The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 1 December 2015

Session 4

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HEALTH AND SPORT COMMITTEE
33rd Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Professor Alison Britton (Law Society of Scotland)
Jamie Hepburn (Minister for Sport, Health Improvement and Mental Health)
Sally Johnson (NHS Blood and Transplant)
Lorna Marson (British Transplantation Society)
Anne McTaggart (Glasgow) (Lab)
Michael Russell (Argyll and Bute) (SNP) (Committee Substitute)
Liz Waite (NHS Blood and Transplant)
Irene Young (NHS Blood and Transplant)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 1 December 2015

[The Convener opened the meeting at 09:47]

Interests

The Convener (Duncan McNeil): Good morning and welcome to the 33rd meeting in 2015 of the Health and Sport Committee. I ask everyone to switch off mobile phones, as they often interfere with the sound system. People will, however, see members using tablet devices instead of hard copies for our committee papers.

We have received apologies from Bob Doris. I welcome Michael Russell, who is joining us as a substitute member. As this is Mr Russell's first appearance at the committee as a substitute member, I ask him to declare any relevant interests.

Michael Russell (Argyll and Bute) (SNP): Thank you, convener. The only one that I can think of is that I am a part-time professor in governance at the University of Glasgow.

The Convener: Thank you.

Decision on Taking Business in Private

09:48

The Convener: The next item on the agenda is day 2 of stage 2 consideration of the Carers (Scotland) Bill. I welcome the Minister for Sport, Health Improvement and Mental Health, who has the same team with him as he had last week. [*Interruption*.]

Sorry, but because I am anxious to get through all the business, I forgot to ask members whether they agree to take in private agenda item 5, on our approach paper on access to newly licensed medicines. Do members agree to take that item in private?

Members *indicated agreement.*

Carers (Scotland) Bill: Stage 2

09:49

The Convener: We now move to the Carers (Scotland) Bill.

Section 28—Duty to prepare local carer strategy

The Convener: Amendment 25, in the name of the minister, is grouped with amendments 26, 27, 30, 33 to 35, 37, 39 to 44 and 47 to 57.

The Minister for Sport, Health Improvement and Mental Health (Jamie Hepburn): This group of amendments concerns responsibility for the preparation of the local carer strategy. Health boards have a vital role in identifying and supporting carers. I agree with the Health and Sport Committee's recommendation that the Carers (Scotland) Bill should complement the new integrated health and social care arrangements. To that end, we will make provision so that all functions under the bill that relate to the delivery of services to adult carers will require to be delegated under integration schemes under the Public Bodies (Joint Working) (Scotland) Act 2014. For young carers, all functions are capable of being delegated to the local authority and the health board.

To further recognise the key role of health boards in identifying and supporting carers, I have lodged amendment 25, which amends section 28(1) of the bill so that the duty on local authorities to prepare a local carer strategy for each local authority area will be placed jointly on the local authority and the relevant health board.

There are a number of amendments that follow on from that key amendment. Amendment 47 amends section 28(5) to set out the definition of "relevant health board" in relation to a local authority. Amendments 48 and 49 make the existing duty on local authorities to have regard to the factors set out at paragraphs (a) to (e) of section 29 in preparing the local carer strategy a joint duty on local authorities and health boards. Amendments 50 to 57 are also consequential to amendment 25. They modify section 30, on publication and review of the local carer strategy, so that the duties on local authorities set out in that section are placed jointly on the local authority and the relevant health board.

I ask members to support the amendments in the group.

I move amendment 25.

The Convener: Thank you. No members have indicated that they wish to speak. Do you have anything to add, minister?

Jamie Hepburn: Indeed not.

Amendment 25 agreed to.

Amendments 26 to 38 moved—[Jamie Hepburn]—and agreed to.

The Convener: Amendment 82, in the name of Rhoda Grant, is grouped with amendments 104 to 106.

Rhoda Grant (Highlands and Islands) (Lab): This group of amendments concerns the local carer strategy. Amendment 82 ensures that the strategy looks at preventative support in order to decrease the number of carers who break down in their role. A good preventative strategy will also cut down the number of people who will require an assessment. It is really important to value the work that carers do and to support them to continue that work. The carer strategy must deal with that issue.

Amendments 104 to 106 deal with equality issues by ensuring that the strategy takes into account protected characteristics and considers how people in those groups can be supported in their caring role. The situation in which they find themselves and their ability to access services can be affected by language, culture and relationships. It is important that the strategy recognises those differences and makes sure that services are person centred and delivered in a way that is accessible to all who need them.

I move amendment 82.

Jamie Hepburn: I thank Rhoda Grant for lodging the amendments. I see the preventative approach as important: as the policy memorandum sets out, it is one of the key principles underpinning the bill, which contains provisions that aim to promote such an approach. For example—as I mentioned to the committee last week—we are removing the regular and substantial test for someone to be recognised as a carer, so that all carers will have access to an adult carer support plan or a young carer statement.

Enabling people to request an adult carer support plan or a young carer statement as soon as they become a carer, or offering one to adult carers and young carers as soon as they are identified, should mean that a plan can be put in place at an early stage. That should reduce the need to deal with crisis situations. Less critical support needs will also be considered as part of the adult carer support plan process or the young carer statement process. Nonetheless, prevention is important and I can see that there could be merit in local carer strategies setting out plans for supporting carers on a preventative basis, which is the main thrust of Ms Grant's amendment 82.

However, I think that we need to consider the amendment further. As it stands, there are questions about whether it would be possible for a local authority to "reduce" a carer's support needs once they have arisen, other than by providing them with support. There might also be a compliance issue with regard to the way in which the bill is drafted. I therefore ask Rhoda Grant to withdraw amendment 82 so that we can work together on a stage 3 amendment that achieves the aim of having local carer strategies that set out preventative plans without there being any unintended consequences.

I also consider it important that the provisions set out in the bill meet the needs of carers with one or more protected characteristics, but I believe that amendments 104 to 106 are not required to achieve that aim. Local authorities and health boards already have a general public sector equality duty under the Equality Act 2010, and it would be unnecessary and wasteful of local authorities' compliance resources to duplicate an existing legal duty. To the extent that amendment 104 might ask for more than the current duty in section 149 of the 2010 act, it could give rise to legislative competence concerns. If compliance needs to be addressed, the 2010 act already contains powers to do that.

As the statutory duty already exists, I ask Ms Grant not to move amendments 104 to 106 and to meet me to have further discussions about amendment 82.

Rhoda Grant: I am happy to meet the minister to discuss amendment 82 and will therefore seek to withdraw it.

However, I am concerned that the minister sees no need for amendments 104 to 106. When the committee took evidence, it was made quite clear to us that if such provisions were not in the bill the issues might be overlooked when the strategies were drawn up. Having listened to the minister's comments, I do not believe that he is willing to have further discussions on the matter, so I might well move those amendments when the time comes.

Amendment 82, by agreement, withdrawn.

Amendment 104 moved—[Rhoda Grant].

The Convener: The question is, that amendment 104 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For

Chisholm, Malcolm (Edinburgh Northern and Leith) (Lab)
Grant, Rhoda (Highlands and Islands) (Lab)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
Milne, Nanette (North East Scotland) (Con)

Against

Keir, Colin (Edinburgh Western) (SNP)
Lyle, Richard (Central Scotland) (SNP)
MacKenzie, Mike (Highlands and Islands) (SNP)
Robertson, Dennis (Aberdeenshire West) (SNP)
Russell, Michael (Argyll and Bute) (SNP)

The Convener: The result of the division is: For 4, Against 5, Abstentions 0.

Amendment 104 disagreed to.

Amendment 83 not moved.

Amendments 39 to 42 moved—[Jamie Hepburn]—and agreed to.

The Convener: Amendment 84, in the name of Rhoda Grant, is grouped with amendment 85.

Rhoda Grant: Amendment 84 seeks to ensure that colleges and universities are consulted in the development of carer strategies. Schools are already included in the bill as part of the local authority, but young carers are also concerned about the support that they receive from colleges and universities, and amendments 84 and 85 will ensure that those institutions look at how they support carers and allow them to access further and higher education.

I move amendment 84.

10:00

Jamie Hepburn: I am not entirely clear that amendments 84 and 85 are necessary. If they are seeking to ensure that the needs of young carers approaching the transition to adult carers are taken into account when the local carer strategy is prepared, I advise Rhoda Grant that the bill already contains provisions to that effect. The provision in section 28(4)(a) provides that local authorities and health boards must involve whichever carer representative bodies they consider appropriate in the preparation of their local carer strategy, while section 28(4)(b) provides that they must take such steps as they consider appropriate to involve carers. The list is not exclusive. If a local authority and a health board believe that it is necessary to consult any educational body in the area, they can choose to do so. I am therefore not convinced that it is necessary to legislate for that.

On that basis, I ask the member to withdraw amendment 84 and not to move amendment 85.

Rhoda Grant: I do not think that colleges and universities are seen as bodies that represent carers. There is a real issue about young people accessing education. I think that the bill will deal with the issues in schools, but there are also issues to deal with in colleges and universities. Indeed, young carers are often penalised for not attending as often as they should, and quite often they do not get the support that they should get from colleges and universities.

I believe that the bill requires to be amended in this way, so I press amendment 84.

The Convener: The question is, that amendment 84 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For

Chisholm, Malcolm (Edinburgh Northern and Leith) (Lab)
Grant, Rhoda (Highlands and Islands) (Lab)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
Milne, Nanette (North East Scotland) (Con)

Against

Keir, Colin (Edinburgh Western) (SNP)
Lyle, Richard (Central Scotland) (SNP)
MacKenzie, Mike (Highlands and Islands) (SNP)
Robertson, Dennis (Aberdeenshire West) (SNP)
Russell, Michael (Argyll and Bute) (SNP)

The Convener: The result of the division is: For 4, Against 5, Abstentions 0.

Amendment 84 disagreed to.

Amendments 43 to 46 moved—[Jamie Hepburn]—and agreed to.

Amendment 105 not moved.

Amendment 47 moved—[Jamie Hepburn]—and agreed to.

Amendments 85 and 106 not moved.

Section 28, as amended, agreed to.

Section 29—Preparation of local carer strategy

Amendments 48 and 49 moved—[Jamie Hepburn]—and agreed to.

Section 29, as amended, agreed to.

Section 30—Publication and review of local carer strategy

Amendments 50 to 57 moved—[Jamie Hepburn]—and agreed to.

Section 30, as amended, agreed to.

Section 31—Information and advice service for carers

The Convener: Amendment 58, in the name of the minister, is in a group on its own.

Jamie Hepburn: Third sector organisations and carers have raised a concern that the bill as currently drafted may be interpreted as imposing a requirement on local authorities to establish a new information and advice service where such a service, or part of it, is already provided by organisations other than the local authority. Members will recall that the committee picked up on that issue during its consideration of the bill at stage 1.

Amendment 58 will add wording to section 31(1) to clarify the policy intention. Although local authorities will have a duty to establish and maintain an information and advice service, it is not envisaged that that duty will require local authorities themselves to provide every aspect of the information and advice that is required to be made available under section 31(2); rather, it is expected that local authorities will understand, co-ordinate and make effective use of other statutory or voluntary sector resources that can and do provide information and advice to carers within their respective areas.

I want the existing information and advice services that are provided so expertly by organisations such as carers centres, young carers projects and health boards to remain in place. I would expect each local authority, in establishing and maintaining an information and advice service or in ensuring the establishment and maintenance of such a service, to make the best possible use of what already exists.

Amendment 58 will make clear that where sources of information and advice for carers are already available within the local authority area, there is no requirement for the authority to create an additional information and advice service. That will also be made clear in the guidance that will be issued to local authorities about information and advice services.

I move amendment 58.

Amendment 58 agreed to.

Amendment 59 moved—[Jamie Hepburn]—and agreed to.

The Convener: Amendment 86, in the name of Rhoda Grant, is grouped with amendment 88.

Rhoda Grant: Amendment 88 proposes a carers charter. I am aware that work to draw up a charter is on-going and that carers groups are keen that the charter be enshrined in legislation. Amendment 88 does not prescribe what should be in the charter, but it ensures that carers will be involved in drawing it up. It is important that when the charter is in place carers are aware of it and the rights that it will enshrine. Consequently, amendment 86 places a duty on advice and information services to make carers aware of the charter and its content.

I move amendment 86.

Jamie Hepburn: As Ms Grant alluded to, a carers' rights charter is not a new concept and such a charter is under development, although it has been somewhat delayed. The charter arose out of the carers strategy and was intended for adult carers only. Although a young carers' rights charter was not required under the strategy, we commissioned separate work on such a strategy. That work is also on-going and we expect to receive the latest draft of a young carers' rights charter from the Scottish young carers services alliance later this month.

The charter that is currently under development will include expectations—what carers can expect—which will be derived from guidance, and it will consolidate existing rights. The charter that is envisaged in amendment 88 is a bit narrower in scope than the charter that we are preparing.

There is not necessarily a burning requirement to have the charter set out in legalisation. I am happy to support Ms Grant's amendments 86 and 88, but in doing so I say that her proposals will require some finessing at stage 3.

I will indicate to the committee some of the areas that may require further amendment. Amendment 88 refers to "any other enactment", which would include United Kingdom legislation, but the Scottish Government may not be in the best position to provide up-to-date information on such legislation. It is important to be clear that the charter will collate and set out rights that have been conferred elsewhere and that it should not create new rights itself, because that would mean that there would not be proper parliamentary scrutiny if any future Government sought to bring forward new rights for carers in the charter; it would not be right to establish new rights in such a document on that basis.

Having set out the key areas that will require further attention at stage 3, I reiterate that I am happy to support Rhoda Grant's amendments that seek to put a carers' rights charter in statute.

The Convener: I ask Rhoda Grant whether she would like to wind up and whether she will press or seek to withdraw amendment 86.

Rhoda Grant: I will press amendment 86 and quit while I am ahead.

Amendment 86 agreed to.

Amendment 60 moved—[Jamie Hepburn]—and agreed to.

The Convener: Amendment 87, in the name of Rhoda Grant, is in a group on its own.

Rhoda Grant: Amendment 87 would place a duty on advice and information services to make carers aware of bereavement support. Too often, carers feel abandoned at a time of bereavement. They are often given little time to find their feet and adapt to their new circumstances. There can be quite intensive intervention in the final days of life;

a carer will be used to having people in and out of the house at that time but might find that all that suddenly stops with bereavement, which means that they can become very isolated. Carers have quite often given up work and neglected friendships in order to carry out their caring role, so they need to be supported through the transition.

I move amendment 87.

Nanette Milne (North East Scotland) (Con): I support Rhoda Grant's amendment. I have heard from Marie Curie that a significant number of people feel totally bereft, quite apart from their proper bereavement, once the person whom they are caring for has died. It is very important to look after those people at what is a time of pretty great need for them.

Jamie Hepburn: I recognise that, as Nanette Milne has said, it can be difficult—even devastating—when a carer's caring role comes to an end. I am aware that some local carers centres continue to support carers after their caring role ends, which a number of members spoke about during the stage 1 debate. There is provision for carers when their caring role ends. Following a death, bereavement care is provided to relatives and carers throughout Scotland in ways that are responsive to their needs and which reflect their spiritual, religious and cultural requirements. The information pack, "When someone has died—information for you", which was developed to help people through the first few days of a bereavement, is widely used across the national health service in Scotland, and the bereavement zone on the NHS inform website offers a lot of practical advice on what to do after a death and on coping with grief. Both those resources offer specific advice for children and young people, which young carers may find particularly helpful. Information on how to access local services can be found on NHS board websites or obtained directly from NHS staff, and national services such as the breathing space service and support from Cruse Bereavement Care Scotland are available for those who need someone to talk to.

The caring role may also come to an end for a reason other than the death of the cared-for person. The cared-for person may, for instance, have been admitted to a care home, which may be difficult for the carer. The bill is focused on providing carers with access to support in order to sustain their caring role. The person-centred outcomes approach will ensure that carers are supported at the right time. As part of that it is critical to review outcomes to ensure the continued relevance of support services for carers. That is important when carers are caring for someone who is coming to the end of their life. The information and advice service provided by each local authority must provide information and advice about health and wellbeing, including counselling services for carers, which we envisage might include bereavement counselling. Despite the good range of services that exist, I recognise that carers might face particular issues and challenges, such as coming to terms with not having a caring role for their loved one or trying to get back into work after not being in employment.

However, Rhoda Grant's amendment, is very wide in scope. It looks as if it covers the provision of information and advice on bereavement support for carers when people other than the cared-for person dies, which I do not think is necessarily the intention behind the amendment. I would like to work with Rhoda Grant so that she can lodge an alternative amendment at stage 3. On that basis, I ask her to withdraw amendment 87 so that we can discuss the matter and get it right for stage 3.

Rhoda Grant: It is really important that carers get bereavement support, which perhaps should form part of the assessment of how they will be supported when their caring role ends. I take on board what the minister said about the breadth of the amendment. I do not want it to be that wide; I want it to provide for support when somebody's caring role ends. With that in mind, I will have further discussions with the minister and will lodge an alternative amendment at stage 3.

Amendment 87, by agreement, withdrawn.

Amendment 61 moved—[Jamie Hepburn]—and agreed to.

Section 31, as amended, agreed to.

Section 32 agreed to.

After section 32

Amendment 88 moved—[Rhoda Grant]—and agreed to.

10:15

The Convener: Amendment 107, in the name of Rhoda Grant, is in a group on its own.

Rhoda Grant: Amendment 107 would ensure that the NHS identifies carers and would ensure that their health needs are attended to. Often, carers, especially young carers, have general practitioners and healthcare staff coming and going from their home but are never asked how they are coping and whether they are getting the support that they require. NHS staff are ideally placed to identify carers of every age and to refer them to support services. There are instances when that has happened and it has proved a godsend to the carers involved. However, often it does not happen and carers feel ignored and abandoned, without help or support.

I move amendment 107.

Jamie Hepburn: I understand and fully appreciate the need to promote carers' health and wellbeing. All the provisions in the bill are designed to ensure that carers can continue to care, if they wish to do so, in good health. The identification of carers' personal outcomes within the context of the adult carer support plan and the young carer statement is central to that.

The focus of the specific integration national health and wellbeing outcome relating to carers is on ensuring that carers are supported to look after their own health and wellbeing and reduce any negative impact of their caring role on their health and wellbeing.

I would like to take a little time to outline the new way forward for the GP contract, which is relevant to supporting carers. The Scottish Government has set a direction of travel around the future arrangements for the GP contract in Scotland, which is designed to reduce bureaucracy and to free up GP time for face-to-face contact with patients. We will be moving towards a more integrated GP contract that supports the GP's role in the wider community.

As I have said, the whole purpose of the bill is to support carers' health and wellbeing. The new way ahead for the GP contract will enable GPs to have more contact with carers, which will enable carers to ask for health checks when appropriate. Carers can also be encouraged, through the adult carer support plan and the young carer statement, to visit their GP to maintain their own health and wellbeing.

The national review of out-of-hours primary care services led by Sir Lewis Ritchie, which reported yesterday, recommends a multidisciplinary team-based approach to the delivery of urgent care services. That proposed new model of care will help to mitigate issues such as the recruitment and retention of GPs. It will also encourage health and social care staff to work together better. Having a person-centred and joined-up approach will help to improve the management of staff availability, especially during peak holiday times, the consistency of the service and the public's expectations of it. All those crucial wider developments will support carers' health and wellbeing.

Under future arrangements, GPs will have a focus on supporting the planning of services locally through clusters of GP practices coming together to plan and develop services for the community. The work to develop and support GP clusters will be a key strand of work for the health and social care partnerships and integration joint boards. Crucially, carers are to be represented on integration joint boards and, together with GPs, they will be able to influence the work to plan and develop GP services for the local community.

The new direction of travel for GPs will free up GP time to deal with patients with complex needs, including time to support their carers. I propose to write to NHS boards to encourage them to continue to identify carers and to support them in health settings. Those health settings include GP practices, but other health settings such as hospitals and community pharmacists are just as important in supporting carers' health and wellbeing.

There are a number of provisions in the bill to support carer identification more generally. A key one is that each local authority and relevant health board must prepare a local carer strategy that sets out their plans for identifying carers in the area and obtaining information about the care that they provide or intend to provide. That will support carer identification by GPs.

In light of all that I have set out, I ask Rhoda Grant to withdraw amendment 107.

Rhoda Grant: Although I welcome everything that the minister said, he set out only small changes. There is a culture out there that does not recognise carers. Some carers do not recognise themselves as carers and do not ask for help, because they are so taken up with their caring role that they feel that they need to continue it.

Health professionals are in a great place to identify carers, but they often do not do so. Some years ago, I wrote to GPs to ask how many young carers they had in their practices. I was surprised by the number of responses that came back saying that they had none. We know that about 25 per cent of young people are carers, and I do not think that that figure has changed hugely between then and now.

I will press amendment 107, because it is important that we make it a duty for everybody to identify and support young carers, especially those who are best placed to identify them.

The Convener: The question is, that amendment 107 be agreed to. Are we agreed?

Members: No.

The Convener: There will be a division.

For

Chisholm, Malcolm (Edinburgh Northern and Leith) (Lab)
Grant, Rhoda (Highlands and Islands) (Lab)
McNeil, Duncan (Greenock and Inverclyde) (Lab)
Milne, Nanette (North East Scotland) (Con)

Against

Keir, Colin (Edinburgh Western) (SNP)
Lyle, Richard (Central Scotland) (SNP)
MacKenzie, Mike (Highlands and Islands) (SNP)
Robertson, Dennis (Aberdeenshire West) (SNP)
Russell, Michael (Argyll and Bute) (SNP)

The Convener: The result of the division is: For 4, Against 5, Abstentions 0.

Amendment 107 disagreed to.

Section 33 agreed to.

After section 33

The Convener: Amendment 62, in the name of the minister, is in a group on its own.

Jamie Hepburn: Section 33 confers powers on the Scottish ministers to issue guidance to local authorities in respect of their functions under the bill. It also allows the Scottish ministers to issue directions to local authorities on the manner in which they are to exercise their functions. There is currently no equivalent provision in relation to the functions conferred by the bill on health boards and directing authorities of schools.

Amendment 62 will address that. It will allow the Scottish ministers to issue guidance and directions to health boards and directing authorities in respect of their functions under the bill, for example in respect of the preparation of young carer statements by health boards for young carers who are pre-school children. The provision will require health boards and directing authorities to have regard to any such guidance and directions when performing their functions under the bill.

I move amendment 62.

Amendment 62 agreed to.

Sections 34 and 35 agreed to.

Section 36—Interpretation

Amendments 63 and 64 moved—[Jamie Hepburn]—and agreed to.

Amendment 89 not moved.

Section 36, as amended, agreed to.

Section 37—Regulations

The Convener: Amendment 65, in the name of the minister, is in a group on its own.

Jamie Hepburn: The power in section 1(3) and the regulations that will be made under it are intended to give effect to the policy that kinship care agreements under the Looked After Children (Scotland) Regulations 2009 are not to be regarded as contracts under the bill. The intention is also to put it beyond doubt that similar agreements that exist between foster carers and local authorities are to be regarded as contracts for purposes of the bill. Section 1(3)(b) is intended to make provision for those people who in policy terms are referred to as “mixed carers”. Mixed carers are carers who undertake both unpaid care and paid care for the same family member.

In its letter to the Scottish Government on 31 March 2015, the Delegated Powers and Law Reform Committee asked for further justification as to the choice of the negative procedure for the exercise of the power in section 1(3) and why the affirmative procedure was not considered to be more appropriate for the power. I have considered that committee’s concern that the power in section 1(3) could potentially expand or restrict the reach of the bill’s provisions on providing support to carers, depending on the manner in which it is exercised. It is certainly the case that unpaid caring is a complex area that could become more so in the future. For example, it is possible that as use of the Social Care (Self-directed Support) (Scotland) Act 2013, which is in the early stages of implementation, becomes more prevalent, further types of mixed carer may emerge.

In light of the Delegated Powers and Law Reform Committee’s concerns, I have lodged amendment 65 to make the power at section 1(3) subject to the affirmative procedure.

I move amendment 65.

Amendment 65 agreed to.

Amendments 66 and 67 moved—[Jamie Hepburn]—and agreed to.

Amendment 90 not moved.

Amendment 68 moved—[Jamie Hepburn]—and agreed to.

Amendment 91 not moved.

Section 37, as amended, agreed to.

Sections 38 and 39 agreed to.

Schedule—Consequential modifications

Amendment 69 moved—[Jamie Hepburn]—and agreed to.

Schedule, as amended, agreed to.

Sections 40 and 41 agreed to.

Long title agreed to.

The Convener: That ends stage 2 consideration of the bill. Members should note that the bill will now be reprinted as amended. The Parliament has not yet determined when stage 3 will take place, but members can lodge stage 3 amendments with the legislation team at any time. Members will be informed of the deadline for amendments once it has been determined.

10:27

Meeting suspended.

10:45

On resuming—

Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill: Stage 1

The Convener: Our next item of business is our third oral evidence session on the Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. I welcome Anne McTaggart, the member in charge of the bill, who will have the opportunity to ask questions later.

This morning we have with us Sally Johnson, director of organ donation and transplantation, and Liz Waite and Irene Young, specialist nurses in organ donation, NHS Blood and Transplant; Professor Alison Britton, convener of the Law Society of Scotland's health and medical law committee; and Lorna Marson, vice-president, British Transplantation Society. I welcome you all.

I do not expect anyone to make an opening statement, so we will go directly to questions.

Richard Lyle (Central Scotland) (SNP): Good morning, ladies. I will direct my question to Sally Johnson, but Liz Waite and Irene Young may want to come in, and I welcome comments from the other witnesses.

On a recent visit to Spain, we found out that there was a specialist doctor dealing with families based in the hospital that we visited in Madrid. It was put to us that that was one of the reasons why Spain's rates of organ donation are superior to Great Britain's. I do not want to take away from the work that you are doing, but what could be done to improve the rates in Great Britain? Would you advocate doing things in the way they are done in Spain? Could you explain what exactly happens in hospital when someone dies? Does the acute doctor speak to the family after the death and then the specialist nurses are brought in or does the specialist nurse come in first?

Sally Johnson (NHS Blood and Transplant): That is quite a wide-ranging question. I will endeavour to answer it, but I may call on my colleagues to give you a bit more discussion about what happens, because they are on the front line.

We now have a very similar system to that in Spain. The difference is that we have a clinical lead for organ donation in every hospital in the UK, who is supported by an embedded specialist nurse. The specialist nurse is someone such as Irene Young, who is dedicated to working with one or more hospitals and who supports the hospital development end of things, so that there are policies and procedures in place to identify and refer organ donors, where that is possible, and ensure that their family is approached after the specialist nurse has been called in.

The best practice, which is mostly followed—although not always, because such things are complicated—is that the doctor would speak to the family and ensure that they understand that their relative is either dead or irretrievably dying and unable to be helped. Once the family has understood that, the specialist nurse would normally come in and provide support to help them to reach a decision about organ donation.

The system is not radically different from that in Spain, although we run an on-call rota, so it is not always the same nurse in every hospital. However, we provide a 24/7 service and there is always a nurse available to talk to a family when required. From that point of view, much of what has been done in Spain has also been done in the UK, following the implementation of the organ donor task force recommendations. That is why donor numbers in the UK have increased by more than 60 per cent in the past six or seven years.

There are two things in Spain worth noting. First, the model of end-of-life care in Spain is very different from the one in the UK. There are many more intensive care beds in Spain and, as a result, more people in Spain die of brain death after spending longer in hospital. Those people's families are approached for organ donation. We do not have as many potential donors as Spain appears to have, which is one reason why our numbers are lower. There is also the issue of consent.

There are two ways in which a person can die and become an organ donor. Someone can be brain dead or brain-stem dead—people who are ventilated, following a serious brain injury. Normally there is quite a lot of time to talk to the families of such patients. However, compared with Spain, there are limited numbers of patients who die in that way in the UK. As a consequence, we have developed a world-class donation after circulatory death service, which relates to people who die in the way we are all familiar with from watching actors die on television. Circulatory death is a slightly different prospect and, in those circumstances, the person is dying and further treatment is futile. In those cases, we approach the family and seek agreement to proceed with organ donation. If the family says yes, we call a retrieval team, which must wait for the person to die and then retrieve the organs. Predicting death is extremely difficult and patients do not always die in a timescale that means that their organs are usable. Therefore, the number of people who go on to become donors from that pool of potential donors is much lower.

Our consent rates for donation after circulatory death are probably some of the best in the world. We have a very wide field of donors and a rate of 50 per cent or so is quite good for that group. We have a lower rate of consent for donors after brain death, although it is rising. In October, the UK consent rate was 69.5 per cent, which suggests that we are moving towards world-class levels. That is a donor rate of 26 people per million of population. That is in line with where we are going with the UK-wide strategy and the Scottish plan for implementing the strategy.

There are a lot of similarities between the processes in the UK and Spain, but there are some differences in the approach to end-of-life care and the potential pool of donors. People often do not realise that the pool of potential donors is tiny. Each year, only about 5,000 people across the UK die in circumstances in which they can become organ donors, even though 500,000 people die each year. That is part of our challenge.

Richard Lyle: One of the things that struck me on the visit to Spain was the fact that the percentage of British expatriates living in Spain who donate organs is higher than the rate for people living in Great Britain. Do we encourage or educate people to say that their organs can go on to save someone's life?

In the past couple of years, my mother-in-law and father-in-law both died, and no one approached us to ask whether we wished to donate their organs. I did not think about it at that time—the bill has made me think about it. I say this with the greatest respect, but do we actually approach families on the basis that we are asking them to donate the organs to save someone else's life?

Sally Johnson: I am pretty confident that in about 90 per cent of cases in Scotland, if someone can be a donor after brain death, that potential will be identified and referred to our service. It is lower in respect of donation after circulatory death—that is a more complicated situation in which to recognise that donation is possible. I suspect that the reason why you were not approached was that your relatives were not able to be donors. We do not approach people when they are not able to be donors.

Scotland has had a long and excellently sustained education programme in schools. It has had excellent campaigns that have increased the number of people on the organ donor register to over 40 per cent in some parts of Scotland. Spain does not have an organ donor register, interestingly—it relies solely on family conversations. From my understanding of the situation in Spain, there is often more time.

If people have not thought about the issue previously, it is very difficult to get them to think about it and to reach a conclusion that is positive when they are shocked and grieving and the issue is coming to them absolutely new. That is why there has been such a focus on trying to get people to have chat about organ donation while they are alive, so that their family and friends know what they would want when they are dead. The reality is that, whatever system you have, it is always helpful if people go into that conversation knowing what their relative's wishes were.

The Convener: There is not always a correlation between the number of people who have signed up and donation rates. Sweden has very high rates of people with awareness who sign up to donate, but that does not equal a higher rate of donation.

Sally Johnson: There is no magic bullet. You have got to get lots of stuff lined up—that is the point.

The Convener: I was just responding to some of your narrative there. I think that we both agree that those things do not always equate to an increase. The Spanish focus is on that important conversation at the point at which a donor can be identified and there is an outcome to be sought. The important conversation is at that time of death, not when we all decide to sign up on a Saturday night over a Chinese meal or something. We will come to some of that later, maybe, in relation to legal requirements or whatever.

Lorna Marson (British Transplantation Society): I am a transplant surgeon as well as being vice-president of the British Transplantation Society. That is just to put whatever I say in context.

Sally Johnson has raised two points that I think are worth reiterating. One is about the provision of intensive care unit beds. That is a challenge for us in relation to organ donation. While there is pressure on intensive care unit beds, it is hard to find the length of time that is required to ensure that those conversations can be had without any sense of urgency, and to allow the relatives to come to terms with what has happened to their loved one. The care of those relatives could be improved with improved provision of intensive care unit beds.

The second point that I want to emphasise is the positive aspects of the publicity campaigns that have been run in Scotland. You are right that the important conversations take place at a tragic time, but one can envisage that it would be much easier for a relative to make the decision for organ donation if they knew that that was the wish of the person who has just died—if they had already had that conversation. The publicity campaigns are very important because they encourage people to have that wee chat.

Liz Waite (NHS Blood and Transplant): I support what Lorna Marson and Sally Johnson have said. If there is the potential for donation in either the intensive care unit or the emergency department, we are contacted. We will be having that conversation with the family if there is the potential for donation.

The Convener: We heard last week that there are some barriers. If we had more intensive care unit beds, would we have more donations?

11:00

Sally Johnson: Our intensive care colleagues would probably say that we would be able to have more organ donors if we had more intensive care beds. I am trying to recall the exact figures. We have about 10 such beds per million of population in the UK, whereas Spain has about 23 such beds per million of population. The gap is quite big.

The Convener: So the focus is on intensive care units, where such conversations are more likely to take place.

Sally Johnson: Yes.

The Convener: A question follows from that. Your submission said that the bill could lead to an additional 70 or so transplants.

Sally Johnson: My statistics department has gone through quite a complicated assessment. The figures depend on a range of things, such as ensuring that every donor is referred after circulatory death and achieving consent rates that are broadly similar to the best in the world. The figure of 70 is at the upper end of what we could expect.

The Convener: I will continue with the issue of the capacity of intensive care units and capacity in the workforce. Does your evidence suggest that, if we generated the additional donors, that would test the existing capacity?

Sally Johnson: That is true. We would have to work this through carefully. We have limited numbers of staff who are on call at any one time and they have to cover quite large distances, as members will appreciate. At times, we might have to call in people who were not normally on call, which would put a strain on the system. We might need additional staff to cover that.

The Convener: So to cope with even an additional 70 donors, we would have to increase staff levels. I am getting at the point that this is not a silver bullet and that a whole lot of issues are involved.

Sally Johnson: In Scotland, we have about 100 donors a year, so an extra 70 would be quite a big hike. That would be quite a lot for the team to cope with.

The Convener: You talk about a lack of capacity to deal with an increase. With the capacity now, are we coping?

Sally Johnson: Yes.

The Convener: We are coping with capacity now, but we could do more if we had more intensive care beds and more staff to deal with any subsequent rise in the number of people who were prepared to donate.

Sally Johnson: That could be the case, but we should be slightly cautious about assuming that having more intensive care beds would automatically bring extra donors. Having more beds would probably give us more capacity to admit people from accident and emergency departments into intensive care but, in reality, if we have more intensive care beds, they are mostly filled by more people who need intensive care.

The Convener: I am aware of displacement; we are talking about saving people’s lives as well.

We heard last week from clinicians that some clinicians are more enthusiastic than others are about donation, which might be part of the problem. Some see their priority in their job as being to save a person rather than to bring about an organ donation. Are the priorities an issue?

You say that you have clinical leads for organ donation. Spain has a division between the clinicians. The clinicians who actively fight to save a person will decide when that person cannot be saved and go through the normal procedures to agree that the person is brain dead, and then they will hand over the case to a different team.

Sally Johnson: In the NHS, people such as Liz Waite and Irene Young will be part of the team that a case is handed to.

The Convener: If we agree that some consultants are more keen than others are on organ donation, we have to recognise the hierarchy—whether we like it or not—that affects how much influence nurses have on the process as against that of consultants.

Lorna Marson: There are two different areas of work. One is the acute situation, if you like, where a potential donor is in an intensive care unit. The other area is the groundwork that goes on to promote organ donation, as part of the organ donation task force’s outcome on work with the Intensive Care Society and intensive care units across the UK.

You are right: arguably, it is a conflict for many intensivists, as they work so hard to save people’s lives. Historically, even some clinicians have struggled with changing their viewpoint to consider organ donation. A huge amount of work is done. As has already been described, NHSBT has set up the clinical leads for organ donation, who are consultants who usually have some input into intensive care, either as anaesthetists or as intensive care consultants. They understand the workings of intensive care units and they are our ambassadors at consultant level for organ donation across the UK.

There is a huge amount of background work with all parts of that team to encourage and promote organ donation. That has been a key part of the work of the last seven years.

The Convener: Those people are not there 24 hours a day, and nor are the nurses.

Lorna Marson: If they have done the work on the ground to promote organ donation—if they have worked with their colleagues to encourage them to believe in organ donation—that will continue to have an effect even if they are not there. That is why we have seen an 82 per cent increase in the number of organ donors since the—

The Convener: So we do not lose out on organ donations because the consultant or the nurses are not there. Irene Young is desperate to get in and say that that is right.

Irene Young (NHS Blood and Transplant): My role is to work with the clinical lead in my hospital and to audit deaths in the unit as well as to educate. Every day, I go into the unit to see whether there is somebody who could become a potential donor on that day. Because of the work that I do with my clinical lead, if someone slips through the net, my clinical lead will challenge the relevant consultant at the weekly senior medical staff meeting.

In a way, we have almost had a drip-feed system. As medical staff have become more comfortable with our role, they have become more comfortable with discussing potential donors with us. They see us going into the unit every day, and if they “forget”—I put that in inverted commas—to refer a potential donor to us, either I or my clinical lead will pick that up on our daily visits to or weekly meetings in the unit. That safety net is replicated in all hospitals in Scotland.

Liz Waite: It is also important to say that, as a result of the work that we have done in hospitals, a lot of our referrals for donation come out of hours. As Lorna Marson and Sally Johnson have alluded to, a huge amount of work has gone on with the clinical leads and with us as a service, so people know how to refer to and get in touch with us. We run a 24/7 on-call service, so we are able to go in out of hours.

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): Quite a lot of the witnesses’ written evidence was about the role of proxies and the authorised investigating person. Those areas have come up in previous evidence, so I am quite interested in them. I am also interested in another issue that is reflected in some of the evidence, which is how what is proposed in the bill compares with what already happens in other parts of the UK.

I will start with proxies. There is an issue with the number. Three are proposed, but I believe that there are two in other parts of the UK, so I imagine that there is no issue of principle with the bill. Is the role of the proxy in other parts of the UK similar to or different from the role that is envisaged under the bill?

Sally Johnson: It is very similar. People are perhaps not aware that, at the moment, 15 people are registered as proxies across the UK, despite the fact that it has been possible to be a proxy for some time now. It is not easy to register. Witnessed evidence that somebody wants to be a proxy has to be provided; then again, people should not be able to just send somebody’s details off to NHSBT to put them on a register without their authorisation. We need to ensure that the processes to authorise people are right.

I do not think that my specialist nurses have ever dealt with a proxy, because they are so rare.

The Convener: Do you just deal directly with the families?

Liz Waite: Yes.

Irene Young: Yes.

Malcolm Chisholm: It may not have been used, for whatever reason, but in principle is the role similar? One of the issues with the bill is about the relationship between proxies and families, but could such situations arise in other parts of the UK, even though they tend not to because there are no proxies?

Sally Johnson: They could, yes. There is always a challenge when you have different people with different roles trying to agree on the same thing. The nurses would probably say that it is hard enough sometimes to get family members to agree without throwing anything else into the mix.

Professor Alison Britton (Law Society of Scotland): We said in our submission that the appointment of a proxy seems to be an accepted form of medical decision making, and we would support the appointment of a proxy. However, we are concerned that the bill provides that the proxy does not need to be informed of their appointment. I find it quite incomprehensible that an individual might not even know that they are a proxy, given that it is such an intimate moment, such an important decision and such a responsibility, particularly when timing may be of the essence in making the decision.

Malcolm Chisholm: That is interesting—presumably an amendment could be proposed. However, in principle you support the idea, and you say that appointing proxies is established practice across the UK. It is useful to know that, because in their evidence on the bill, some people have suggested that it is a new idea and have asked why it is being introduced.

Professor Britton: In other forms of decision making—for example, if the patient becomes incapacitated—it would not be unusual to look for a proxy or for somebody to act as an advocate. However, the emphasis in the bill is on a three-tiered, cascading proxy process, and we would not want to see the family marginalised in any way. It seems to us that the role of the family is absolutely fundamental, and if they are the ones who are sitting round the bedside, surely they are the ones to have the conversation with, rather than taking the time to find a proxy who may or may not know that they have been appointed.

Malcolm Chisholm: Does Lorna Marson also want to comment?

Lorna Marson: I would just reiterate what Professor Britton has said. I am not clear what added value a proxy would bring in the circumstances. We have to understand that there is an urgency to the decision-making process—some families already withdraw authorisation for organ donation because of the length of time that that takes. Also, as professionals—in particular, as specialist nurses—we are reliant on the family so that we can gain as much information about the donor as possible, including medical and behavioural information, in order to assess the safety of organs for transplantation. Elsewhere in the country, there have been recent high-profile cases of transmission to recipients of donor disease, and we are reliant on the families for a lot of information. Anything that marginalises those families and takes them away from making the decision has the potential to be detrimental to the process and to the safety of those organs for transplantation.

Malcolm Chisholm: Thank you for those answers.

I move on to the role of the authorised investigating person. My understanding is that there is such a role in Wales. Do you see what the bill proposes as different from the role in Wales?

Sally Johnson: There is no such role in Wales. In Wales, the specialist nurse approaches the family. I will try to explain the differences between the two legal systems. Currently, anybody in the UK can join the organ donor register, record a refusal to donate or appoint a representative or proxy, except in Scotland. In the UK—except in Wales, as of today—if you have not done one of those three things, it is your family’s responsibility to make the organ donation decision on your behalf. In Wales, if you have done none of those things, your inaction is deemed to be consent, and the expectation is that, unless the family has strong evidence that you did not wish to be a donor, you will go on to donate.

From what I have been able to understand from reading the bill, the authorised investigating person needs to apply a series of cascading tests to determine whether there is any reason why the person should not be an organ donor, and then they authorise the donation. That role does not appear to be entirely consistent with supporting the family through the process; it appears to be an additional role. I am unclear as to how that would work with the other people involved in the process, how the timing would work and what that might mean for a family’s experience of organ donation.

11:15

Malcolm Chisholm: The intention is, I think, that the AIP would not be an additional role. The member in charge of the bill may ask you questions about that. I drew the analogy with Wales because the intention seems to be that the role of the specialist nurse will change. Is it not the case that the new legislation has led to a change in the role of the specialist nurse?

Sally Johnson: The specialist nurse has a more presumptive approach when they talk to the family, but it is still about working it through with the family. The suggestion is not that the family is at the end of the process or that they may not have a voice at all. However, the discussions that we have had with our nurses give us the sense that the legal requirements of being an authorised investigating person present some conflicts with the specialist nurse’s family care role.

Malcolm Chisholm: It would be interesting to hear the view on that of the Law Society of Scotland.

Professor Britton: Further to what has been said, it looks as though the AIP would have a very complex and onerous role, because not only are they interpreting, but they are looking at a cascading process, particularly in relation to proxy decision making. At the end of the day, there is no mention of consent in the bill, the policy memorandum or explanatory notes. The focus of the bill is on authorisation, and the buck stops with the AIP—they take the final decision whether authorisation can be given.

The individual carrying out that role should not be a healthcare professional, because that would seem to raise a conflict of interest. The AIP would advise and counsel the family and take the medical history, but they may have one view and the family may have other views, and they would have to decide whether authorisation could be given. It remains unclear to us exactly who would take on the role.

Malcolm Chisholm: The issue merits further investigation. My understanding is that the intention is for it not to be a new role, but a change in the role of the people who currently deal with such matters.

The Convener: Where does the buck stop now?

Sally Johnson: Ultimately, the buck stops with the family.

The Convener: Is that based on the information and discussion that they have had?

Sally Johnson: If someone has given authorisation on the organ donor register, it is true that they have given authorisation. However, we are in a uniquely sensitive situation and we want to work with the consent and co-operation of the families. That is not just because we think that that is what is best for the family but because it is safest for the potential transplant recipient. We do not want to have a family that does not co-operate and does not give us all the information that we need to ensure that the transplant is safe.

You have had evidence from some families, so you know that some of the questions that we have to ask are quite difficult and intrusive. It is hard enough to put those questions to a family that has said that they want to support organ donation, but it would be very much harder to put them to a family that did not want to support organ donation.

Malcolm Chisholm: This is my final point. Surely there is no suggestion in the bill that the wishes of the family will be overridden? There is obviously an issue when there is a proxy, which may happen in a small number of cases.

The NHSBT submission says that there will be 70-plus extra donors, which I would have thought was a strong argument in itself for the bill. It goes on to say that

> “the law as currently proposed may result in conflict with the families”.

It is not clear to me why that should be the case, because the families will still be asked and there is no suggestion that the nurse will disregard their views.

Sally Johnson: My reading of the bill and the accompanying memorandum was that if the authorised investigating person authorised donation, donation would proceed, regardless of the family’s situation. Unless the family had strong evidence that the individual had said that they were not prepared to authorise organ donation, I read the bill as saying that the AIP would authorise it regardless. That is where the concern arises.

Professor Britton: I agree with Ms Johnson. In our submission I pointed out the confusion. Under the bill, the family would be consulted only to clarify what the patient’s wishes may have been. At paragraph 37, the policy memorandum says:

> “the Bill does not allow relatives to block the removal of organs by reference to their own views or preferences about organ donation; they are consulted only to help establish whether the deceased person had expressed any objection”.

Paragraph 55 of the policy memorandum refers to the current position in which organs are not removed if doing so would cause

> “significant distress to the family ... even if ... authorisation ... exists.”

It says:

> “Nothing in the Bill changes this”.

Despite what we have heard about the importance of the role of the family, it is really not clear at all what the role of the family is going to be.

Irene Young: From a practical point of view, we are dealing with families at a very sensitive period in their lives. If an outside agency or person who does not have a clinical role comes in and decides that donation is to go ahead and the family does not agree with that, that may cause problems. When a family says no, part of my role is to try to find out why they are saying no. It may be because they do not understand the organ donation process, but my job is to try to tease that out. Quite often, if we can correct their misconceptions about the donation process, they change their minds and go on to say yes. If the decision is made by an AIP, that part of the role may go and potential donors may be lost.

The Convener: The tasks that would be carried out by the AIP are standard—they are not in contention. They are things such as establishing whether the person can be a donor, whether they were resident in Scotland and all the legal requirements. The tasks themselves are standard—you could describe them as being even more than that. Is it not a question of clarity? Earlier, we identified some problems with the complexities within the system. Some clinicians are more enthusiastic than others, and there are different priorities. Is there not a role for a more presumptive organ donation and retrieval scheme? Last week, someone said that specialist nurses actually do a lot of those tasks now.

Irene Young: Yes.

The Convener: So it is not a question about whether the job needs to be done. Would it not be better if the matter was on a firmer legal footing? Would that aid the presumption—the direction of travel?

Sally Johnson: We will work within whatever legal framework we are given—that is our role. However, from an NHSBT perspective, it is really important that we make sure that it is as easy as possible for all the families and clinical staff involved to come to what we believe is the right outcome, which is to say yes to donation.

The bill needs to be clear about who is responsible for what and how the different parts of the process will work—and that it will happen smoothly and, importantly, quickly. We know that, particularly for donors after circulatory death, the families have had no rest—they are absolutely strung out but they cannot take much more time to make a decision. Therefore, the longer it takes, the more likely it is that we end up with the wrong outcome.

Rhoda Grant: I want to turn the questions on their heads. My understanding is that the AIP's role is to give people a bit of comfort that things are being done properly, that everything is being properly investigated and that people's organs are not being taken without their consent. How can we achieve the same level of confidence here, perhaps using specialist nurses? What precautions would have to be in the bill and what happens anyway to ensure that organs could not be taken without consent and to give families comfort about that?

Sally Johnson: I am quite shocked by the idea that people think that organs are taken without appropriate authorisation at the moment.

Rhoda Grant: I did not mean to suggest that, but the bill would change the situation, so how do you give people comfort that it will not happen?

Sally Johnson: Giving people confidence in that situation is about being able to set out clearly the expectations of the people of the country in which you are living. In Wales we have said, "You have choices and you need to make decisions; if you do not make decisions, this is what will happen." There has been an intensive communications campaign, which has lasted two years and has involved two leaflet drops to every single household, plus an additional drop to everyone approaching the age of 18. There needs to be something that gets everyone to understand the law that is operating. In Wales, it is day 1 of the new system today, so the launch is happening now—that is where I would have been if I had not been giving evidence to this committee.

To some extent, we have a new situation in dealing with families and ensuring that they have confidence, but the expectation is that the nurses will explain to families how the law works in Wales and what the options are and that they will tell families that they have checked the organ donor register to see what their relative decided. The relative will either have recorded a decision or not recorded a decision. If they have not recorded a decision, the expectation is that they will go on to be an organ donor.

However, under the law in Wales and within the code of practice, there are clear expectations about what can be done if somebody has not joined the organ donor register but has clearly made their wishes known to their family. A person's unwillingness to be a donor would be tested for reasonableness. A nurse would explore with the family the fact that the person had not recorded a decision on the register and explain that they were therefore expected to donate because they were deemed to have given their consent. The nurse would ask the family whether they had any information otherwise. If the family said, "Well, he told us he didn't want to be a donor," the nurse would then need to explore what that conversation was like. They would need to explore whether it was just a flippant remark made on the way out to make a cup of tea—such as, "Well, they wouldn't want my liver, not after all I've drunk, so don't sign me up for that"—or whether it was a proper discussion between the family about what they wanted to happen. If it was the latter, donation would not proceed, because that would be clear evidence that a person did not wish to be a donor. If it was the former, the nurse would need to test that with the family to see how strong the intention was. You would provide confidence by working with the family, in much the same way that we do currently.

Professor Britton: I have a brief observation. In the bill as currently drafted, a proxy decision maker may not necessarily be a family member and they would be consulted in the three-stage, cascading process perhaps even before any family member had been approached.

11:30

Rhoda Grant: I will leave the issue of a proxy to one side, as a proxy would be used instead of a family member. People who represent the views of looked-after children, for example, were very keen on a proxy, because those children do not have close family who could make the decision for them. We do not see a proxy as the norm; it is the exception to the rule.

I go back to the AIP. Earlier in the process, we took evidence from clinicians, who said that they have a duty of care towards the family as well. That is normal. Therefore, if it looked as though the presumption to donate would cause the family additional distress—bearing in mind that they would already be distressed—the donation would not go ahead. Despite the family's role under the bill, the duty of care on clinicians would give them that protection.

Lorna Marson: To my mind, that is absolutely one of the most important issues with the bill. Ultimately, it is very unlikely that any of us who work in the clinical arena will go directly against the wishes of a family who are at the beginning of an intense grieving process. As a clinician, I think that that is right because we have all seen the power of negative publicity. One bad story about transplanters taking organs from somebody whose family did not want them to do so could have a significant impact on the number of organ donors. We have seen historically that organ retention scandals impact on people's behaviour.

For many reasons, it is right that the family's wishes are taken into account, almost irrespective of the legislation. My colleagues work every day with families to try to encourage them to authorise organ donation, but they ultimately accept it if families have strongly held views against it. That will not and should not change.

The Convener: Does Rhoda Grant want to test that further? We have had evidence about where the European convention on human rights would come into play in this field.

Rhoda Grant: Yes. I will ask a final question. Do we need the AIP? Could specialist nurses provide the protections set out in the bill?

Lorna Marson: You should ask them.

Irene Young: My concern about the AIP's role relates to situations where a family are against donation but the AIP decides in favour of it. My role, as Lorna Marson and Sally Johnson explained earlier, is to find out as much information about the donor as possible to ensure that the donation is safe. If a decision is made that goes against the family's direct wishes, how co-operative would they be with me when I needed to find out some of the most important information for the transplantation? That is my big concern. If another person with another role is brought into the equation and the family are not quite sure who that person is, that may cause problems.

Liz Waite: There is also a huge amount to say about our relationship with families and the work that we do with them. As we have already heard, bereavement is a dreadful time for them, and to change things dramatically could cause problems. Currently, we work collaboratively with intensive care units and A and E departments, which form a relationship with those families, if they can, to take them through the dreadful grieving process. We support that with the collaborative work that we do in organ donation, where we have the chance to form a relationship and gain all the understanding and information that we need from the family at that difficult time.

Professor Britton: From a legal point of view, if such engagement with the family was on-going, we would not see the AIP needing to legally arbitrate because a decision could not be reached and there was conflict with the family.

If a clinical approach is taken and people who have years of experience in the area spend time with the family, we certainly see less potential for conflict.

The Convener: In that context, we have heard that overruling families' wishes could engage article 8 of ECHR. Do you see that happening?

Professor Britton: We did not look at that in our submission. Article 8 is about the right to a private life. I will take the issue away and think about it a bit more, but in examining rights under article 8 I do not think that we would be examining anything different from what we would already be looking at—the autonomy of the individual, their views and whether we could build a picture of what their preference would have been.

In the absence of any evidence in that regard, I suppose that there might be a challenge, but given the conversation that we have had today I do not envisage a situation in which the views and values of the family and the views of the individual would not be fully explored.

Rhoda Grant: I want to follow up what Irene Young said. We are talking about almost the worst-case scenario, because we all agree that if a family did not agree to donation no one would put them through such an experience. However, as an added protection, without the role of the AIP, if a family felt that they were in some way being pushed into agreeing to donation they could just refuse to share information about the potential donor, could they not?

Irene Young: I suppose that a family could do that, which would be to the detriment of potential transplantation. Donation can go ahead with a limited amount of information, but there is then a danger of transmitting potentially life-threatening conditions to the person who receives the transplant. It is vital that we are able to build up a relationship with families, so that they trust us and impart information to us. We also contact the family GP and other clinicians who have been involved in the patient's care, but it is vital that we get information from the family about the person's day-to-day existence. A GP might not know everything about the person, who might not have regularly attended the GP practice. I must gain the family's trust to enable them to give me the information that I need.

Mike MacKenzie (Highlands and Islands) (SNP): There seems to be a fundamental implicit assumption in the bill that replacing the current opt-in system with an opt-out system will, in and of itself, give rise to a greater supply of organs. Do the witnesses agree with that assumption? If not, why not?

Lorna Marson: I do not think that it is clear from the international evidence—from the Spanish model or from Belgium and other countries that have legislated for an opt-out system—that doing that in itself increases the number of organs for donation. I do not think that we know the answer.

Mike MacKenzie: Does that mean that we cannot really say one way or another?

Lorna Marson: Some opt-out systems, such as the system in Belgium, were set up 20 years ago, so if they are not clearly increasing the number of organ donors one could argue that the change in legislation in itself will not make a difference to organ donor numbers.

Mike MacKenzie: Do the other witnesses have a view? Even if you are reluctant to state a view, it would be interesting for the committee to consider the arguments on both sides. Some previous witnesses suggested that legislation will increase supply, whereas others think that it might have the opposite effect. It would be useful for the committee to hear the pros and cons from your respective perspectives.

Professor Britton: From a legal point of view, we would ask what legislation will bring to the process that is not already there. We cannot comment on the medical side and the statistics in that regard.

The Convener: We can accept that many factors will influence donor numbers. However, is it the case that countries that have soft opt-out systems generally have a higher number of organ donations?

Sally Johnson: There is some evidence that there is a correlation between a high donor rate and soft opt-out, but cause and effect has not been absolutely proven. That is the difference.

The Convener: That is helpful.

Sally Johnson: Think about Spain and Belgium. Since 1989, Spain has been pursuing 40 donors per million population. We have been at this game since 2008. We are doing pretty well at catching up. I would caution against thinking that anything is a magic bullet. I wish that there were one—if there were I would be firing it.

The Convener: I understand. What we are searching for is whether we can do better. This is partly about cultural change and a change in attitude among people who work in this area. Would this proposal help? Would it generate the debate that takes us the next step? We acknowledge that it is incremental and we are not criticising the current system. We are examining a proposal that seeks to take us the next step and make additional progress.

Sally Johnson: There is definitely evidence in Wales in that regard. When Wales started on this journey, hardly anyone in the country had thought about organ donation. In the latest survey—I cannot remember the exact figures but Wales would certainly be able to tell you—more than 80 per cent of the population was aware of the legislation. Wales has got something into the consciousness of the public as a result of a legislative process accompanied by a thorough communication process. We wait to see what will happen.

Lorna Marson: That is an interesting point. We do not know whether a very good communication process without a change in legislation would have the same impact. There is evidence that the publicity campaigns that we have run in Scotland have led to an increase in the number of people signing up for the organ donor register.

Mike MacKenzie: Is it possible to argue that, irrespective of whether the bill goes any further, the conversations that we have had that cover areas tangential to the subject matter of the bill are of benefit? Can it be argued that the bill is already having a helpful effect?

Professor Britton: There seems little doubt that the conversations in the media have raised the profile of the issue. It is reaching people’s homes and their consciousness. This really should be about dialogue and communication. If the bill contributes to that good communication, it is a positive thing.

Mike MacKenzie: Last week, the committee heard from a gentleman who is a bioethicist. We had a fairly theoretical discussion, which seemed to centre on a view that we own our organs even after death. I struggle with that concept. I cannot imagine that we will own anything after our death. Are you able to shed light, from a more practical standpoint on the ethics that attend this issue?

Sally Johnson: There are as many views as there are ethicists.

Lorna Marson: It is a topic of debate. Do your organs belong to the state—whatever that is—at the time of death or do they belong to you or your family? As a clinician and a surgeon, and therefore at the practical end of the scale, I would say that that is an important argument for a bioethicist but, if you are faced with such decisions in the middle of the night, you adopt a rather more pragmatic approach around making the right decision, not just for the transplant community but for the donor family. We have to remember that donor families who agree to donate organs gain a huge amount—it is sometimes a solace. I am sure that you have heard from donor families during your discussions that some good has come out of the tragedy. I would avoid the question by responding in a more pragmatic way.

Professor Britton: It is about respect. An agreement through which the family feels that their loved one's wishes have been respected, whether or not organ donation has taken place, has more value than a debate about the legal ownership of organs.

11:45

Liz Waite: The families that we have worked with feel that their loved ones have given something huge for the benefit of others.

Mike MacKenzie: Thank you.

Dennis Robertson (Aberdeenshire West) (SNP): The organ donation register has been set up on the pattern of the Welsh system. The Law Society indicated that there was a data protection issue in relation to proxies. Is that the case?

If we do not have a witnessed signature from the proxy or representative, is it the case that the information is not data protection compliant and therefore could not be entered into the register?

Professor Britton: That issue was not covered by our submission. We referred to the proxy decision maker knowing that they would be involved in the process, but we did not see the value in looking at whether signatures had been provided.

Dennis Robertson: How would data protection cover entering the details of a proxy without their consent?

Professor Britton: Data protection would not be compromised unless the proxy decision maker was being forced to make a decision at that time. There is nothing on the face of the bill to suggest that the proxy decision maker would be forced into making a decision.

If a person is not making a decision, he or she is not being a proxy or representing the wishes, views or values of the adult in question.

Dennis Robertson: Does the register compromise data protection in any way?

Professor Britton: In my view, if a proxy decision maker who has been appointed without their knowledge refuses to make a decision, there would not be any compromise.

Sally Johnson: My understanding and the advice that I received is that we cannot hold data about people that has not been given to us by the person.

Setting aside the rigmarole of the signature being witnessed and so on, I cannot volunteer Liz Waite as my proxy and ask the organ donor register to hold her data without her consent. That is really important.

Dennis Robertson: Are you saying that the information could not be entered into the register?

Sally Johnson: It could not be entered without the agreement of the person who has been nominated.

Dennis Robertson: Under the Human Tissue (Scotland) Act 2006, a 12-year-old can enter themselves in the register and thus opt in without parental consent. In England and Wales, the age of consent is 18 and in the bill it has been proposed at 16 for Scotland.

Does that present a degree of conflict? Does that make it difficult to enter information in the register?

Professor Britton: I have three observations to make. The first is that the current position, as Mr Robertson has rightly said, is that a young person from the age of 12 can opt in. The Law Society view is that it is a different question whether young people should be deemed to have opted in unless they opt out. That would be a slightly more onerous decision for them to make. We would prefer that they had the opportunity to weigh up the pros and cons of making that decision.

The Age of Legal Capacity (Scotland) Act 1991 allows a young person to consent or refuse consent to medical treatment from the age of 16. I am not sure that agreeing to organ donation is actually medical treatment. That is perhaps something that will need to be thought about further.

However, the last point and perhaps the most important one is that if we are looking for consistency in relation to the UK, we should note that the Welsh provision has decided on the age of 18. If somebody from another jurisdiction was in Wales—for example, if there was a young person from Scotland in Wales who was 17 and their organs were going to be taken—it could create quite a difficult situation, whereas if the Scottish minimum age limit was 18 years of age, there would be consistency across the UK.

If this is about enabling the public to make informed choices, it would probably be easier if there was consistency and if the age limit was the same in Wales, in Scotland and indeed in any other jurisdiction in the UK that took this approach on board.

The Convener: Does anyone else want to respond to that point about age? Would it cause NHSBT a problem if the age was 16 in one area and 18 in another?

Sally Johnson: It adds a complexity. As I understand it, one of the requirements of the bill as it is written is that the individual is resident in Scotland at the time of death. Someone could be resident in Scotland at the time of their death, but they might die on a day trip to London. Unfortunately such things do happen. Then we would have inconsistencies in the approach.

We have to train all our nurses to understand the law in each country because death, sadly, is no respecter of country boundaries. Therefore the more complexity there is, the higher the risk of getting it wrong. That is the only thing that we would say. It is just an operational matter. It is about trying to remember all the twiddles in the different laws—and they are all different.

Dennis Robertson: The other area that we have not explored much is the time factor. I am slightly confused because I do not know what the time factor is as regards the discussion with the family and what the window would be for organs being available for donation.

We are aware that that discussion needs to take place and it needs to take place fairly quickly. The bill refers to the timeframe but it does not specify so many hours or days or whatever. What timeframe do we actually have? For instance, someone might have a sudden death on a theatre table. Everyone going to theatre has a degree of risk but there can be sudden deaths or unexpected deaths. How do we deal with that and what is the timeframe?

Liz Waite: Let us take the discussion away from sudden death and look at what we were saying previously about brain-stem death or donation after circulatory arrest. In the case of brain-stem death, there is a timeframe in which a series of tests will be carried out and there will also be discussion from a clinician about the fact that that person will not survive. There will then be the added discussion of futility—that we are going to look at options with that family and one of them would potentially be organ donation. It is the same in the case of donation after circulatory death. There will be a planned collaborative conversation between a clinician, a specialist nurse and the family to take forward the discussions around organ donation.

If the family says yes to organ donation, the other timeframe is to do with how we plan that process. That is where timings come in for the families and for the units. We could have somebody donating a number of organs. All organs have to be offered out and placed across the country, so that can take time. We have blood tests and other tests to perform. We have spoken already about the safety of transplantation; there are elements within that process that we have to follow and that takes time. There are also theatres to be set up and there is the expertise of the surgical teams who will come out to retrieve those organs. That is all within the timeframe. Those are all discussions that are covered in the training that we have had in how we take the families through that whole process and explain to them what that timeframe may be.

It could take 10 to 16 hours from the conversation to get everything in place before death can happen for that person, particularly with donation after circulatory death, and their organs can be retrieved. That is the timing that we speak about and how we take forward those very important discussions with the family in that information setting.

Dennis Robertson: Do we require a timeframe in legislation or perhaps in the guidance notes or whatever, or should it be flexible? Should we have a specific timeframe so that people are aware of the time restraint and know that conversations need to happen quickly and that we do not have days?

Liz Waite: We do not have days, but the timeframes for taking forward the process with the families can be flexible.

Richard Lyle: In asking my earlier questions, I complimented the work that you do, so no one is criticising, but how many hospitals do you cover? Data shows that the consent rate rises to around 33 per cent when specialist nurses for organ donation are involved, but also that specialist nurses for organ donation are involved in only about 76 per cent of approaches to families. Do we physically need more specialist nurses so that there is one in each hospital? I see nodding heads.

I do not know how many hospitals you cover. You work 24/7 and out of hours and so on and I compliment the work that you do, but I am interested in how many hospitals you personally cover.

Liz Waite: At the moment, the service has 18 specialist nurses in 26 hospitals in Scotland, but we cover all the hospitals and we have a team of people who are on call. As the statistics that you quoted show, there are times when we are not involved. That could be because of the need to travel to hospitals, or it could be because something happens out of hours and we have been called and are trying to get there. Sometimes, the conversations might happen pretty quickly between the clinician and the family because the family has asked the question already. Some families raise the issue of donation and they may ask the question. We could be en route to the hospital and we will take part in those discussions and take forward donation if that is agreed. In some of the cases that you refer to where we are not present, the clinicians might well have started the process already.

Richard Lyle: With the greatest respect, it would be very hard for you if a clinician has had a discussion with the family and they have said no, because they are distressed. Would it not be very hard for you to try to get them back into the room to rediscuss?

Liz Waite: It would be very difficult. In many of those situations in which we have not been involved, we would go back and speak to the family again, and they have probably given very good reasons. We have already spoken about the education of our clinicians. The clinician will try to explore any misconceptions that the family have and why they maybe do not want donation to go ahead.

Irene Young: I am based in the royal infirmary in Edinburgh and part of my role is to go down to the unit every day to say hello and find out what is happening that day. The point of that is to try to get the clinicians to refer patients to us as early as possible. I might not be on call that day, but I can start the process and my on-call colleague can then make their way to the hospital and will take over from me and carry out the rest of the process overnight. The reason for doing that is to ensure that we cut down the time as much as possible and that we do not put the family through a long drawn-out process.

That is the idea behind having an embedded SNOD in hospitals. Most of us cover either one hospital or two. I cover only the royal infirmary, because it is quite a big hospital with several intensive care units and an emergency medicine department. Some of my colleagues cover two of the smaller district general hospitals, because there is less potential there.

Richard Lyle: If we had a specialist nurse in every hospital in Scotland, would that raise the organ donation rate—yes or no?

12:00

Sally Johnson: We cannot be certain. We are testing whether, if a nurse engages and approaches more families—in a role that is called the designated requester role—that nurse becomes more expert and achieves higher consent rates. The early evidence from that is promising.

At the moment our nurses make on average 15 approaches a year, whereas a designated requester makes about 60. If we had a nurse in every hospital, the number of approaches that each made would drop below 15, and we might lower the rate of consent.

The Convener: Should there be one such nurse in every intensive care unit?

Liz Waite: The availability of such nurses in Scotland is such that there is one in every intensive care unit, particularly in the big donating hospitals. In district general hospitals, we have supplementary provision, where somebody else will cover a hospital.

The Convener: So to all intents and purposes, the approach is already happening in practice.

Sally Johnson: Yes.

The Convener: Given that a nurse engages with only a few families each year, what are the other aspects of the role? Does it involve education, communication and so on?

Liz Waite: There is education, promotion and the development of a whole-hospital approach to organ donation throughout a hospital. A huge amount goes on.

Sally Johnson: And there is the audit.

Liz Waite: We have mentioned the audit. Every death is audited, which is important to show that we are not missing anybody.

Dennis Robertson: Do we have figures that indicate how many donations are from people who are under 18—from the paediatric side—and how many are from adults? Are there more donations from the younger age group?

Sally Johnson: I can let the committee have information about donors over the past few years broken down by age, if that would be helpful. I do not carry that data for Scotland in my head.

The Convener: Generally, are donations from the younger age group in the minority?

Sally Johnson: The average age of our donors is over 50.

The Convener: In Spain, the average age is over 60 and they are doing older for older.

Sally Johnson: I offer one word of caution.

The Convener: That is why you are here.

Sally Johnson: We use all but about 5 per cent of the organs from our donors. We do not retrieve an organ from a donor unless we have a transplant unit that is prepared to implant it. When the people in a unit receive an organ and look at it, they mostly say that it is fine and put it in, but sometimes, they look at the organ and decide that using it would be too risky—a very small percentage of organs are discarded at that point, before implantation. Our discard rate is significantly lower than that of our Spanish colleagues, and we need to pursue transplants, not donors.

Mike MacKenzie: That is interesting.

The Convener: That is an interesting point to leave us with.

Another point that we touched on during our day trip to London—remind us never to do that again—concerns habitual residence. Some written submissions said that the continuous six-month period is too short, as it could include groups such as international students and foreign contractors. Are there any views on that?

Sally Johnson: I think that a year is safer, to make sure that people have time to find out about the law and become informed. It would also give us consistency with our colleagues in Wales—and potentially Northern Ireland, where a bill will be looked at next week.

Professor Britton: The Law Society endorses that. A year seems a reasonable period of residency.

The Convener: Let us finish by discussing cost. Today's evidence has covered a number of areas where a cost would arise, but the outcome would be that maybe 70 more organs were available for donation. The other side of the equation has not been mentioned—I do not know whether there is another side to it.

Increased donations would reduce the number of people on dialysis, so how should the committee take your evidence on issues such as a lack of capacity and whether it would be possible to retrieve another 70 organs, given the overall figure in Scotland, which is quite surprising? What is the other side of the cost? What would we save and what would the balance be?

Sally Johnson: Money would be saved only if we did not put somebody else on dialysis to replace the person who was taken off. The dialysis unit would have to be closed to produce cash-releasing savings.

The Convener: I presume that people do not go on dialysis for fun.

Sally Johnson: They do not go on it for fun, but the laws of supply and demand are difficult.

The Convener: I am afraid that that is the health service.

Sally Johnson: Indeed. There are choices about investment. If you invest in the things that enable the consent and authorisation process to change, you also have choices about whether to invest in things such as the new technologies to perfuse organs, which might give us just as many transplants. Transplant surgeons are developing clever boxes that they can put organs into when the organs are removed from the body. Those boxes in effect replicate the circumstances of the body as closely as possible and can improve the functioning of the organ. We are looking at whether we can make untransplantable organs transplantable.

A range of opportunities faces the funders, our colleagues in the Scottish Government, in considering what they give us money for—whether that is changing consent systems or new technologies, such as those that will allow us to transplant hearts from people who have died after circulatory death, which we are in the process of evaluating. In that circumstance, just the organ retrieval costs about £35,000, but the outcomes look promising, so there are choices to be made.

The Convener: Do you have a figure for what you have proposed? You have identified a number of areas—you have said, "The proxy will cost us money, identifying people will cost us money and the communications programme will cost us money." Is there a figure for all or any of that?

Sally Johnson: Not from NHSBT, but I believe that my colleagues in the Scottish Government have done work on that.

The Convener: Have they? We will ask them, then.

Lorna Marson: I suppose that I am privileged in that I do not have to worry too much about cost—I just spend the money. However, transplantation is one of the most cost-effective treatments in the history of the NHS. Kidney transplants account for the highest number of single-organ transplants, and there is no doubt that, after one year, a successful transplant is more cost-effective than a year of dialysis, and that benefit continues year on year.

Northern Ireland has had a really proactive renal transplant programme over the past five years and has been able to shut down some dialysis times—not units, but times. The twilight time is the worst time for patients to go on dialysis, and for one or two days a week in Belfast, twilight dialysis slots are now not needed, because the number of transplants has been increased to the extent that fewer dialysis slots are required.

Transplantation is highly cost effective. Sally Johnson's point is well made. Where we invest the money to obtain the gains is a question of on-going debate. Novel technologies are an interesting area, but a transplant is a highly effective treatment.

Anne McTaggart (Glasgow) (Lab): I thank the committee members and witnesses for today's evidence. I also give my best wishes and say good luck to my Welsh colleagues, who kick off today. As has been mentioned, Northern Ireland is also slightly ahead of us with its system.

I really just want to say thank you. I sincerely applaud you all for the work that you do. You are at the front line and you are the ones with the most knowledge and experience. I salute you all.

The bill came about because we need to increase our organ donations. We know that 571 or 572 people—you can correct me—are waiting for an organ transplant. We heard that we have a great publicity campaign, and we do. Everything that we have done to date has been wonderful but, as the convener asked, where do we go from here?

Organ donations have to increase. We need to be able to do more in order to save more lives. We are all aware that three people die daily in the UK for lack of a transplant. We have to do something different, because what we are currently doing is not fit for purpose, in a sense. We are not reaching the targets that we said we would reach.

Sally Johnson mentioned the increase in donations. I would like to hear your views on the figures that I have here, which state that deceased donor rates have fallen by 7.5 per cent and the number of deceased donor transplants has fallen by 13 per cent. The second quarter figures for this year indicate that there may well be a 16 per cent decrease in deceased donor rates in 2015-16.

Sally Johnson: I am pleased that things have turned round. We had our highest-ever donor numbers in October, with 143 donors across the UK and 365 transplants. That is 26 donors per million of population, which is the level that we aim to be at every month by 2020. That suggests to me that we have got some things right in what we are able to do. I am not in a position to say whether changing the legislation would give that more impetus.

Anne McTaggart: You are right about the 2020 target. The Scottish Government set a target to increase the number from 17.9 per million of population in 2012-13 to 26 per million of population by 2020. You will be well aware of that, and you just mentioned the increase. We are looking for an increase from 17.9 per million, but in the past three years the rate has increased by only 0.3 per million.

Sally Johnson: We have a new strategy, and part of the thing about strategies is that they take off gradually rather than steeply. Some of the strategic things that we have put in place—whether that is designated requesters or some of the other processes—are beginning to bear fruit. That is why we had 26 donors per million of population last month.

There is no organ donation system in the world where the figures steadily increase. Even in Spain, they go down and back up again. We just have to keep plugging away at new initiatives to change things and ensure that everything is done perfectly.

Anne McTaggart: I am absolutely aware that the bill is not a silver bullet or the be-all and end-all. There would not be a 100 per cent increase just because of the legislation. However, we cannot shy away from the international evidence that we have seen, which does not cover just a couple of years. The increase has been going on for 20, 30 or 40 years. The evidence is not just yesterday’s news. I think that Ms Marson mentioned the international evidence. Does she want to comment?

Lorna Marson: I do not think that the international evidence is clear. In Spain, the opt-out legislation existed long before the increase in organ donor numbers was seen. Spain then introduced practical, logistical and structural changes to the way in which organ donation happens—that is similar to what we have done since 2008—and that is when organ donor numbers there increased; the increase did not seem to be temporally related to the legislation there.

Croatia has the second-highest number of donors per million of population, and it has an opt-in system. I do not think that the legislation in isolation is what makes the difference.

12:15

Anne McTaggart: I disagree, because the international evidence clearly indicates that, although no legislation is the silver bullet, it is a means to getting an increase in the number of organ transplants.

I want to correct something that I said at the committee last week. I stated that international evidence shows a 15 to 20 per cent increase in donation rates, but it is potentially a 25 to 30 per cent increase. That was my mistake, for which I apologise.

I will move on to my last two questions. Some of today’s conversations have been about the role of the AIP and where the buck would stop for decision making. Are you aware that, currently, the law states that the family cannot legally deny organ removal for transplantation if the deceased was on the organ donor register?

Professor Britton: We are aware of that but, as a matter of policy, process and protocol, it is widely and generally recognised that families are consulted.

Anne McTaggart: The bill would not change that.

Professor Britton: In that case, the Law Society respectfully asks that you please revisit the policy memorandum to provide clarity. We all recognise the importance of good communication, and any ambiguity at such a difficult time may be problematic.

Anne McTaggart: There is absolutely no way that we would want the front-line task to be any more complicated than it already is for the clinicians, SNODs, CLODs or whoever is doing it. The bill would not change that role. Thank you for your comments on that—I will go back to the policy memorandum.

My other question is on the age of consent. We have had changes in the age limits for various things, including voting, but I take on board what the panel says and respect its wishes. We may well look at that. The bill does not set things in tablets of stone; my aim is for the bill to be workable, for the benefit of all who need it. There will be possibilities for amendments, and I want to hear the evidence that the committee takes.

Professor Britton: It is important to have clarity and a consistent approach when time is of the essence. If other jurisdictions in the UK are going to embark on this path, having the same age limit will promote decision making at the time.

Anne McTaggart: I will explain why the provision is in the bill. It came out of evidence that I took when I was on the road consulting people about the bill. Young people felt that, given that they can now vote and do a lot of other things at 16, they should be able to donate at that age. They can donate at the age of 12 with the consent of their parents or guardians. I am grateful to Rhoda Grant for picking that up.

The proxy is important. The Scottish Youth Parliament was concerned that some young people do not have a family member, which leaves them in a difficult position. People will also be aware that families sometimes do not agree. I will give an example of that. One person who gave evidence was filling out her forms and said, “I definitely want to donate my organs. Do not allow my husband to decide for me when I pass away, because he will definitely not allow that to happen.” She did not want her wishes to be overturned. It works both ways, which is why the proxy aspect is in the bill. The provision is also in line with the UK Government’s current policy, in which I think that the proxy is called a nominated person. What I propose is no different and would bring us into line with what the UK does.

The Convener: As there are no further comments, I thank Anne McTaggart and all our panel members for an interesting and informative session. Thank you very much for your precious time. I hope that we can reflect some of your views in our report.

12:20

Meeting continued in private until 12:42.

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