The Palliative Care (Scotland) Bill was introduced in the Scottish Parliament on 1 June 2010 by Gil Paterson MSP. It seeks to place Scottish Ministers under a statutory duty to provide palliative care for those with life-limiting conditions and their family members, and to set up reporting arrangements so that provision can be monitored by Scottish Ministers and the Parliament.

This briefing is split into two parts – palliative care services in Scotland (including an overview of relevant legislation, data and policy developments) and a discussion of the Bill itself.
# CONTENTS

**EXECUTIVE SUMMARY** ................................................................................................................................. 3

**PALLIATIVE CARE IN SCOTLAND** .................................................................................................................. 3

- Legislation ............................................................................................................................................................. 3
- Provision of palliative care services in Scotland ................................................................................................. 4
- Recent Reports and Policy Initiatives .................................................................................................................. 5

**THE PALLIATIVE CARE (SCOTLAND) BILL** .................................................................................................... 5

- The statutory duty to provide palliative care ......................................................................................................... 5
- The definition of palliative care used in the Bill ..................................................................................................... 6
- Provisions relating to reporting and indicators ..................................................................................................... 7
- Costs identified through the Financial Memorandum .............................................................................................. 7

**INTRODUCTION** .................................................................................................................................................... 9

**CONSULTATION ON THE DRAFT PROPOSAL** .................................................................................................. 9

**PART 1: PALLIATIVE CARE IN SCOTLAND** .................................................................................................... 10

- WHAT IS PALLIATIVE CARE? ................................................................................................................................. 10
- LEGISLATION .......................................................................................................................................................... 11
  - Relevant health legislation ..................................................................................................................................... 11
  - Relevant social services legislation ...................................................................................................................... 12
- PROVISION OF PALLIATIVE CARE IN SCOTLAND .............................................................................................. 12
  - Number of deaths and population trends ........................................................................................................ 12
  - Place of death .................................................................................................................................................... 13
  - Specialist care ................................................................................................................................................... 14
  - Generalist services ............................................................................................................................................ 16
  - Funding ................................................................................................................................................................ 17
- RECENT REPORTS AND POLICY INITIATIVES .................................................................................................... 17
  - Living and Dying Well ......................................................................................................................................... 19
  - Post-Living and Dying Well ............................................................................................................................. 21

**PART 2: THE PALLIATIVE CARE (SCOTLAND) BILL** .......................................................................................... 22

- ANALYSIS OF RESPONDENTS TO THE COMMITTEE’S CALL FOR EVIDENCE .............................................. 22
- STATUTORY DUTY TO PROVIDE PALLIATIVE CARE .......................................................................................... 23
  - The view of respondents .................................................................................................................................. 24
- THE DEFINITION OF PALLIATIVE CARE CONTAINED IN THE BILL ................................................................. 26
  - The view of respondents .................................................................................................................................. 26
- PROVISIONS RELATING TO REPORTING AND INDICATORS ............................................................................. 29
- COSTS IDENTIFIED THROUGH THE FINANCIAL MEMORANDUM ..................................................................... 32

**SOURCES** ............................................................................................................................................................ 37

**APPENDIX 1: EXAMPLES OF VARIED PROVISION OF GENERAL PALLIATIVE CARE** .................................. 45

**APPENDIX 2: A TIMELINE AND SUMMARY OF SELECTED PALLIATIVE CARE REPORTS AND POLICY DOCUMENTS** ................................................................................................................................. 46

**APPENDIX 3: NHS NATIONAL SERVICES SCOTLAND’S RESPONSE TO THE PROPOSED INDIVIDUAL INDICATORS** ........................................................................................................................................... 49
EXECUTIVE SUMMARY

The Palliative Care (Scotland) Bill (the Bill) was introduced in the Scottish Parliament on 1 June 2010 by Gil Paterson MSP. The Bill seeks to place Scottish Ministers under a statutory duty to provide palliative care for those with life-limiting conditions and their family members, and to set up reporting arrangements so that provision can be monitored by Scottish Ministers and the Parliament. By doing so it aims to give legislative effect to the key objectives of the Scottish Government’s palliative care strategy, ‘Living and Dying Well’, which was published in October 2008.

PALLIATIVE CARE IN SCOTLAND

Many of the definitions of palliative care, including that of the Scottish Government strategy and the Bill itself, are in line with that of the World Health Organisation (WHO): “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Palliative care services are often described as being either specialist or generalist. Specialist palliative care is provided through multidisciplinary teams, which have undergone recognised specialist palliative care training, and is provided in a variety of acute, hospice and community settings. General palliative care can also be delivered in a variety of settings, but is delivered by generalist professionals, such as GPs, community nurses, nurses and doctors from other specialties, allied health professionals, social workers and social carers, as well as the person’s own carer.

Legislation

There is no specific legislation covering palliative care in Scotland. Instead it is covered under general duties within the National Health Service (Scotland) Act 1978 (c 29) (the 1978 Act), as amended, most notably section 1, which provides Ministers with a general duty to promote a comprehensive and integrated health service, and section 2 which provides Ministers with the power to institute health boards in order to carry out functions in relation to the general duty in section 1.

Those with palliative care needs may also be eligible for a range of social or community care services to support them in day to day living. The key piece of legislation is the Social Work (Scotland) Act 1968 (c 49) (as amended), which provides local authorities with the duty to assess the community care needs of anyone that requests it, but also to deliver a package of care in order to meet those needs (sections 12 and 12A). In addition, it provides local authorities with a duty to assess the needs of carers and to provide relevant information to carers (sections 12AA and 12AB).
Provision of palliative care services in Scotland

When considering the provision of services, one of the key issues is the lack of collected and/or centrally collated data. Whilst a number of sources are often referred to, these are not always relaying information specific to palliative care. In addition, whilst data from them can be requested and used by Government and NHS Boards, this may not be collated and published. So, for example, it is not known how many people are receiving palliative and end of life care at any one time.

The last comprehensive assessment of the provision and funding of palliative care services was undertaken by Audit Scotland (2008) for the period 2006-07, which had to carry out its own primary research using various methods, in order to better assess palliative care activity, costs, planning and delivery. The briefing discusses some of the main findings from the Audit Scotland report together with available data often referred to as providing an indicator of the services that are available.

Number of deaths and population trends

In 2009 a total of 53,856 people died in Scotland, and the largest number of deaths took place in the 60-74 and 75+ age groups, though the majority (over 60%) of all deaths took place in the 75+ age group alone. As those in this age group tend to have the most complex needs this indicates the significant numbers that may require specialist palliative and end of life care. Available data on population trends also indicates the likelihood that such services will become more acutely required in the coming years.

Place of death

Whilst data is collected for all deaths, this is not collated and published. However, ISD Scotland has published data for the five year period 2004-08 on the place of death amongst those with cancer, though it is not known how many of these individuals were receiving palliative care services. It shows that 52% of all deaths from cancer in the time period occurred in NHS Acute Hospitals, around 24% were at home, approximately 18% were in hospices, and the remainder were in other institutions, such as care homes. However, this varied markedly by age group. Audit Scotland’s own carers survey showed that the place of death varied according to the cause of death eg people dying of cancer were more likely to die at home or in a hospice.

Specialist and generalist services

Audit Scotland found that specialist services vary greatly by NHS Board, with each having their own way of delivering specialist services. This is illustrated by considering the limited but more up to date ISD Scotland data on palliative care beds and the medical and nursing workforce. It is also clear that the voluntary sector plays a crucial role. Audit Scotland found that 70% of inpatient activity across Scotland was in voluntary hospices, and, 72% of day care places were provided in voluntary hospices, though this was not available in four NHS Boards areas. There is little data on generalist services. However one area where data exists is the Quality Outcome Framework indicator, under the General Medical Services contract, for GP practices to have in place a palliative care register. The latest data shows that 96% of GP Practices have such a register but that there are only 6,884 patients registered on it.

Funding

Whilst it is not possible to provide a figure for the amount of funding that goes to generalist palliative care services given the nature of it, Audit Scotland found that £59m was spent on specialist palliative care in 2006-07. Of this, 44% came from the voluntary sector, whilst NHS Boards spent £15.5m on their own specialist services.
Recent Reports and Policy Initiatives

The briefing discusses policy developments and the findings of a number of reports, which consider palliative care services. Prior to the publication of Living and Dying Well, there were two key reports.

The first was the Scottish Partnership for Palliative Care’s ‘Palliative and end of life care in Scotland: A cohesive approach’, published in May 2007, which sought to identify a way of dealing with the variable number and quality of palliative care services across Scotland. It made recommendations on the use of assessment tools and patient pathways, whilst also seeking to clarify issues relating out of hours service provision and the role of NHS 24. It sought better data collection through the use of eHealth systems, better joint working by health and social care, and increased resources, to facilitate the introduction of its approach. The second key report was Audit Scotland’s ‘Review of palliative care services in Scotland’, published in August 2008, which is discussed throughout the briefing.

Living and Dying Well

The Scottish Government’s strategy, ‘Living and Dying Well: A National Action Plan for Palliative Care and End of Life Care in Scotland’, was published in October 2008. It aimed to address the issues raised in many of the previous reports, not least those by the SPPC and Audit Scotland. Overall it sought to use: “…the concepts of assessment and review, planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland”. The strategy was committed to providing a holistic service based on choice, which met the medical, physical, social and spiritual needs of the patient, and also the needs their carers. The briefing goes on to discuss the key points of the strategy, and its actions eg on assessments, patient pathways, NHS Board delivery plans, the use of eHealth and the setting up of working groups to take forward a range of issues.

Following Living & Dying Well, the Public Audit Committee took account of it as part of its consideration of the Audit Scotland report. This led to an initial response from the Scottish Government in March 2009 and a further progress report in October 2010. The latter provided information on the implementation of the strategy and the progress being met. These are outlined in the briefing itself. The Scottish Government has announced that a more in-depth ‘Living and Dying Well: Building on Progress’ document will be published later in 2010

THE PALLIATIVE CARE (SCOTLAND) BILL

In analysing the Bill itself, the briefing uses information from Part 1 of the briefing, but also the findings from the Health & Sport Committee’s (the Committee) own call for written evidence on the Bill. The latter is used only to provide members with an impression of the issues being raised in connection with the Bill. The Committee’s call for written evidence was launched on 7 July 2010 and closed on 1 September 2010. In total, 70 submissions were received. Overall, 54.3% of respondents agreed with the Bill, 35.7% disagreed and 10% were either neutral or did not make their position clear. Those in the ‘voluntary’, ‘local authority’, ‘humanist’ and ‘individual’ categories were more likely to agree with the Bill, whilst those from health professional, NHS Board and palliative care backgrounds were more likely to be against the Bill.

The statutory duty to provide palliative care

The Member in charge of the Bill believes that the general duties in the 1978 Act are not sufficient to ensure an equitable provision of palliative care across the country. Therefore section 1 of the Bill proposes inserting a new section 48A which would “place a duty on Scottish Ministers to provide or secure the provision of palliative care for persons who have been
diagnosed with a life-limiting condition and their family members based on the reasonable needs of such persons”. The provision does not stipulate how such services should be provided.

Overall, 52.9% of respondents agreed with this provision, 34.3% disagreed and 12.9% were neutral/unclear in their opinion. Those from a health and palliative care background were more likely to have disagreed with the provisions.

**Arguments in favour**

For those in favour there was an acceptance, at least implicitly, of the various arguments made in the Policy Memorandum, not least that the current general duties and provisions contained in the 1978 Act were not sufficient in themselves to promote or deliver the availability and quality of palliative care. It was widely believed amongst those in favour that a statutory duty would secure a more comprehensive and equitable coverage of palliative care services across the country. Other points made included that it would: help to widen the scope and raise awareness of palliative care beyond cancer to other terminal illnesses; promote patient choice in supporting them to die in their place of choice; and encourage better joint working between agencies.

**Arguments against the duty**

A key argument made against the provision was that it was unnecessary given the work being undertaken through Living and Dying Well, and the belief such a duty lead to more rapid improvements than would otherwise be the case. In addition there was a widely held view by those against that the general duty contained in the 1978 Act was sufficient, and that a specific duty could set a precedent and encourage other areas of health care and specialisms to seek the same. Other issues discussed included: the effect prioritising one area of health care over others could have; that it could raise public expectations; and what would happen if patients or family members felt that palliative care had not been delivered to their expectation or need.

**The definition of palliative care used in the Bill**

For those with a life limiting condition, section 1 of the Bill seeks to insert a new section 48C into the 1978 Act which defines palliative care as “treatment which controls and relieves pain, discomfort or other symptoms caused by or related to a life-limiting condition with the intention of improving quality of life”, and includes psychological, social or spiritual help and support. The definition also encompasses help and support for family members, which would cover psychological, social or spiritual help and support to assist family members in dealing with the fact that their relative has a life limiting condition and the consequences of that condition. Finally, the definition provides that palliative care should be provided according to the reasonable needs of the person with the life-limiting condition or the family member.

Just over 40% of respondents were in general agreement with the definitions, whilst 15.7% disagreed overall. Just over 11% were neutral or unclear in their overall stance, and 31.4% made no comment at all.

**Overall views**

A significant number of respondents were happy overall with the definition of palliative care in the Bill, though there was discussion amongst some respondents about the difficulties in agreeing a definition and the implications it may have, eg in raising public expectations about what they might expect. Some believed the definition was not specific enough and might lead to difficulties in defining what patients and family members would be legally entitled to. Specific discussions also took place on the terms “life limiting condition”, “family members” and “reasonable need”, which are discussed further in the briefing.
Provisions relating to reporting and indicators

Section 1 of the Bill seeks to insert a new section 48B into the 1978 Act, which would require Scottish Ministers to lay an annual report before the Scottish Parliament containing information relating to 11 indicators that are set out in the Bill. This is so as to allow best practice to be highlighted across the NHS. It is proposed that Health Boards be responsible for providing Ministers with the information which will lead to the Annual Report, though it is also contended that much of the information is already available to Boards. It then provides Ministers with the duty of providing information in the report on a Scotland-wide basis as well as for each Health Board area. Finally, the proposed section 48B would also allow Ministers to modify and add to the indicators, with the aim of keeping pace with developments in *Living and Dying Well*.

In terms of the views of respondents, 12.9% were for the provision, 28.6% were against, and 37.1% were neutral/unclear in their position. As with the situation with the statutory provision over the delivery of palliative care, respondents from a health and palliative care background were more likely to have disagreed with the provisions.

Discussion of the annual report

Only a few respondents considered the annual report and the comments were positive, from agreeing that all data should be published in one place, to an acceptance that it would allow services to be audited and continuously improved. However, there were some comments querying whether an annual report would be necessary, at least in the longer term.

Discussion of the indicators

For those in favour of the provisions, there was a general view that obtaining the evidence from the indicators would be useful in the ongoing development of palliative care, though for many of these it was felt important to ensure that the collection of the associated data did not become a burden.

For those against or neutral towards the indicators, one key issue was the extent to which they would produce meaningful data, with arguments centred on how attempting to measure access to palliative care was complex eg because of the range of different conditions to which palliative care may be appropriate or identifying precisely when a patient has palliative care needs and starts to receive services. Other points raised included that collecting meaningful data would require a refinement of the definition, that it would be burdensome for NHS Boards to collect the data, and that there would be implications for both local authorities and the voluntary sector despite the Bill not placing a duty on them. However, despite such concerns many of these respondents did accept that improvements were necessary in the collection of data concerning palliative care, and the reporting of it. A number of respondents considered that the developing of a more limited list of indicators should be developed eg under the auspices of *Living and Dying Well*.

Discussion of Individual indicators

Many respondents discussed individual indicators in detail, indeed a small number considered each of the indicators in turn, identifying the pros and cons of each as they saw it. Such respondents tended to highlight specific difficulties in interpreting what particular indicators meant, the definitions used, how each would be collected, and possible effects on services.

Costs identified through the Financial Memorandum

The Financial Memorandum (Explanatory Notes, para 43-79) discusses the potential costs associated with the Bill. As the Bill seeks to give legislative effect to the aims of *Living and Dying Well*, there is a discussion of funding that has already been allocated as a result of it,
together with an assessment of the known expenditure on specialist and generalist services. Although there is an acceptance that there is uncertainty about the costs of delivering palliative care in the Bill does not seek to go beyond what is already in Living and Dying Well, and therefore it should not require any further funding on top of that identified by the Scottish Government. There is an acceptance of additional costs in relation to the duty on reporting and the collection of data for the indicators. However, it is believed this will not be a large cost given the information that is already collected by and known to NHS Boards. It is not envisaged that there will be any direct costs upon local authorities or the voluntary sector.

In terms of the views of respondents 8.6% were in agreement with the Financial Memorandum, with just over 37.1% disagreeing, 25.7% being neutral/unclear on their position and 28.6% making no comment.

For some respondents that were content or neutral/unclear in their assessment of the Financial Memorandum, even if there were to be an increase in costs as a result of the strategy and / or the Bill, then this would be worth it in order to achieve good quality and comprehensive palliative care provision. Such respondents were also more likely to argue that over time, there may be potential savings in developing comprehensive palliative care services. For those against, this tended to be discussed in terms of the financial implications of the statutory duties proposed in the Bill.

The statutory duty to provide palliative care

The main views voiced in this regard was that the Financial Memorandum was likely to be an underestimate of the likely costs that would be required, that it could lead to an impact on the availability of other services in the NHS, and that it would have an effect on public expectations.

There was some support from respondents to the argument that the Bill would not lead to any additional services to what is already planned through Living and Dying Well, though this was qualified ie the assumption could be correct as regards generalist services given these were the focus of the strategy, but that further consideration was needed over the cost of developing specialist services. Other points made included that the current funding for Living and Dying Well was insufficient, and that any uncertainty over the definition of what palliative care is, and at what point palliative care is triggered as a result, then this would make it difficult to make any assessment of the resultant cost.

The statutory duty on reporting

Whilst a number of respondents to the Committee’s call for evidence were in agreement that there would only be limited costs associated with data collection, a larger number had concerns. Points made in this regard included: collection costs would be greater than those for Living and Dying Well; and that data systems would have to be adapted or created, which would have resource implications in collecting the data.

Costs on local authorities and the voluntary sector

The Bill does not place any duties on local authorities or the voluntary sector. However, most local authorities believed there would be implications, such as: in the provision of home care services and care homes; and, an increase in the number of social care assessments being requested. There was also a call for clarification on whether NHS Boards would have to pay for palliative care which is not undertaken by them. The Financial Memorandum considered that there would be no resource implications for the voluntary sector as it contended that increased demand would be met through generalist services in the community. However, it was noted that the voluntary sector provides a wide range of such services in conjunction with other partners, such as the NHS.
INTRODUCTION

The Palliative Care (Scotland) Bill (SP Bill 50) was introduced on 1 June 2010 by Gil Paterson MSP. It is accompanied by Explanatory Notes (including the Financial Memorandum) (SP Bill 50-EN) and a Policy Memorandum (SP Bill 50-PM). The long title of the Bill states:

“An Act of the Scottish Parliament to require palliative care to be provided to persons with a life-limiting condition and to members of such persons’ families; and to require reports on the provision of palliative care to be made to the Scottish Parliament.”

The Bill stems from the evidence that palliative care services are of variable provision and quality around Scotland. Therefore, the Bill seeks to “secure access to palliative care (including end of life care) for everyone in Scotland with a progressive life-limiting condition and their family members” (Policy Memorandum, para 4). This is to be achieved by:

- placing Scottish Ministers under a statutory duty to provide palliative care for those with life-limiting conditions and their family members; and
- setting up reporting arrangements so that provision can be monitored by Scottish Ministers and the Parliament. This will require Scottish Ministers to report annually on the provision of palliative care, based on the data arising from 11 key indicators which are set out in the Bill

Through these provisions, the Bill is seeking to give legislative effect to the key objectives of the Scottish Government’s palliative care strategy, ‘Living and Dying Well’, which was published in October 2008.

The Health and Sport Committee (the Committee) has been appointed lead Committee and will begin taking evidence on the Bill on Wednesday 27 October 2010.

This briefing is split into two parts – palliative care services in Scotland (including an overview of relevant legislation, data and policy developments) and a discussion of the Bill itself. There is cross referencing between these parts, and, as a result, they have been published together in one briefing. However, the briefing is designed so that readers can be selective if they wish.

CONSULTATION ON THE DRAFT PROPOSAL

The original draft proposal for a palliative care Bill was lodged by Roseanna Cunningham MSP on 14 November 2008, with the consultation taking place from that date until 9 March 2009. Subsequently, Roseanna Cunningham MSP was appointed as a Scottish Minister and was unable to take the proposal forward. This resulted in the process for that particular proposal coming to an end. However, Gil Paterson MSP lodged an identical proposal, and in March 2009 published his statement of reasons as to why a further consultation was not required (Paterson, 2009a). He argued that given the original consultation together with the other work undertaken by Roseanna Cunningham MSP a further consultation was not necessary. At its meeting on 1 April 2009, the Committee (2009) agreed.

In September 2009 Gil Paterson MSP (2009b) published a summary of responses from the original consultation. The consultation received 106 responses. Most of these came from individuals (55%), followed by health professionals (22%) and hospices and charities (9%). The remainder came from societies, church organisations, forums or groups and local authorities. Overall, 64% of respondents were in favour of the proposal, 15% were against and 21% neutral. Support for the proposal was strongest amongst individuals and church organisations, which, as will be seen below, is a similar finding from responses to the Committee’s call for evidence on the Bill.
PART 1: PALLIATIVE CARE IN SCOTLAND

The following sections provide background to the key legislative provisions, policy developments and reports on palliative and end of life care. However, it is first useful to discuss what is commonly meant by “palliative care”.

WHAT IS PALLIATIVE CARE?

The modern approach to palliative care in Britain is widely acknowledged to have begun with the founding and opening of St Christopher’s Hospice (online) in London by Dame Cicely Saunders in 1967. She did so after recognising the inadequacy of care of the dying in hospitals. St Christopher’s was the first hospice to link expert pain and symptom control, care, education and clinical research. As Audit Scotland (2008, para 7) notes the number of hospices grew quickly thereafter, to a point in the 1980s where ten new hospices were being opened across the UK by the voluntary sector during each year. NHS Quality Improvement Scotland (QIS) (2004, p 7) notes that this period also saw the development of specialist teams in community and hospitals settings.

Many definitions of palliative care, including that of Scottish Government (2008a) strategy, are in line with that of the World Health Organisation (WHO) definition:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO, Online).

This overall definition of palliative care is clarified through the descriptive list in figure 1. It follows that palliative care can be provided at any stage following diagnosis of a relevant illness or condition, and not solely in the last few days, weeks or months of life. It is for this reason that the SPPC (2007), the Scottish Government (2008a) and indeed some of those who submitted to the Committee’s call for evidence refer to “palliative and end of life care”, to distinguish between the different stages of a person’s illness or condition.

The SPPC (online) notes that, traditionally, palliative care has been associated with cancer patients, but it has become accepted that it should also be a routine part of care for those living with and dying from a wide variety of non-malignant conditions, including dementia, heart failure, neurological conditions and renal failure. However, as Living and Dying Well (Scottish Government, 2008, para 14) notes different illnesses or conditions have different illness trajectories, each with their own patterns of relative stability, intermittent crisis, changing needs and end of life care needs. Therefore, it is important that these are well understood in order to plan more effective services to meet the needs of all those with palliative and end of life care and their carers.

Figure 1: WHO descriptors for palliative care
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
As will be seen in the coming sections, these services tend to be discussed under two main headings – specialist and generalist.

Specialist palliative care tends to be discussed in relation to the developments from the 1960s onwards (as outlined above). As NHS QIS (2004, p 20) discusses, care is provided by multidisciplinary teams, who have undergone recognised specialist palliative care training. These teams work in partnership with those providing generalist palliative care (see below) with the aim of ensuring that the complex needs of patients and their families are met. It can be accessed in a number of care settings including acute hospitals, specialist units, hospices, the person’s own home and in community settings.

General palliative care can also be delivered in a variety of settings, but is delivered by generalists professionals, such as GPs, community nurses, nurses and doctors from other specialties, allied health professionals, social workers and social carers, as well as the person’s own carer. Appendix 1 contains a diagram created by Audit Scotland (2008), showing examples of the varied provision of general palliative care services. SPPC (online) states that general palliative care is based on the understanding and practice of palliative care principles, which include:

- a focus on quality of life which includes good symptom control
- a whole person approach which takes into account the person’s past life experience and current situation
- care which encompasses both the person with the life-threatening illness and those that matter to that person, with a respect for patient choice and an emphasis on open and sensitive communication

**LEGISLATION**

**Relevant health legislation**

As discussed in the Policy Memorandum accompanying the Bill, there is no specific legislation covering palliative care in Scotland. Instead it is covered under general duties within the National Health Service (Scotland) Act 1978 (c 29) (the 1978 Act), as amended. Section 1 of the 1978 Act provides Ministers with a general duty:

```
“…to promote in Scotland a comprehensive and integrated health service designed to secure—
(a) improvement in the physical and mental health of the people of Scotland, and,
(b) the prevention, diagnosis and treatment of illness,
and for that purpose to provide or secure the effective provision of services in accordance with the provisions of this Act.”
```

Section 2 of the 1978 Act provides Ministers with the power to institute health boards in order to carry out functions in relation to the general duty in section 1. Whilst the bulk of health services (including palliative care) are provided for through this general duty, Part 3 (s 36-48) of the 1978 Act specifies a number of services that Ministers have a duty to provide. These include the care of mothers and young children (s 38), and vaccinations and immunisations (s 40). The Policy Memorandum (para 31), as well as a number of submissions to the Committee, also make specific reference to the generic provisions in section 36 (the provision of accommodation and services) and section 37 (prevention of illness, care and after-care) when discussing the provision of palliative care. The Member in charge of the Bill believes that the current provision of palliative care shows that the general duties in the 1978 Act are not sufficient to ensure equitable and comprehensive services across the country, hence his wish for a specific duty.
Relevant social services legislation

The provisions in the Bill consider palliative care within the context of health legislation. However, as discussed in the Policy Memorandum, palliative care can be viewed as a more holistic concept including the spiritual and social needs of those with palliative care needs, and their carers. As a result they may be eligible for a range of social or community care services to support them in day to day living. However, the key piece of legislation is the Social Work (Scotland) Act 1968 (c 49) (as amended), which provides local authorities with the duty to assess the community care needs of anyone that requests it (including those who are chronically sick), but also to deliver a package of care in order to meet those needs (sections 12 and 12A). In addition, it provides local authorities with a duty to assess the needs of carers and to provide relevant information to carers (sections 12AA and 12AB).

PROVISION OF PALLIATIVE CARE IN SCOTLAND

A key issue identified in many of the reports leading up to Living and Dying Well, as well in the documents accompanying the Bill, concerned the lack of collected and/or centrally collated data on palliative care services. Such data is important for the continual planning and monitoring of service provision. The Scottish Government (in Public Audit Committee, 2010, para 15-21) noted that there are a number of area where national data is being collected and used to improve planning of care for patients with palliative care and end of life care, such as the Scottish Morbidity Register (SMR), General Register Office for Scotland (GROS) reports and community care Single Shared Assessments. However, these are not always relaying information specific to palliative care, and whilst data from them can be requested and used by Government and NHS Boards, this may not be collated and published. So, for example, it is not known how many people are receiving palliative and end of life care at any one time.

The last comprehensive assessment of the provision and funding of palliative care services was undertaken by Audit Scotland (2008) for the period 2006-07. In order to better assess palliative care activity, costs, planning and delivery, Audit Scotland surveyed all 14 area NHS Boards, together with all the voluntary adult and children’s hospices. It also carried out a series of interviews, including with nearly 1,000 people from bereaved families, focus groups with patients receiving palliative care services and a survey of district nurses. The following subsections briefly outline some of the key findings from the Audit Scotland report together with available data often referred to as providing an indicator of the services that are available.

Number of deaths and population trends

One indicator of the likely numbers of people requiring palliative care services is to consider the number of deaths that take place in the country. In 2009 a total of 53,856 people died in Scotland. This figure is analysed by age in Table 1.

Table 1: Number of deaths in 2009, by age

<table>
<thead>
<tr>
<th></th>
<th>All ages</th>
<th>0-14</th>
<th>15-39</th>
<th>40-59</th>
<th>60-74</th>
<th>75+</th>
<th>% of all deaths aged 60+</th>
<th>% of all deaths aged 75+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>53,856</td>
<td>333</td>
<td>1,514</td>
<td>5,759</td>
<td>13,623</td>
<td>32,627</td>
<td>85.9</td>
<td>60.6</td>
</tr>
</tbody>
</table>

Source: General Register Office for Scotland (2010)

As Table 1 shows, in 2009 the largest number of deaths took place in the 60-74 and 75+ age groups, though the majority (over 60%) of all deaths took place in the 75+ age group alone. As those in this age group tend to have the most complex needs the Table indicates the significant numbers that may require specialist palliative and end of life care.
Available data also shows the likelihood that such services will become more acutely required in the coming years. Table 2, below, shows the most recent projections for 2033 made by GROS which were based on the 2008 population data. Whilst reductions are expected in most of the age groups, the 60-74 group is projected to increase by nearly 33% and the over 75 age group increasing by 85%. Given that, due to a growing elderly population and decreasing birth rate, GROS (2009) predicts the number of deaths to also increase by nearly 14% from 52,400 in 2008 to 59,600 in 2033, it can be surmised that greater demand will be placed on palliative and end of life care in the future.

### Place of death

A key objective of recent developments in palliative care has been to promote as much choice as possible for patients receiving end of life care in deciding where they wish to be cared for and to die. Whilst there data is collected for all deaths, this is not collated and published. However, ISD Scotland (2010a) has published data on the place of death amongst those with cancer. The aim of this is to assist the NHS in Scotland define the type and location of services needed to support cancer patients at the end of life. However, it should be noted that it is not known how many of these individuals were receiving palliative care services. Table 3, below, provides place of death data for all cancer deaths over the five year period 2004-2008.

### Table 3: Place of death from cancer by age group, all cancers, Scotland, 2004-08

<table>
<thead>
<tr>
<th>Age at Death</th>
<th>NHS Acute Hospital</th>
<th>Home</th>
<th>Hospice</th>
<th>Other Institution</th>
<th>All places of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 15</td>
<td>73</td>
<td>64</td>
<td>4</td>
<td>0</td>
<td>141</td>
</tr>
<tr>
<td>15-44</td>
<td>835</td>
<td>520</td>
<td>471</td>
<td>9</td>
<td>1,835</td>
</tr>
<tr>
<td>45-64</td>
<td>7,887</td>
<td>4,753</td>
<td>3,624</td>
<td>187</td>
<td>16,451</td>
</tr>
<tr>
<td>65+</td>
<td>30,372</td>
<td>13,010</td>
<td>9,195</td>
<td>4,518</td>
<td>57,095</td>
</tr>
<tr>
<td>All ages</td>
<td>39,167</td>
<td>18,347</td>
<td>13,294</td>
<td>4,714</td>
<td>75,522</td>
</tr>
</tbody>
</table>

Source: ISD Scotland (2010a)

In considering only the place of death Table 3 shows that 52% of all deaths from cancer in the time period occurred in NHS Acute Hospitals, around 24% were at home, approximately 18% were in Hospices, and the remainders were in other institutions, such as care homes. ISD Scotland (2010b) considers that the pattern probably reflects that “people in the terminal stages of a cancer illness may be admitted to hospital for medical reasons such as investigations, treatment or symptom control and for social reasons, such as to provide respite to a carer”. Of those deaths occurring in the under 15s, 45% died at home, which is greater than within the other age groups (which range between 23 and 29%). The oldest age group of 65+ is the most likely of the age groups to die in other institutions, with 95% of all such cases being in this age group.

Audit Scotland’s (2008, para116-118) own carers survey showed that the place of death varied according to the cause of death. People dying of cancer were more likely to die at home or in a hospice, people with organ failure were more likely to die in hospital, and people with neurological conditions were more likely to die in a care home. Overall, 72% of people died in a hospital or care home. However, Audit Scotland found that this did not necessarily mean that this was a failure in the system should a person have wanted to die at home or a hospice, noting a number of points including those discussed by ISD Scotland (2010b), above.
Although it is difficult to assess what happened in the case of patient’s own choices, a possible indicator is the view of carers. Audit Scotland found that of those carers that completed its survey, 80% considered the place their relative or friend died was the correct one.

**Specialist care**

Audit Scotland (2008, para 30-31) found that each NHS board had its own way of delivering specialist palliative care services. In 2006-07 it found that seven NHS boards had NHS hospices or specialist palliative care units, six had local voluntary hospices and two had no hospice or specialist palliative care units. It also noted that specialist palliative care for children is provided on a national basis by the Children’s Hospice Association Scotland (CHAS) through two hospices and a hospice at home service. However, nine NHS boards also made use of hospital-based specialist palliative care teams, which did not have dedicated specialist palliative care beds but instead provided services to patients in general hospital wards, other specialty wards, outpatient clinics, day hospitals and in the community. Whilst there is not a single up to date document which lists all current services, the SPPC website does have an interactive map of palliative care services in Scotland. Under Palliative care services by NHS Board, it lists a total of 78 services across the country, which include both generalist and specialist services. However, it also considers Hospices and Specialist Palliative Care Units separately, and it lists 20 such services (including two children’s hospices) across 11 NHS Boards.

The importance of voluntary hospices was illustrated by a number of findings in the report, including: 70% of inpatient activity across Scotland was in voluntary hospices (para 37); and, 72% of day care places were provided in voluntary hospices, though this was not available in four NHS Boards areas (para 34). However, Audit Scotland (2008, para 38-43) also found that there was an inequity in provision of palliative care services depending on a person’s illness or condition. It found that, in 2006-07, 90% of specialist inpatient, day patient and outpatient care was delivered to patients with cancer. Yet these accounted for 30% of all deaths, and the report found people with other conditions were unlikely to receive specialist care. Through its survey of carers, Audit Scotland also found that those people with cancer living at home were more likely to receive support from a District Nurse, Marie Curie nurse\(^1\), Macmillan nurse\(^2\) or a hospice nurse. Those with neurological conditions or organ failure were more likely to receive home carer support through the local authority.

In terms of access for other groups, Audit Scotland (para 42-43) concluded that people in rural areas found it more difficult to access both specialist and generalist services, for a number of reasons including lengthy travelling distances to access such services. In addition it noted that it was not possible for NHS Boards and hospices to demonstrate whether there was access for everyone because of lack of collected data by socio-economic group or ethnicity, and only a minority of hospices and NHS Boards were collecting data on the religion of patients.

**Beds**

In its survey Audit Scotland (2008, para 34) found that in 2006/07, the majority of specialist palliative care beds were in the voluntary hospice sector, though the report (2008, para 31) also found that in a number of NHS Boards hospitals will provide services through teams but in general hospital wards. ISD Scotland (2010c) produces data on palliative medicine beds in NHS hospitals. Table 4, below, outlines the numbers of average available staffed beds (AASBs). As can be seen nine of the 14 area NHS Boards have palliative medicine beds in their hospitals. It shows that in Scotland as a whole the numbers of AASBs have increased from 149.1 in 2001 to 163.6 in 2010, and there has been a consistent upwards trend from 2001

---

1 Marie Curie Nurses offer expert home nursing care and emotional support to families affected by cancer and increasingly those to those with other conditions at the end of life.
2 Macmillan Nurses are palliative care clinical nurse specialists based in hospitals, hospices or the community.
to 2010. However, there have been different trends at Board level. NHS Borders, NHS Grampian and NHS Lothian have maintained the same level of AASBs in 2010 as they had in 2001. NHS Dumfries and Galloway, NHS Lanarkshire and NHS Tayside have seen increases in AASBs over the time period. NHS Fife has seen a slight decrease in AASBs between 2001 to 2010. NHS Greater Glasgow & Clyde and NHS Highland have also seen decreases but as can be seen they were at a very low level to begin with. The situation in these Boards and indeed those that have had no provision perhaps illustrates what Audit Scotland (2008) found in terms of the level of specialist services being provided through the voluntary sector and the work of specialist teams.

Table 4: Average available staffed beds\(^3\), palliative medicine specialty, Scotland, 2001 to 2010

<table>
<thead>
<tr>
<th>NHS Board</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010(*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borders</td>
<td>4.6</td>
<td>5.0</td>
<td>4.9</td>
<td>5.2</td>
<td>4.7</td>
<td>6.3</td>
<td>5.3</td>
<td>3.7</td>
<td>5.1</td>
<td>4.6</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>6.0</td>
<td>6.1</td>
<td>6.2</td>
<td>6.2</td>
<td>6.8</td>
<td>8.3</td>
<td>8.4</td>
<td>9.1</td>
<td>11.0</td>
<td>10.5</td>
</tr>
<tr>
<td>Fife</td>
<td>27.0</td>
<td>27.1</td>
<td>28.4</td>
<td>27.0</td>
<td>27.0</td>
<td>27.0</td>
<td>27.0</td>
<td>27.0</td>
<td>26.7</td>
<td>26.4</td>
</tr>
<tr>
<td>Grampian</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
<td>21.0</td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>x</td>
<td>x</td>
<td>0.0</td>
<td>0.3</td>
<td>0.1</td>
<td>0.1</td>
<td>x</td>
<td>x</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>Highland</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>0.3</td>
<td>1.3</td>
<td>2.0</td>
<td>2.2</td>
<td>2.9</td>
<td></td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>39.5</td>
<td>40.0</td>
<td>40.0</td>
<td>39.9</td>
<td>40.1</td>
<td>40.0</td>
<td>40.0</td>
<td>40.6</td>
<td>41.0</td>
<td>43.2</td>
</tr>
<tr>
<td>Lothian</td>
<td>30.0</td>
<td>25.2</td>
<td>30.3</td>
<td>22.6</td>
<td>30.1</td>
<td>30.0</td>
<td>30.0</td>
<td>30.0</td>
<td>30.0</td>
<td></td>
</tr>
<tr>
<td>Tayside</td>
<td>21.0</td>
<td>21.0</td>
<td>24.7</td>
<td>25.0</td>
<td>25.0</td>
<td>25.0</td>
<td>25.0</td>
<td>25.0</td>
<td>25.0</td>
<td>25.0</td>
</tr>
<tr>
<td>Scotland</td>
<td>149.1</td>
<td>145.3</td>
<td>155.6</td>
<td>147.4</td>
<td>154.8</td>
<td>158.0</td>
<td>158.1</td>
<td>158.6</td>
<td>162.0</td>
<td>163.6</td>
</tr>
</tbody>
</table>

(*) All data received by 6th August 2010.
0.0 Figures less than 1

Source: ISD Scotland (2010c)

**Workforce**

The Audit Scotland (2008) report found significant differences across the country in terms of the numbers of specialist palliative care staff in each NHS Board area. Across Scotland in 2006-07 the average was 6.8 per 100,000 population, but the range was extremely varied - 4.1 in NHS Ayrshire and Arran, 7.3 in NHS Greater Glasgow & Clyde, 11.2 in NHS Highland and 22.3 in NHS Orkney. However, this data included both NHS and hospice staff.

ISD Scotland workforce statistics do contain some data. The most recent were published in December 2009. Firstly, Table 5 outlines the number of NHS doctors that are employed in the palliative medicine specialty throughout Scotland.

Table 5: Medical staff, palliative medicine specialty, Scotland, 2001 to 2009, as at 30 September

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>Change 08 - 09</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headcount</td>
<td>54</td>
<td>55</td>
<td>57</td>
<td>59</td>
<td>62</td>
<td>69</td>
<td>76</td>
<td>67</td>
<td>63</td>
<td>-6.0%</td>
</tr>
<tr>
<td>Whole Time Equivalent (WTE)</td>
<td>37.3</td>
<td>40.2</td>
<td>43.6</td>
<td>46.4</td>
<td>48.0</td>
<td>55.9</td>
<td>61.5</td>
<td>51.4</td>
<td>50.1</td>
<td>-2.5%</td>
</tr>
</tbody>
</table>

Source: ISD Scotland (2009a)

Table 5 shows that the numbers of doctors in palliative medicine have increased in both headcount and WTE terms between 2001 and 2009. However, it is noticeable that whilst there was a generally upward trend between 2001 to 2007, the numbers fell back in 2008 and again in 2009, so that between 2008 and 2009, there was a 6.0% decrease in the headcount numbers and a corresponding 2.5% decrease in WTE terms.

\(^3\) The average daily number of beds which are staffed and are available for the reception of inpatients (borrowed and temporary beds are included).
Table 6 considers the figures for 2009 by NHS Board. It illustrates the varied nature of palliative care service delivery. Three NHS Boards – Shetland, Orkney and Tayside have no palliative medicine doctors, whilst of the remainder the range is from 1 (1.0WTE) in NHS Ayrshire & Arran to 14 (9.5WTE) in NHS Tayside. Further analysis by ISD Scotland (2009a) shows that of the 63 doctors working in this specialty in 2009, 22 were of consultant grade and a further 15 were specialty doctors. Of the remainder 22 were in training grades. Analysis also shows there were no vacancies at 30 September 2009.

Audit Scotland (2008) also considered the numbers of nurses who worked with specialist care teams. It found there was an average of 12.4 per 100,000 population in 2006-07. Again the range was significantly varied – 0 in NHS Borders, 13.6 in NHS Forth Valley and 82.5 per 100,000 population in NHS Western Isles. However, as with doctors this number will have included those working directly in the NHS and in hospices. Whilst it is not possible to obtain the numbers of nurses that may be working in palliative medicine wards, ISD Scotland (2009a) does publish the numbers of Clinical Nurse Specialists (CNSs)\(^4\) within its workforce data programme. As there has only been three years of data, Table 7 outlines the numbers of CNSs who work in the field of palliative medicine. It shows that, overall there were 68 (61.8WTE) CNSs in this specialty, and again there was a marked variance in the numbers across the country, from 0 in Western Isles to 8 in NHS Lothian and 21 in NHS Tayside.

### Generalist services

There is very little data concerning generalist services being provided. As noted above, such services will be provided in a range of settings and by a number of different health, social care, and voluntary sector professionals, together with an individual’s carers. For many of the professionals, such as GPs, nurses and social workers, those with palliative and end of life care needs will be one part of their overall caseloads.

---

\(^4\) A registered nursing professional who has acquired additional knowledge, skills and experience, together with a professionally and/or academically accredited post-registration qualification (if available) in a clinical specialty. They practice at an advanced level and may have sole responsibility for care episode or defined client/group.
One area where there is data specific to palliative care is the Quality Outcome Framework (QOF) indicator under the General Medical Services (GMS) contract for GP practices to have in place a palliative care register. Audit Scotland (2008, para 60) noted that in 2007 practically all (99.9%) of GMS GP Practices received QOF payments for having such a register. However, it also noted found there were only 5,000 patients recorded on them across Scotland, which it considered only represented 12% of those with potential palliative care needs. In the latest available data for 2009/10, data from ISD Scotland (2010d) shows that around 96% of GMS GP practices had met the requirements of this QOF indicator and that 6,884 patients were registered.

However, Audit Scotland (2008) also noted evidence of the importance of generalist services. Through its carers survey it found that three-quarters of the patients that died were visited by their GP during the last three months of their lives. In addition of the District Nurses that responded to its survey, 93% stated they had palliative care patients as part of their caseload and that almost a third of their time was spent supporting those patients.

**Funding**

Audit Scotland (2008, para 61) found that it was not possible to provide a figure for the amount of funding that went to generalist palliative care services given the nature of it. This also meant it was difficult to consider how effective it was. However, through its survey of NHS Boards and hospices, it found that £59m was spent on specialist palliative care in 2006-07. Of this, 44% came from the voluntary sector, with the associated concern that any reduction in this could have a serious impact on service delivery (para 48), whilst NHS Boards themselves spent £15.5m on their own specialist services (para 49).

Under the guidance contained in [HDL (2003)18](#) (Scottish Executive, 2003) (see Appendix 2) NHS Boards are required to fund 50% of the agreed annual running costs of independent voluntary hospices providing specialist palliative care services in their area. Audit Scotland (2008, para 50-52) found that in 2006-07 NHS Boards funded between 41% and 53% of the costs of voluntary hospices. This is detailed in the report itself. Whilst it found commissioning arrangements to be improving, Audit Scotland did still find difficulties between NHS Boards and Hospices in what should be funded.

**RECENT REPORTS AND POLICY INITIATIVES**

Prior to the Scottish Government’s strategy being published in 2008, there were a number of policy statements and reports which sought to develop and build on the commitments to develop holistic palliative care based on need, contained in the first post-devolution health strategy ‘*Our national health, a plan for action, a plan for change*’ (Scottish Executive, 2000). These were numerous and are summarised in Appendix 2. They included condition-specific strategies, such as ‘*Cancer in Scotland: Action for Change*’ (Scottish Executive, 2001). In addition this time period saw the development of clinical standards for specialist palliative care (Clinical Standards Board for Scotland, 2002), which were used to assess performance in hospital, community and hospice settings throughout Scotland (NHS Quality Improvement Scotland, 2004).

However, by May 2006, with the publication of ‘*The Future Care of Older People in Scotland*’ (Scottish Executive, 2006) it was clear there were concerns with the type, range and quality of palliative services and the funding of them. This report called for the effectiveness of end of life care initiatives in Scotland to be evaluated, and suggested utilising the experience of the End of Life Care Programme in England (ELCP). The ELCP began in 2004 following the publication of the Department of Health’s ‘*Building on the Best: Choice, Responsiveness and Equity in the________

---

5 Now part of NHS Quality Improvement Scotland (QIS).
NHS’ in December 2003, part of which sought to develop better quality palliative care in order that patients could choose their place of death. The ELCP was set up to help health and social care professionals improve end of life care for their patients, regardless of their disease, through sharing good practice, evaluation, training and education. It also recommended greater use of three tools for improving palliative and end of life care – the Gold Standards Framework (GSF), the Liverpool Care Pathway (LCP) for the Dying Patient and Preferred Place of Care (PPC). These are briefly described in figure 2.

Such tools were being used in Scotland, indeed the GSF had been adapted for Scotland to create the GSF Scotland (GSFS) but there was a view that a more consistent approach was required. This was born out in the SCCP‘s ‘Palliative and end of life care in Scotland: A cohesive approach’, published in May 2007, which sought to identify a way of dealing with the variable number and quality of palliative care services across Scotland. Its recommendations included:

- supporting the continued and expanding use of the principles and approach of the GSFS in all care settings, and
- encouraging a uniform approach to achieving the goals of the LCP in all care settings

It also sought to clarify some of the issues relating to out of hours service provision and the role of NHS 24. In particular it was concerned about important information about a patient’s palliative care needs not being available to those who needed it or being able to obtain it in a timely manner. It recommended making greater use of the Emergency Care Summary (ECS) (where basic patient information can be extracted electronically from the GP record), and also the Palliative Care Summary (PCS) (which contains specific information on a patient’s palliative care needs), which could be ‘bolted on’ to the ECS. In addition the report recommended the roll out of a new Do Not Attempt Resuscitation (DNAR) policy, based on that developed by NHS Lothian. Finally, it sought better joint working by health and social care, and increased resources, to facilitate the introduction of its approach.

It is important to note that during this time, developments took place in other policy areas and not just health. One of these was based on the recognition that increasing numbers of people required palliative and end of life care in care homes. In May 2006, the SPPC and the then Scottish Executive published ‘Making good care better: National practice statements for general palliative care in adult care homes in Scotland’. These aimed to clarify for residents and care home staff what was expected in the delivery of palliative care services in care homes, and

---

**Figure 2: Recognised tools under ELCP**

**Gold Standards Framework**

A framework of strategies, tasks and enabling tools designed to help primary care teams improve the organisation and quality of care for patients in the last stages of life in the community. Practices are encouraged to:

- identify patients in need of palliative/supportive care towards the end of life;
- assess their needs, symptoms, preferences and any issues important to them; and,
- plan care around patient's needs and preferences and enable these to be fulfilled, in particular allow patients to live and die where they choose.

**Liverpool Care Pathway (LCP) for the Dying Patient**

An integrated care pathway. While the GSF is used from the point of diagnosis onwards, the LCP is used to care for patients in the last days or hours of life once it has been confirmed that they are dying. It is designed to facilitate effective communication within the multi-disciplinary team and with the patient and family; anticipatory planning including psychosocial and spiritual care; and, appropriate symptom control and bereavement care. It replaces all other documentation in this phase of care and is applicable in hospital, hospice, care home and community settings.

**Preferred Place of Care (PPC) advanced care planning tool**

A patient-held document designed to enable nurses, doctors and others to discuss with patients and carers their preferences relating to end-of-life care in ways that are intended to promote informed choices. The PPC plan includes the opportunity to discuss and record:

- a) the patient’s thoughts about care choices and preferences (including their preferred place of death); and,
- c) the services that are available within a locality.
were written so that the Care Commission could use them to assess the standards of palliative care services in care homes. This resulted in a Care Commission report in April 2009, entitled ‘Better care every step of the way’. It considered 1,036 inspections during the period April 2007 to March 2008. It found that 587 (57%) of the care homes in its sample understood the importance of providing palliative and end of life care, but that in 449 (43%) care home providers and staff do not recognise that they should be delivering palliative and end of life care to residents who have life limiting illnesses. It made a number of recommendations including one to the Scottish Government that the National Care Standards should be updated to reflect palliative care.

The Scottish Government published its strategy for the NHS, ‘Better Health, Better Care’ (Scottish Government, 2007) in December 2007, and in response to the SPPC and other reports, committed itself to developing and publishing a new strategy for palliative care in 2008. However, prior to its publication, Audit Scotland published its ‘Review of palliative care services in Scotland’ in August 2008. Many of its findings have been discussed in the ‘Provision of Palliative Care in Scotland’ section, above. However, overall it found:

- there was significant variation across Scotland in the availability of, and easy access to, specialist palliative care services, with services remaining primarily cancer-focused
- most palliative care was provided by generalist staff in hospitals, care homes or patients’ own homes. However, palliative care needs were not always recognised or well supported
- palliative care needed to be better joined up, particularly at night and weekends.
- support was not widely available for carers
- in 2006/07, £59 million was spent on specialist palliative care. Almost half of this came from the voluntary sector. It was not possible to say how much is spent on general palliative care

In addition it called for NHS Boards to assess the current and future needs of their local populations and update their palliative care plans accordingly; improve protocols for referral with the voluntary sector; and, it sought more consistent employment, across NHS Boards, of assessment tools (eg GSF and LCP) and DNAR policies to bring about service improvements.

Living and Dying Well

The Scottish Government’s strategy, ‘Living and Dying Well: A National Action Plan for Palliative Care and End of Life Care in Scotland’ (Scottish Government 2008a), was published in October 2008. It aimed to address the issues raised in many of the previous reports, not least the SPPC (2007) and Audit Scotland (2008) reports. Overall it sought to use:

“...the concepts of assessment and review, planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland.”

It was committed to providing a holistic service based on choice, which met the medical, physical, social and spiritual needs of the patient, and also the needs their carers.

Living and Dying Well (Scottish Government, 2008a, para18) considered that the key to providing appropriate palliative care was first to take steps to identify those who would benefit from it. As such it stated that it was important to: “ensure that triggers for the assessment or review of palliative and end of life care needs are recognised in all care settings at times of diagnosis, at times of changing or complex needs, and at the very end of life”. It suggested that such triggers should include:

- diagnosis of a progressive or life-limiting illness
- critical events or significant deterioration during the disease trajectory indicating the need for a ‘change of gear’ in clinical management
significant changes in patient or carer ability to 'cope' indicating the need for additional support
the 'surprise question' (ie clinicians would not be surprised if the patient were to die within the next 12 months)
onset of the end of life phase, which it accepted was not easy but argued that increasing clinical expertise was becoming available

It recognised the value of the GSFS, LCP and PPC but also tools that assessed social needs (eg community care Single Shared Assessment and the carer's assessment), and discussed the technological developments that allowed the effective transfer of information between different bodies to enable a patient-centred approach. However, it did not recommend any specific tools to be used in making such assessments, rather NHS Boards were tasked with using “recognised tools”. It recommended that NHS Boards should implement consistent DNAR policies and associated documentation across all care settings, and also committed NHS QIS to new performance indicators for out of hours care. Other actions are outlined in Figure 3. The strategy also announced the setting up of a number of advisory groups (eg including the Palliative Care eHealth Advisory group) under which a number of working groups were formed to take forward specific actions, eg guidance on referral criteria, commissioning arrangements between NHS Boards and the voluntary sector, and information for patients and carers.

As regards funding, this is outlined in the answer to Parliamentary Question (PQ) S3W-30385 (Scottish Parliament, 2010), which stated that, ultimately it is still a matter for NHS Boards to plan and provide services based on local need, and to provide appropriate funding to providers. However, the PQ also discussed how the DES for palliative care would receive £3m funding for to support improvements in generalist palliative care, through general practices. It also stated that £500,000 development funding was provided in 2008-09 for use centrally and to support NHS boards in the development of delivery plans. Further additional funding of £120,000 in 2008-09 and £500,000 in 2009-10 was made available to support implementation of the plan, to ensure that generalist palliative care was supported and to ensure the development of care in community settings.
Post-Living and Dying Well

Following the publication of the strategy, the Public Audit Committee (2009a) published its findings into the Audit Scotland (2008) report in January 2009. It welcomed the Scottish Government’s strategy, but made a number of recommendations, including:

- that it receive an update on the work of the Palliative Care eHealth Advisory Group in its work on the issue of national data collection
- NHS boards need robust commissioning arrangements with their partners for the delivery of palliative care services to ensure they deliver value for money
- the Scottish Government should issue guidance to NHS Boards on what should be included in their funding allocation to voluntary sector bodies, to supplement existing guidance
- the Scottish Government should ensure that the DNAR policy which is developed and adopted by NHS Boards is a consistent, national policy

These points were addressed by the Scottish Government in a response to the Committee in March 2009 (Public Audit Committee, 2009b). In terms of data collection, the Scottish Government provided a lengthy response and reflected on the current national data collections, the outputs that would arise from NHS Board Delivery Plans, the development of the ePCS, the work of the short-life groups and how the new NHS QIS standards would define measurable standards for all care settings. In addition it discussed how the new Palliative Care DES would provide nationally collated statistics including on the number of patients on the palliative care register, and the number of patients who had a care plan in place within two weeks of being put on the register. In relation to commissioning, the Scottish Government stated that it expected NHS Boards to reflect their working arrangements with partners in the voluntary sector through their Delivery Plans and also committed itself to reviewing current guidance (HDL (2003)18) on the funding and support of voluntary hospices. Finally, in relation to the DNAR policy, the Scottish Government stated that NHS Boards would be asked how they would implement a consistent national policy within their Delivery Plans, and also discussed how this would be pursued by the National Lead for Palliative Care eHealth (see Figure 6).

The Scottish Government has recently written a further progress report on the implementation of its strategy for the Public Audit Committee for its meeting on 6 October 2010. It announced that a more in-depth ‘Living and Dying Well: Building on Progress’ document would be published later in 2010, which would also explain how the outputs of the working groups have been taken forward. However, it provided information on some key areas, such as those in Table 8:

### Table 8: Progress made in implementing key areas of Living & Dying Well

<table>
<thead>
<tr>
<th>Area</th>
<th>Description of progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Board Delivery Plans</td>
<td>All were submitted by March 2009 and Boards were asked to review them in October 2009. In addition, the National Clinical Lead for Palliative and End of Life care visited all of the NHS Boards in late 2009 and early 2010. These reviews demonstrate that substantial progress has been achieved across Scotland against all of the actions in Living and Dying Well.</td>
</tr>
<tr>
<td>Developing NHS QIS Palliative Care Standards</td>
<td>This is to be taken forward under the auspices of the new Healthcare Quality Strategy (HQS) (Scottish Government, 2010a). NHS QIS has agreed that palliative and end of life care should be included in one of the work programmes of HQS. It will require joint working between NHS QIS and a range of bodies including NHS National Education for Scotland, SPPC and NHS Boards.</td>
</tr>
<tr>
<td>Roll Out of the Electronic Palliative Care Summary (ePCS)</td>
<td>This allows data to be sent automatically and on a daily basis from GP systems to Out of Hours services. It allows practices to clearly see essential information on patients with palliative care needs, view or print lists of the patients on the Palliative Care Register, and set regular patient review dates. It also allows the opportunity to develop advance care plans which may include medical diagnoses as agreed between patient and GP, and the patient’s wishes on preferred place of care and DNAR. The system is now being rolled out after being piloted, and 10 out of 14 area...</td>
</tr>
</tbody>
</table>
Implementation of Directed Enhanced Service (DES) for Palliative Care

This DES was designed to enhance the work already undertaken through the QOF indicator on the creation of a palliative care register. It is aligned with the ePCS. Guidance is to be issued to support practices in identifying appropriate patients for the palliative care register, the sharing of advanced care plans, and determining a patient’s preferred place of end of life care and seeking to deliver this wherever possible. Initial analysis of the uptake of the DES for the year 2009-10 indicates that 56% of practices are participating, and funding has been agreed with the profession for the DES for the years 2010-12.

The Work of the Palliative Care eHealth Advisory Group on Collating National Data

Progress has continued based on the areas discussed in the Scottish Government’s initial response to the Public Audit Committee in March 2010. However, whilst acknowledging it is important that national data is collected, it again discussed how “a wider, more encompassing approach to improvement will be developed” through the Healthcare Quality Strategy. It described how a quality measure was currently being developed for palliative care, which would utilise evidence representing the wishes and choices for patients and their carers and would demonstrate the effectiveness of having a planned approach to end of life care.

Care homes

Following on from the Care Commission’s report (2008) and other developments a new national Palliative Care in Care Homes Steering Group has been established, including representation from the NHS, care home providers in the private and public sectors, NHS Education for Scotland, COSLA, the Care Commission and the SPPC. The Steering Group will support the implementation of the recommendations in Better Care Every Step of the Way, work which will inform the potential review of the National Care Standards.

Children and Young People

The development of recommendations on appropriate service configurations to meet the needs of adolescents and young adults with palliative and end of life care needs, was one of the areas of work that required further work under Living and Dying Well. This was taken forward through one of the short-life working groups, which, in its final report, emphasised that effective provision of care for this age group demands adaptation and preparation from professionals working in both children’s and adult services. This is to be taken forward through Living and Dying Well: Building on Progress and implemented through NHS Boards’ reviewed and updated Delivery Plans. In addition, A Scottish Children’s and Young People’s Palliative Care Executive (SCYPPEX) has now been formed to address the specific palliative care needs of children and young people, and it has suggested extending he recommendations of the short-life working group to embrace the needs of children also.

PART 2: THE PALLIATIVE CARE (SCOTLAND) BILL

In analysing the Bill itself, use will be made of the information from the sections above, but also the findings from the Committee’s own call for written evidence on the Bill. However, as regards the latter, it should be noted that this is not a comprehensive review of the evidence received; rather, it is used to alert Members to the substantive discussion points that arose from the submissions.

Each of the provisions in the Bill will be discussed in turn, following a brief analysis of the respondents that submitted evidence to the Committee.

ANALYSIS OF RESPONDENTS TO THE COMMITTEE’S CALL FOR EVIDENCE

The Committee’s call for written evidence (Health & Sport Committee, 2010) was launched on 7 July 2010 and closed on 1 September 2010. In total, 70 submissions were received. The various responses have been split into twelve categories, and these together with the number of respondees in each are outlined in Table 9, below.
The largest single grouping was the ‘voluntary’ category which accounts for 11 respondents, closely followed by ‘Individual’ (10) and ‘NHS Board’ (10). As regards the latter it should be noted that there were a few instances of multiple responses from one Board area eg 5 came from different bodies within NHS Greater Glasgow and Clyde (NHS GG&C), and included the Board’s submission to the Finance Committee. Responses from palliative care bodies have been split into two categories to reflect the difference between providers (eg hospices) and associations (eg the Association for Children’s Palliative Care).

Table 9: Categories of respondent together with the position taken on the Bill

<table>
<thead>
<tr>
<th>Category</th>
<th>Neutral / Unclear</th>
<th>Disagree</th>
<th>Agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td></td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Faith based</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Humanist</td>
<td></td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Individual</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Local Authority</td>
<td>1</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Medical individual</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Medical practice</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Non-Departmental Public Body (NDPB)</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>NHS Board</td>
<td>2</td>
<td>7</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Palliative care association</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Palliative care provider</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Voluntary</td>
<td>2</td>
<td>9</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Health professional representative body</td>
<td>5</td>
<td>3</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Professional regulatory body</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>7</strong></td>
<td><strong>25</strong></td>
<td><strong>38</strong></td>
<td><strong>70</strong></td>
</tr>
<tr>
<td><strong>%</strong></td>
<td>10.0</td>
<td>35.7</td>
<td>54.3</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The call for evidence asked respondents to state whether they agreed with the general principle of the Bill. A number of respondents interpreted this question as asking about the principle of providing palliative care, of which there was universal agreement. Therefore, the basis of Table 9 comes from taking into account the whole submission. Overall, 54.3% of respondents agreed with the Bill, 35.7% disagreed and 10% were either neutral or did not make their position clear. Those in the ‘voluntary’, ‘local authority’, ‘humanist’ and ‘individual’ categories were more likely to agree with the Bill, whilst those from health professional, NHS Board and palliative care backgrounds were more likely to be against the Bill.

**STATUTORY DUTY TO PROVIDE PALLIATIVE CARE**

The current legislative provisions for palliative care are discussed in ‘Legislation’, above. Taking into account the evidence from reports such as that of Audit Scotland (2008), the Member in charge of the Bill believes that the general duties in the 1978 Act are not sufficient to ensure an equitable provision of palliative care across the country. Therefore, section 1 of the Bill proposes inserting Section a new Part (Part IIIA: Palliative care) and a new schedule (Schedule 9A: Reporting and indicators) into the 1978 Act. Part IIIA sets out the requirements for the provision of palliative care by the Scottish Ministers. Whilst the Bill does not stipulate how palliative care is to be delivered, it proposes a new section 48A would “place a duty on the Scottish Ministers to provide or secure the provision of palliative care for persons who have been diagnosed with a life-limiting condition and their family members based on the reasonable needs of such persons” (Explanatory Notes, para 10). However, the provision does not require Ministers to provide treatment, help or support where there is already a duty on another to do so, which means:

“…the Bill does not transfer responsibilities between Scottish Ministers and local authorities or between the Scottish Ministers and health boards in relation to the provision of services which could amount or be viewed as palliative care services”. (Policy Memorandum, para 35).
The Policy Memorandum (para 30-35) proposes a number of advantages of the proposal, all based round that it would “provide the necessary momentum to achieve equitable provision as envisaged by [Living and Dying Well]”. The others are discussed in the section below.

The view of respondents

Table 10 outlines the views of respondents by category grouping. This largely mirrors the trend shown in Table 1, the difference being an increase in those with a neutral or unclear position and a slight decrease in those agreeing and disagreeing.

**Table 10: Respondents views on the statutory duty to provide palliative care, by category**

<table>
<thead>
<tr>
<th>Category</th>
<th>Neutral / Unclear</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td>1</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Faith based</td>
<td>1</td>
<td>3</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Health professional representative body</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Humanist</td>
<td></td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Individual</td>
<td>2</td>
<td></td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Local Authority</td>
<td></td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Medical individual</td>
<td></td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Medical practice</td>
<td></td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>NDPB</td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>NHS Board</td>
<td>2</td>
<td>7</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Palliative care association</td>
<td></td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Palliative care provider</td>
<td></td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Professional regulatory body</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Voluntary</td>
<td>2</td>
<td></td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>24</td>
<td>37</td>
<td>70</td>
</tr>
<tr>
<td>%</td>
<td>12.9</td>
<td>34.3</td>
<td>52.9</td>
<td>100</td>
</tr>
</tbody>
</table>

**Arguments in favour of the duty**

For those in favour there was an acceptance, at least implicitly, of the various arguments made in the Policy Memorandum (para 30-25), not least that the current general duties and provisions contained in the 1978 Act were not sufficient in themselves to promote or deliver the availability and quality of palliative care. The British Humanist Association (2010, p2) felt the specific duty would “affirm that palliative and end of life care are a core function of the health service”, a view shared by a number of others including the Salvation Army and Church of Scotland (2010, p2). CARE (2010, p 1) considered that unless such a duty existed NHS Boards would not fulfil their obligations in this area.

It was widely believed amongst those in favour that a statutory duty would secure a more comprehensive and equitable coverage of palliative care services across the country (eg Alzheimer Scotland (2010), Royal College of Psychiatrists (2010) and University of Edinburgh (2010)). Others, such as Shetland Islands Council (2010, p1) also emphasised the benefit the duty would bring in terms of providing help and advice to patients and their families. Rev Dr Donald McDonald (2010, p1) considered that the duty would help to ensure implementation of the Living and Dying Well Strategy. St Margaret’s Hospice (2010, p1) felt that if the specialty of palliative care has “within its grasp the mechanism to ensure an agreed standard of provision across Scotland by legislation” then it should. Other points made included, that the duty would:

- help to widen the scope and raise awareness of palliative care beyond cancer to other terminal illnesses (eg Alzheimer Scotland (2010) and the Humanist Society of Scotland (2010))
promote patient choice in supporting them to die in their place of choice (eg Aberdeenshire Council (2010))
encourage better joint working between agencies (eg NHS GG&C Mental Health AHP Advisory Committee (2010))
assist in combating the high number of NHS complaints concerning end of life care (eg University of Edinburgh (2010))

Arguments against the duty

There were a number of arguments against the introduction of a duty on providing palliative care through the 1978 Act. The Scottish Partnership for Palliative Care (2010, p3) considered that it was unnecessary given the work being undertaken through Living and Dying Well. It was not convinced the proposed duty would lead to more rapid improvements than would otherwise be the case - a view shared by a range of other respondents including the Association of Palliative Medicine (2010), The Prince and Princess of Wales Hospice (2010) and the Royal College of Nursing (RCN) Scotland (2010). It should be noted that there respondents who were not against the principle of having such a duty, but were uncertain whether the Bill would offer more than could be provided under the strategy (eg Care Not Killing (2010)).

There was a widely held view by those against the provision that the general duty contained in the 1978 Act was sufficient (eg British Medical Association (BMA) Scotland (2010)), and that if a specific duty to provide palliative care was inserted, it could set a precedent and encourage other areas of health care and specialisms to seek the same (eg Association for Children’s Palliative Care (2010), NHS GG&C Clinical Directors CHCP/CHPS (2010) and Dr Christopher J Sugden (2010). Other respondents, such as NHS National Services Scotland (2010, p 1) felt there was a danger that in “singling out a particular entity for legislation in a universal health service risks unbalancing the service”. Others were concerned about the effect prioritising one area of health care over others could have (eg Compassion in Dying (2010, p1) and NHS Lanarkshire (2010)). NHS Lothian (2010a, p1-2) stated:

“...the creation of a specific duty may in fact be counter-productive given the consequent risk of separating-out the provision and monitoring of palliative care from all other forms of care, thereby potentially leading to palliative care being an ‘add-on’ and imposed service requirement rather than an integrated component of core high quality healthcare provision”.

Another area of disagreement centred on public expectations. Strathcarron Hospice (2010, p1) felt this proposed duty, together with the other provisions in the Bill, could encourage people to think they were entitled to specific types and levels of care. RCN Scotland (2010, p1) believed it could bring about “inappropriate demands for treatment and services, possibly prompted by a misinterpretation of what palliative care is, which would create unnecessary difficulties for clinicians”. This point was also made by a number of respondents who were concerned that the Bill did not make clear the distinction between specialist and generalist palliative care, what level of care would be acceptable nor the starting point at which someone would receive palliative care under the Bill. These points are discussed further in the section on ‘The definition of Palliative Care in the Bill’, below. However, in relation to the proposal for a specific duty this led several respondents to question what would happen if patients or family members felt that palliative care had not been delivered to their expectation or need (eg Royal College of General Practitioners (RCGP) (2010) and Strathcarron Hospice (2010). Dignity in Dying (2010, p2) although in favour of a statutory duty, felt it was important that members of the public be given clear information on their rights around end-of-life care and on the services available to them.
THE DEFINITION OF PALLIATIVE CARE CONTAINED IN THE BILL

Section 1 of the Bill proposes a new section 48C to be inserted into the 1978 Act. This provides the interpretation of Part IIIA and Schedule 9A. The Explanatory Notes (para 11-16) state that the definition for “palliative care” reflects broadly the definition used by the World Health Organisation (WHO), which is discussed in ‘What is palliative care?’, above. The definition does not contain a list of eligible conditions, as it was considered this may unintentionally preclude certain groups. Instead it utilises the term “life-limiting condition”, which is defined as “a condition, illness or disease which is progressive and fatal and the progress of which cannot be reversed by treatment”. In addition, the Bill does not require diagnosis of a specific “life-limiting” condition. The WHO definition uses the term “life-threatening illness”. However, as explained in the Policy Memorandum (para 47) “life-limiting” was preferred in the Bill because it was not deemed to encompass as many conditions, and was also more indicative that the condition was irreversible. In addition, the use of the term is consistent with Living and Dying Well.

For those with a life limiting condition, the Bill defines palliative care as “treatment which controls and relieves pain, discomfort or other symptoms caused by or related to a life-limiting condition with the intention of improving quality of life”, and includes psychological, social or spiritual help and support. The definition also encompasses help and support for family members, which would cover psychological, social or spiritual help and support to assist family members in dealing with the fact that their relative has a life limiting condition and the consequences of that condition. Finally, the definition provides that palliative care should be provided according to the reasonable needs of the person with the life-limiting condition or the family member.

The view of respondents

In the call for evidence, respondents were asked whether they were content with the definitions in the Bill, particularly that of palliative care. The level of agreement or otherwise is outlined in Table 11.

Table 11: Respondents views on the definitions in the Bill particularly that of palliative care, by category

<table>
<thead>
<tr>
<th>Category</th>
<th>Neutral / Unclear</th>
<th>No comment</th>
<th>Unsupportive</th>
<th>Supportive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faith based</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Humanist</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Individual</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Local Authority</td>
<td>2</td>
<td></td>
<td>4</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Medical individual</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Medical practice</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>NDPB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NHS Board</td>
<td>1</td>
<td>4</td>
<td></td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Palliative care association</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Palliative care provider</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Voluntary</td>
<td>1</td>
<td>3</td>
<td></td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Health professional representative body</td>
<td>1</td>
<td>5</td>
<td></td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Professional regulatory body</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>8</strong></td>
<td><strong>22</strong></td>
<td><strong>11</strong></td>
<td><strong>29</strong></td>
<td><strong>70</strong></td>
</tr>
<tr>
<td><strong>%</strong></td>
<td><strong>11.4</strong></td>
<td><strong>31.4</strong></td>
<td><strong>15.7</strong></td>
<td><strong>41.4</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

This shows, just over 40% of respondents were in general agreement with the definitions (though this did not mean they had no suggestions on some specifics) whilst 15.7% disagreed
overall. Just over 11% were neutral or unclear in their overall stance, and 31.4% made no comment at all. Respondents, when they did make comment on the definitions tended to reflect on specific elements of the “palliative care” definition and the reasoning given in the accompanying document, and it is these that will be reflected on in this section.

**Definition of palliative care – general**

A significant number of respondents were happy overall with the definition of palliative care in the Bill. The University of Edinburgh (2010, p 2) stated it was “very content with the definitions contained in the Bill which relate to the World Health Organisation definitions”. The Scottish Council on Deafness (2010, p 3) stated “the definition is broad enough to cover life-threatening conditions that have not traditionally been considered”.

However, there was discussion amongst some respondents about the difficulties in agreeing a definition and the implications of that. RCN Scotland (2010, p 2) stated that “preconceptions and presumptions about the definition of palliative care make it a challenging term to use without ambiguity”. It reflected on the original consultation on the proposal for a Palliative Care (Scotland) Bill and noted that only a small number of respondents to that were in favour of the approach eventually taken in the Bill. It felt this was “suggestive that there could be ongoing uncertainty about what palliative care is, risking the meaningful implementation of any legislation”. Strathcarron Hospice (2010, p2) also felt palliative care was difficult to define precisely and was concerned that it could raise expectations that cannot be met. It felt that the Bill did not adequately define good quality palliative care. Similar concern were voiced by RCGP (2010, p2), which added that this led to difficulties in defining what it is patients and family members would be legally entitled to.

**Life-limiting condition**

Most of the comments on these sections of the Bill centred on the choice of the term “life-limiting condition”. Amongst those in favour of using the term was Alzheimer Scotland (2010, p1) which was pleased that there was no requirement for a diagnosis of a specific condition. It argued that access to palliative care should be on the basis of need and not diagnosis, a view shared by Marie Curie Cancer Care (2010). The Royal College of Psychiatrists (2010, p 2) also agreed, arguing the definition would “lead to a smoother pathway into appropriate care for patients with such conditions”. In addition, it was also pleased that the term emphasised that palliative care services were not solely for patients with cancer. NHS Lothian (2010a, p3) was also content with the definition as it covered "any condition, illness or disease that is progressive, cannot be reversed by treatment, and is ultimately fatal". South Lanarkshire Council (2010, p 2) felt the adoption of “life-limiting” rather than WHO's "life threatening" appeared to “encompass both categories of progressive and fatal, as well as irreversible conditions more equally”.

However, there were a number of points made against the use of the term and its definition. The RCGP (2010, p2-3) felt that people in this group may have conditions that deteriorate over a number of years, and so posed the question: “at what point, in legal terms, would the patient start receiving palliative care?”. It suggested defining palliative care in terms of need rather than being so prescriptive. A similar argument was made by the MS Society for Scotland (2010, p 2), which noted that for a small percentage of people, MS is a progressive and fatal life-limiting condition, but for others improved management and treatment means it can be managed. As with RCGP it felt the definition was not responsive to need but still reliant on a condition. Veronica Neefjes (2010, p 1-2) felt the definition of a life-limiting condition would exclude a

---

6 Paterson (2009b, p3) states that of the 106 responses to the original consultation, only 41 provided views on the definition with 23 agreeing with the approach taken. Therefore, there are two ways of looking at this. The first is to say that a majority (56%) of those that responded to the question agreed with the definition. The other, which is the approach of RCN Scotland, considers those agreeing with the definition used to the total number of respondents, to show that only 22% agreed with the proposal.
group of children diagnosed with non-progressive but irreversible conditions that cause severe
disability, lead to susceptibility for health complications and the likelihood of premature death eg
children with severe cerebral palsy, and children with multiple disabilities following trauma, who
may currently receive palliative care. She added:

“The assumption that there is no place for palliative care until all curative options
have been exhausted may interfere with an early discussion of palliative issues,
including limitations of unduly burdensome interventions at the end of life. Moreover,
this may inhibit patients and family members from voicing fears and concerns about
the burdens of life-prolonging interventions and the dying process.”

Finally, NHS National Services Scotland (2010, p 2) argued that without specifying conditions as
part of the definition of “life-limiting” it could be more difficult to be able to collect data on
conditions for the purposes of measuring the indicators set out in the Bill (see the discussion on
the provisions concerning reporting and indicators in the next part of the briefing).

**Family Members**

Under the proposed section 48C, the term “family members” is defined as including parents,
children and grandparents as well as uncles, aunts, nieces, nephews, great aunts and great
uncles and spouses. “Civil partners” and “cohabitants” are also included and are themselves
further defined.

Overall, there was little discussion of the term, though Alzheimer Scotland (2010, p 1) was one
of the respondents that specifically mentioned its support for the inclusion of “family members”
and how it was defined in the Bill. However, there were number of others that questioned how
“family members” had been defined in the Bill, for instance RCGP (2010, p3) which felt the
definition did not cover those possibly more likely to be in a caring role and in need of support,
such as neighbours and friends.

The Medical Education Trust, Doctors Who Respect Human Life and the Medical Ethics Alliance
(2010, p 3) questioned whether the needs of family members should be included in the
definition at all:

“...family members of terminally ill patients do not, strictly speaking, receive palliative
care. They receive holistic help and support to enable them to care for the patient
and to reduce their level of stress when so doing. Such help and multidisciplinary
support is a feature of good practice in many medical specialties, and should not be
defined as palliative care.”

**Reasonable need**

As noted above, the Bill states that palliative care should be provided according to the
reasonable needs of the person with the life-limiting condition or the family member. The term
“reasonable need” is not defined in the Bill, though the Explanatory Notes (para 15) state:

“The use of “reasonable needs” clarifies that the duty to provide care is bound by
what is reasonable for any individual to receive. In other words the Scottish
Ministers’ duty is to provide a palliative care service to all relevant people, but only to
the extent that it meets the particular and reasonable needs of those individuals.”

Again, this was not a widely debated issue across submissions, and the points that were made
sought clarification on what “reasonable need” meant. Care Not Killing (2010, p 3) discussed
the issue in relation to the fact that no distinction is made between specialised and general
palliative care in the Bill. It believed that the Bill should be clearer as to what level of palliative
care support might be deemed to be ‘reasonable’ in different contexts:
“We suggest that [generalist] palliative care should be available to all (regardless of whether a condition is life-limiting or not) and that specialist palliative care provision should be available to all of those for whom it is needed. Some discussion around this point would be welcome. A lack of clarity on this point could lead to costly legal actions if patients were led to believe that they had a ‘right’ to specialist palliative care services.”

A similar point was made by the Royal College of Physicians and Surgeons of Glasgow (2010), though as noted above the Bill does not seek to stipulate how palliative care should be delivered.

PROVISIONS RELATING TO REPORTING AND INDICATORS

Section 1 of the Bill also seeks to insert a new section 48B into the 1978 Act, which would require Scottish Ministers to lay an annual report before the Scottish Parliament containing information relating to 11 indicators that are set out in the Bill. As discussed in the section on ‘Provision of Palliative Care in Scotland’, above, there are particular issues surrounding the availability of data concerning palliative care at a local and national level. It is also clear that this data is not readily available in one place. Indeed, as things stand there is still no available figure on the numbers of people receiving palliative care in Scotland. It is such issues the Bill is seeking to remedy, arguing that the provision would allow Scottish Ministers and the Parliament to scrutinise, compare and contrast the delivery of palliative care services nationwide. This would then allow best practice to be highlighted across the NHS (Policy Memorandum, para 50). The indicators themselves would be set out in a new schedule 9A, inserted into the 1978 Act, and are detailed in Appendix 3.

The proposed Schedule also proposes that Health Boards be responsible for providing Ministers with the information which will lead to the Annual Report. It then provides Ministers with the duty of providing information in the report on a Scotland-wide basis as well as for each Health Board area. Finally, the proposed section 48B would also allow Ministers to modify and add to the indicators, with the aim of keeping pace with developments in Living and Dying Well.

As regards the necessary infrastructure that would be necessary to collect relevant data, the Financial Memorandum (Explanatory Notes, para 63-65 and 71-74) considers the impact on the Scottish Government and Health Boards in particular. It notes that the Bill does not require the setting up of a central database, though does discuss occasions where Scottish Ministers have done so, such as in the creation of a standardised database for the registration and management of violent and sex offenders. It might be argued that such a database may help in collating data for the Annual Report.

The main bulk of data collection is envisaged as taking place through NHS Boards. It is argued that NHS Boards already collect a significant amount of information relating to the delivery of palliative care services through the use of a number of assessment tools.

The view of respondents

In the call for evidence, respondents were asked if they had any comments concerning the provision for reporting and indicators in the Bill. Table 12, below, outlines the overall view of respondents on the provisions. As can be seen the largest number of respondents (37.1%) were neutral on the issue, or their stance on the provisions was unclear. Of the remainder, 28.6% were against the provisions, 12.9% were for and 21.4% made no comment. As with the situation with the statutory provision over the delivery of palliative care, respondents from a health and palliative care background were more likely to have disagreed with the provisions.
Table 12: Respondents views on the provisions relating to indicators and reporting, by category

<table>
<thead>
<tr>
<th>Category</th>
<th>No comment</th>
<th>Neutral / Unclear</th>
<th>Disagree</th>
<th>Agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td></td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Faith based</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Health professional representative body</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Individual</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Local Authority</td>
<td>5</td>
<td></td>
<td>1</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Medical individual</td>
<td>1</td>
<td>1</td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Medical practice</td>
<td></td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>NDPB</td>
<td>1</td>
<td></td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>NHS Board</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Palliative care association</td>
<td>1</td>
<td></td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Palliative care provider</td>
<td>1</td>
<td></td>
<td>1</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Professional regulatory body</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Voluntary</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>15</strong></td>
<td><strong>26</strong></td>
<td><strong>20</strong></td>
<td><strong>9</strong></td>
<td><strong>70</strong></td>
</tr>
</tbody>
</table>

| %                                            | 21.4       | 37.1              | 28.6     | 12.9  | 100   |

Discussion of the annual report

As noted above much of the discussion concerning reporting was in the context of the indicators themselves. Of those that did consider the provisions relating to the annual report, the MS Society in Scotland (2010, p3) agreed that all data should be published in one place, whilst Compassion in Dying (2010, p3) considered that annual reporting would ensure that services can be audited and continuously improved. However, there were calls for a review to take place at some point after implementation, should the Bill be passed, to ascertain whether the need for an annual report was necessary (eg Care Not Killing (2010) and CARE (2010)).

Main issues discussed by those in favour of the indicators

For those in favour of the provisions, there was a general view that obtaining the evidence from the indicators would be useful in the ongoing development of palliative care (eg Aberdeenshire Council (2010) and Compassion in Dying (2010)). MS Society Scotland (2010) felt the provisions would increase the potential for best practice learning as well as promoting more openness and transparency. It, together with others, was also pleased that recording and monitoring feedback from patients, families and carers was included. However, amongst those that agreed with the provisions it was felt important to ensure that the collection of the associated data did not become a burden (eg Christian Medical Fellowship (2010) or just a ‘tick box’ exercise (eg Rev Donald M MacDonald (2010)). Julie King (2010) whilst appreciating the potential value of each indicator considered that a lot of detail would be produced. As such, she argued, it would be important that there was an understanding of how the indicators should be viewed overall so as to give an accurate picture of service provision as opposed to measuring a particular area in isolation. Compassion in Dying (2010) was also concerned that the nature of the definition of palliative care in the Bill may in itself make it difficult to collect the range of data that would be required for the indicators.

Main issues discussed by those against or neutral towards the indicators

For those against or neutral towards the indicators, one key issue was the extent to which the indicators as set would produce meaningful data. SPCC (2010, p3-4) outlined the reasons why attempting to measure access to palliative care is complex, including:
the range of different conditions to which palliative care may be appropriate
the range of different points along a disease trajectory at which palliative care may be appropriate
identifying precisely when a patient has palliative care needs and starts to receive it
the range of settings and sectors in which palliative care may be provided
the range of professionals who may be involved in the provision of palliative care
the fact that palliative care is very often an integral component of good general care and not identified as a distinct element by patients or practitioners
practical and ethical difficulties and sensitivities in getting patient and family feedback on the quality of services experienced

Many of these were raised in connection with the proposed indicators or for particular areas of the NHS (eg RCGP (2010, p2) considered some of these and other issues in relation to primary care). The SPPC (2010) stated that a further refinement of the definitions contained in the Bill would be necessary if consistent and meaningful data was to be generated on all the indicators suggested. The definition of “palliative care” itself in the Bill was raised in this regard by a number of respondents, including RCN Scotland (2010, p2), which questioned how meaningful the quantitative data arising from the indicators would be. Alzheimer Scotland (2010, p1), felt the indicators would not enable the measurement of equity of provision across the wide range of life-limiting conditions. The Care Commission (2010, p2) said it saw no evidence of involvement with it or NHS QIS concerning the development of the indicators, when both bodies had been involved in the scrutiny, regulation/peer review of palliative care services for a number of years. RCGP (2010) and the Royal College of Psychiatrists (2010) considered that trying to obtain data from generalist services would be difficult, whilst Care Not Killing (2010) felt there should be specific indicators for generalist and specialist palliative care.

In terms of collecting the data, a number of respondents appeared to be unconvinced by the view in the Financial Memorandum that it would not be burdensome for NHS Boards to collect the data, for instance the Association of Palliative Care (2010, p2), which was concerned that collecting the data could in fact have the paradoxical effect of reducing the quality of care by taking health professionals away from patient care. NHS National Services Scotland (2010, p1) stated that, as a principle, reporting arrangements should be integrated into data collection systems for all patients, rather than setting up a specific system. NHS Lothian (2010a, p2) and NHS Lanarkshire (2010, p2) considered that new data systems would need to be created and appropriate linkages made between existing data sets.

The Bill places no duties on local authorities on the voluntary sector. However, a number of respondents from these sectors noted that the provisions on indicators and reporting would have an impact on them. Strathcarron Hospice (2010, p 1) stated that the indicators were “very onerous and probably unworkable. As a Hospice, we would not be able to complete this reporting process within our existing resources”. As regards local authorities, the City of Edinburgh Council (2010, p 1) considered that the indicators on community care assessments and carers assessments would require it to collect information and statistics not already collected, which would require both practice and IT changes. Similar points were made by Shetland Islands Council (2010) which also discussed the need to increase co-ordination between the local authorities and NHS Boards to identifying key personnel to collect and record the information.

The need for better reporting systems

A number of respondents that had issues with the indicators, did accept that that improvements were necessary in the collection of data concerning palliative care, and the reporting of it. The Association of Palliative Care (2010, p2) was one of these but it wanted information gathered on a more limited number of issues, a view shared by St Margaret’s Hospice (PAL65). A number
of respondents considered that the developing of a more limited list of indicators should be
developed under the auspices of *Living and Dying Well* (eg (Marie Curie Cancer Care (2010)
and NHS GG&C Clinical Directors CHCP/CHPS (2010)). A number of bodies representing
particular groups (eg the Association for Children’s Palliative Care (2010) and the Scottish
Council on Deafness (2010)) felt the indicators should better reflect the needs of those groups.

Discussion of Individual indicators

Many respondents discussed individual indicators in detail, indeed a small number considered
each of the indicators in turn, identifying the pros and cons of each as they saw it (eg Medical
Education Trust, Doctors Who Respect Human Life and the Medical Ethics Alliance (2010) and
Dr C Preston (PAL47)). Such respondents tended to highlight specific difficulties in interpreting
what particular indicators meant, the definitions used, how each would be collected, and
possible effects on services. NHS National Services Scotland's (2010) submission considered
the implications of each indicator, and what it would take for current systems (particularly the
electronic palliative care summary (ePCS)) to be adapted to be able to collect the data. These
comments are shown in Appendix 3, purely as an example of the types of issues that are raised,
which themselves are open to debate. Other types of respondent, eg local authorities or
hospices, have their own concerns about specific indicators.

COSTS IDENTIFIED THROUGH THE FINANCIAL MEMORANDUM

The Financial Memorandum (Explanatory Notes, para 43-79) discusses the potential costs
associated with the Bill. As the Bill seeks to give legislative effect to the aims of *Living and
Dying Well*, there is a discussion of funding that has already been allocated as a result of it,
一起 with an assessment of the known expenditure on specialist and generalist services.
However, there is an acceptance that there is uncertainty about the costs of delivering palliative
under the strategy, due to and absence of information about palliative care delivered by
generalists and the number of those actually receiving palliative care. In addition, it notes a lack
of certainty about how many more people would be eligible to receive palliative care as a
consequence of the strategy.

The Financial Memorandum does attempt to estimate the cost of implementing *Living and Dying
Well* by using data associated with the implementation of the English strategy\(^7\), on palliative
care. Given that 55,000 people die in Scotland per annum, which is 11% of equivalent number
for England, the Financial Memorandum surmised that 11% of the funding committed by the UK
Government for the English strategy would mean an equivalent Scottish cost of £9.68m in year
one and £21.8m in year two.

However, the overall point made in the Financial Memorandum is that the statutory duty to
provide palliative care in the Bill does not seek to go beyond what is already in *Living and Dying
Well* - as the Scottish Government has already assessed what extra funding to provide in
meeting its objectives, the Bill would not incur any additional costs. Therefore, for generalist
services it points to the £3m per annum funding to develop the DES for palliative care and the
£1.2m funding over 2008-09 and 2009-10 to support NHS Boards in implementing the strategy.
In terms of specialist services it notes the £59m figure Audit Scotland (2008) arrived at in its
report, but argues that as the duty to provide palliative care services will rest with Scottish
Ministers, should they choose to pass this onto NHS Boards then any further funding would be a
matter for them. It also notes the aim of *Living and Dying Well* to deliver as many services in
the community as possible and notes the funding and efforts already made under the strategy to
promote this.

\(^7\) Department of Health. (2008) *End of Life Care Strategy - promoting high quality care for all adults at the end of
life.*
There is an acceptance of additional costs in relation to the duty on reporting and the collection of data for the indicators. However, it is believed this will not be a large cost given the information that is already collected through a variety of systems (as discussed in ‘Provision of Palliative Care in Scotland’, above). The argument is made that most of the necessary data is already known to NHS Boards and there is an acceptance there may be costs in collating it. However, it is also argued that as there are no centrally available figures on how much it already costs NHS Boards to collect data relating to palliative care, it is difficult to estimate costs for collecting data for all the indicators. However, it is assumed that any cost would be absorbed by the NHS Boards themselves. Where the Financial Memorandum does note specific cost, is in the circumstance where it is decided to set up a national database in order to collate all the data from the NHS Boards in order that the Annual Report can be compiled. It discusses a number of databases already set up, including the tobacco retailers database set up under the Tobacco and Primary Medical Services (Scotland) Act 2010 asp 3, and considers that overall costs will range in the first year from £51,500 to £375,000: “…but are likely to be closer to the former, given the number of locations involved and the nature and the amount of information to be held”. Ongoing costs are estimated to be £10,000 per annum.

The Financial Memorandum does not foresee any direct costs upon local authorities. In terms of the voluntary sector it contends that the development of generalist community services under Living and Dying Well will mean that there will not be a significant demand on voluntary sector services. Finally, the Financial Memorandum makes a case that a more comprehensive delivery of quality palliative care services could lead to potential savings.

The view of respondents

Table 13, below, outlines the overall views of respondents to the Financial Memorandum. Only 8.6% were in agreement with the Financial Memorandum, with just over 37% disagreeing with the assumptions made within it. However, over half of respondents were neutral, did not make their position clear or made no comment on the Financial Memorandum.

Table 13: Respondents views on the costs identified in the Financial Memorandum, by category

<table>
<thead>
<tr>
<th>Category</th>
<th>Neutral / Unclear</th>
<th>No comment</th>
<th>Disagree</th>
<th>Agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Faith based</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Health professional representative body</td>
<td>1</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Humanist</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Individual</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Local Authority</td>
<td>1</td>
<td>5</td>
<td></td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Medical individual</td>
<td>1</td>
<td>3</td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Medical practice</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>NDPB</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>NHS Board</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Palliative care association</td>
<td>2</td>
<td>3</td>
<td></td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Palliative care provider</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Professional regulatory body</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Voluntary</td>
<td>6</td>
<td>5</td>
<td></td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>20</td>
<td>26</td>
<td>6</td>
<td>70</td>
</tr>
<tr>
<td>%</td>
<td>25.7</td>
<td>28.6</td>
<td>37.1</td>
<td>8.6</td>
<td>100</td>
</tr>
</tbody>
</table>
The importance of developing palliative care and the potential for savings

For some respondents that appeared content or were neutral/unclear in their assessment of the Financial Memorandum, even if there were to be an increase in costs as a result of the strategy and / or the Bill, then this would be worth it in order to achieve good quality and comprehensive palliative care provision (eg The Salvation Army and Church of Scotland (2010, p6) and Carole Cannon (2010, p1).

Many of those who were content or were neutral/unclear in their position were also more likely to agree with the assessment in the Financial Memorandum that, over time, there may be potential savings. SPPC (2010, p 5) believed that “the provision of palliative care does have the potential to deliver efficiency savings (for example by reducing inappropriate admissions) as well as improving the safety and quality of the patient and carer experience”. CARE (2010, p 2), which believed the Bill could lead to increased expenditure being required for the delivery of palliative care services also stated: “we accept that some of these costs may be offset by increasing community-based generic palliative care provision and thus saving on in hospital/hospice provision”. The Christian Medical Fellowship (2010, p 2) stated:

“It is our belief that if society's taboo on discussing death could progressively be broken in the context of knowing that good palliative care was reliably available, then many more patients might decline expensive and sometimes fruitless procedures towards the end of life. Thus, cost savings greater than the costs of providing palliative care according to the Bill’s intentions might ultimately be achieved.”

Those who were not content with the Financial Memorandum tended to focus on the possible effect of a statutory duty to provide palliative care and the provisions on reporting.

The statutory duty to provide palliative care

As noted above, the Financial Memorandum (para 58-61) notes there is lack of information about the number of people currently receiving palliative care and so it looks to the funding of the English strategy to provide an indication of how much it would cost to implement the Scottish strategy. This received a little criticism most notably from the Royal College of Physicians and Surgeons of Glasgow (2010, p 2), which considered this to be too simplistic, and briefly discussed the issues connected with making such assumptions:

“Scotland has a population, the majority of which is tightly confined within the Central Belt, with areas of extreme poverty and deprivation (as well as affluence). A significant minority of the population of Scotland is scattered across a wide area of the Highlands and Islands, resulting in significant challenges in the provision of effective and timely services. Rural poverty, again, can bring challenges which are not reflected in any of the costings.”

It is also not clear what status the Financial Memorandum gives to the resulting figures from the analysis (£9m in year one and nearly £22m in year 2), as it argues that the costs in implementing the Scottish strategy are already being met through Living and Dying Well. Yet, as noted above the funding that has already gone into the strategy is below that of the English strategy.

Other respondents to the Committee, believed that it was an underestimate of the likely costs that would be required by instituting such a duty eg BMA Scotland (2010) and NHS GG&C Beatson West of Scotland Cancer Care (2010). RCGP (PAL50, p 3) considered the costings to be vague and argued that there would be costs associated with staffing, training and education as well as appropriate carer support. It was also concerned that funding the Bill would impact on the availability of other services in the NHS. NHS Lothian (2010b, p2) noted the difficulties in separating out aspects of palliative care routinely provided by generalists together with the
unknown cost and evidence base around much of non-cancer palliative care. It believed that if the Bill was passed and Scottish Ministers devolved their duty to provide palliative care to NHS Boards public expectations would rise, as would the potential for legal challenge, which would have an effect on costs. NHS Borders (2010, p 1) considered there was a degree of uncertainty over the financial implications of the Bill, and felt it was essential that there were clear financial review and monitoring process built into any implementation process.

There was some support from respondents to the argument that the Bill would not lead to any additional services to what is already planned through Living and Dying Well, though this was qualified. Both the Association of Palliative Care (2010, p2) and The Prince and Princess of Wales Hospice (2010, p2) believed that this assumption could be correct as regards generalist services given these were the focus of the strategy. However, they felt further consideration was needed over the cost of developing specialist services.

Although the Financial Memorandum makes the case that the Bill itself will not increase costs, there was some comment about whether the current funding for Living and Dying Well was sufficient. NHS GG&C (2010, p1) noted that it was required to carry out a needs assessment in order to identify the needs of its population in relation to palliative care. NHS GG&C found that on the basis of its findings the level of financial support provided through Living and Dying Well was short of what it identified in the assessment.

Others (eg Strathcarron Hospice (2010, p3) and Veronica Neefjes (2010, p3)) considered problems with the definitions in the Bill (see above). Their basic argument was that if there is uncertainty over what palliative care is, and at what point palliative care is triggered as a result, then this would make it difficult to make any assessment of the resultant cost.

**The statutory duty on reporting**

The Financial Memorandum argues that much of the data required by the Bill is already being collected by NHS Boards. However, given NHS National Services Scotland’s (2010) submission to the Committee, together with the issues identified in ‘Provision of Palliative Care in Scotland’, above, it appears there may be at least be some difficulties.

In terms of respondents to the Committee’s call for evidence a few organisations (eg St Margaret’s Hospice (2010) and PAMIS (2010)) were in agreement with the Financial Memorandum concerning the costs associated with data collection. However, a larger number had concerns. NHS National Services Scotland (2010), NHS Borders (2010), NHS GG&C (2010) and NHS Lothian (2010b) all considered the cost of data collection had been underestimated in the Financial Memorandum, though it was also felt by several that this was difficult to quantify. Both the Association for Palliative Care (2010, p2) and the Scottish Partnership for Palliative Care (2010, p5) considered that the collection costs would be greater than those for Living and Dying Well. In addition, it should be noted that several local authorities (see discussion on indicators, above) suggested that new data systems would be required by them to collect information requested by NHS Boards from them, on community care assessments and carers assessments, which would have resource implications.

Finally, the Financial Memorandum considered the prospect of a national database in order to support the collation of data for the provision of an annual report. It is important to note that this is not a requirement of the Bill, only a suggestion that the Scottish Government may wish to consider should the Bill be passed. A number of examples are discussed in the Financial Memorandum, but it makes particular note of the tobacco retailers register that will be set up under the Tobacco and Primary Medical Services (Scotland) Act 2010. This has set up costs of £7,500, first year running costs of £44,000 and £10,000 ongoing costs. Whilst there will be significant numbers of retailers to register, particularly initially, the Scottish Government (2010b) recently consulted on proposals to only contain limited data on the register. The proposals
suggested were: the name and address of the person completing the form; whether they are banned from carrying on a tobacco business at the premise specified in the application; whether they are exempt from the displays ban as a specialist tobacconist, and whether the floor area of the premise specified in the application exceeds 280 square metres.

Another possible model to consider is that of the National End of Life Care Intelligence Network, which was set up as part of the English strategy (Department of Health, 2008). The network is tasked with collating existing data and information on end of life care for adults in England. This is with the aim of helping the NHS and its partners plan, commission and deliver end of life care services that respond to the wishes of dying people and their families. This does go beyond what was envisaged in the Financial Memorandum, as it is an online resource and contains a range of additional information and resources. However, it is a bolt on to an existing data resource and does contain the types of data that would be required under the Bill for reporting. The House of Commons Library (2010) has advised that the network was set up in May with funding of £1.1m for 2010-11, though there was no further information on the likely ongoing costs from 2011-12 onwards. In terms of the Bill, this can only be considered as an illustration of what could be set up should the Scottish Government choose to do so if the Bill is passed.

**Costs on local authorities**

As noted above, the Bill does not place any duties on local authorities. However, most of the local authorities that submitted to the Committee did not agree with the assumption made in the Financial Memorandum that there would be no significant costs for local authorities. The City of Edinburgh Council Health and Social Care Department (2010) and Glasgow City Council Social Work Services (2010) both considered that there would be cost implications for the delivery of palliative care for home care services and care homes. Glasgow City Council (2010, p1-2) discussed how the provisions overall could lead to an increase in the number of social care assessments that were demanded at a time when there was significant pressure on the system. It also noted possible resource implications of introducing the Liverpool Care Pathway (LCP) in nursing homes, which could resulting in additional costs having to be borne by the Local Authority.

Dundee City Council Social Work Department (2010) believed there could be an inequality between someone who received palliative care in hospital, which would be “free” as far as they are concerned, compared to someone who receives care at home from social work, which is a chargeable service. It also considered there was a need for clear funding streams eg social work services are supporting many terminally people who have no involvement with nursing services. It was concerned that such people may not get the most appropriate support, as social care staff are being asked to take responsibility for care which is not appropriate to their level of training. Finally, it sought clarification on whether NHS Boards would have to pay for palliative care which is not undertaken by them.

**Costs on the voluntary sector**

As discussed above, the Bill does not place any duties on the voluntary sector. The Financial Memorandum considers there will be no additional resource implications for the sector as Living and Dying Well envisages greater generalist palliative care through care in the community. There was a little comment on this from the voluntary sector, though this is questioned by Marie Curie Cancer Care (2010), which noted that the voluntary sector provides a wide range of services in conjunction with other partners, such as the NHS. It added that such services range from hospice-based care to palliative care provided both specialist and generalist staff within the community. Strathcarron Hospice (2010, p 3) felt there was no evidence to make the assertion in the Financial Memorandum, and was concerned at the future funding of hospices. It
contended that the 50% funding of hospices from NHS resources was not being met, which was putting more pressure on voluntary sources of income.

**SOURCES**


Alzheimer Scotland. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL03.pdf

Association for Children’s Palliative Care. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL02.pdf


British Medical Association Scotland. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL06.pdf


Humanist Society of Scotland (2010). *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland)* Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL23.pdf


MacDonald, Rev Dr D M. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland)* Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL26.pdf

Marie Curie Cancer Care. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland)* Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL27.pdf

Medical Education Trust, Doctors Who Respect Human Life and the Medical Ethics Alliance. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland)* Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL30.pdf

MS Society for Scotland. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland)* Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL32.pdf

National End of Life Care Intelligence Network. [Online]. Available at: http://www.endoflifecare-intelligence.org.uk/home.aspx
Neefjes, V. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL35.pdf


NHS Greater Glasgow & Clyde (2010). Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL37.pdf


NHS Greater Glasgow & Clyde Mental Health AHP Advisory Committee. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL40.pdf

NHS Greater Glasgow & Clyde Beatson West of Scotland Cancer Care. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL38.pdf

NHS Lanarkshire. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL42.pdf

NHS Lothian. (2010a) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL44.pdf

NHS Lothian. (2010b) Response to the Finance Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL43.pdf

NHS National Services Scotland. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL45.pdf


PAMIS. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL46.pdf


Royal College of General Practitioners. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL50.pdf

Royal College of Nursing Scotland. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL51.pdf


Royal College of Psychiatrists in Scotland. (2010) Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill. [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL54.pdf


Scottish Partnership for Palliative Care. *Hospices and Specialist Palliative Care Units.* [Online]. Available at: http://www.palliativecarescotland.org.uk/palliative-care/services-in-scotland/hospices-and-specialist-units

Scottish Partnership for Palliative Care. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL60.pdf


St Christopher’s Hospice. [Online]. Available at: http://www.stchristophers.org.uk/page.cfm/Link=1/t=m/goSection=1

St Margaret’s Hospice. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL65.pdf

Sugden, Dr C J. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: [http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL67.pdf](http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL67.pdf)

University of Edinburgh. (2010) *Response to the Health & Sport Committee’s Call for Written Evidence on the Palliative Care (Scotland) Bill.* [Online]. Available at: [http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL68.pdf](http://www.scottish.parliament.uk/s3/committees/hs/inquiries/PalliativeCareBill/PAL68.pdf)

APPENDIX 1: EXAMPLES OF VARIED PROVISION OF GENERAL PALLIATIVE CARE
## APPENDIX 2: A TIMELINE AND SUMMARY OF SELECTED PALLIATIVE CARE REPORTS AND POLICY DOCUMENTS

<table>
<thead>
<tr>
<th>Report or Policy Initiative</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>‗Our national health, a plan for action, a plan for change‘ (Scottish Executive, 2000)</td>
<td>The then strategy for the National Health Service in Scotland. It recognised that palliative care should be available to all on the basis of need not diagnosis. It accepted that palliative care dealt with the totality of a person’s care needs, including not only pain and other symptom relief but also spiritual and social needs. It also noted the needs of carers. It made commitments on a Managed Clinical Network (MCN) approach to palliative care, the needs of those with end-stage heart failure, and new clinical standards for palliative care and specialist palliative care. It also placed an expectation of NHS Boards that they would work closely with Hospices. December 2000</td>
</tr>
<tr>
<td>‗Cancer in Scotland: Action for Change‘ (Scottish Executive, 2001)</td>
<td>The then health service cancer strategy. It acknowledged that palliative care had a wider application than cancer, and reiterated the role of MCNs and the creation of clinical standards as discussed in ‘Our national health’. However, it also sought: better integration of the planning and delivery of palliative care services between NHS Boards, local authorities and the voluntary sector; better education and training for staff; and better workforce planning. Similar recommendations were made in other condition-specific strategies, such as ‘Coronary heart Disease and Stroke Strategy for Scotland‘ (Scottish Executive, 2002). July 2001</td>
</tr>
</tbody>
</table>
| ‗Clinical Standards: Specialist Palliative Care‘ (Clinical Standards Board for Scotland, 2002) | The current clinical standards for specialist palliative care, developed with the Scottish Partnership for Palliative Care, and which apply to specific elements of the service. They cover the following areas:  
- Access to Specialist Palliative Care Services  
- Key Elements of Specialist Palliative Care  
- Managing People and Resources  
- Professional Education  
- Inter-professional Communication  
- Communication with Patients/Carers  
- Therapeutic Interventions  
- Patient Activity  
These were used to assess performance in hospital, community and hospice settings throughout Scotland where specialist palliative care services are provided. June 2002 |
| ‗NHS HDL(2003)18 - Funding of Specialist Palliative Care Provided by Independent Voluntary Hospices in Scotland‘ (Scottish Executive, 2003) | This related primarily to independent voluntary hospices providing specialist palliative care for adults. It stated, within the context of in each NHS Boards’ palliative care strategy, and expectation that that they will fund 50% of the annual running costs of any such hospice within their area. It also provides guidance on certain aspects of hospices’ running costs, with the aim of promoting consistency of approach across Scotland. Although different arrangements apply to the funding of palliative and respite care for children with life-limiting conditions, it was also expected that the underpinning principles and guidance would relate to independent hospice provision for children. April 2003 |
| ‗National Overview: Specialist Palliative Care‘ (NHS Quality Improvement Scotland, 2004) | This report summarised the findings from all the local reports which were made following the assessment of services according to the clinical standards from 2002 (see above). It made a number of recommendations concerning the planning and delivery of services, workforce planning and evaluating existing services. These included:  
- The planning and delivery of specialist palliative care services should include all those involved to ensure that best use is made of resources. January 2004 |

---

8 Now part of NHS Quality Improvement Scotland (QIS).
<table>
<thead>
<tr>
<th>Report or Policy Initiative</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>- All patients who may use, or are currently using, specialist palliative care services should be assessed against a set of criteria drawn up jointly by those referring and those providing the service. Referrals should be routinely audited to ensure that the criteria are appropriate, and that referrals comply with these criteria.</td>
<td></td>
</tr>
<tr>
<td>- Audit of the different types of service provision and delivery linked to outcomes should be carried out to inform future service provision.</td>
<td></td>
</tr>
<tr>
<td>- Establish local MCNs, which are managerially and administratively supported.</td>
<td></td>
</tr>
<tr>
<td>'National Framework for Service Change in the NHS in Scotland: Report of the Care in Local Settings Action Team' (Scottish Executive, 2005a)</td>
<td>Discussed palliative care in the context of cancer. It acknowledged that many people will continue to die in hospital, and considered that there was great potential for developing and delivering specialist palliative care services in community hospitals. It also found that the delivery of palliative care within the home setting reduces hospitalisation during the last three months of life, preventing avoidable admissions close to death. In addition, it stated that the delivery of co-ordinated care, particularly palliative care, involving practice based teams, specialists and social care can reduce avoidable hospital admission. It made a number of recommendations, including that: Cancer Networks should collaborate with Community Health Partnerships (CHPs) to develop protocols for the delivery of palliative care in community settings, taking into account the NHS QIS standards; and, that, if they wish, patients and their carers should be supported to remain at home during the terminal phase of their illness. These themes were reiterated in the final Kerr Report, particularly the second volume, 'A Guide for the NHS in Scotland' (Scottish Executive, 2005b). The resulting NHS strategy 'Delivering for Health' (Scottish Executive, 2005c) also discusses palliative care in the context of community hospitals, but as with the Kerr Report promoted a model of care whereby people with long term conditions are cared for in the community where possible without hospitalisation, and with a shift from reactive episodic care to continuous support.</td>
</tr>
<tr>
<td>'The Future Care of Older People in Scotland' (Scottish Executive, 2006)</td>
<td>Discussed the value of palliative care but believed consideration should be given to additional investment in improving palliative care services in Scotland, utilising the experience of the End of Life Care Programme in England, and also called for the effectiveness of end of life care initiatives in Scotland to be evaluated.</td>
</tr>
<tr>
<td>'Palliative and end of life care in Scotland: A cohesive approach' (Scottish Partnership for Palliative Care (SPCC), 2007)</td>
<td>This was the report of a short-life working group created by the SPPC itself, which sought to identify a way of dealing with the variable number and quality of palliative care services across Scotland. It made recommendations that are more fully discussed in the main briefing.</td>
</tr>
<tr>
<td>'Better Health, Better Care' (Scottish Government, 2007)</td>
<td>Stated a commitment to the delivery of high quality palliative care to everyone in Scotland who needs it, on the basis of established principles of equity and personal dignity and of clinical need rather than diagnosis. Also made a commitment to publish an action plan during 2008 introducing a single, comprehensive approach to the provision of palliative care across Scotland.</td>
</tr>
<tr>
<td>'Review of palliative care services in Scotland' (Audit Scotland, 2008)</td>
<td>The last comprehensive report on palliative care services in Scotland. It found significant variation across Scotland in the availability of, and easy access to, specialist and high quality generalist palliative care palliative care services. In 2006/07, it found £59 million was spent on specialist palliative care, with almost half of this came from the voluntary sector. However, it could not say how much was spent on general palliative care. The specific findings from the report are discussed in the main part of the briefing.</td>
</tr>
<tr>
<td>Report or Policy Initiative</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>‘Living and Dying Well: A National Action Plan for Palliative Care and End of Life Care in Scotland’ (Scottish Government 2008a)</td>
<td>Taking into account of a number of reports, most notably those from SPPC and Audit Scotland, the key objective of the strategy is to ensure good quality palliative care is available to all who need it. It aims to address many of the issues raised by them. It considers several key areas including: assessment; planning and delivery; communication and coordination; and, education and workforce development. It is referred to throughout the main part of the briefing.</td>
</tr>
<tr>
<td>October 2008</td>
<td></td>
</tr>
<tr>
<td>‘Better Cancer Care, An Action Plan’ (Scottish Government, 2008b)</td>
<td>This reiterated the overall plans contained in the Scottish Government’s strategy Living and Dying Well, though added to this with further specific actions for cancer patients and their carers.</td>
</tr>
<tr>
<td>October 2008</td>
<td></td>
</tr>
<tr>
<td>‘1st Report 2009 (Session 3): Review of palliative care services in Scotland’ (Public Audit Committee, 2009)</td>
<td>This set out the Committee’s findings in relation to the report by the Audit Scotland report (above). It welcomed the Scottish Government’s strategy which was published after the Audit Scotland report. However, it also made a number of recommendations, which are discussed in the main part of the briefing.</td>
</tr>
<tr>
<td>January 2009</td>
<td></td>
</tr>
<tr>
<td>‘The Healthcare Quality Strategy for NHS Scotland’ (Scottish Government 2010a)</td>
<td>Following on from Better Health, Better Care (see above) the ‘Quality Strategy’ aims to create high quality, person-centered, equitable, clinically effective and safe healthcare services, and to be recognised as being world-leading in its approach. It announced the formation of a Quality Alliance, to report progress on a regular basis with reference to set of 12 high-level Quality Outcome Measures. One of these relates to palliative care – the percentage of last 12 months of life spent in preferred place of care. The document adds that the rationale behind this particular measure is that it will captures the outcomes of Living and Dying Well ie use of tools to identify and assess people with palliative and end of life care needs; delivery and coordination of care across care settings to address those needs by consistent access to, and review of, anticipatory care plans (including palliative care summary and DNACPR).</td>
</tr>
<tr>
<td>May 2010</td>
<td></td>
</tr>
<tr>
<td>‘Scottish Government Progress Report – September 2010: Review of palliative care services in Scotland’</td>
<td>This report was compiled to inform the Public Audit Committee of progress made in the implementation of Living and Dying Well, and also to report on progress in meeting the Committee’s specific recommendations in its report (see above). It stated there was widespread evidence that the approach taken in the strategy was progressing well and achieving results across the country. It is discussed in the main part of the briefing.</td>
</tr>
<tr>
<td>This report is contained in Public Audit Committee (2010)</td>
<td></td>
</tr>
</tbody>
</table>
## APPENDIX 3: NHS NATIONAL SERVICES SCOTLAND’S RESPONSE TO THE PROPOSED INDIVIDUAL INDICATORS

<table>
<thead>
<tr>
<th>No.</th>
<th>Indicator</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Number of persons who received palliative care services:</td>
<td>Requires ePCS to support</td>
</tr>
<tr>
<td></td>
<td>- with life-limiting condition</td>
<td>Requires clear definition of life-limiting condition (see response to Q.3)</td>
</tr>
<tr>
<td></td>
<td>- family members of such person</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>The average time it has taken for persons diagnosed as having a life-limiting condition to receive a first assessment of their palliative care needs and longest time it has taken any such person to receive such an assessment</td>
<td>Definitions will be required and are likely to develop over time.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assume that dates required for waiting times are in the ePCS.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assume this indicator is based only on patients on the palliative care register and to be on the register, the patient has not only been diagnosed with the defined list of life-limiting illnesses but also deemed to be suitable for palliative care. This requires clear definition for the indicator to be calculated.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Requires ePCS to be completed; however, note that ePCS documentation indicates the ePCS is dynamic and not all fields require to be completed. This may necessitate, identifying certain fields as mandatory.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The snapshot points in time and period of time being monitored must be clearly defined given dynamic nature of the data collected.</td>
</tr>
<tr>
<td>3</td>
<td>The average time it has taken for persons with a life-limiting condition whose palliative care needs have been assessed to receive palliative care for the first time and the longest time it has taken for any such person to receive such care.</td>
<td>See comments for indicator 2 above.</td>
</tr>
<tr>
<td>4</td>
<td>The number of persons with life-limiting condition who have received palliative care and community care assessment</td>
<td>Dependent on the ePCS being complete; may require mandatory fields to be specified.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Because the ePCS is dynamic, will require specifying timescale that indicator is measuring and the snapshot point in time the data are extracted.</td>
</tr>
<tr>
<td>5</td>
<td>The proportion of carers caring for a person with a life-limiting condition who have received a carer’s assessment</td>
<td>See comments for indicator 4</td>
</tr>
<tr>
<td>6</td>
<td>Place and cause of death of any person with a life-limiting condition who has received palliative care.</td>
<td>Current ISD report on place of death from cancer is not limited to patients who receive palliative care.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Definition of life-limiting condition requires clarity.</td>
</tr>
<tr>
<td>7</td>
<td>The number of persons with a life-limiting condition who have received palliative care and who have died at any place which has been recorded in their medical records as being their preferred place of death</td>
<td>Dependent on the ePCS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Because the ePCS is dynamic, will require specifying timescale that indicator is measuring and the snapshot point in time the data are extracted. Obviously, preferences can change over time.</td>
</tr>
<tr>
<td>No.</td>
<td>Indicator</td>
<td>Comment</td>
</tr>
<tr>
<td>-----</td>
<td>---------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>8</td>
<td>Number of persons with a life-limiting condition who have received palliative care and who have died at any place which has been recorded in their medical records as being their preferred place of death</td>
<td>▪ Dependent on the ePCS. Obviously, preferences can change over time.</td>
</tr>
</tbody>
</table>
| 9   | Information on the nature of the psychological, social and spiritual health and support given to persons with a life-limiting condition and to their family members | ▪ This requires to be defined more clearly. ‘Nature’ needs to be specified, for instance it could mean education and training for the carer.  
▪ Clarity on whether there are in fact two indicators: one for patient and second for family. For instance, a patient with no family should be excluded from any ‘family’ indicator. |
| 10  | The number of persons mentioned in each in 1 above who have completed a survey conducted by or on behalf of Scottish Ministers or the health boards on the standard of such care | ▪ Is there a need to distinguish between those who declined to respond and those who were offered the opportunity to participate in the survey? |
| 11  | The number of persons who received education and training relating to the provision of palliative care services | ▪ It is not clear if this relates to health care, social care, voluntary sector etc. staff and if these require to be separately recorded.  
▪ A denominator of all possible staff may be useful to establish ratio of those who have received training.  
▪ It is not clear the training / education relates to a specific period of time  
▪ It is not clear if this may relate to patients and family members |
Scottish Parliament Information Centre (SPICe) Briefings are compiled for the benefit of the Members of the Parliament and their personal staff. Authors are available to discuss the contents of these papers with MSPs and their staff who should contact Jude Payne on extension 85364 or email jude.payne@scottish.parliament.uk. Members of the public or external organisations may comment on this briefing by emailing us at spice@scottish.parliament.uk. However, researchers are unable to enter into personal discussion in relation to SPICe Briefing Papers. If you have any general questions about the work of the Parliament you can email the Parliament’s Public Information Service at sp.info@scottish.parliament.uk.

Every effort is made to ensure that the information contained in SPICe briefings is correct at the time of publication. Readers should be aware however that briefings are not necessarily updated or otherwise amended to reflect subsequent changes.