act 2000 (asp 4)>

Dr Richard Simpson

2 After section Z1, insert—

<Review and revision of Charter>

(1) The Scottish Ministers must carry out a review of the Charter at least once in any period of 5 years.

(2) The purposes of a review under subsection (1) are—

(a) to ensure that the Charter continues to accurately summarise the rights and responsibilities of patients and relevant persons (as existing at the date of review), and

(b) to assess how effective the Charter is in raising awareness of the rights and responsibilities of patients and relevant persons.

(3) When reviewing the Charter under subsection (1), the Scottish Ministers must also review how effective the arrangements for the publication and distribution of the Charter have been in promoting awareness of the Charter and, if they consider it appropriate, take such steps as they consider necessary to improve those arrangements.

(4) In carrying out a review under subsections (1) and (3) the Scottish Ministers must consult such persons as they consider appropriate.

(5) The first review under subsection (1) must be completed not later than 5 years from the date on which the Charter is published under section (Charter of Patient Rights and Responsibilities) (1).

(6) The Scottish Ministers must revise the Charter where, following a review under subsection (1), the Scottish Ministers consider that the Charter—

(a) does not accurately summarise the rights and responsibilities of patients and relevant persons, or

(b) is not sufficiently effective in raising awareness of the rights and responsibilities of patients and relevant persons.

(7) The Scottish Ministers may revise the Charter at any other time if they consider it appropriate to do so (whether following a review under subsection (1) or otherwise).

(8) Where the Scottish Ministers revise the Charter under subsection (6) or (7), they must—
(a) publish it as so revised (in such form and manner as they consider appropriate),
(b) notify each relevant NHS body of the publication of the Charter as so revised.

(9) Before publishing the Charter under subsection (8)(a), the Scottish Ministers must—
(a) consult such persons as they consider appropriate, and
(b) lay a copy of the Charter before Parliament.

(10) In this Act, a reference to the Charter is a reference to the Charter as it may be revised from time to time.

Section 1

Dr Richard Simpson
3 In section 1, page 2, leave out lines 12 and 13

Dr Richard Simpson
4 In section 1, page 2, line 14, leave out <raises> and insert <raise>

Section 3

Dr Richard Simpson
5 In section 3, page 2, line 29, leave out <and the charter>

Dr Richard Simpson
6 In section 3, page 2, line 32, leave out <and the charter>

Section 5

Dr Richard Simpson
9 In section 5, page 3, line 6, leave out <and the charter>

Dr Richard Simpson
10 In section 5, page 3, line 7, leave out <and the charter>

Dr Richard Simpson
11 In section 5, page 3, line 10, leave out <and the charter>

Section 6

Nicola Sturgeon
12 In section 6, page 3, line 30, at end insert—
<( ) The treatment time guarantee is in addition to, and does not affect, any duty of a Health Board to—>
(a) comply with any orders, regulations or directions made by the Scottish Ministers (whether under the 1978 Act or otherwise) which relate to targets for periods of time within which treatments or services are to be provided, or

(b) have regard to any guidance issued by the Scottish Ministers which relates to such targets.>

Section 9

Nicola Sturgeon

13 In section 9, page 5, line 8, leave out subsection (3)

After section 9

Nicola Sturgeon

14 After section 9, insert—

<Treatment time guarantee: suspension

(1) This section applies where the Scottish Ministers consider that exceptional circumstances exist.

(2) The Scottish Ministers may direct that the treatment time guarantee be suspended for such period as they consider necessary.

(3) But such period of suspension must not exceed 30 days.

(4) The Scottish Ministers may by order—

(a) extend the duration of a period of suspension under subsection (2) beyond the 30 day limit in subsection (3) for such further period as they consider necessary,

(b) suspend the treatment time guarantee for such period in excess of 30 days as they consider necessary.

(5) An order made under subsection (4) (other than one to which subsection (7) applies)—

(a) must be laid before the Scottish Parliament, and

(b) ceases to have effect at the expiry of the period of 28 days beginning with the date on which it was made unless, before the expiry of that period, the order has been approved by resolution of the Parliament.

(6) Subsection (7) applies to an order made under subsection (4) consisting only of—

(a) provision revoking an earlier order under subsection (4), or

(b) such provision and provision made by virtue of section 21(1)(c).

(7) An order to which this subsection applies is subject to annulment in pursuance of a resolution of the Parliament.

(8) In reckoning for the purposes of subsection (5)(b) any period of 28 days, no account is to be taken of any period during which the Scottish Parliament is—

(a) dissolved, or

(b) in recess for more than 4 days.

(9) Subsection (5)(b) is without prejudice to—
(a) anything previously done by reference to—
   (i) a direction under subsection (2),
   (ii) an order under subsection (4), or
(b) the making of a new order under subsection (4).>

Section 10

Nicola Sturgeon

15 In section 10, page 5, line 11, leave out <9> and insert <(Treatment time guarantee: suspension)>  

Section 12

Dr Richard Simpson

16 In section 12, page 5, line 26, leave out <provide feedback, comments, concerns or complaints> and insert <give feedback or comments, or raise concerns or complaints,>

Dr Richard Simpson

17 In section 12, page 5, line 28, leave out <raise such concerns with or give such feedback to> and insert <give such feedback or comments to, or raise such concerns or complaints with>

Dr Richard Simpson

18 In section 12, page 5, leave out line 30 and insert—
   <( ) a provider of the patient advice and support service.>

Dr Richard Simpson

19 In section 12, page 5, line 31, leave out subsection (3) and insert—
   <(3) Where feedback or a comment is given to, or a concern or a complaint is raised with, a provider of the patient advice and support service, the provider may pass the feedback, comment, concern or complaint to the relevant NHS body (but only with the consent of the patient).>

Section 11

Dr Richard Simpson

20 In section 11, page 6, line 7, leave out from <feedback> to end of line 8 and insert <feedback or comments given, or concerns or complaints raised, in relation to health care—>

Dr Richard Simpson

21 In section 11, page 6, line 12, leave out <identifying> and insert <using feedback, comments, concerns or complaints to identify>
Dr Richard Simpson
22 In section 11, page 6, line 14, leave out <made and handled> and insert <raised, and
(ii) how feedback, comments, concerns or complaints will be handled,>

Section 14

Nicola Sturgeon
23 In section 14, page 7, line 12, at end insert <, and
( ) in a manner which co-ordinates with the services of other providers of advice and support.>

Nicola Sturgeon
24 In section 14, page 7, line 16, at end insert—
<( ) Healthcare Improvement Scotland,>

Section 15

Dr Richard Simpson
25 In section 15, page 7, line 31, after <patients> insert <(and in particular, promote awareness of the Charter)>

Dr Richard Simpson
26 In section 15, page 7, line 32, leave out <make a complaint, raise concerns or give feedback> and insert <give feedback or comments, or raise concerns or complaints>

Nicola Sturgeon
27 In section 15, page 7, line 35, at end insert—
<( ) make persons aware of and, where appropriate, direct them to—
(i) other sources of advice and support (including persons who provide advice and support in relation to matters other than the health service),
(ii) persons providing representation and advocacy services,>

Mary Scanlon
Supported by: Nicola Sturgeon
28 In section 15, page 8, line 1, leave out subsection (4)

Nicola Sturgeon
29 In section 15, page 8, line 2, at end insert—
<( ) Nothing in this Act prevents a provider of the patient advice and support service from providing advice and support in relation to matters other than the health service.>
But the provision of such other advice and support by such a provider must not prejudice its provision of advice and support services under subsection (1).>

Section 18

Nicola Sturgeon

30 In section 18, page 9, line 4, at end insert—

<( ) In this section, references to this Act include references to orders, regulations and directions made under this Act.>

After section 18A

Nicola Sturgeon

31 After section 18A, insert—

<Payments to or in respect of certain persons infected with hepatitis C as a result of NHS treatment etc.: eligibility>

Payments to or in respect of certain persons infected with hepatitis C as a result of NHS treatment etc.: eligibility

(1) Section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 (asp 13) (payments to certain persons infected with hepatitis C as a result of NHS treatment etc.) is amended as follows.

(2) In subsection (1)—

(a) in paragraph (a)—

(i) after sub-paragraph (i), insert “and”,
(ii) the word “and” following sub-paragraph (ii) is repealed, and
(iii) sub-paragraph (iii) is repealed,
(b) in paragraph (b)—

(i) after sub-paragraph (i), insert “and”,
(ii) the word “and” following sub-paragraph (ii) is repealed, and
(iii) sub-paragraph (iii) is repealed, and
(c) after paragraph (b) insert—

“(c) dependants of persons mentioned in paragraph (a) or (b).”.

(3) After subsection (2), insert—

“(2A) In subsection (1)(c), “dependant”, in relation to a person mentioned in subsection (1)(a) or (b) (the “infected person”), means—

(a) a spouse or civil partner of the infected person;
(b) a person living with the infected person as husband or wife or in a relationship which has the characteristics of the relationship between civil partners (or if the infected person was in hospital immediately before death, had been so living when the infected person was admitted to hospital);
(c) such other persons as the scheme may specify; and the scheme may specify or elaborate the meaning of dependant for this purpose.”.

(4) In subsection (3)—
(a) in paragraph (b), after “dead person” insert “falling within subsection (1)(a) or (b)”, and
(b) in paragraph (e), after “dead person” insert “falling within subsection (1)(a) or (b)”.

(5) In subsection (4)(a), after “(1)” insert “(a) or (b)”.

Section 19

Dr Richard Simpson

32 In section 19, page 9, line 15, at end insert—

<“the Charter” means the Charter of Patient Rights and Responsibilities published under section (Charter of Patient Rights and Responsibilities);>

Section 21

Nicola Sturgeon

33 In section 21, page 10, line 14, after <section> insert <(Treatment time guarantee: suspension)(4) or>

Section 22

Nicola Sturgeon

34 In section 22, page 10, line 25, after <sections> insert <(Payments to or in respect of certain persons infected with hepatitis C as a result of NHS treatment etc.: eligibility),>

Schedule

Dr Richard Simpson

7 In the schedule, page 11, line 16, leave out paragraph 9A and insert—

<No avoidable harm or injury is to be caused to the patient by the health care provided.>

Dr Richard Simpson

8 In the schedule, page 11, line 18, leave out <, clean and safe environment at all times> and insert <environment which is as clean and safe as is reasonably possible>
Long Title

Nicola Sturgeon

35 In the long title, page 1, line 1, after <care;> insert <to make further provision about eligibility under the scheme made under section 28 of the Smoking, Health and Social Care (Scotland) Act 2005;>
Groupings of Amendments for Stage 3

This document provides procedural information which will assist in preparing for and following proceedings on the above Bill. The information provided is as follows:

- the list of groupings (that is, the order in which amendments will be debated).
- the text of amendments to be debated at Stage 3, set out in the order in which they will be debated. **THIS LIST DOES NOT REPLACE THE MARSHALLED LIST, WHICH SETS OUT THE AMENDMENTS IN THE ORDER IN WHICH THEY WILL BE DISPOSED OF.**

Groupings of amendments

**Group 1: Charter of patient rights and responsibilities**
1, 1A, 2, 3, 5, 6, 9, 10, 11, 25, 32

**Group 2: Patient feedback, comments, concerns or complaints**
4, 16, 17, 18, 19, 20, 21, 22, 26

Debate to end no later than 20 minutes after proceedings begin

**Group 3: Treatment time guarantee: relationship with existing duties**
12

**Group 4: Treatment time guarantee: suspension**
13, 14, 15, 33

**Group 5: Patient advice and support service**
23, 24, 27, 28, 29

**Group 6: Protections and Limitations**
30

Debate to end no later than 40 minutes after proceedings begin

**Group 7: Payments to or in respect of certain persons infected with Hepatitis C**
31, 34, 35

**Group 8: Health care principles**
7, 8

Debate to end no later than 1 hour and 5 minutes after proceedings begin
Patient Rights (Scotland) Bill - Stage 3: The Bill was considered at Stage 3.

The following amendments were agreed to without division: 1A, 1, 2, 3, 4, 5, 6, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 7 and 35.

Amendment 8 was agreed to (by division: For 100, Against 15, Abstentions 0).

Patient Rights (Scotland) Bill - Stage 3: The Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon) moved S3M-7978—That the Parliament agrees that the Patient Rights (Scotland) Bill be passed.

After debate, the motion was agreed to (DT).
The Deputy Presiding Officer: The next item of business is stage 3 proceedings on the Patient Rights (Scotland) Bill. Members should have the bill as amended at stage 2, which is Scottish Parliament bill 42A, the marshalled list, and the groupings, which the Presiding Officer has agreed. The division bell will sound and proceedings will be suspended for five minutes for the first division this afternoon. The voting period for the first division will be 30 seconds. Thereafter, I will allow a voting period of one minute for a division after a debate. Members should refer to the marshalled list of amendments if they are in any doubt.

Section 21—Patient Rights Charter

The Deputy Presiding Officer: Group 1 is on a charter of patient rights and responsibilities. Amendment 1, in the name of Richard Simpson, is grouped with amendments 1A, 2, 3, 5, 6, 9 to 11, 25 and 32.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I will speak to amendments 1, 2, 3, 5, 6, 9 to 11, 25 and 32.

Amendment 1 removes section Z1 as inserted into the bill at stage 2 and replaces it with a requirement on the Scottish ministers to publish a charter of patient rights and responsibilities within six months of the section coming into force. The charter must set out a summary of the rights and responsibilities, extant at the date of publication, of patients and relevant persons. The charter may also include a summary of the duties on relevant national health service bodies, a summary of the behaviour that is expected from patients and relevant persons, and any other information that the minister considers to be relevant, such as waiting time periods.

Relevant persons are defined as persons who have a personal interest in the health care of a patient, such as a relative or carer, and such other persons as the Scottish ministers consider to be appropriate. The charter cannot create new rights and responsibilities, or alter existing ones in any way. It must be published in such a manner and form as ministers think appropriate. Before publishing the charter, ministers must consult those whom they think appropriate and must also lay a copy of the charter before the Parliament.

Ministers must tell the relevant national health service bodies about the publication of the charter. Relevant NHS bodies must make the charter available without charge and, in doing so, must take into account the particular needs of those who will be using the charter when they consider the form that it will take.

Amendment 2, on the review and revision of the charter, states that it must be reviewed at least once every five years to ensure that the rights and responsibilities contained within it are still accurate, and to assess how effective the charter is at raising awareness of the rights and responsibilities of patients and relevant persons. When a review is carried out, ministers must also consider the effectiveness of the distribution and publication arrangements for the charter and they must improve those processes where appropriate. When carrying out a review of the charter, the Scottish ministers must consult those whom they think appropriate.

Following a review, ministers must revise the charter if they consider that it does not accurately summarise the rights and responsibilities of patients, or if they consider that it is not effectively raising awareness of the rights and responsibilities of patients and relevant persons. Ministers may also revise the charter at any other time that they consider to be appropriate. When ministers revise the charter, they must publish it as so revised and notify each relevant NHS body of that publication. Before publishing the revised charter, ministers must consult such persons as they consider to be appropriate and they must lay a copy of the revised charter before the Parliament.

Amendment 3 deletes section 1(2)(e) of the bill, which says that health care is to “have regard to and respect for the rights and responsibilities conferred on patients by the Charter to be made by the Scottish Ministers” that was referred to under what was previously section (Z1)(1).

Amendments 5 and 6 remove the reference to the charter having to be upheld by relevant NHS bodies and having to be upheld in turn by any person with whom the relevant NHS body enters into a contract agreement or arrangements to provide health services.

Amendments 9 and 10 remove the reference to the charter from sections 5(1) and 5(2) of the bill, which are about the duty of NHS bodies to have regard to any guidance that the Scottish ministers issue and the duty of the ministers to consult such persons as they consider to be appropriate before providing such guidance.

Amendment 11 removes the power of the Scottish ministers in section 5(3) to give directions about the practical application of the charter.

Amendment 25 specifies that the patient advice and support service, in promoting awareness and
understanding of the rights and responsibilities of patients, should, in particular,
“promote awareness of the Charter”
of patient rights and responsibilities. I accept that the wording might be subject to slight criticism—it is a little cumbersome—but it gets the point across.

15:00
Amendment 32 is consequential on amendment 1. It inserts a provision that means that reference to “the Charter” under the bill is a reference to the “Charter of Patient Rights and Responsibilities published under”
the section that amendment 1 inserts.

The affect of amendment 1 will be that the charter will be an information document, summarising the various rights and responsibilities of NHS users. It will not be a Scottish statutory instrument, so it cannot confer rights and responsibilities. The charter is designed to bring together a user-friendly summary of the rights, responsibilities and entitlements of patients and other relevant persons such as carers or relatives and other family members. The charter will be drawn up after consultation with relevant people and organisations, and it will be laid before the Parliament when it is finalised.

Under amendment 2, the charter must be reviewed every five years, or more often if appropriate, in order to take account of significant change. When it is reviewed, ministers must consider how effective the arrangements for the publication of the charter are. They must consult those whom they consider appropriate. After review, the charter might have to be revised and, if it is revised, ministers must consult relevant people.

Amendment 3 is consequential on amendments 1 and 2, with section Z1 being removed from the bill. Amendment 1 means that the charter will no longer confer any rights or responsibilities on patients, and it would therefore be inappropriate for section 1(2)(e) to remain in the bill.

I commend the amendments in this group to the Parliament, and I move amendment 1.

Irene Oldfather (Cunninghame South) (Lab): Amendment 1A seeks to extend the reach of Richard Simpson’s amendment 1 so as specifically to include those who lack capacity under the Adults with Incapacity (Scotland) Act 2000. In drafting the amendment I consulted the bill team about whether people who lacked capacity would already be directly covered by amendment 1, and the advice that I was given was that there is nothing particular in that amendment in that regard, so it would therefore be helpful to add my amendment to strengthen their rights.

Rights are meaningful and are able to be claimed only if one has knowledge and understanding of them. People who lack capacity, for whatever reason, share a common thread: the barriers and difficulties that they face in relation to communication and understanding. It is therefore incumbent on us to ensure that appropriate steps are taken to communicate their rights to them.

When the cross-party group on Alzheimer’s reviewed the experiences of patients with illness in accident and emergency units, I was struck by one carer’s comments about her mother’s situation. She said that when her mother arrived at A and E, it was akin to being parachuted into a foreign country and surrounded by unfamiliar faces and people, who spoke to her in a language that she simply did not understand. We have an obligation and duty to give people information in a way that is understandable to them. If we do not do so, we discriminate against them, albeit inadvertently. I hope that members will support my amendment.

I move amendment 1A.

Ross Finnie (West of Scotland) (LD): I am very supportive of the amendments in Richard Simpson’s name, and I am deeply grateful to Irene Oldfather for advising the Parliament that she sought advice before lodging her amendment, and for telling us that she was advised that the wording as proposed in amendment 1 would not cover or extend to adults with incapacity.

Members ought to reflect for a moment on that advice, which I take in good faith—I am not challenging Irene Oldfather’s position. For the benefit of members, I will read out what the proposed new section, as drafted by Richard Simpson, says:

“a relevant NHS body must take account of the particular needs of the persons to whom the Charter is to be made available as to the form of the Charter”.

If, in the ordinary use of the English language, those words mean that we exclude and discriminate against adults with incapacity, there is something seriously wrong with the way in which we are framing our legislation. For the purpose of this afternoon, I will not get into a silly debate. If Irene Oldfather has been advised that it is important and imperative that that extension is made, I will go along with that. If a more clearly worded amendment is needed to ensure that the particular needs of the persons for whom the charter is to be made are addressed and that the bill is not capable of being construed as discriminating against adults with incapacity, I accept Irene Oldfather’s proposition that we have a problem. However, we might also have a
problem with people who draft statutes telling us that these words do not mean what they say.

The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): I welcome Dr Richard Simpson’s amendments to remove section Z1 on a patient charter, which was inserted into the bill at stage 2, and instead to introduce a duty to publish a charter of patient rights and responsibilities in a way that avoids some of the potential pitfalls of section Z1 and, therefore, the bill as amended at stage 2.

As I made clear at stage 2, although I supported the principle behind the amendments to introduce a patient charter, the drafting of the amendments was problematic for several reasons. For example, if the bill were to remain as it is, ministers would have to make an order listing all the statutory rights and responsibilities that patients have. Such an order would have to be subject to negative procedure and would need to be continually updated and brought before the Parliament every time it was amended. In addition, if the charter is to cover reserved as well as devolved legislation, there may be an issue whether that is within the devolved competence of the Scottish ministers.

That is why I am pleased to support Richard Simpson’s amendments, which provide that ministers must publish a charter of patient rights and responsibilities that must contain all the rights and responsibilities that patients have. As we have heard, the charter may also contain information, such as the behaviour that is expected from patients and information about waiting times. Because the charter will not be a statutory instrument, it will be possible to design it in the way that is most practical and useful for patients. The group of amendments also provides for mechanisms for consultation with appropriate people on the contents of the charter and for the charter to be reviewed and improved if appropriate.

I also support the technical amendments in the group. As Richard Simpson pointed out, those amendments are consequential on amendments 1 and 2. They reflect the fact that the charter, as amended today, will be a versatile information document rather than a statutory instrument. The Scottish Government is happy to support those amendments.

I turn to amendment 1A, in the name of Irene Oldfather. She has made a powerful case for her amendment and I support the principle and intention behind it. Nevertheless—this comment may help Ross Finnie—I believe that the amendment is not, in itself, strictly necessary. It inserts an extra example into a list of examples of needs that NHS bodies must take into account when making the charter available to patients. The list of examples in amendment 1 is not meant to be exhaustive and would include adults with incapacity. That said, I cannot see any problem with adding an extra example to the list; indeed, that may well strengthen the bill in the way that Irene Oldfather has described. In the light of that, the Government is prepared to support amendment 1A.

The Deputy Presiding Officer: Before I call Richard Simpson to wind up the debate, I remind members that this is stage 3 of a bill. It is important legislation and there are far too many private conversations taking place in the chamber.

Dr Simpson: I acknowledge the cabinet secretary’s support for this group of amendments, especially amendment 1.

On amendment 1A, despite the fact—as Ross Finnie points out—that amendment 1 seems to cover all the bases, the specifying of that example is welcome. Dementia will be one of the main health challenges that we face and we know that there are existing problems with the management of patients within the system. Although amendment 1A is perhaps gilding the lily, such gilding is not inappropriate and I will, therefore, support amendment 1A.

Irene Oldfather: I am grateful for the support that has been expressed across the chamber. My amendment reflects the advice that I was given. I have to say, however, that the word “discrimination” was mine and not that of the bill team.

I think that the minister and the cabinet secretary have accepted that, in identifying adults with incapacity, we take a step further along the line towards assisting them better. In supporting this amendment we not only take the practical step forward of assisting people who lack capacity to understand their rights, we also take a step on the long road towards destigmatising people who lack capacity. We are saying to them that they are a vital and integral part of our society and that, here in their Parliament, we are giving them a voice and are standing up for them and recognising their needs. That is all very important.

Amendment 1A agreed to.

Amendment 1 agreed to.

After Section 21

Amendment 2 moved—[Dr Simpson]—and agreed to.

Section 1—Patient rights

Amendment 3 moved—[Dr Simpson]—and agreed to.

The Deputy Presiding Officer: Group 2 is on patient feedback, comments, concerns or
complaints. Amendment 4, in the name of Richard Simpson, is grouped with amendments 16 to 22 and 26.

Dr Simpson: I will speak to amendments 4, 16 to 22 and 26.

We are in the process of devising a comprehensive NHS system of complaints and, as the cabinet secretary said, although a complaints system has already been in existence, this will be the first time that it is placed squarely within primary legislation.

Some of the amendments are technical, and are designed simply to improve the quality of this section, which was debated at stage 2.

Amendment 4 is a technical amendment to correct a grammatical error.

Amendment 16 ensures consistency of language throughout the bill in terms of complaints, feedback and so on, in line with changes.

Amendment 17 widens the scope of the section to refer to feedback, comments and concerns as opposed to simply concerns and feedback, as currently drafted.

Amendment 18 removes the reference to patient rights officers and replaces it with a reference to the provider of the patient advice and support service, in order to take account of the deletion at stage 2 of section 17, which referred to patient rights officers.

Amendment 19 widens the scope of the section to include feedback, comments, concerns and complaints, as opposed to concerns and feedback, as is currently drafted, and also removes the reference to the patient rights officer and replaces it with a reference to the provider of the patient advice and support service.

Amendment 20 ensures consistency of the language that is used throughout the bill, in terms of complaints, feedback and so on, in line with the changes that were made at stage 2.

Amendment 21 clarifies the stage 2 amendment about the identification of best practice, and should be read together with sections 11(1) and 11(2), which set out the relevant NHS bodies and, in turn, the service providers, which are to use feedback, comments, complaints and concerns that are received to identify best practice.

Amendments 22 and 26 ensure consistency of language throughout the bill in terms of complaints, feedback and so on, in line with the changes that were made at stage 2.

Essentially, the amendments ensure consistency of language, broaden the scope of the bill, remove the references to the patient rights officers and replace them with references to providers of the patient advice and support service, and place the appropriate duties on the relevant NHS bodies with regard to the use of comments, concerns, complaints or, indeed, positive feedback.

I move amendment 4.

Nicola Sturgeon: The amendments in this group, as Richard Simpson has indicated, are largely technical in nature. They tidy up or clarify amendments that we agreed at stage 2. I do not think that I need to add anything to the comments that Richard Simpson has already made. I need say only that I am content to support amendments 4, 16 to 22 and 26.

Amendment 4 agreed to.

Section 3—Duty to uphold certain rights and principles

Amendments 5 and 6 moved—[Dr Simpson]—and agreed to.

Section 5—Health care principles and Charter: guidance and directions

Amendments 9, 10 and 11 moved—[Dr Simpson]—and agreed to.

Section 6—Treatment time guarantee

15:15

The Deputy Presiding Officer (Alasdair Morgan): Group 3 is on the treatment time guarantee and its relationship with existing duties. Amendment 12, in the name of the minister, is the only amendment in the group.

Nicola Sturgeon: I listened carefully during previous stages of the bill to concerns that members expressed about a perceived—I stress the word perceived—negative impact that a legal treatment time guarantee could have on other access targets. Concerns were expressed that focusing in primary legislation on that particular stage of the patient journey may suggest that targets around other stages of the patient journey were somehow less important.

Amendment 12 seeks to address that specific point. It sets out that the treatment time guarantee is in addition to, not prejudicial to and not instead of current and future access targets. The amendment clarifies that health boards will still be expected to deliver on other waiting time targets. For example, they will still be expected to deliver on the 18-week referral-to-treatment time target—indeed, the 12-week target is intended to sit within that—the four-hour accident and emergency target, cancer targets, child and adolescent mental health targets and the new health improvement,
efficiency, access and treatment target for psychological therapies.

Amendment 12 helps to put the treatment time guarantee into that overall context, so I urge members to support it.

I move amendment 12.

Dr Simpson: The minister has outlined the effects of amendment 12. It is important for the Parliament, in supporting this section of the bill, to recognise how far we have come since 1999.

This section of the bill will now ensure that, once a patient has begun the specialist part of the clinical journey, they will not be sidelined so that another patient can be promoted to meet the guarantee, within any tolerances set by the health minister at the time.

At times in the past, an unintended consequence of targets has been that once a guarantee was broken, new patients would be favoured. Now that we understand fully the purpose of the treatment time guarantee, I hope that the Royal College of Nursing and the British Medical Association, which have opposed the treatment time guarantee section of the bill, will understand that it is a long stop that is highly beneficial to patients.

It is interesting to speculate, for example, how the treatment time guarantee might have affected the patient in my constituency who was reported this week in the cancer statistics as having waited 178 days for melanoma treatment from a maxillofacial unit. I suspect that if the treatment time guarantee had been in place, that waiting time would have been considerably shorter.

I am pleased to support amendment 12.

Amendment 12 agreed to.

Section 9—Treatment time guarantee: guidance and directions

The Deputy Presiding Officer: Group 4 is on the suspension of the treatment time guarantee. Amendment 13, in the name of the minister, is grouped with amendments 14, 15 and 33.

Nicola Sturgeon: The Subordinate Legislation Committee raised concerns that the Parliament had no role or scrutiny function in relation to the suspension of the treatment time guarantee. I have given its concerns careful consideration.

I hope that members will accept that we have tried to meet the concerns of the Subordinate Legislation Committee in a way that still gives ministers the flexibility that would inevitably be required in any set of circumstances that would lead to the suspension of the guarantee.

I hope that members will be able to support this group of amendments.

I move amendment 13.

Dr Simpson: I support this group of amendments. If we had had a serious pandemic and the bill had been in place, exactly this provision would have been required to give the minister the necessary flexibility. Admitting patients when our intensive care units are already loaded with pandemic flu patients would be a serious problem and we would be in danger of breaching the legislation. I welcome the amendments.

Amendment 13 agreed to.

After section 9

Amendment 14 moved—[Nicola Sturgeon]—and agreed to.

Section 10—Treatment time guarantee: key terms

Amendment 15 moved—[Nicola Sturgeon]—and agreed to.

Section 12—Encouragement of patient feedback etc

Amendments 16 to 19 moved—[Dr Simpson]—and agreed to.

Section 11—Arrangements for handling and responding to patient feedback etc

Amendments 20 to 22 moved—[Dr Simpson]—and agreed to.
Section 14—Patient advice and support service: establishment and funding

The Deputy Presiding Officer: We come to group 5, on the patient advice and support service. Amendment 23, in the name of the minister, is grouped with amendments 24 and 27 to 29.

Nicola Sturgeon: This is an area about which we had some discussion in the Health and Sport Committee at stage 2. Certain views were expressed about the patient advice and support service. The amendments that I will move aim to address the concerns that were expressed and to clarify the role and scope of the proposed service.

We all appreciate that in order to maximise the effectiveness of the patient advice and support service, which I think we all agree with in principle, the service must be aware of and work with other advice and support services. It should also build on and learn from the valuable experiences of the current independent advice and support service.

Amendment 23 seeks to emphasise the important relationship between the patient advice and support service and other organisations such as Citizens Advice Scotland, as does amendment 27.

Amendment 27 also serves to reinstate a reference to advocacy services that was inadvertently dropped at stage 2, which I am sure was not the committee’s intention.

Amendment 24 will exclude the new healthcare improvement Scotland from providing the patient advice and support service. That is in keeping with the views that were expressed not just at stage 2, but at stage 1, that patients value a service that is genuinely independent of the NHS. I certainly think that the strength of a well-functioning patient advice and support service is that it is independent of the NHS.

Amendment 29 acknowledges that the service will not be prohibited from providing advice on matters other than those relating to the health service. That was always the original intention, but many members expressed the view at stage 2 that they would like that to be clarified. Many people who access a service such as this have not only health-related queries but problems relating to housing or benefits, which might also affect their health. The holistic nature of this service was supported at stage 2.

On amendment 28, in the name of Mary Scanlon, I understand that many have construed the original provision much more narrowly than was intended and, as a result, I am content to support the amendment, which proposes the removal of the provision.

I move amendment 23.

Mary Scanlon (Highlands and Islands) (Con): Amendment 28 was suggested by the Law Society of Scotland’s mental health and disability committee. It considered that the wording of section 15(4) is too narrow, in that it sets out an obligation only to provide advice and guidance to patients on their rights as contained in the bill by defining

“a reference to the rights of patients”

under section 15(2) as a reference to rights that exist only under the bill. However, patients have many other significant rights beyond those contained in this bill. As it stands, the bill places no obligation on the patient advice and support service to inform a patient of or provide advice or guidance on those other rights. The restrictive nature and wording of section 15(4) is considered to be a significant weakness in the bill. If the limitation in this section were not removed, any advice that was given could be fundamentally flawed in that it would imply that patients’ only rights are those under the bill. In effect, patients would be deprived of their other rights. There must be an obligation to provide patients with advice and guidance on all rights, whether contained in the bill or set out in other statutes or common law.

I acknowledge that the cabinet secretary supports amendment 28.

Dr Simpson: I support the Government amendments to section 16 because they will allow us to achieve our common objective of establishing a system independent of the health board, readily available to the patient and integrated with other advice systems linked directly or indirectly to advocacy. Previous amendments on this matter referred to citizens advice bureaux, which have provided an excellent service since their commencement. Although it would not be appropriate to name one organisation in connection with the proposed patient advice and support service, I point out that CABx embody a holistic approach that is appreciated by patients.

I also welcome Mary Scanlon’s amendment 28, as it will underpin patients’ confidence in a system of support that will identify need and assist in a holistic way.

Amendment 23 agreed to.

Amendment 24 moved—[Nicola Sturgeon]—and agreed to.

Section 15—Patient advice and support service

Amendments 25 and 26 moved—[Dr Simpson]—and agreed to.

Amendment 27 moved—[Nicola Sturgeon]—and agreed to.
Amendment 28 moved—[Mary Scanlon]—and agreed to.

Amendment 29 moved—[Nicola Sturgeon]—and agreed to.

Section 18—Protections and limitations

The Deputy Presiding Officer: Group 6 is on protections and limitations. Amendment 30, in the name of the minister, is the only amendment in the group.

Nicola Sturgeon: Amendment 30 is a technical amendment that seeks to make it explicit that the limitations and protections applying to the bill will also apply to any orders, regulations and directions made under it. Committee members and others made it clear that they did not want to end up with lawyers at every bedside; I do not think that that was ever going to be the case but, nevertheless, with the other changes to the bill, this amendment makes it absolutely clear that that will not happen.

I move amendment 30 and hope that members will support it.

Amendment 30 agreed to.

After section 18A

15:30

The Deputy Presiding Officer: Group 7 is on payments to or in respect of certain persons infected with hepatitis C. Amendment 31, in the name of the minister, is grouped with amendments 34 and 35.

Nicola Sturgeon: Members will appreciate that amendments 31, 34 and 35 introduce a separate issue to the bill. I will explain why we took the opportunity to lodge them.

Amendment 31 proposes changes to section 28 of the Smoking, Health and Social Care (Scotland) Act 2005. Members will recall that that section allows the Scottish ministers to make a scheme for the making of payments to certain persons infected with hepatitis C as a result of NHS treatment with blood or blood products. The scheme that the Scottish ministers have adopted under that provision is operated by the Skipton Fund, and it operates on a United Kingdom-wide basis.

New support provisions for that group of persons were announced for England on 10 January 2011. The Scottish ministers have discussed the issue with patient representatives, and are deciding what arrangements should be put in place in Scotland. An announcement on that will be made shortly. If we decide to announce similar arrangements in due course, a new group of eligible persons—that is, relatives of patients who died prior to August 2003—will be introduced. The amendments to the 2005 act need to be agreed to before support can be provided to any newly eligible persons.

As I have said, we have still to announce our final policy intentions, but it is nevertheless prudent that we amend the 2005 act now. If the amendments are agreed to, they will mean that any future policy decisions that we take to make payments to newly eligible groups can be implemented without having to wait for another legislative opportunity to amend the 2005 act. Obviously, the first such opportunity after this one would be in the next session at the earliest—it would be much later this year. Therefore, agreeing to the amendments will avoid what could be a considerable delay before any newly eligible claimants could apply for support.

I hope that members will support the amendments. I took the opportunity to brief the Opposition spokespeople prior to lodging the amendments so that they understood the intention. I know that the issue of those infected with hepatitis C as a result of NHS treatment has been debated in Parliament on many occasions in the past, and I hope that members will see the need for the amendments and will give them their whole-hearted support.

I move amendment 31.

Jackie Baillie (Dumbarton) (Lab): I am happy to say that Labour members support amendments 31, 34 and 35, in the cabinet secretary's name, and we thank her for the briefing in advance of the debate.

I recognise that the bill might not be the most appropriate legislative vehicle, but it has the benefit of being quick, and timing is all in politics.

It is right that those infected with hepatitis C as a result of treatment by the NHS with blood or blood products should be compensated. However, if she is able to do so, will the cabinet secretary detail the likely funding impact that that will have over a number of years and whether that funding is being identified within the health budget?

Ross Finnie: I rise to indicate Liberal Democrat support for the amendments. I, too, express my gratitude to the cabinet secretary for the briefing on the subject.

Like Jackie Baillie, I think that it is right and proper that the earliest opportunity should be taken to introduce the provisions following the changes that have been announced. I understand the propriety of the cabinet secretary requiring to have a legislative framework before she can make an announcement but, like Jackie Baillie, I earnestly hope that the proposals have been
made on the premise that, all being well, the cabinet secretary will be able to come to the chamber and make an announcement that she will utilise the provisions, which I am sure members will approve today.

Nicola Sturgeon: I thank Jackie Baillie and Ross Finnie for their support for the amendments.

I appreciate that, through the amendments, I am asking for enabling powers that we need in order to make payments to any group that is not currently eligible. As I said in my earlier remarks, I have not yet announced our policy intention. I should say that we were not as fully consulted as I would have liked us to have been prior to the Department of Health’s announcement, and we have made our views on that known.

I want to do two things before announcing our policy intention. First, I want to ensure that we have the right legislative framework in place, as Ross Finnie said. Secondly, I want to take the views of patient representatives. Without referring to any particular group or individual, I think that it is fair to say that there are differences of opinion about the adequacy of what has been announced south of the border. We want to take time to consider carefully the implications and what the right move is for the Scottish Government. I will announce our intentions on the issue as soon as possible.

To respond to Jackie Baillie’s question, I say that there will be financial implications, although I cannot say exactly what they will be in advance of deciding on the package. However, we might be talking about a financial implication of up to £10 million in the first year of implementation. Obviously, that money will have to be found from within existing budgets. Whatever we decide to implement, we will take care to ensure that it is fully funded.

Amendment 31 agreed to.

Section 19—Interpretation
Amendment 32 moved—[Dr Richard Simpson]—and agreed to.

Section 21—Orders, regulations and directions
Amendment 33 moved—[Nicola Sturgeon]—and agreed to.

Section 22—Short title and commencement
Amendment 34 moved—[Nicola Sturgeon]—and agreed to.

Schedule—Health care principles

The Deputy Presiding Officer: Group 8 is on health care principles. Amendment 7, in the name of Richard Simpson, is grouped with amendment 8.

Dr Simpson: Principle 9A uses the term “unnecessary harm”, but it is not completely clear what that might mean. In the quality strategy, the safe quality ambition uses the phrase “avoidable harm”. Amendment 7 would make the principle consistent with the strategy and avoid misinterpretation.

Amendment 8 relates to the principle that patients should be “cared for in an appropriate, clean and safe environment”. That can apply only when it can be reasonably achieved. What is “appropriate, clean and safe” will vary depending on the circumstances and the location of treatment. The change that amendment 8 proposes should not be interpreted as a softening of Parliament’s unanimous desire to ensure that hospitals are clean at all times, but it is important to be realistic. There are many circumstances in which patients will have to be treated in an environment that is less than fully clean. Amendment 8 will allow that to happen.

I move amendment 7.

Ross Finnie: I have no problems at all with amendment 7, but I have a problem with amendment 8. The schedule to the bill is headed “Health care principles”—it is not a detailed manual of how health care is to be delivered in every circumstance in every hospital, by every roadside, on every pathway and in any other circumstance that we might care to think of. In the context of the problems that we have had in relation to cleanliness, I found it profoundly helpful to have as a principle that patients are to be cared “in an appropriate, clean and safe environment at all times.”

I have the same problem that I had the first time I entered into the debate, which is that, to me, the word “appropriate” conveys a clear sense that what is appropriate or not appropriate might well be different in a hospital and by a roadside. Therefore, there is no need to enter the caveats that appear in amendment 8, under which we would talk not about an environment that is clean and safe at all times but about one that is “as clean and safe as is reasonably possible”.

That waters down the principle. I do not see why we should dilute principles. I can well understand the practical implications but, if we are setting principles, let us not water them down. Therefore, I oppose amendment 8.

Nicola Sturgeon: I confirm my support for the underlying principle and intention of the
amendments at stage 2 that inserted health care principles 9A and 9B into the bill’s schedule. However, I explained at that time that I had concerns that the scope of principles 9A and 9B was too wide and might lead to unintended consequences for the national health service. The bill currently talks about having a “clean and safe environment at all times.”

Although I absolutely agree with Ross Finnie that we all have that aspiration, that terminology does not take account of certain circumstances in which people might require NHS treatment. The example that I used at committee is the one that I will use again today. Somebody who is in a road accident and requires to be treated at the side of the road is not being treated in a “clean and safe environment”, but they are being treated in the best environment that can be provided at that time. That is the type of example that we are talking about.

I am pleased that Dr Simpson agreed as much and that he recognises, as we all do, that there are circumstances in which the urgency of a medical intervention takes priority over the environment in which treatment is taking place. He committed to working with us to amend the wording of those principles, which has given rise to these amendments.

Although I understand where Ross Finnie is coming from, I disagree with his view that the amendments in any way dilute our commitment to clean and safe hospitals and treatment environments for all patients. One thing that I hope the Government has achieved, with—to be gracious, as I always am—the support of everybody on all sides of the chamber, is to put the cleanliness of our hospitals much higher up the agenda than it has ever been. Even if there were to be any softening on that part of any Government—and there is not on the part of this Government—our new health care environment inspectorate would see to it that that was not allowed to happen in practice. We have raised standards here, and the impact of that can be seen in the hospital infection rates, which are declining and will, I hope, continue to do so.

We should ensure that we pass the bill in a practical manner. Amendments 7 and 8 achieve that. The Government will support them, and I urge other members to do so.

**Dr Simpson:** It depends on how Ross Finnie reads the existing wording and where the word “appropriate” applies. If it applies to the general environment rather than to the two words that follow, there could be some room for debate. Although I hear where Ross Finnie is coming from, I do not agree with his conclusion.

The cabinet secretary is right to give the example of a road traffic accident. However, anyone who has been in an accident and emergency ward will have seen that, on occasions, treatments in that situation have to be undertaken that are anything but as clean as everyone would wish them to be, simply because of the need for urgency and speed at that time.

As I said in introducing the amendment, it in no way absolves staff from trying to achieve maximum safety and cleanliness at all times. Indeed, that is clearly stressed in the amendment as it is drafted. To suggest that staff would not wish that to be the case is inappropriate, but to ring them with a requirement for absolute cleanliness at all times would also be inappropriate. I welcome the cabinet secretary’s support for these further amendments, which will make the principle appropriate and proportionate.

**Amendment 7 agreed to.**

**Amendment 8 moved**—[Richard Simpson].

**The Deputy Presiding Officer:** The question is, that amendment 8 be agreed to. Are we agreed?

**Members:** No.

**The Deputy Presiding Officer:** There will be a division. As it is the first division, I will suspend Parliament for five minutes.

15:43

**Meeting suspended.**

15:48

**On resuming**—

**The Deputy Presiding Officer:** We come to the division on amendment 8.

**For**

Adam, Brian (Aberdeen North) (SNP)
Alexander, Ms Wendy (Paisley North) (Lab)
Allan, Alasdair (Western Isles) (SNP)
Baillie, Jackie (Dumbarton) (Lab)
Baker, Claire (Mid Scotland and Fife) (Lab)
Baker, Richard (North East Scotland) (Lab)
Boyack, Sarah (Edinburgh Central) (Lab)
Brankin, Rhona (Midlothian) (Lab)
Brocklebank, Ted (Mid Scotland and Fife) (Con)
Brown, Gavin (Lothians) (Con)
Brown, Keith (Ochil) (SNP)
Brownlee, Derek (South of Scotland) (Con)
Butler, Bill (Glasgow Anniesland) (Lab)
Campbell, Aileen (South of Scotland) (SNP)
Carlaw, Jackson (West of Scotland) (Con)
Chisholm, Malcolm (Edinburgh North and Leith) (Lab)
Coffey, Willie (Kilmarnock and Loudoun) (SNP)
Constance, Angela (Livingston) (SNP)
Crawford, Bruce (Stirling) (SNP)
Don, Nigel (North East Scotland) (SNP)
Doris, Bob (Glasgow) (SNP)
Eadie, Helen (Dunfermline East) (Lab)
Ewing, Fergus (Inverness East, Nairn and Lochaber) (SNP)
Fabiani, Linda (Central Scotland) (SNP)
Ferguson, Patricia (Glasgow Maryhill) (Lab)
FitzPatrick, Joe (Dundee West) (SNP)
Foulkes, George (Lothians) (Lab)
Fraser, Murdo (Mid Scotland and Fife) (Con)
Gibson, Kenneth (Cunninghame North) (SNP)
Gibson, Rob (Highlands and Islands) (SNP)
Gilson, Karen (Clydesdale) (Lab)
Glen, Marilyn (North East Scotland) (Lab)
Goldie, Annabel (West of Scotland) (Con)
Gordon, Charlie (Glasgow Cathcart) (Lab)
Grahame, Christine (South of Scotland) (SNP)
Grant, Rhoda (Highlands and Islands) (Lab)
Harper, Robin (Lothians) (Green)
Harvie, Christopher (Mid Scotland and Fife) (SNP)
Harvie, Patrick (Glasgow) (Green)
Henry, Hugh (Paisley South) (Lab)
Hepburn, Jamie (Central Scotland) (SNP)
Hyslop, Fiona (Lothians) (SNP)
Ingram, Adam (South of Scotland) (SNP)
Johnstone, Alex (North East Scotland) (Con)
Kelly, James (Glasgow Rutherglen) (Lab)
Kelly, Margaret (Midlothian) (SNP)
Kerr, Andy (East Kilbride) (Lab)
Kidd, Bill (Glasgow) (SNP)
Lamont, Johann (Glasgow Pollok) (Lab)
Lamont, John (Roxburgh and Berwickshire) (Con)
Livingstone, Marilyn (Kirkcaldy) (Lab)
Lochhead, Richard (Moray) (SNP)
MacAskill, Kenny (Edinburgh East and Musselburgh) (SNP)
Macdonald, Lewis (Aberdeen Central) (Lab)
Martin, Paul (Glasgow Springburn) (Lab)
Marwick, Tricia (Central Fife) (SNP)
Mather, Jim (Argyll and Bute) (SNP)
Matheson, Michael (Falkirk West) (SNP)
Maxwell, Stewart (West of Scotland) (SNP)
McAveety, Mr Frank (Glasgow Shettleston) (Lab)
McCabe, Tom (Hamilton South) (Lab)
McConnell, Jack (Motherwell and Wishaw) (Lab)
McGrigor, Jamie (Highlands and Islands) (Con)
McKee, Ian (Lothians) (SNP)
McKelvie, Christina (Central Scotland) (SNP)
McLaughlin, Anne (Glasgow) (SNP)
McLetchie, David (Edinburgh Pentlands) (Con)
McMahon, Michael (Hamilton North and Bellshill) (Lab)
McMillan, Stuart (West of Scotland) (SNP)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
McNulty, Des (Clydebank and Milngavie) (Lab)
Milne, Nanette (North East Scotland) (Con)
Mulligan, Mary (Linlithgow) (Lab)
Murray, Elaine (Dumfries) (Lab)
Neil, Alex (Central Scotland) (SNP)
Oldfather, Irene (Cunninghame South) (Lab)
Park, John (Mid Scotland and Fife) (Lab)
Paterson, Gil (West of Scotland) (SNP)
Peacock, Peter (Highlands and Islands) (Lab)
Peattie, Cathy (Falkirk East) (Lab)
Robison, Shona (Dundee East) (SNP)
Russell, Michael (South of Scotland) (SNP)
Salmond, Alex (Gordon) (SNP)
Scanlon, Mary (Highlands and Islands) (Con)
Scott, John (Ayr) (Con)
Simpson, Dr Richard (Mid Scotland and Fife) (Lab)
Smith, Elaine (Coatbridge and Chryston) (Lab)
Smith, Elizabeth (Mid Scotland and Fife) (Con)
Somerville, Shirley-Anne (Lothians) (SNP)
Stevenson, Stewart (Banff and Buchan) (SNP)
Stewart, David (Highlands and Islands) (Lab)
Sturgeon, Nicola (Glasgow Govan) (SNP)
Swinney, John (North Tayside) (SNP)
Thompson, Dave (Highlands and Islands) (SNP)
Watt, Maureen (North East Scotland) (SNP)
Welsh, Andrew (Angus) (SNP)

White, Sandra (Glasgow) (SNP)
Whitefield, Karen (Airdrie and Shotts) (Lab)
Whilton, David (Strathkelvin and Bearspain) (Lab)
Wilson, Bill (West of Scotland) (SNP)
Wilson, John (Central Scotland) (SNP)

Against
Brown, Robert (Glasgow) (LD)
Finnie, Ross (West of Scotland) (LD)
Hume, Jim (South of Scotland) (LD)
McInnes, Alison (North East Scotland) (LD)
Munro, John Farquhar (Ross, Skye and Inverness West) (LD)
O'Donnell, Hugh (Central Scotland) (LD)
Pringle, Mike (Edinburgh South) (LD)
Purvis, Jeremy (Tweeddale, Ettrick and Lauderdale) (LD)
Rumbles, Mike (West Ayrshire and Inverclyde) (SNP)
Scott, Tavish (Shetland) (LD)
Smith, Iain (North East Fife) (LD)
Smith, Margaret (Edinburgh West) (LD)
Stephen, Nicol (Aberdeen South) (LD)
Stone, Jamie (Caithness, Sutherland and Easter Ross) (LD)
Tolson, Jim (Dumfriesshire West) (LD)

The Deputy Presiding Officer: The result of the division is: For 100, Against 15, Abstentions 0.

Amendment 8 agreed to.

Long Title

Amendment 35 moved—[Nicola Sturgeon]—and agreed to.

The Deputy Presiding Officer: That ends consideration of amendments.
Patient Rights (Scotland) Bill

The Deputy Presiding Officer (Alasdair Morgan): The next item of business is a debate on motion S3M-7978, in the name of Nicola Sturgeon, on the Patient Rights (Scotland) Bill.

15:50

The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): I thank the Health and Sport Committee and its clerks for all the work that they have done on the bill. As always, the committee was challenging but constructive and was a pleasure to work with. The work at stage 2 and today at stage 3 has undoubtedly strengthened the final article of the bill.

I thank my bill team officials, who have done an excellent job throughout. They have worked incredibly hard and their efforts have also helped us to strengthen the bill as we have gone through the parliamentary process. I genuinely believe that we have a bill that will make a difference to patients in Scotland, which has always been the intention of the Government and, I hope, of everybody else in the Parliament.

The manner in which patients are treated when they receive health care, as well as the quality of the clinical care that they receive, is fundamentally important. That is why we introduced the Patient Rights (Scotland) Bill. Genuinely excellent care already exists in the health service—I would be the first to acknowledge that. However, I would also be the first to acknowledge that that genuinely excellent care needs to happen more reliably and more consistently. It needs to happen for every person, every time they have contact with the health service. When it does not happen, patients must have a clear and unambiguous right to complain and to have their concern addressed. That is what the bill is all about.

Throughout the process, we have all agreed about the importance of patient rights. That has been welcome. We have all agreed that action needs to be taken to strengthen and ensure those rights. However, we have had honest differences of opinion about the best way of doing that. Those differences have led us to work together. The bill that is before members today is strong, practical and effective.

Following discussion at stage 2, we agreed to work closely with Richard Simpson to develop elements of the bill, one of which was the patient charter of rights and responsibilities, which is now a strength of the bill at stage 3. As we discussed a short time ago, the bill establishes a duty to publish a charter that will summarise all the rights and responsibilities of patients, including rights that are not established in the bill, such as data protection and equality rights. I hope that that addresses members’ earlier concerns that the bill would somehow create a hierarchy of rights and that patients would find it difficult to know the full breadth of their rights or might think that the rights in the bill were their only rights. More important, the charter will be drawn up in consultation with those whom it will most affect, so I hope that it will be a relevant, practical and useful document for patients and national health service staff.

The treatment time guarantee is another aspect that has developed throughout the parliamentary process. As I have said, the treatment time guarantee is intended to operate within the overall 18-week patient journey target. In the discussion on amendments, Richard Simpson said that we have the shortest waiting times on record—those were not his exact words, but that is what he meant. We have the shortest waiting times on record and we have made incredible progress. That began under the previous Administration, but it has continued and, I would argue, accelerated under the current Administration. I record my thanks to all the NHS staff who have worked hard to make that possible.

We all know that, for some patients—usually a very small number—their condition means that it will always take longer than normal to diagnose them and determine the treatment that they need. At the moment, if diagnosis takes such patients beyond the waiting time guarantee, they have no waiting time guarantee protection whatever. This treatment time guarantee is intended to provide—in the words that Richard Simpson used earlier—a long stop. It ensures that patients whose conditions take some time to diagnose and whose waiting time therefore exceeds the 18-week target still have certainty that they will receive their elective in-patient or day-case treatment within 12 weeks of agreeing the treatment. That reduces anxiety for both patient and family. I believe that that is sensible; it builds on our success on waiting times in recent years.

The bill introduces a comprehensive, nationally procured patient advice and support service. The current service has a lot of strength and is valued by those who use it, but it is not consistent throughout the country. That will change as a result of the bill. That will be beneficial to patients who need more support in accessing their rights such as those with mental health problems or a learning disability or the elderly. That is why a vote for the bill is a vote to help and support patients in Scotland.

The bill also introduces a legal right to complain. Many members questioned the value and necessity of a legal right to complain, but I passionately believe that introducing it is an
important step forward in helping patients to make their voices heard. It is also an important step forward in reassuring patients that their voices count and will be listened to. As I have said, we know that a lot of fantastic work goes on in the health service day after day. Much of the feedback that we get from patients recognises that. The bill is about listening to patients, learning from their experiences and improving the way in which services are delivered. Above all else, the bill is about saying to patients, “It is okay to complain.”

I am often struck by how often I speak to patients who have something to complain about but who feel that the very act of complaining is somehow disloyal to the health service that they value so much. The bill unashamedly and deliberately sends a signal to patients that not only is it okay to complain, exercising that right does a service to the health service and future patients by ensuring that, where things go wrong, we address them and minimise the chance that they will happen again.

The last area that I want to touch on is the separate issue of contaminated blood, which was introduced into the bill today. It was important to use this opportunity to amend the Smoking, Health and Social Care (Scotland) Act 2005 in advance of the decision that we will take on the future support of those affected by hepatitis C as the result of infected blood or blood products. I am very pleased that the amendments on the subject were supported by the Parliament today. They will ensure that, subsequent to our decision on eligibility for support, applications can be dealt with far sooner than they would be if changes were not introduced until later in the year.

I thank colleagues for the constructive way in which they have gone about the passage of the bill. I hope that everybody will vote for it at decision time. In voting for the Patient Rights (Scotland) Bill, I believe that we will take a big and bold step in setting out the foundation of a statutory framework of patient rights that will last far sooner than they would be if changes were not introduced until later in the year.

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That the Parliament agrees that the Patient Rights (Scotland) Bill be passed.

15:59

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I thank colleagues on the Health and Sport Committee and the committee clerks for the help and support that they have given throughout the process. I also thank the cabinet secretary and the Government bill team for the assistance with which they provided me in getting in place some of the language and other aspects of the amendments that we considered today.

I am pleased to open on behalf of my party in support of the bill. That is a sentence that I could not have written when first we were presented with the bill. I remember Ross Finnie taking me to task considerably and at some length for my highly critical stance on the original bill. I believe that the bill, as amended, will make a valuable contribution to the important journey that the Parliament has been on since its inception.

We have come a long way. The whole culture of the NHS in Scotland has changed and will continue to change. Moreover, my party, the Government party and the Scottish Liberal Democrats—I am less sure about our Conservative colleagues—remain wedded to a modernised but still very public service. Central to that is the concept of partnership, to which all of us are wedded—partnership between health professionals and patients and between the institution of the NHS and the public.

We will not embrace the wholesale changes that are now happening in England. However, in the bill, we are aligning ourselves in one respect with the English charter approach of the previous United Kingdom Government. The charter will meet the concerns of the Law Society of Scotland, which at stage 1 identified some 17 rights under statute, common law or NHS practice that were not set out in the bill. As the cabinet secretary said, it will end concerns that there is any form of hierarchy. I am sure that such a hierarchy was not intended in the original bill, but its existence was clearly implied.

The charter will provide a comprehensive guide and will have to be in formats that meet the various needs of all our citizens. Today we have agreed that those should include specified formats for people with a degree of incapacity. That reflects the groundbreaking Adults with Incapacity (Scotland) Act 2000, which was followed by our English colleagues a considerable time later.

The effect of the charter will have to be monitored. However, no matter how comprehensive or how well promoted it is, we have not yet answered the central question that the committee was posed with, as patients will not have any meaningful redress or compensation if their rights are infringed. That may have to wait for
another session of Parliament and consideration of the report of the no-fault compensation group. Elements of the bill may need to be reconsidered in light of that. No-fault compensation will be a crucial further step in moving from a defensive, closed approach, according to which mistakes are not recognised openly as opportunities for individuals and systems to learn but are seen as things to be hidden as far as possible.

We did not think that the way in which the treatment time guarantee was originally written, which applied it solely to in-patient treatments, was helpful. There will now be a series of undertakings to patients on what they can reasonably expect and a long-stop guarantee that they will not be passed by so that another patient can be placed within the tolerances of a target. Patients are rarely unreasonable. As one constituent said to me the other week:

“when I arrived at the hospital for my scheduled hip operation in the worst of the bad weather it was like a war zone. So when they apologised telling me they had to postpone my operation I fully understood I was then offered a choice of going to the Golden Jubilee or waiting for my chosen surgeon to have a free slot it was my choice and I felt everyone was doing their best.”

A charter targets and guarantees to underpin the mutuality of partnership, open discussion, clear information that makes sense and choices wherever possible, but it is not a platform for litigation.

In the new complaints section of the bill, Labour has sought to further the same principles of partnership and mutuality. Now there is not just a legalised complaints system but an NHS complaints system that invites patients and their families and carers to be part of a constant cycle of improvement. The four Cs approach that was supported by the Scottish Human Rights Commission’s team and proved so successful in the challenging surroundings of our state hospital is now to be part of the NHS. I hope that the Government will invite the commission and the Scottish Public Services Ombudsman to support the introduction of that new approach.

As the cabinet secretary indicated, most patients do not want to complain; sometimes they are fearful of complaining. Frankly, in the past boards have had a tendency often to respond with reports of process, instead of welcoming input as an important means of improvement and then telling the patient what they have done to make changes for the future. I always encouraged my patients to send in compliments or positive feedback if they had had a good experience. Staff respond to that. More important, managers can then see whether positive lessons can be learned that can be applied to other areas. Individually, comments may not amount to much, but when collated they may point to patterns and help to identify problems before they become the third C, that of concerns. A cobweb, a wheelchair left in a corridor or a notice partially hidden—none of those is hugely important but, if on day two, three or four the cobweb is still untouched or the chair still blocks egress, they can become concerns.

There are concerns about the 10 per cent of staff who, despite the substantial improvements that have been made, still do not wash their hands before touching a patient or moving a bedpan followed by a food tray—a comment I heard from a constituent the other day. We need to encourage patients to express concerns without having to go through a formal complaints system.

There are complaints, though. In the state hospital, those declined as the rest of the system developed and staff and patient satisfaction improved. The feedback loops that we are building in are critical to the success of the system as a means of improving care. All the feedback loops—to the patient, the family member, the carer, the patient advice and support staff, the board, the health department and health improvement Scotland—will be crucial.

Finally, there is the patient advice and support system. We now have an independent system capable of an holistic approach. I urge the Scottish Government to ensure that all existing contracts are extended immediately until the act is commenced and new contracts are established. The uncertainty created by the proposal to create a new and expensive raft of patient rights officers has already caused some damage that the Scottish Government must move quickly to repair.

I commend the bill, as amended, to Parliament.

16:07

Mary Scanlon (Highlands and Islands) (Con): The health secretary commented on patients’ loyalty to the NHS. That is a good point, but a small minority have a bad experience and often want to provide feedback to ensure that others do not have a similar experience. That should be seen as loyalty rather than complaining.

Scottish Conservatives voted against the bill at stage 1, and rightly so. The bill at stage 3 is substantially different and builds on the first patients charter, introduced by the Conservatives in 1990, which was reviewed and updated by the Labour-Lib Dem Scottish Executive 10 years later, in 2000. Now, another decade later, we have a bill at stage 3 that brings patient rights and, indeed, responsibilities into the modern age.

It is appropriate to outline our reasons for voting against the bill at stage 1 and to acknowledge the recognition by the Scottish Government that the first bill was not fit for purpose. The bill, as
introduced, did not seek to enshrine all rights available to patients and the new rights could not be legally enforced. At stage 2, that changed to a patient rights charter, along the lines of the Conservative charter in 1990.

The bill as introduced talked about a duty on NHS bodies

"to have regard to certain rights and principles".

I lodged an amendment at stage 2 to change that to a duty to uphold health care principles. It was agreed to unanimously.

As Richard Simpson said, there was a focus on complaints as the only means of feedback and communication. Many patients and families do not want to go down the road of complaining. That has changed to a more positive approach focusing on feedback, comments, concerns and, if necessary, complaints. There is undoubtedly a need to have a more open and accessible system of patient feedback and to handle patient concerns in a sensitive and supportive manner.

Like others, Conservatives did not want a charter for lawyers that set out new rights that were not legally enforceable. The patients charter will address all those issues in a more modern and effective manner. The committee—or should I say Dr Richard Simpson—ensured that patient responsibilities as well as rights were included in the charter. That is only right.

We were, and remain, concerned that the treatment time guarantee will skew clinical priorities, but I accept the health secretary’s amendment to ensure that the clinical needs of all patients are taken into account and hope that it will address the issue. The committee was unanimous in supporting that measure.

However, despite the new health improvement, efficiency, access and treatment target for psychological therapies for 2014, I remain concerned that mental health services will remain the Cinderella of the NHS, given that resources will continue to be focused on meeting the treatment time guarantee.

In the stage 1 report, the committee concluded that

"a majority of the Committee is not persuaded by the evidence which has been advanced to date, that primary legislation is the most appropriate means of promoting patient rights."

The committee was, therefore, "unable to make a recommendation to the Parliament on the general principles" of the bill.

As the health secretary said, what we have before us today has been achieved as a result of excellent committee scrutiny and the health secretary responding to all the concerns that were raised at stage 1 to bring forward a bill and a charter that are fit for a modern NHS and which are built on respect and dignity for patients, and better communications and working relationships between patients and the NHS.

I appreciate that we have been on a journey, but I am pleased to say that the Scottish Conservatives will support this much improved bill.

16:11

Ross Finnie (West of Scotland) (LD): The Scottish Liberal Democrats voted against the bill at stage 1. We did so because of a number of quite important principles to do with the purpose of legislation, which have been widely debated and rehearsed, particularly by me and the cabinet secretary. That was a not unhelpful discourse. We will support this much-amended bill this evening; I will explain why in a moment.

However, I am bound to say that that does not change the Liberal Democrats’ view that legislation is a matter of law and should have a purpose and effect in law. Although I agree with much of what the cabinet secretary said, the passing of a bill cannot be regarded as groundbreaking or something for which the whole world will applaud us, as the first country to have a law on patient rights, if that law, even in its amended form, still will have no real legal effect.

Given that I was so critical of Dr Richard Simpson—who was so eloquent in his criticism of the bill that I misunderstood his position; for that I apologise—it would be churlish of me not to acknowledge the enormous amount of work that he has done in developing amendments that, together, have created the prospect of a charter. We will support the bill because we think that the charter is important, but with this caveat: I still do not believe that a Parliament that is worthy of the name needs to have a bill in order to create a charter. We ought to pause and reflect on that.

However, we must move forward; life is too short. We hope that the charter will set out clearly and concisely what patient rights are and what patients can expect. It will also make it clear that, as the Law Society pointed out to us, there are some 17 legal rights in addition to those that were originally set out in the bill, to which patients can have recourse if they genuinely need to. Bringing all that together will be enormously helpful.

From the evidence, it was clear that the temptation to follow the need for a patient rights bill was driven by confusion about exactly what patient rights were and the range of those rights. There was also confusion because there was effectively no single document that brought them together in an easily understandable form. There
was, of course, a degree of disappointment in discovering that the Patient Rights (Scotland) Bill, as it was introduced, gave not one legal right whatever, but that has now been amended.

There are other enormously helpful elements in the bill as amended. Patient advice has been substantially changed in a way that is very much in the interests of the patient and eliminates the need to invent a more bureaucratic system to implement it. We now have a system that will be helpful to the patient.

I am sure that it is important that we have the right to complain. Perhaps I am unusual but, in my almost 12 years as a member of Parliament, not one constituent has written to me to tell me that their complaint was sent back to them with a short letter explaining that they have no right to complain. However, I have found that complaints have been dealt with in a profoundly unsatisfactory way. As Richard Simpson said, certainly in the west of Scotland, the health boards still tend to narrate complaints at all stages, thus indicating how perfectly they were dealt with, leaving us to ask why the complaint was written in the first place. The fundamental differences in how the system operates that the bill introduces and the fact that someone can simply make a comment give encouragement to do something different and take a more positive role.

As I have indicated, I share Richard Simpson’s view that the complaints loop will not be complete until we act on the report on no-fault compensation that the cabinet secretary published recently. That is the missing link in addressing the complaints situation.

The cabinet secretary’s amendments concerning patients and sufferers of hepatitis C are a welcome addition. I hope that having those powers conferred upon her, the cabinet secretary will be able to respond positively, although she did point out that there are some difficulties with the way in which the fund has been implemented down south. Nevertheless, we agree with the general principles.

The Liberal Democrats are satisfied that the patient charter will benefit all those who use the health service. I pay tribute to the cabinet secretary; as always, she has responded positively to matters that have been raised with her. We have not always agreed with each other, but the critical point is her willingness to make progress, to respond constructively and to place before the committee and Parliament amendments that induce a proper debate. Many of the subjects that were a part of the original bill have been improved as a consequence of the process of debate and her genuine attention.

The bill spans the charter, the treatment time guarantee—which, as Mary Scanlon said, has been amended to change the sense that it might dominate the process of clinical judgment and care—patient advice, the right to complain, the complaints process and payments for patients with hepatitis C, making the bill one that I can support, despite my real and genuine reservations. If I am fortunate enough to be returned to Parliament, I will continue to oppose any bill that does not confer any legal rights. I certainly hope that in future we will be able to make charters without going through the whole legislative process.

16:19

Ian McKee (Lothians) (SNP): One of the criticisms that is sometimes made of the national health service is that, as a monopoly, it runs the risk of ignoring the genuine needs and concerns of patients. If we are being honest, we know that that has sometimes been the case.

Other countries have attempted to put the patient in the driving seat by introducing competition and privatisation into health services, but that brings other problems—too numerous to list now—and Scotland has, rightly in my opinion, avoided going down that route.

How do we avoid the trap that many monopolies fall into of becoming an organisation for producers rather than consumers? The answer is by constant vigilance, and the Patient Rights (Scotland) Bill is an important tool that can help. It is perhaps significant that much of the opposition to the bill has come from producers, whereas patient organisations—the consumers—largely support it.

At stage 1, I found very persuasive the argument that the bill could be confusing, even misleading; although it is entitled “Patient Rights”, it does not list all patient rights. Although I recognise the argument by the minister and others that existing rights that are not enshrined in the bill are not weakened by that omission, it seems sensible to include in the bill the establishment of a charter, so that the average patient on the Morningside omnibus knows his or her entitlements. Therefore, I welcome the adoption of a charter at stage 2 and its continuing presence at stage 3.

The star attraction in the bill is the treatment time guarantee. Lawyers and others might quibble that a legal guarantee without legal redress is worthless, but most of us agree that neither patient nor NHS will benefit if the health service in Scotland becomes a rich feeding trough for lawyers, as is now the case in some other countries.

The attraction to patients and patient organisations of specifying a treatment time
guarantee in the bill is that it gives waiting times much more importance in the minds of those who provide health care and so makes it much more likely that such a guarantee will be observed.

Another worry of mine when the Health and Sport Committee was taking evidence on the bill was whether strict attention to fulfilling the guarantee for patients nearing the end of the guarantee period might delay an operation or procedure for a person whose health could be seriously put at risk by such a delay. For instance, it would obviously be wrong for an operating list to be full of relatively minor operations that needed to be performed urgently simply to meet the terms of the guarantee, if that entailed putting off an operation or operations that were clinically urgent but which had been on the waiting list for a much shorter time.

I am pleased to say that the bill makes it clear that clinical needs must always be given priority in such situations—and, if such a situation exists, that is an acceptable ground for breaking the treatment time guarantee. That is a commonsense stipulation.

I praise the establishment of robust mechanisms for collecting patient feedback and providing patient advice and support. For too long we have encouraged an environment in which complaints have been the main form of feedback. Although it is important that complaints are received and acted upon, there are many pieces of advice or observations from patients that are far removed from being complaints that could help in the running of the health service. It is right that we pay attention to those. Being in hospital or on the end of health care delivery, from whatever source, can be a bewildering experience, so a robust, independent patient support service is very welcome.

We must not let ourselves be beguiled by the notion of a free health service. The NHS is not free; it is paid for by the taxes of those who use it. It is vital to establish mechanisms to protect the rights of those who not only use the NHS but pay for it, and the bill goes a long way towards doing that.

Like other members, I had concerns on first reading the bill at stage 1. That we can now all agree that the bill should be passed speaks well of the Government, the Health and Sport Committee and the Parliament. I ask the Parliament to support the bill.

16:24

Rhoda Grant (Highlands and Islands) (Lab): I am pleased to speak in this stage 3 debate on what is a very much improved bill. As other members have said, the Health and Sport Committee could not recommend the bill to the Parliament at stage 1. Basically, the bill as introduced did not improve patient rights and was in danger of creating a hierarchy of rights, by emphasising those in the bill and unintentionally undermining those that were not in the bill. The bill as introduced provided no new rights in relation to the complaints procedure and was in danger of creating different systems in different areas. I am glad that the bill has now been improved sufficiently to allow all parties in the Parliament to pass it today.

There are still patients who feel that the bill does not go far enough, but it is difficult to retain a health service based on mutuality if it is also surrounded by litigation. I hope that the bill will ensure that problems can be dealt with before they reach the stage of litigation and that patients will always be afforded dignity and the involvement that they should have in their care. If that happens, litigation will not be necessary other than in extreme circumstances. It is also clear that there is a fine balance between rights and responsibilities in the health service. We need a health service that is based on mutual respect between all staff and patients. There must also be respect throughout the ranks of the health service, where old-fashioned hierarchies often still exist.

The bill has been amended to instruct the Government to pull together all patient rights into a patient rights charter—a single point of reference that encompasses all rights and responsibilities. Every patient has the right to the same level of respect, treatment and involvement in their care, regardless of their age and circumstances. I was dismayed recently to see that elderly patients do not always appear to receive the same level of care as patients in other areas. Staffing levels appear to be different, as are basic resources such as blankets and pillows. That is unacceptable. Elderly patients have the same rights as everybody else; indeed, because they are more vulnerable, they should probably receive more care.

The bill means that NHS boards will have to uphold the health care principles rather than have regard to them. The first principle is:

“anything done in relation to the patient must take into account the patient’s needs”.

That can only benefit elderly patients.

The bill has also been amended to allow the patient advice and support service to provide holistic advice and support. We received evidence that the citizens advice bureaux currently provide a holistic service in that they advise on patient rights and complaints but can also offer advice to the same patients on much wider issues such as benefits. When people are unwell, an additional
burden is placed on them if they have to access a number of agencies to receive the help and advice that they require. The CABx’ one-stop-shop approach is really helpful and means that the adviser has a full picture of the patient’s needs. The one problem with the existing service is that it is not uniform across NHS boards—it is up to individual boards to contract for the service. Some boards take it seriously, funding and advertising it properly, but others do not. That means that there is a postcode lottery regarding service levels. Following amendment, the bill now builds on the best practice of the old service and should ensure that a uniform service is provided throughout all health board areas.

The bill brings something new and meaningful to patients by creating a charter of all rights, and it will make those rights much more transparent and accessible to patients. It will also ensure that patients receive the advice and assistance that they require. However, it will not be the last word on patient rights; it will be for successive Governments to build on the health care principles and ensure that the health service delivers for patients. They will also need to ensure that there is equity of resource, to empower staff to deliver those principles across all disciplines.

16:28

Willie Coffey (Kilmarnock and Loudoun) (SNP): We should see today not as the end, but as the beginning of a process of change in how the NHS handles complaints—especially complaints potentially involving medical negligence. As a constituency MSP, I have found the handling of such complaints the most unsatisfactory aspect of my constituency work. I know that those who get as far as consulting their MSP will represent some of the most difficult cases that we have to deal with, and we all know that many complaints are dealt with perfectly well and that people are generally satisfied with the responses that they receive, but it is clear to me that there is some dissatisfaction with the present arrangements. In passing the bill, the Parliament is signalling its recognition of the need for change.

The current arrangements appear to discourage complaints. That was confirmed in research that was carried out by the Scottish Health Council in 2009, which found that 53 per cent of those who experienced a problem with NHS treatment took no action. Many people believed that lodging a complaint would make no difference, and some patients were concerned that it could affect their treatment and their relationship with health professionals. In addition, many of those whose problem was with medical care were too busy coping with the consequences to complain.

The statutory right to complain that is included in the bill needs to be widely publicised. Also, through new patient advice and support systems, patients must be encouraged to provide feedback on their care, including positive responses when things go well. When necessary, patients should be supported to submit formal complaints, and there should be a clear expectation that they will be treated seriously and with respect.

In my opening remarks I said that there is a need for a culture change. One of the areas in need of such a change is where the complaint refers to an action that could be defined as medical negligence. Because many patients and staff believe in the NHS as a mutual organisation, such complaints cause particular difficulties. I know that they consume vast amounts of clinicians’ and managers’ time and that, too often, they damage the relationship between the NHS and patients.

In parallel with the bill, the Government is taking advice on a system of no-fault compensation. I know that such a system will not resolve all complaints of medical negligence, but it could focus attention on learning lessons rather than having managers and doctors fighting off inquiries of patients or, indeed, lawyers. I look forward to seeing the final outcome of that work.

As has been said often throughout the debate on the bill, managing complaints within the NHS must strike a balance between the managerial and the clinical. The approach that is adopted by clinicians, especially senior consultants, will be a critical factor. Complaints should be seen not as a threat but as an opportunity for service improvement or as an opportunity to learn, as Richard Simpson said.

I hope that everyone who works in the NHS—clinicians, management and staff—will embrace the bill as a major step forward and a golden opportunity to make Scotland a better place, and I hope that the chamber will fully endorse the bill at decision time.

16:31

Helen Eadie (Dunfermline East) (Lab): I would like to thank the various organisations and individuals who have given feedback on the bill. They have done so assiduously throughout the process and they must know how much we appreciate their advice and guidance and the way in which they have informed our deliberations. The advice and guidance of the clerks to the Health and Sport Committee are also much appreciated, and I echo the tributes that have been paid by Richard Simpson, Ross Finnie and others to the cabinet secretary for her responsiveness to the
issues that were raised during the passage of the bill.

One of the things that emerge quite strongly when we speak to people about complaints processes is that many people simply do not like to complain about health professionals in any role. Patients feel vulnerable and worry that, if they complain, they might suffer some reprisals. I hope that the bill will make the complaining process more effective and ensure that people feel less threatened and that the process has been worth their while. My constituent Eddie MacKay of Aberdour never had the apology that he badly needed from the one person whose apology would have made a difference to him: the chairman of NHS Lothian. Occasionally, we underestimate the value of a simple apology from the most appropriate person. Eddie lost his wife and two sons when they were under the care of the NHS and he has no family left.

The Health and Sport Committee was interested to see the initial qualified welcome that was given to the bill by a variety of patients organisations such as the Royal National Institute for Deaf People and the Scottish Association for Mental Health. The Royal College of Nursing said that the reasons why there are times when care does not match the values that we share are complex, which is why it has consistently argued throughout the passage of the bill that primary legislation is not the means by which we should be trying to make a difference to patients’ rights.

The RCN still believes that, although there have been some positive amendments to the bill, legislation is not the best course by which to improve the rights of patients, so the welcome is not universal—and although, as Ian McKee says, the opposition comes from the producers, the Public Services Ombudsman and the Law Society act on behalf of patients and families and they share the RCN’s concerns about sanctions. However, I am pleased that that issue is now being addressed. Those organisations recognised that the bill was controversial and did not enjoy universal support in the Parliament.

With the adoption of a parents charter, which was introduced by my colleague Richard Simpson, the bill is quite different from that which was introduced. The RCN’s preference was for a patient rights charter. It said that a charter that can be reviewed and revised is preferable to a set of rights that are enshrined in primary legislation, as changes in the future would require further legislation.

The RCN also believes that enshrining patient rights in primary legislation could unbalance the relationship between health care professionals and patients, could be extremely costly and could have unforeseen consequences. In its opinion, those risks outweigh the potential advantages of the bill. In my opinion, only time will tell.

SAMH remains disappointed that most mental health treatment will not be subject to the treatment time guarantee in the bill, but it welcomes the fact that potential changes to the guarantee will be subject to affirmative resolution as it hopes that that will enable treatments such as mental health care to be considered in the future. However, it welcomes the bill overall as a step forward in providing patient-centred, rights-based medical treatment.

A number of organisations believe that the various amendments that have been made to the bill have strengthened it. Many organisations, such as the Law Society of Scotland, have expressed their support for the bill. I welcome the bill and I give it my good wishes for the future.

16:36

Irene Oldfather (Cunninghame South) (Lab): As other members have said, we have come a long way since stage 1 of the bill when many members, including me, expressed concerns about the need for it to cover all rights and to ensure that there is a one-stop shop for advice on patient rights, particularly for those who find muddling through the system difficult.

Stakeholders representing those with incapacity said at that time that if there was one thing that they would like to get into the bill it would be a provision on information. Staff too often think that by handing out a sheet of paper they have complied with the need to provide information. There is a responsibility to ensure that a patient understands the information that they are given and that it is given to them in a way that enhances their understanding. I believe that we have certainly moved that agenda forward today.

I am grateful for the support from across the chamber for recognising in particular the needs of those who lack capacity. I do not want to rerun the debate on my amendment 1A, but I think that as we give examples such as Braille and other languages we did the right thing in also highlighting the needs of those who lack capacity.

I think that the bill is a piece of legislation about which we can say we worked together to make it better. Like Ross Finnie, I pay tribute to the work that Richard Simpson put in and from which we have all benefited. I am also grateful to the cabinet secretary for the support that she gave my amendment.

Rights are meaningful only if one knows what they are and how to claim them. I believe that the bill ensures greater fairness and greater equity in the system for all patients but, in particular, it
reinforces the position of elderly vulnerable people with Alzheimer’s and dementia and those who lack capacity. I am pleased to commend the bill to the chamber.

16:38

Jamie Stone (Caithness, Sutherland and Easter Ross) (LD): I am the convener of the Subordinate Legislation Committee. I and my colleagues on the committee have been fairly involved with the bill, so as well as thanking the clerks to the Health and Sport Committee, the members of that committee and the cabinet secretary and her team, I put on record my thanks to the clerks and the legal team who back up the Subordinate Legislation Committee and to my colleagues, three of whom—Rhoda Grant, Helen Eadie and Ian McKee—have taken part in the debate. That level of knowledge on my committee has been extremely useful.

I will touch briefly on the debate on the amendments this afternoon. I welcome the give by the cabinet secretary when she agreed with my committee’s concerns about the suspension of the treatment time guarantee and granted a role for Parliament for suspensions in excess of 30 days. It would be churlish not to acknowledge the cabinet secretary’s constructive approach. I think that that has led to the bill being improved and it has safeguarded the role of Parliament.

In the brief time that is available to me, I will touch on three points that have been well made in the debate. The cabinet secretary said that we have “genuinely excellent care” in the NHS. We have all experienced that. I had a small operation on an eye in Aberdeen royal infirmary and I cannot fault Mr Reddy, the consultant ophthalmologist, and his team for the treatment I received. I know that others have received such treatment.

Secondly, Mary Scanlon referred to Richard Simpson’s mention of patient responsibility, which is absolutely correct. We, as elected members, should never forget about it. I have talked before about elderly people who hoard medication, do not take it properly or do not tell the doctor about it. That is all about responsibility.

Thirdly, I echo the point that Willie Coffey made late in the debate: do we really want to see doctors wade their way through heaps of complaints? Indeed we do not; that is a terrifying prospect because it would get in the way of what they should be doing.

I will finish with a point about what I consider to be patient rights, which I made on 17 November when we debated the bill at stage 1. I represent a vast and far-flung rural constituency. The rights that my constituents have talked to me about, which I have mentioned before—the cabinet secretary will be glad to see me out of this chamber in a few months’ time—include an ambulance service that works; a patient transport service that is not just a one-way service that takes people to Inverness and leaves them there; access to dentists; and the ability to get treatment and not be disadvantaged because of where one lives.

I welcome the bill. I take on board my colleague Ross Finnie’s caveats about whether we really need legislation to put in place a charter. I do not remember there being legislation for the citizens charter of a one-time Government at Westminster. Nevertheless, we are where we are. We have worked together and put together a bill that is to the betterment of health in Scotland.

This morning John Farquhar Munro and I had a visit from staff from citizens advice bureaux in Ross-shire. Day in, day out, those people are at the sharp end of dealing with the stuff that we are discussing today. They were not aware that we would have this debate today, but they said, “It’s a very good bill. Would you and John Farquhar please support it?” I have great pleasure in doing so.

16:41

Murdo Fraser (Mid Scotland and Fife) (Con): The context of this debate is of course patients’ right to complain in the national health service. I think we all agree that the national health service is a very good institution that provides a very good standard of care, but it is not perfect—nothing on this earth is—and, on occasion, people have reason to complain.

In my experience—others have touched on this point—people are reluctant to complain. Earlier in the week I met young mothers of babies who had been born with neonatal issues and who had spent some time in hospital. Even though the mothers identified that there had been problems with their children’s treatment, when I asked them whether they had complained they said that they felt very reticent about doing so, because the care that they had received from the staff whom they had encountered was of a high quality and they felt that making a formal complaint would denigrate that, even though they had legitimate concerns about some of the administrative approaches to how they were dealt with—there were particular issues around staffing levels and the funding of the resource. We have to be conscious of that issue.

Ian McKee made a good point in his contribution about the NHS not being free. We assume that it is a free service, but of course we pay for it through our taxes. As the people who pay for it, we are quite entitled to expect a good-quality
service in exchange for the money that we put in. Sometimes we are reluctant to complain—we see that often.

We all deal with constituency cases of people who are complaining. Very often they want to make a complaint because they are at the end of their tether with the health service. They feel that all they wanted from someone in charge was a simple apology for the way that they, or perhaps an elderly relative, had been treated. Sometimes they end up going down the legal route simply because they feel that no other road is open to them.

I know that we are continuing to develop complaints handling in the NHS. We have to look at how we make it easier for people to make complaints and get an apology without necessarily having recourse to a formalistic and legal route.

The Scottish Conservatives did not believe that the bill as originally proposed would achieve anything worth while. We agreed with many of the medical groups who said that it was unwise to seek to enshrine patient rights in primary legislation. I have a lot of sympathy with the remarks that Ross Finnie made in that context.

In addition, concerns were expressed at stage 1 about the treatment time guarantee and the employment of patient rights officers. We thought that there was no point in having legal rights in the bill if they could not be enforced, and we thought that making the rights legally enforceable would create more problems than it would solve and would create the doleful prospect of a lawyer at every bedside—doleful, that is, for everyone apart from the lawyers, who I am sure would welcome the extra work.

However, after something of a comprehensive retreat on the part of the cabinet secretary, the bill was transformed beyond recognition at stage 2. It now provides for a patient rights charter, which we can support. As Mary Scanlon said, it was the Conservatives—indeed, I think it was Michael Forsyth, in the Scottish Office—who proposed a patient charter 20 years ago. I am sure that in the spirit of political consensus Lord Forsyth would be delighted that the Scottish Parliament is following his leadership today.

In briefings on the bill, the British Medical Association and the RCN continued to express concern about enshrining rights in legislation, but both organisations conceded that the creation of a patient charter is a sensible alternative. The amendment of the bill in that regard was a sensible compromise, which I hope the BMA and the RCN regard as an improvement.

The bill has also been amended to remove the provisions on patient rights officers. We were far from convinced that the NHS needed between 65 and 80 full-time-equivalent new posts, which would take money from the health budget that could be better spent on front-line services. The bill was improved by the deletion of the provisions.

We remain concerned about the treatment time guarantee. At stage 2, an amendment in the name of the cabinet secretary included provision to require NHS boards to take account of the clinical needs of all patients and prioritise appropriately as they try to meet the treatment time guarantee. The amendment helped to dilute our concern that health boards would skew clinical priorities as they strove to meet the guarantee.

As I said, the bill has changed beyond recognition. For that reason, we welcome it. Although we still have some reservations, we think that it is worthy of support. However, it is not the bill that the cabinet secretary intended. Our passing of the bill will be a victory for the Parliament over the Government.

16:47

Jackie Baillie (Dumbarton) (Lab): As Mary Scanlon said, we have travelled far with the Patient Rights (Scotland) Bill, which has been considerably improved since its introduction. I thank the Health and Sport Committee, the bill team, the clerks and everyone who contributed to the process.

We all supported the concept of patient rights in principle, but it is fair to say that many members were less than convinced by the bill when it was introduced—we heard from the Liberal Democrats and the Conservatives in that regard. Indeed, the need for legislation was questioned. The Health and Sport Committee was unable to make a recommendation to the Parliament because its members thought that the bill would lead to confusion and that far from enshrining all patient rights it was narrowly focused. We shared those reservations but we decided to persist and try to make the bill better.

The Scottish National Party’s manifesto pledge was to give every patient “a legally binding waiting time guarantee”.

The bill falls short of that commitment. It was interesting to hear from Ian McKee, who is passionately against such an approach. I am not sure that he felt like that when he stood for the Parliament on the SNP manifesto in 2007, but I welcome all converts.

Many witnesses thought that the lack of sanctions in the bill is a potential weakness. However, we do not want to foster a culture of litigation or create a bonanza for lawyers, so the approach is ultimately right.
Ross Finnie was right to question the basis for legislation. The bill has little legal effect and we need to be careful not to heighten expectations among the general public of what it can achieve. We need to be careful to ensure that legislation is more than simply declaratory or assertive of something. We need legislation that sensibly advances patient rights within a framework that recognises the mutuality of the NHS and the balance that should exist between rights and responsibilities of patients and staff.

We favoured an approach that would enable the cabinet secretary to introduce a comprehensive charter of rights. Like many members, I pay tribute to my colleague Richard Simpson for his work on framing amendments to give effect to that. I am also grateful to all the parties that are represented in the chamber and to organisations that supported that change, such as the RCN and SAMH. There are many things in the health service that are not conditioned by legislation, but health boards are in no doubt about their importance. Richard Simpson was, of course, correct to point out that the charter mirrors the approach that was taken by the previous UK Labour Government in England. That is welcome.

There is no doubt in my mind that we need to improve the NHS complaints system. It is not fit for purpose and I am not sure whether the NHS learns lessons as a result of the complaints that it receives. Helen Eadie was right to point out that most people who come to us to describe an unhelpful experience in the NHS do not really want to complain; in many cases they simply want the NHS to apologise. We should never underestimate the power of just saying sorry, but it is important that people also want the NHS to learn from mistakes so that no one else has to experience what they experienced. The modernised system, which reflects that used by the state hospital, is much more positive. There should be compliments, as it is right to praise people when they do something right, comments that may be an early indication of potential problems, concerns that enable people to prevent a problem from escalating, and, finally, the possibility of making complaints.

Members have referred to no-fault compensation as being the missing link in the complaints system. We welcome the review group’s report. We should look closely at how such a scheme would work in practice for the benefit of patients, the NHS and its staff. If it enables us to say sorry, which is what most relatives want to hear, we should embrace it.

We acknowledge that the passing of the bill will bring renewed focus on patient rights, but we need to be careful not to overclaim what it will achieve. We are all passionate about the NHS, which Labour created in 1948, and we all value NHS staff and all their hard work in treating our constituents and families. We believe in a mutual NHS that is patient centred and we all want the best for every patient every time. Labour members believe that the bill represents a further step on that journey and we are pleased to support it.

16:52
Nicola Sturgeon: I thank all colleagues who have spoken in the debate for their thoughtful contributions and their work as the bill has progressed through Parliament.

A number of members, including Richard Simpson, Ross Finnie and Mary Scanlon, said that the bill has improved as it has progressed through the parliamentary process. I agree with that—I think that that is the purpose of parliamentary scrutiny. Unlike Murdo Fraser, I do not consider that improvement to be a victory for Parliament over Government or vice versa. Rather, it is an example of Parliament working as it should work and of what it is all about. It is to the credit of all of us that we have emerged at the end of stage 3 with a bill that is stronger than it was at the beginning of stage 1. I put on record my thanks to everybody who has helped to make that possible.

Several members spoke about the charter. I, too, agree that the charter is an important development and avoids the creation of a hierarchy of rights or the suggestion being given out that only the rights in the bill matter and other rights are somehow diminished as a result. That was never the bill’s intention. However, I am not sure that I would agree with my Conservative colleagues that it takes us back to the days of the Tory charter of patients’ rights; perhaps we can agree to disagree on that. The rest of us will probably hope that the charter will last longer and will have considerably greater impact than the charter that the Conservatives referred to.

Several members, including Richard Simpson, Ross Finnie—I think—Ian McKee and Willie Coffey, raised the issue of the linkages between the bill and no-fault compensation. Members will be aware that the report of the expert group that we set up to look into no-fault compensation, chaired by Sheila McLean, was published earlier this week. I thank that group for its work—it has produced a very good report. It will be for the Parliament in the next session to decide how the work progresses, but I am proud that the Government has made progress in that direction. I very much hope that we will be able to continue that work in the next session.

Mary Scanlon, Ross Finnie and other members raised the issue of the right to complain. As Ross Finnie said, he and I have had discussions
throughout the passage of the bill about the right to complain. [Interuption.]

The Presiding Officer (Alex Fergusson): Sorry, but could whoever has the electronic instrument that is making that noise please turn it off?

Nicola Sturgeon: I do not think that it is mine, Presiding Officer but, just in case, I have asked my colleague to remove it from my desk. It is a bit uncomfortable that I am talking about the right to complain at the moment.

Ross Finnie made the point that at present people who complain are not told that they cannot complain because they have no right to do so. That is of course true but, in many respects, the measure is not at its most important when it comes to those who exercise the right to complain, although I believe that raising the status of the complaints process will help to improve the process of complaints handling, to which all members have referred. In a sense, that aspect of the bill is most important for those who do not exercise their right to complain because they feel that it is disloyal to the health service or perhaps because they fear repercussions. We are saying to them that there is a legal right to complain, that it is all right to exercise it and that it is actually in the interests of the health service to do so. That is important. The provisions on patient feedback are also important, because we must encourage a two-way relationship.

Several comments have been made on the treatment time guarantee. Perhaps we do not have time for a pedantic argument at this stage in the afternoon, but I say to Jackie Baillie that a guarantee that boards are required by law to abide by seems to me to be a legally binding guarantee in anybody’s language. Therefore, I am pleased that that is yet another manifesto commitment delivered by the SNP Government.

Jackie Baillie: I am clear that the intention behind the SNP’s commitment to a legally binding guarantee was to give patients recourse to litigation. The bill does not do that.

Nicola Sturgeon: Not for the first time, Jackie Baillie is writing things into the SNP manifesto to assert that we have not delivered them. We have delivered what we said we would, and more. That is extremely important. The measure builds on the progress that the Government has made on reducing waiting times. As Ian McKee rightly said, it ensures clinical discretion, but it also ensures a long-stop guarantee for patients, which is absolutely in their interests.

In each and every one of the respects that I have mentioned, we have reached a point at which we have a bill that will make a tangible, appreciable and meaningful improvement to the way in which patients interact with the health service. At stage 1, when I gave evidence to the Health and Sport Committee, I said that the bill was in part about trying to bring about a culture change in the health service. That led to something of a philosophical debate with Ross Finnie—I always enjoy my philosophical debates with him. However, I believe that the point is important. We talk a great deal about partnership working and mutuality. The bill takes us further along the road to making those aspirations a reality. It firmly and clearly puts patient rights at the heart of the health service. It says clearly that the health service has a duty to ensure that the manner in which patients are treated, and not just the quality of the clinical care that they get, matters. It says that the health service has a duty to ensure that it lives up to and delivers the highest standards at all times. That is important.

I am proud that the SNP Government, helped by the Opposition parties, has achieved a situation in which the Parliament is the first in the UK to legislate for patient rights, which is a significant step forward. I again thank everybody who has contributed to the process. [Interuption.]

The Presiding Officer: Quiet, please. There is far too much noise in the chamber.

Nicola Sturgeon: I am glad to say that, this time, it is not being caused by my mobile phone, which is good.

I have already thanked the Health and Sport Committee. I thank the Opposition parties and the officials. Finally, I thank the groups who contributed to the bill through written evidence. They have helped in the process of making it stronger. I have no doubt that we will shortly pass a bill that will strengthen patient rights and help to make the national health service in Scotland the very best that it can be.
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Patient Rights (Scotland) Bill
[AS PASSED]

An Act to make provision about the rights of patients when receiving health care; to make further provision about eligibility under the scheme made under section 28 of the Smoking, Health and Social Care (Scotland) Act 2005; and for connected purposes.

Charter of Patient Rights and Responsibilities

(1) The Scottish Ministers must, within 6 months of the coming into force of this section, publish a document to be known as the Charter of Patient Rights and Responsibilities (“the Charter”).

(2) The Charter must set out a summary of the rights and responsibilities (as existing at the date of publication) of patients and relevant persons.

(3) The Charter may also include—
   (a) a summary of the duties of relevant NHS bodies,
   (b) a summary of the behaviour expected from patients and relevant persons,
   (c) such other information as the Scottish Ministers consider relevant in relation to health care or the health service (for example, information relating to targets for the periods of time within which patients are to be treated).

(4) Nothing in the Charter is to—
   (a) give rise to any new rights,
   (b) impose any new responsibilities, or
   (c) alter (in any way) an existing right or responsibility.

(5) For the purposes of this section and section Z3, a “relevant person” is—
   (a) a person who has a personal interest in the health care of a patient (for example a member of the patient’s family or a carer),
   (b) such other categories of person as the Scottish Ministers consider appropriate.

(6) The Charter is to be published in such form and manner as the Scottish Ministers consider appropriate.

(7) Before publishing the Charter under subsection (1), the Scottish Ministers must—
(a) consult such persons as they consider appropriate,
(b) lay a copy of the Charter before Parliament.

(8) The Scottish Ministers must, as soon as reasonably practicable after publication of the Charter under subsection (1), notify each relevant NHS body of the publication of the Charter.

(9) Each relevant NHS body must make available without charge copies of the Charter to patients, staff and members of the public.

(10) In carrying out the duty under subsection (9), a relevant NHS body must take account of the particular needs of the persons to whom the Charter is to be made available as to the form of the Charter (for example by making it available in different languages or in Braille or by having regard to the particular needs of adults with incapacity within the meaning of section 1(6) of the Adults with Incapacity (Scotland) Act 2000 (asp 4)).

Z3 Review and revision of Charter

(1) The Scottish Ministers must carry out a review of the Charter at least once in any period of 5 years.

(2) The purposes of a review under subsection (1) are—

(a) to ensure that the Charter continues to accurately summarise the rights and responsibilities of patients and relevant persons (as existing at the date of review), and
(b) to assess how effective the Charter is in raising awareness of the rights and responsibilities of patients and relevant persons.

(3) When reviewing the Charter under subsection (1), the Scottish Ministers must also review how effective the arrangements for the publication and distribution of the Charter have been in promoting awareness of the Charter and, if they consider it appropriate, take such steps as they consider necessary to improve those arrangements.

(4) In carrying out a review under subsections (1) and (3) the Scottish Ministers must consult such persons as they consider appropriate.

(5) The first review under subsection (1) must be completed not later than 5 years from the date on which the Charter is published under section Z2(1).

(6) The Scottish Ministers must revise the Charter where, following a review under subsection (1), the Scottish Ministers consider that the Charter—

(a) does not accurately summarise the rights and responsibilities of patients and relevant persons, or
(b) is not sufficiently effective in raising awareness of the rights and responsibilities of patients and relevant persons.

(7) The Scottish Ministers may revise the Charter at any other time if they consider it appropriate to do so (whether following a review under subsection (1) or otherwise).

(8) Where the Scottish Ministers revise the Charter under subsection (6) or (7), they must—

(a) publish it as so revised (in such form and manner as they consider appropriate),
(b) notify each relevant NHS body of the publication of the Charter as so revised.

(9) Before publishing the Charter under subsection (8)(a), the Scottish Ministers must—

(a) consult such persons as they consider appropriate, and
(b) lay a copy of the Charter before Parliament.

(10) In this Act, a reference to the Charter is a reference to the Charter as it may be revised from time to time.

Patient rights

1 Patient rights

(1) It is the right of every patient that the health care received by the patient be as described in subsection (2).

(2) Health care is to—

(a) be patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs,

(b) have regard to the importance of providing the optimum benefit to the patient’s health and wellbeing,

(c) allow and encourage the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing,

(d) have regard to the importance of providing such information and support as is necessary to enable the patient to participate in accordance with paragraph (c) and in relation to any related processes, taking all reasonable steps to ensure that the patient is supplied with information and support in a form that is appropriate to the patient’s needs.

(3) It is the right of every patient to give feedback or comments, or raise concerns or complaints about health care received.

(4) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify subsection (2).

2 Patient rights: further provision

(1) In construing the right of a patient under section 1(1), the matters set out in subsection (2) below must be taken into account.

(2) The matters are—

(a) the rights of other patients under section 1(1),

(b) the desirability of action delivering health care being proportionate, and otherwise appropriate, to the circumstances of each case,

(c) those specified in section 18(1)(a) and (b).

Health care principles

3 Duty to uphold the health care principles

(1) For the purposes of the rights conferred by section 1, each relevant NHS body must—

(a) in performing its health service functions, uphold the health care principles in so far as they are relevant to the function being performed, and

(b) ensure that any person with whom it enters into a contract, agreement or arrangements to provide health care upholds the health care principles in so far as they are relevant to the service being provided.
(2) For the purposes of this Act, a “relevant NHS body” is—
   (a) a Health Board,
   (b) a Special Health Board,
   (c) the Common Services Agency for the Scottish Health Service (“the Agency”).

4 Health care principles

(1) In this Act, “health care principles” are the principles set out in the schedule.

(2) The Scottish Ministers, after consulting such persons as they consider appropriate, may by order modify the schedule.

5 Health care principles: guidance and directions

(1) A relevant NHS body must, for the purposes of section 3, have regard to any guidance issued by the Scottish Ministers in relation to the practical application of the health care principles.

(2) Before providing guidance in relation to the health care principles, the Scottish Ministers must consult such persons as they consider appropriate.

(3) The Scottish Ministers may give a relevant NHS body directions as to the practical application of the health care principles; and a relevant NHS body must comply with any such direction.

Treatment time guarantee

(1) In pursuance of the right conferred by section 1(1), an eligible patient is to start to receive an agreed treatment within the maximum waiting time.

(2) The guarantee described in subsection (1) is to be known as the treatment time guarantee.

(3) A Health Board must take all reasonably practicable steps to ensure that it complies with the treatment time guarantee.

(4) Those steps include, in particular, steps for—
   (a) monitoring each treatment time guarantee,
   (aa) appropriately prioritising the start of the patient’s agreed treatment taking account of the patient’s clinical needs and the clinical needs of other eligible patients awaiting agreed treatments in accordance with the treatment time guarantee,
   (b) making the necessary arrangements for the agreed treatment of the patient to start in accordance with the treatment time guarantee either—
      (i) within its area, or
      (ii) if it is unable (or anticipates it will be unable) to treat a patient in its own area, through another Health Board or a suitable alternative provider of the treatment.

(5) The treatment time guarantee is in addition to, and does not affect, any duty of a Health Board to—
(a) comply with any orders, regulations or directions made by the Scottish Ministers (whether under the 1978 Act or otherwise) which relate to targets for periods of time within which treatments or services are to be provided, or

(b) have regard to any guidance issued by the Scottish Ministers which relates to such targets.

7 Treatment time guarantee: further provision

(1) The Scottish Ministers must by regulations make the further provision about the treatment time guarantee specified in subsection (2).

(2) The further provision is—

(a) the descriptions of patients which are eligible for the treatment time guarantee, and

(b) how waiting time is to be calculated (in particular, specifying the circumstances in which days are not to be counted towards a maximum waiting time).

(3) The Scottish Ministers may by regulations specify—

(a) treatments and services (including categories of treatments and services) in respect of which the treatment time guarantee does not apply,

(b) action that a Health Board is to take to ensure that it complies with a treatment time guarantee,

(c) circumstances in which the maximum waiting time for a patient may be extended or recalculated (and how such extension or recalculation is to be done),

(d) circumstances in which responsibility for a treatment time guarantee may transfer to a different Health Board,

(e) the information that a Health Board is to provide to patients about the treatment time guarantee, including—

(i) how waiting times are calculated,

(ii) the circumstances in which the maximum waiting time may be extended, recalculated or suspended,

(iii) such other information as the Scottish Ministers consider appropriate.

(4) The Scottish Ministers may by order—

(a) amend the duration of the maximum waiting time for the time being specified in section 10,

(b) specify such different period of time to be the maximum waiting time under section 10 in relation to any treatment or services specified in such order.

8 Breach of the treatment time guarantee

(1) This section applies where a Health Board has not complied with a treatment time guarantee.

(2) The Health Board must—

(a) make such arrangements as are necessary to ensure that the agreed treatment starts at the next available opportunity,
(b) provide an explanation to the patient as to why the treatment did not start within the maximum waiting time,

(c) give the patient details of—

(i) the advice and support available (including in particular the patient advice and support service described in section 15), and

(ii) how to give feedback or comments or raise concerns or complaints.

(3) In making the arrangements mentioned in subsection (2)(a), the Health Board—

(a) must not give priority to the start of any treatment where such prioritisation would, in the Health Board’s opinion, be detrimental to another patient with a greater clinical need for treatment,

(b) must have regard to the patient’s availability, and

(c) must have regard to other relevant factors.

9 Treatment time guarantee: guidance and directions

(1) Health Boards must, when taking steps to start the treatment of eligible patients, have regard to any guidance issued by the Scottish Ministers which relates to the treatment time guarantee (and in particular, Health Boards’ compliance with it).

(2) The Scottish Ministers may direct a Health Board to take specified action in relation to its compliance with the treatment time guarantee (including, in particular, the steps it must take).

9A Treatment time guarantee: suspension

(1) This section applies where the Scottish Ministers consider that exceptional circumstances exist.

(2) The Scottish Ministers may direct that the treatment time guarantee be suspended for such period as they consider necessary.

(3) But such period of suspension must not exceed 30 days.

(4) The Scottish Ministers may by order—

(a) extend the duration of a period of suspension under subsection (2) beyond the 30 day limit in subsection (3) for such further period as they consider necessary,

(b) suspend the treatment time guarantee for such period in excess of 30 days as they consider necessary.

(5) An order made under subsection (4) (other than one to which subsection (7) applies)—

(a) must be laid before the Scottish Parliament, and

(b) ceases to have effect at the expiry of the period of 28 days beginning with the date on which it was made unless, before the expiry of that period, the order has been approved by resolution of the Parliament.

(6) Subsection (7) applies to an order made under subsection (4) consisting only of—

(a) provision revoking an earlier order under subsection (4), or

(b) such provision and provision made by virtue of section 21(1)(c).
(7) An order to which this subsection applies is subject to annulment in pursuance of a resolution of the Parliament.

(8) In reckoning for the purposes of subsection (5)(b) any period of 28 days, no account is to be taken of any period during which the Scottish Parliament is—

(a) dissolved, or

(b) in recess for more than 4 days.

(9) Subsection (5)(b) is without prejudice to—

(a) anything previously done by reference to—

(i) a direction under subsection (2),

(ii) an order under subsection (4), or

(b) the making of a new order under subsection (4).

10 **Treatment time guarantee: key terms**

For the purposes of this section and sections 6 to 9A—

“agreed treatment” means a specific treatment agreed between an eligible patient and the Health Board;

“eligible patient” means a patient of a description specified in the regulations to be made in pursuance of section 7(2)(a) as being eligible for the treatment time guarantee;

“Health Board” includes the National Waiting Times Centre Board;

“maximum waiting time” is the period of 12 weeks beginning with the date on which the patient agrees to the agreed treatment;

“treatment” means a surgical or medical intervention ordinarily provided by the Health Board (other than such treatments or services as may be specified in regulations made in pursuance of section 7(3)(a));

“treatment time guarantee” has the meaning given in section 6(2).

12 **Encouragement of patient feedback etc.**

(1) A relevant NHS body is to encourage patients to give feedback or comments, or raise concerns or complaints, on health care.

(2) Patients may give such feedback or comments to, or raise such concerns or complaints with—

(a) the relevant NHS body, or

(ab) a provider of the patient advice and support service.

(3) Where feedback or a comment is given to, or a concern or a complaint is raised with, a provider of the patient advice and support service, the provider may pass the feedback, comment, concern or complaint to the relevant NHS body (but only with the consent of the patient).

(4) The relevant NHS body must consider feedback, comments, concerns or complaints received with a view to improving the performance of its functions.
(4A) The Scottish Ministers may require a relevant NHS body to provide them with information regarding the performance of the duties under subsections (1) and (4).

(5) The Scottish Ministers may give a relevant NHS body directions about the performance of the duties under subsections (1) and (4).

11 Arrangements for handling and responding to patient feedback etc.

(1) The Scottish Ministers must ensure that each relevant NHS body has adequate arrangements in place for the matters described in subsection (3).

(2) A relevant NHS body must ensure that each of its service providers has adequate arrangements in place for the matters described in subsection (3).

(3) The matters are—

(a) handling and responding to feedback or comments given, or concerns or complaints raised, in relation to health care—
   (i) by or on behalf of patients,
   (ii) by or on behalf of such other persons as the Scottish Ministers may specify by regulations made under subsection (4)(a),

(aa) using feedback, comments, concerns or complaints to identify best practice,

(b) publicising—
   (i) how feedback and comments are to be given, or concerns and complaints are to be raised, and
   (ii) how feedback, comments, concerns or complaints will be handled,

(c) giving a person who gives feedback or comments, or raises concerns or complaints details of the advice and support available to patients,

(d) publicising the details of the advice and support available to patients (and, in particular, the patient advice and support service serving the relevant NHS body),

(e) monitoring the feedback, comments, concerns or complaints received with a view to—
   (i) identifying any areas of concern, and
   (ii) improving the performance of its functions.

(4) The Scottish Ministers may—

(a) by regulations make provision about the—
   (i) arrangements mentioned in subsections (1) and (2),
   (ii) matters described in subsection (3),

(b) give a relevant NHS body directions about such arrangements or matters.

(4A) Directions under subsection (4)(b) may, in particular, include provision for the resolution of complaints by conciliation or mediation.

(5) In this section, a “service provider” is any person who provides health services for the purpose of the health service under a contract, agreement or arrangements made under or by virtue of the 1978 Act.

(6) The powers conferred on the Scottish Ministers by virtue of this section are without prejudice to their powers under the 1978 Act.
(7) Nothing done under or by virtue of this section is to preclude an investigation under the Scottish Public Services Ombudsman Act 2002 (asp 11) in respect of any matter.

13 **Repeal of the Hospital Complaints Procedure Act 1985**

The Hospital Complaints Procedure Act 1985 (c. 42) is repealed.

**Patient advice and support service**

14 **Patient advice and support service: establishment and funding**

(1) In the 1978 Act, in section 10(1) (Common Services Agency), after “section” insert “and section 10ZA”.

(2) After section 10 of that Act insert—

“10ZA Provision of patient advice and support service

(1) The Agency must secure the adequate provision of the patient advice and support service described in section 15 of the Patient Rights (Scotland) Act 2011 (asp 00) in relation to each relevant body.

(2) In exercising its function under subsection (1), the Agency must have regard to the desirability of the service being provided—

(a) in the most efficient and effective manner possible, and

(b) in a manner which co-ordinates with the services of other providers of advice and support.

(3) There may be more than one provider of the patient advice and support service.

(4) The patient advice and support service is not to be provided by—

(a) a Health Board,

(b) a Special Health Board,

(ba) Healthcare Improvement Scotland,

(e) the Agency.

(5) Each relevant body must make to its provider of the patient advice and support service, in respect of the provider’s expenses (as respects its activities relating to the service), payments of such amounts, and at such times, as the Scottish Ministers may direct.

(6) For the purposes of this section, a “relevant body” is—

(a) a Health Board, and

(b) any other body that the Scottish Ministers may by order specify.”.

15 **Patient advice and support service**

(1) The patient advice and support service to be secured by the Agency under section 10ZA of the 1978 Act is to provide advice and support services to patients and other members of the public in relation to the health service.

(2) In particular, the patient advice and support service is to—

(a) promote an awareness and understanding of the rights and responsibilities of patients (and in particular, promote awareness of the Charter),
(b) advise and support persons who wish to give feedback or comments, or raise
concerns or complaints about health care,
(c) provide information and advice on such matters as it considers likely to be of
interest to persons using the health service,
(ca) make persons aware of and, where appropriate, direct them to—
(i) other sources of advice and support (including persons who provide advice
and support in relation to matters other than the health service),
(ii) persons providing representation and advocacy services,
(d) provide such—
(i) other advice or support,
(ii) reports on its activities,
as the Agency may specify.
(4A) Nothing in this Act prevents a provider of the patient advice and support service from
providing advice and support in relation to matters other than the health service.
(4B) But the provision of such other advice and support by such a provider must not
prejudice its provision of advice and support services under subsection (1).
(5) For the purposes of subsection (2), the responsibilities of a patient include the
responsibility of the patient—
(a) for the patient’s own health and wellbeing, and
(b) to behave appropriately in the receipt of health care.
(6) The Scottish Ministers may by regulations make further provision about the patient
advice and support service and in particular about the services it is to provide.

17 Duties to share information
(1) A relevant body must (where reasonably practicable and otherwise appropriate) give
providers of the patient advice and support service information about—
(a) the relevant body (and the health service generally) including its organisation,
procedures and specific services that it provides,
(b) any changes to the information mentioned in paragraph (a), and
(c) such other relevant matters as providers of the patient advice and support service
may reasonably request.
(2) The Agency must secure that providers of the patient advice and support service give
relevant bodies information about—
(a) the services that providers of the patient advice and support service provide,
(b) such other relevant matters as relevant bodies may reasonably request.
(3) No information is to be given under subsection (1) or (2) which would infringe patient
confidentiality.
(4) For the purposes of this section “relevant body” has the same meaning as in section
10ZA(6) of the 1978 Act (provision of patient advice and support service).
18 Protections and limitations

(1) Nothing in this Act prejudices—

(a) the exercise of clinical judgement,

(b) the effective and efficient use of the health service organisation and resources.

(1A) Subject to subsection (2), nothing in this Act prejudices any other enactment or rule of law.

(2) Nothing in this Act gives rise to—

(a) any liability to pay damages,

(b) any right of action for specific implement,

(ba) any right of action for specific performance of a statutory duty,

(c) any right of action for interdict,

(d) any right of action for suspension.

(3) The rights conferred on a patient by this Act are in addition to, and do not affect, any other rights in relation to health care that a patient has, or may acquire, under any other enactment or rule of law.

(4) Subsection (3) does not affect the generality of subsection (1A).

(5) In this section, references to this Act include references to orders, regulations and directions made under this Act.

Inquiries and default and emergency powers

18A Powers of the Scottish Ministers

(1) In sections 76, 77, 78 and 78A of the 1978 Act (inquiries and default and emergency powers) references to that Act include references to this Act.

(2) Section 77 of the 1978 Act applies to a Special Health Board in relation to the functions conferred or imposed on it by or under this Act.

Payments to or in respect of certain persons infected with hepatitis C as a result of NHS treatment etc.: eligibility

18B Payments to or in respect of certain persons infected with hepatitis C as a result of NHS treatment etc.: eligibility

(1) Section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 (asp 13) (payments to certain persons infected with hepatitis C as a result of NHS treatment etc.) is amended as follows.

(2) In subsection (1)—

(a) in paragraph (a)—

(i) after sub-paragraph (i), insert “and”,

(ii) the word “and” following sub-paragraph (ii) is repealed, and

(iii) sub-paragraph (iii) is repealed,

(b) in paragraph (b)—
(i) after sub-paragraph (i), insert “and”,
(ii) the word “and” following sub-paragraph (ii) is repealed, and
(iii) sub-paragraph (iii) is repealed, and
(c) after paragraph (b) insert—

“(c) dependants of persons mentioned in paragraph (a) or (b).”.

(3) After subsection (2), insert—

“(2A) In subsection (1)(c), “dependant”, in relation to a person mentioned in subsection (1)(a) or (b) (the “infected person”), means—

(a) a spouse or civil partner of the infected person;
(b) a person living with the infected person as husband or wife or in a relationship which has the characteristics of the relationship between civil partners (or if the infected person was in hospital immediately before death, had been so living when the infected person was admitted to hospital);
(c) such other persons as the scheme may specify; and the scheme may specify or elaborate the meaning of dependant for this purpose.”.

(4) In subsection (3)—

(a) in paragraph (b), after “dead person” insert “falling within subsection (1)(a) or (b)”, and
(b) in paragraph (e), after “dead person” insert “falling within subsection (1)(a) or (b)”.

(5) In subsection (4)(a), after “(1)” insert “(a) or (b)”.

General

Interpretation

(1) In this Act, unless the contrary intention appears—

“the 1978 Act” means the National Health Service (Scotland) Act 1978 (c. 29);
“the Agency” has the meaning given by section 3(2)(c);
“the Charter” means the Charter of Patient Rights and Responsibilities published under section Z2;
“health care” means services provided under the health service;
“health care principles” has the meaning given by section 4(1);
the health service” means the health service established in pursuance of section 1 of the National Health Service (Scotland) Act 1947 (c. 27);
“health service function” means any function under or by virtue of the 1978 Act which is a function concerned with, or connected to, the health service;
“patient advice and support service” is to be construed in accordance with section 15(1);
“relevant NHS body” has the meaning given by section 3(2).
(2) In this Act, unless the contrary intention appears, terms used in this Act and the 1978 Act have the same meaning as they have in the 1978 Act.

20 Ancillary provision

(1) The Scottish Ministers may by order make such consequential, supplemental, incidental transitional, transitory or saving provision as they consider necessary or expedient for the purposes of, or in consequence of, or for the purposes of giving full effect to, any provision of this Act.

(2) An order under this section may modify any enactment, instrument or document.

21 Orders, regulations and directions

(1) Any power conferred by this Act on the Scottish Ministers to make an order or regulations—

(a) must be exercised by statutory instrument,

(b) may be exercised so as to make different provision for different purposes (including different areas),

(c) except an order under section 22(3), includes power to make such consequential, supplemental, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient.

(2) No—

(a) order is to be made under section 1(4), 4(2) or 7(4),

(b) order is to be made under section 20 containing provisions which add to, omit or replace any part of the text of an Act,

unless a draft of the statutory instrument containing the order or regulations has been laid before, and approved by resolution of, the Parliament.

(3) Any other statutory instrument containing an order or regulations under this Act (except an order under section 9A(4) or 22(3)) is subject to annulment in pursuance of a resolution of the Parliament.

(4) Any power to make directions under this Act includes power to vary or revoke such directions.

(5) Any power to make directions under this Act may be exercised—

(a) generally or to meet the circumstances of a particular area or matter,

(b) either in relation to all cases to which the power extends, or in those cases subject to exceptions, or in relation to any specified cases or classes of case, and

(c) subject to such other exceptions or conditions as the Scottish Ministers think fit.

22 Short title and commencement

(1) This Act may be cited as the Patient Rights (Scotland) Act 2011.

(2) This section and sections 18B, 20 and 21 come into force on Royal Assent.

(3) The remaining provisions of this Act come into force on such day as the Scottish Ministers may by order appoint.
Patient Rights (Scotland) Bill
Schedule—Health care principles to be upheld by relevant NHS bodies and relevant service providers

SCHEDULE
(introduced by section 4(1))

HEALTH CARE PRINCIPLES TO BE UPHELD BY RELEVANT NHS BODIES AND RELEVANT SERVICE PROVIDERS

5 Patient focus

1 Anything done in relation to the patient takes into account the patient’s needs.
2 Patients are treated with dignity and respect.
3 Privacy and confidentiality are respected.
4 Health care is provided in a caring and compassionate manner.
5 Support necessary to receive or access health care is available.
6 The patient’s abilities, characteristics and circumstances are considered.

Quality care and treatment

7 Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.
8 The range of options available in the patient’s case is considered.
9 Health care is based on current recognised clinical guidance.
9AA No avoidable harm or injury is to be caused to the patient by the health care provided.
9B Patients are cared for in an appropriate environment which is as clean and safe as is reasonably possible.

Patient participation

10 Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing.
11 Patients are provided with such information and support as is necessary to enable them to participate in accordance with paragraph 10 and in relation to any related processes (general or specific).
12 Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect.

Communication

13 Communication about a patient’s health and wellbeing is clear, accessible and understood.
14 Communication about general services and processes and decisions is clear, accessible and understood.

Complaints

15 Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures.
Waste of resources in the provision of health care is avoided.
Patient Rights (Scotland) Bill
[AS PASSED]

An Act to make provision about the rights of patients when receiving health care; to make further provision about eligibility under the scheme made under section 28 of the Smoking, Health and Social Care (Scotland) Act 2005; and for connected purposes.

Introduced by: Nicola Sturgeon
On: 17 March 2010
Bill type: Executive Bill