Health and Sport Committee

Stage 1 Report on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill
# Contents

## Introduction  
1

## Background  
2

- Proposal for a Members’ Bill 2
- Types of consent systems 2
- Current organ donation systems in the UK 3
- Scottish legislation and policy 3

## Purpose of the Bill  
4

- Increasing the numbers of organs and tissue available for transplantation 4
- Trends in organ donation in Scotland 6
- Evidence from other countries 8
- Costs of the Bill 9
- Savings of the Bill 10
- Is this Bill necessary? 11
  - Changes to the infrastructure 11
  - Education and awareness-raising 12
  - Changing the conversation 13

## Main provisions in the Bill  
15

- Appointing proxies 15
  - Requirements for registering a proxy 19
  - European Convention on Human Rights issues 20
- The role of authorised investigating persons 21
- Publicity campaign 27
- Persons to whom the Bill applies 31
  - Adults with incapacity 31
  - Resident in Scotland 32
  - Age 34
- Other provisions in the Bill 37
- Consideration by other Committees 37
  - Finance Committee 37
  - Delegated Powers and Law Reform Committee 37
Petition PE1453

Overall Conclusions

Annexe A

Extracts from the minutes of the Health and Sport Committee and associated written and supplementary evidence

List of other written evidence

Online Survey

Annexe B

Note of informal meetings

Annexe C

Note by the Clerk of fact finding visit to Madrid 16 November 2015

Annexe D

Report from the Delegated Powers and Law Reform Committee and Report from the Finance Committee
Health and Sport Committee
Stage 1 Report on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill, 3rd Report, 2016 (Session 4)

Health and Sport Committee

To consider and report on health policy, the NHS in Scotland, sport and other matters falling within the responsibility of the Cabinet Secretary for Health, Wellbeing and Sport, and measures against child poverty.

[Contact information]

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Note: The membership of the Committee changed during the period covered by this report, as follows:
Fiona McLeod replaced Bob Doris on 21 February.
Introduction

1. The Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill\textsuperscript{1} ["the Bill"] was introduced in the Scottish Parliament by Anne McTaggart MSP on 1 June 2015. The Health and Sport Committee was designated as lead committee for Stage 1 consideration of the Bill on 9 June 2015.

2. The Committee issued a call for views on the Bill on 8 September. This call for views ran until the 12 October and thirty three responses were received.\textsuperscript{2} The Committee also carried out an online survey on the main provisions in the Bill. This ran from 8 September to 16 October and a total of 856 responses were received.\textsuperscript{3}

3. The Scottish Government responded to the Committee on the Bill on the 7 October 2015.\textsuperscript{4}

4. The Committee took evidence on the Bill over four meetings in November and December 2015. On 17 and 24 November the Committee took evidence from stakeholders with a range of views on the Bill, this was followed by an evidence session on the 1 December which focused on the practical aspects of the Bill proposals with NHS Blood and Transplant (NHSBT), the British Transplantation Society and the Law Society of Scotland. On 8 December the Committee heard from Maureen Watt, Minister for Public Health followed by Anne McTaggart MSP, member in charge of the Bill. The Committee received further written evidence from Anne McTaggart MSP on 1 December\textsuperscript{5} and 15 December\textsuperscript{6} and from the Scottish Government on 16 December 2015.\textsuperscript{7}

5. A full list of witnesses and the written evidence received can be found at Annex A.

6. The Committee also held three informal meetings with organ donor recipients and those awaiting a transplant (on 4 November 2015), families of organ donors (on 11 November) and finally a meeting with faith and belief group representatives (on 12 November).

7. The Committee undertook a fact-finding visit to Madrid, Spain.
where it met with Dr Rafael Matesanz, Director of the Organizacion Nacional de Trasplantes (ONT) and with Dr Andres Belmonte (Transplant Co-ordinator) and Dr Natalia Polanco of the Hospital Universitario 12 de Octubre.\textsuperscript{8}

8. The Finance Committee published its report on the Financial Memorandum of the Bill on 2 December 2015.\textsuperscript{9} The Delegated Powers and Law Reform Committee published its report on the Bill on 3 December 2015.\textsuperscript{10}

9. The Committee would like to thank everyone who provided written and oral evidence as part of its consideration of the general principles of the Bill. The Committee especially wishes to thank those who provided personal accounts of their experiences of waiting for an organ to be donated or of authorising organ donation following the death of a loved one.

## Background

### Proposal for a Members’ Bill

10. Anne McTaggart MSP lodged a draft proposal for a Members’ Bill on 26 June 2014. The proposal was accompanied by a consultation document\textsuperscript{11} which explained that the Bill looks to amend the law on human transplantation, including by authorising (in certain circumstances) the posthumous removal of organs and tissue from an adult who had not given express consent. The overall aim of the Bill is to increase the number of organs and tissues made available for transplantation in Scotland.

11. The Bill provides for a move to a “soft opt-out” system which allows (in certain circumstances) for the removal of parts of a deceased adult’s body (organs, in particular) for the purposes of transplantation in the absence of express authorisation. The Bill was introduced on 1 June 2015 and the Health and Sport Committee was designated as the lead Committee for scrutinising this Bill on 9 June 2015.

### Types of consent systems

12. There are opt-in and opt-out systems for organ donation and transplantation across the world. An opt-in system is where an individual expresses their choice to donate organs or tissue and an opt-out system is where the individual is required to explicitly make it known while they are alive that they are not in favour of their organs being used for transplant when they die. The key difference between the two systems is that an opt-in system involves an individual expressly stating that they wish that their organs and tissue be used for transplant on their death. On the other hand, an opt-out system assumes that organs and tissue are available for transplant unless there is a specific instruction to the contrary. The opt-in system is also known as an explicit or informed consent system and opt-out is also sometimes known as presumed consent.\textsuperscript{12}
13. There are different ways that opt-out and opt-in systems work in practice and these are broadly categorised as ‘hard’ or ‘soft’. Soft opt-in and opt-out usually means the family has a say in the final decision about organ donation at the time of the person’s death. Under opt-in this means that even if someone wished their organs to be donated on their death, if the family object, the family’s wishes will be respected. Similarly, a soft opt-out system would involve consulting with the family to capture any unregistered objection, with scope not to proceed if this would cause severe distress to the family. Where hard opt-out or opt-in systems are in place, the declaration of the person when they were alive is final and there is no role for the family in the decision about organ donation at the time of the individual’s death.¹³

Current organ donation systems in the UK

14. Organ donation and transplantation has always been delivered on a collaborative basis across the UK. This means that organs which become available in Scotland are made available to patients across the UK and vice versa. Organ donation and transplantation activity across the UK is co-ordinated by NHS Blood and Transplant, (NHSBT), which is an English and Welsh Special Health Authority and operates in Scotland under a contractual arrangement with the Scottish Government.

15. However, even though the constituent parts of the UK have organ donor and transplant services delivered on a collaborative basis they are not required to operate the same organ donor system.

16. In July 2013, the National Assembly for Wales passed the Human Transplantation (Wales) Act, which came into force on 1 December 2015. The Act introduced a new “soft opt-out” system for organ donation for Wales which allows organs and tissues to be removed unless the deceased objected during their lifetime. The family of the deceased person must be consulted to establish whether the deceased was known to have any unregistered objections.

Scottish legislation and policy

17. The Human Tissue (Scotland) Act 2006 (2006 Act) provides the current legislative framework for organ donation and transplantation in Scotland. The equivalent legislation for the rest of the UK is the Human Tissues Act 2004 (2004 Act). Both Acts provide for an opt-in system for organ donation where individuals must authorise the removal and use of their organs after death for the purposes of transplantation. This legislation also sets out a range of provisions relating to other aspects of donation and transplantation. One of the differences between the Acts is that in England and Wales the 2004 Act allows for up to two ‘appointed representatives’ and the Scottish 2006 Act does not allow for any. Appointed representatives are individuals who have been nominated to make decisions about consent on the deceased person’s behalf.
18. Express authorisation is needed under the 2006 Act before any organs may lawfully be removed for transplantation and this authorisation can be in the form of a discussion with relatives or in writing (e.g. by carrying a donor card), or by signing up to the NHS Organ Donor Register. The existence of authorisation is not always enough and, although there is no statutory requirement for a deceased person’s relatives to give consent, the practice is not to proceed with organ removal if the relatives object. This practice is generally respected even if the deceased person was on the organ donor register or carrying a donor card.

19. In Scotland over the period 2008-13, some 62% of donors were not on the register at the point of death. It is noted in NHSBT’s ‘Activity Report’ that families are more likely to authorise donation when the deceased individual has previously expressed their wish to donate by joining the organ donor register or discussing with their family.\(^{14}\)

20. Under the 2006 Act the nearest relative can authorise donation on behalf of a deceased person where that person had not expressed a wish to donate in life. In circumstances where their wishes had not been made known family members can still authorise donation on behalf of the deceased.

Purpose of the Bill

Increasing the numbers of organs and tissue available for transplantation

21. The member in charge of the Bill has stated from the outset that the overall aim of the Bill is to increase the number of organs and tissue made available for transplantation in Scotland, and hence to allow more transplants to be carried out, reducing waiting lists and saving lives.\(^{15}\) This aim is reiterated in the Policy Memorandum to the Bill.

22. Paragraph 25 of the Policy Memorandum indicates that an increase in donation rates of 25-30% is expected when an opt-out system is introduced.\(^{16}\) According to the 2014-15 figures for Scotland, of 98 deceased donors, this could mean an increase of between 24 and 29 donors.

23. The Committee received mixed evidence to whether the Bill, if enacted, would result in an overall increase in organs available for transplant within the UK. A number of respondents agreed\(^{17}\) that the Bill will increase the number of organs available for transplant, a few disagreed\(^{18}\) and some respondents, whilst agreeing with the aim of the Bill, and for a change to a presumed consent system, did not necessarily agree with the specific provisions in this Bill.\(^{19}\)

24. All of the faith and belief groups that the Committee met with noted that they agreed with organ donation and the need to increase donation rates. The decision to donate organs should be seen as a gift and many families of organ donors took
comfort from the fact that they had gifted organs. Some of the faith groups raised concern that the move to an opt-out system could mean that organ donation may be, in some circumstances, no longer seen as a gift. Some of the transplant recipients, those awaiting a transplant and families of organ donors that the Committee met with also highlighted that organ donation should be a gift and that they were concerned that the move to an opt-out system could result in the feeling of comfort from having done something good being removed.

25. Others such as NHS Forth Valley and Revival are supportive of the Bill however they do not agree with all the provisions within it. The Committee explores the detailed provisions within the Bill later in this report.

26. The Scottish Government asked NHSBT to provide them with an estimate for Scotland, should it move to a presumed consent system, which utilised the same methodology taken for calculating the Welsh estimated increase. NHSBT provided a range of possible outcomes, with their preferred most reasonable estimate being that there might be up to 39 additional organ donors in Scotland, or around 120 organ transplants, which might be available for recipients UK wide. This estimate suggested that there might be approximately 12 additional organs available for transplant to Scottish recipients, given that organs donated in Scotland can be allocated to recipients from across the UK.

27. NHSBT noted in written evidence that their statisticians had estimated that the new law could result in an extra 70+ donors in Scotland, and that this was an upper end estimate.

28. The Scottish Government advised that it is not fully convinced by the NHSBT estimates due to initial assumptions that would have been made by NHSBT to make the calculation. These include:

- assumption that conversion rate from authorisation to actual donation would remain the same. The Scottish Government believes possible "bottlenecks" in the system – finite facilities and resources in hospitals mean the conversion rate is more ‘fixed’.

- assumption that changing to opt-out means that a possible donor’s next of kin would be more likely to authorise donation. The Scottish Government feels that this evidence is open to different interpretations.\textsuperscript{22}

\textsuperscript{1} a single organ donor can result in multiple transplants
Trends in organ donation in Scotland

29. The Scottish Government provided data on organ donations rates in Scotland which compares rates in 2014/15 with 2007/08. They note that this data shows that between those years the number of deceased donors has increased by 82% and that this is above the target increase of 50% set by the Organ Donation Taskforce.

Figure 1: Deceased donor rates and transplants, waiting list numbers and family authorisation rates, Scotland, 2007/08 to 2014/15.

Source: NHSBT and *Based on mid 2014 population estimates.

30. Anne McTaggart MSP did not dispute the figures but noted that the data gives the impression that the Scottish Governments organ donation strategy is working, which she does not agree is necessarily the case.

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ii 2007/08 is the year before the Organ Donation Task Force was established. This year is often referenced as a baseline as it can then show the difference that the Organ Donation Taskforce activities have made to organ donation rates.
31. Anne McTaggart MSP responded to the Committee that data on donation rates showed that in the past year (to 2014/15):

- deceased donor rates fell by 7.5%
- the number of deceased donor transplants fell by 13%
- second quarter figures for this year indicate there might be a 16% decrease in deceased donor rates for 2015/16
- family refusal rates were 46.1%, an increase of 7%.

32. The Scottish Government stated that although the figures that Anne McTaggart MSP presented are correct, it believed that her analysis was a “little unfair” and should not be used as an argument in support of the Bill.25

33. The Scottish Government advised that although donor numbers have fallen slightly across the United Kingdom for various reasons, the fall was in relation to the previous year’s rates (19.8 per million per population) which were the best that it had ever seen and that although there was a drop in donations last year (18.4 per million population), last year’s figures were still the second best Scotland had ever seen. Its long term strategy sets a target to increase overall deceased donation rates from 17.9 per million population in 2012-13 to 26 per million population by 2020.

34. The Scottish Government’s position is that the message has to be about the long-term trends and not year-to-year fluctuations, and that the long-term trend in Scotland is that donor and transplant numbers are increasing. It confirmed that the transplant waiting list in Scotland has dropped by 20% since 2007.26

35. NHSBT noted that there is no organ donation system in the world where the organ donation rates steadily increase and advised that even in Spain, which has one of the highest organ donation rates in the world, the organ donation rates go down and back up again.27

36. In written evidence, Anne McTaggart explained that whilst donation rates have increased since 2007, the fact that there was a decrease in donation rates in 2014-15 with a predicted decrease in 2015-16 indicates the limits of the current approaches and underlines the need for legislative change as part of the overall solution.28
Evidence from other countries

37. The Bill’s Policy Memorandum cites evidence from various other European countries to indicate that a move to an opt-out system of organ donation can result in an increase in donor rates. It cites a joint study undertaken by Harvard University and the University of Chicago in 2005, which found that organ donation rates increase by approximately 25-30% in countries where an opt-out system is introduced.

38. The high rate of organ donation in Spain is often cited as one of the reasons why other countries should change to an opt-out system. However it is not clear whether the change to an opt-out system in Spain in 1979 made any difference to the donor rates, given the improvements in donor rates seen from 1989 followed significant structural changes to the nationally organised organ donation system. Members of the Committee heard during their visit to Spain that it is therefore not clear whether the change in legislation helped. Dr Matesanz, Director of the Organización Nacional de Trasplantes (ONT) in Spain said “that many elements have to be right if an increase in organ donor rates is to occur”.

39. NHSBT draw attention to the fact that the UK uses all but around 5% of the organs from donors. NHSBT do not retrieve an organ from a donor unless it has a transplant unit that is prepared to implant it. A very small percentage of organs are discarded when the organ is seen by the receiving unit and they decide that to use the organ would be too risky. The discard rate in the UK is significantly lower than Spain and NHSBT believe that the focus should be about more effective organ retrieval as well as being about increasing the number of donors.

40. The British Transplant Society is unsure whether international evidence shows that a change to an opt-out system does result in an increase in donations stating that—

> 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.

41. The British Heart Foundation noted that given the balance of the evidence that they have seen in international studies, their policy position is that a multifaceted approach is required and a soft opt-out is an integral part of that.

Scottish Government

42. The Scottish Government explained that while it commends the Bill it is not able to support it, setting out three key reasons:

- there is still a lack of clear-cut evidence that presumed consent with opt-out would result in any increase in organ donor rates or organ transplants;
introducing a legal provision to ‘opt-out’ of organ donation is unnecessary as this option is already provided via the existing NHS Organ Donor Register. Additionally, opting-out has the potential to reduce the opportunities to assess whether someone may have changed their mind about organ donation during their life-time, and may unintentionally lead to instances where organ donation could have gone ahead, but did not.

- the introduction of presumed consent (‘authorisation by operation of the law’), as set out in the Bill and its accompanying documentation, does not adequately address the needs of those who may wish to opt-out, but who do not do so, for whatever reason. This may result in distress to families, or to complaints or legal challenges at European level.

43. The Scottish Government suggests waiting until results are available from the Welsh Government on their recent change to an opt-out system.33

44. The UK Donations Ethics Committee and NHS National Services Scotland also commented that with Wales implementing its own opt-out scheme, it may be sensible to wait to see the effect of the Welsh Act and if there are any lessons to be learnt from the Welsh experience.

Member in charge

45. Anne McTaggart MSP argued that due to decreases in organ donation rates in Scotland it was imperative that the donation system changed to one of opt-out to ensure that the transplant waiting lists decreased. She argued that there was 50 years of evidence proving the link between opt-out systems and an increase in donor rates and that nine out of the ten best performing countries in Europe have opt-out organ donation systems.34

46. In response to the Scottish Government’s proposal to wait and see how donor rates were affected in Wales as a result of their change to a soft opt-out system, the member in charge suggested a timeline that she expected for a future Scottish Government Bill on changing to an opt-out system. Anne McTaggart argued that any future Scottish Government Bill would not come into force until 2020 or 2021.35

47. Anne McTaggart MSP raised concerns that this was a three or four year delay when the benefits of her Bill could start helping the 571 people in Scotland currently on the transplant waiting list.36

Costs of the Bill

48. The Financial Memorandum states that the two main areas of costs for Scottish Ministers would be the set-up and implementation costs and the cost of a publicity campaign.37
49. It is estimated by the member in charge that the overall costs over ten years would be £7.5 million. This amount was later revised, in a letter to the Finance Committee, to £6.8 million.\(^{38}\)

50. The Scottish Government noted these costs but indicated that it believes the actual costs were more likely to be around £22.2 million over 10 years, primarily because of the need for a new team of ‘authorised investigating persons’ (AIPs) and the need for an on-going awareness-raising campaign, both of which were not included in the Financial Memorandum.\(^{39}\)

51. Anne McTaggart disputed the Scottish Government’s estimated costs for the Bill explaining that it is not £22 million, as there are no recurring publicity campaign costs given the Scottish Government’s existing legislative obligation to promote information and awareness about the donation for transplantation. She also commented that there are no costs for AIPs given that is not a new role, adding that the majority of the stakeholders agreed with the estimate in the financial memorandum and that so far the Welsh costs have been verified as actual costs and on target to be within the allocated budget of £7.5 million.\(^{40}\)

52. The Committee explores these costs later in this report.

**Savings of the Bill**

53. The Financial Memorandum states that—

\[\text{There will also be costs associated with an increase in the number of transplant operations. However, these financial costs could be offset by the long-term savings of a reduction in the burden of the health service through reduced dialysis provision and associated long-term care costs.}\]

54. The Financial Memorandum notes that the average cost for a kidney transplant from a deceased donor in 2013-14 was estimated at £54,364 per case (this includes the first year of follow-up costs). The follow-up costs for each subsequent year are listed as £5,210. Each year there is an average saving in kidney dialysis avoided listed as £32,953.

55. The Scottish Government stated in oral evidence that it did not think that there was a direct read-across from the amount that would be saved to the amount that it would have to spend.\(^{41}\)

56. The Scottish Government noted that the member in charge’s implied position is that the financial benefits generated from any additional transplants will offset the additional costs to NHS Boards over time and therefore all costs can be accommodated from within existing Boards budgets.\(^{42}\)

57. The Scottish Government feels that this is a much generalised assumption that would need detailed discussions with NHS Boards and to be tested with them.
58. Anne McTaggart MSP believes that an increase in transplants would have a resulting benefit in decreasing medical management costs. i.e. a kidney transplant will result in a health board no longer having to carry out dialysis.

59. The Committee notes the differing perspectives on the current organ donation rates in Scotland and the rest of the United Kingdom; and the range of expected outcomes for organ donations rates of moving to an opt-out system of organ donation as proposed by the Bill.

60. The majority of the Committee agree that there is no clear evidence that moving to an opt-out system would, of itself, lead to an increase in organ donation rates. In that regard they consider that it would be prudent to wait and see what the impact on organ donation rates is from the move to a soft opt-out system in Wales.

61. The minority of the Committee considered that given the numbers of people waiting for donated organs a range of actions need to be taken now including moving towards a soft opt-out system. They considered that the number of soft opt-out systems currently operating across the world provides compelling evidence to demonstrate that the soft opt-out system in the Bill will increase organ donation rates.

62. Irrespective of legislative change, the Committee recommends that the Scottish Government consider a range of actions to increase organ donation rates. This could include structural change to the organ donation system (such as additional specialist nurses and consultants being recruited and infrastructure changes such as increased intensive care beds in hospitals) and publicity and awareness raising should be a priority given this will lead to greater increases in organ donation rates.

Is this Bill necessary?

63. A recurring theme during the Committee’s scrutiny of the Bill was whether this legislation was necessary in order to increase organ donation rates, or whether this could be achieved through other routes.

64. The Committee heard about a number of factors other than legislation which could increase donation rates, including the following detailed below.

Changes to the infrastructure

65. One of the reasons Dr Matesanz saw as important to Spain’s success in organ donation was having a good healthcare structure in place to manage the donation system.

66. NHSBT noted the potential impact on infrastructure of the increased availability of organ donations. They contended that they could do more if they had more
intensive care beds and more staff to deal with any rise in the number of people willing to donate. NHSBT also noted that the UK has around 10 intensive care beds per million of population, whereas Spain has about 23 such beds per million population.\(^\text{43}\)

67. NHSBT was keen to state that some caution should be exercised in assuming that more intensive care beds would automatically bring extra donors, pointing out that in reality if there were more intensive care beds it would mostly be filled by more people who need intensive care.\(^\text{44}\)

68. NHS National Services Division, in a written submission to the Finance Committee stated that “if there was to be an increase in transplantation activity as a result of the Bill, National Services Division would expect to manage this within the existing financial portfolio”.

69. The Scottish Government noted in oral evidence that there had to be a “whole-hospital approach” which aims to make sure that people across the whole hospital are thinking about organ donation and not just the transplant teams.\(^\text{45}\)

**Education and awareness-raising**

70. NHSBT advised that Scotland has had a long and excellently sustained education programme in schools and excellent campaigns that have increased the number of people on the organ donor register.\(^\text{46}\) The Scottish Government advised that the education pack that is in every secondary school in Scotland is held up as a good model for other parts of the UK and that there is a need to continue with this and other publicity.\(^\text{47}\)

71. Lorna Marson, representing the British Transplant Society commented that—

> I want to emphasise the positive aspects of the publicity campaigns that have been run in Scotland…The publicity campaigns are very important because they encourage people to have that wee chat.\(^\text{48}\)

72. Some witnesses felt that introducing this Bill would automatically help increase awareness of organ donation and therefore help increase donation rates.\(^\text{49}\) Others believed that a good publicity campaign, without this Bill, could have exactly the same outcome.\(^\text{50}\)

73. The Royal College of Physicians and Surgeons of Glasgow explained that, as shown by the increase in donation rates over the past six years, public awareness, including getting the message out into schools, can have a positive effect without the need for a legislative change.\(^\text{51}\)

74. Dr Matesanz was of a slightly differing opinion and explained to Committee members that classic approaches to increasing organ donation such as publicity campaigns, donor registries and recording information on drivers’ licences might increase awareness of donation but there was no evidence it led to any increase
in ‘real’ donors (that is after death when the deceased family is asked about organ donation). Publicity campaigns etc. also tended to only convince those sections of the population that have already recognised the benefits of donation.\textsuperscript{52}

**Changing the conversation**

75. During the Committee’s visit to Spain, Dr Matesanz stated that the most important part of the organ donation process was the conversation with the family. Dr Matesanz stated that by concentrating on the discussion with the family at the point of death rather than publicity etc. the refusal rate by families to organ donation in Spain is 15%. The current family refusal rate in the UK is approximately 42%. It should also be noted that the refusal rate for British families living in Spain is only 10%.

76. Data from NHSBT, in their ‘Organ Donation and Transplantation Activity report 2013-14’ shows that in instances where a specialist nurse in organ donation is involved in the approach to families, to ask for consent to organ donation, the family approval rate increases by almost 50%.\textsuperscript{53}

77. NHSBT advised that it is currently testing whether, if a nurse engages and approaches more families in a role that is called the designated requester role—whether it achieves higher consent rates and “at present the early evidence is promising”.\textsuperscript{54}

78. The Scottish Government considered that there was a need to change the nature of the conversation but did not believe that a change of legislation was needed to instigate this. It advised that it had already started the process of changing the conversation by trying to ensure that a specialist nurse in organ donation was always present to have this conversation with the family rather than an intensive care consultant.\textsuperscript{55}

79. The Scottish Government raised a concern that should the Bill be passed then the conversation may change but it would also take place later as additional processes, such as contacting proxies would need to be carried out, and this could actually cause additional stress to the family and would result in a less effective conversation.\textsuperscript{56}

80. Anne McTaggart MSP believes that the change to an opt-out system would automatically result in the conversation changing for the better. Anne McTaggart MSP noted in evidence that a change in legislation would empower the transplant staff to move forward and approach the conversation from a different point than it currently does.\textsuperscript{57}

\textsuperscript{53} The specialist nurse in organ donation is the focal point of contact for organ donation within a Hospital; the role encompasses many different aspects, which all come together in the identification and referral of potential organ and tissue donors. Aspects of the role include identification of potential organ and tissue donors in collaboration with the clinical teams in critical care environments, working with clinical teams to ensure the relevant pathways are established to support timely identification and referral of potential organ and tissue donors, carrying out a Potential Donor Audit and provision of teaching and education sessions to various healthcare staff.
81. BMA Scotland agrees, and notes that a change in legislation would allow the conversation to be more effective, allowing the medical staff to state “We are not aware that the patient has any objections to their organs being donated. Therefore, unless you know that they had any objections, we would like to progress this and help somebody benefit from this sad situation.” BMA Scotland believe that the families would find that an easier conversation to have than the conversation that they have at present.  

82. The Scottish Intensive Care Society has concerns that the legislation may change the conversation in a less positive way. They were concerned that the change to an opt-out system may cause greater distress to a family and lead them to believe that they are being forced to accept organ donation because the person has not opted-out.

83. Anne McTaggart MSP noted that different people have differing views on what contributed to Spain’s success. Advising that she sees the change to an opt-out system, improvements to donation and transplantation infrastructure and public education and awareness-raising as being three necessary components to successfully implement a soft opt-out system.

84. The Committee agrees with the member in charge and the Scottish Government that in order to increase organ donations rates, a range of actions are needed across all the different parts of the organ donation process. The Committee notes the importance of a multi-pronged approach to organ donation regardless of whether there is a change in legislation.

85. There was a divergence with regard to whether this Bill was necessary in order to facilitate this multi-pronged approach.

86. The Committee welcomes the evidence from NHSBT and the Scottish Government that action is already underway to improve the quality of conversations held with bereaved families which could potentially reduce family refusal rates.

87. A majority of the Committee believes given the concerns raised and the work that is already underway to improve the nature of the conversation between medical professionals and families of organ donors, this Bill is not necessary to deliver these improvements in this area.
88. A minority of the Committee considers that this legislation is necessary in order to drive forward changes in the conversation between medical professionals and families of organ donors, necessary to reducing family refusal rates.

89. The Committee notes the new role of designated requester currently being piloted by NHSBT and asks the Scottish Government to respond advising whether, if the data from the pilot is positive, it will support the role-out of this new role across the NHS in Scotland (and if so, how such activity would be funded).

Main provisions in the Bill

90. The remainder of this report considers the main provisions of the Bill.

Appointing proxies

91. The Bill adds a new section to the Human Tissue (Scotland) Act 2006 to allow for an adult to appoint up to three proxies. The role of the proxy is to make decisions about authorisation (for the removal of the adult’s organs for transplantation), on the deceased person’s behalf. If more than one proxy is appointed they will be appointed in a priority order in which they would then be contacted.61

92. A proxy can be appointed to make decisions about all of a person’s organs or only specified organs; however an adult may not appoint one proxy in relation to some organs and another proxy to make decisions in relation to other organs.62

93. If an adult subsequently decides before their death to either authorise posthumous removal of organs or to register an objection to such removal then this will supersede any earlier proxy appointment.63

94. At present authorisation for organ donation can be provided after death by the donor’s nearest relative. A subsection in the Bill looks to block such nearest-relative authorisation where a proxy is in the process of deciding or has decided whether to give authorisation.64 The Policy memorandum does note however that—

…it is already established practice not to remove organs or tissue if doing so is likely to cause significant distress to the family of the deceased, even if the necessary authorisation for removal exists. Nothing in the Bill changes this, and it is likely to remain the case, even under the soft opt-out system that it creates, that family distress will be taken into account before any final decisions are made.65
95. Whilst the concept of a proxy is new to the organ donation system in Scotland it has been part of the organ donation systems in the rest of the UK for some time. England, Wales and Northern Ireland all allow for a person to nominate up to two authorised representatives (the equivalent of proxies).  

96. NHSBT advised that although the option of appointing authorised representatives is available in the rest of the UK only 15 such appointments have been made. To date no appointed representatives have been contacted to make a decision about organ donation on behalf of a deceased person. 

97. In supplementary written evidence the British Heart Foundation provided data on Welsh registrations on the organ donor register as at 15 November 2015. This data was produced approximately 2 weeks before the change to organ donation legislation commenced and shows that only 8 appointed representatives, out of a population in Wales of approximately 3 million, had been registered. 

98. NHSBT updated the organ donor register in light of the Welsh legislation and advised that the new organ donor register can currently accommodate the registering of only two proxies per person, in line with other jurisdictions of the UK. It did not consider the register could be easily changed to accommodate the registering of three proxies without disabling functions required by legislation in other parts of the UK.

Views

99. There were mixed views on this provision.

100. Those who supported the provision looked on the role of the proxy as being similar to that of an executor of a will and believed that the ability to appoint proxies would be welcomed by those who were estranged from their families or looked-after children. The Scottish Youth Parliament welcomed the proxy role explaining that it provided young people more options, such as those aged 16 to 18, who were in care, and who may not feel comfortable with their nearest relative or legal guardian making the final decision about what happened to their organs after their death.

101. CARE for Scotland agreed with the provision as in many cases relatives may not actually have any knowledge of the deceased person’s wishes.

102. The Scottish Ambulance Service noted that whilst the role of a proxy may cause an additional delay it could be useful for people who believe that their family may object to organ donation. This would allow them to appoint someone else to ensure their wishes were carried out. The Scottish Ambulance Service also highlighted that the suggestion that existing practice may continue (whereby organ donation does not proceed if there will be significant distress caused to the family of the deceased) "appears to contradict the spirit of the Bill or the benefit of the proxy."

16
103. Those who opposed the provision of proxies\textsuperscript{74} highlighted two main issues. The first was that their inclusion may lead to the family being marginalised or excluded from the organ donation process.

104. The British Transplant Society questioned what added value a proxy would bring to the process. They, and others such as NHSBT, advised that medical practitioners were reliant on family members to gain as much knowledge as possible about the donor, in order to assess the safety of organs for transplant. If the family was removed from the decision making process they may withdraw their cooperation and not provide this vital information.\textsuperscript{75}

105. NHS Fife did not agree with the provision to appoint a proxy, also raising the concern that that the appointment of a proxy could potentially lead to family and proxy disagreement at a very difficult time. If a doctor accepted the proxy decision against the wishes of close family, it believes this could result in a loss of trust between the doctor looking after the patient and the family.\textsuperscript{76}

106. The second main issue relating to proxies was whether or not their inclusion would add an additional layer of bureaucracy to the process which could result in delays that could harm the organ donation process.\textsuperscript{77} This is because each proxy could be needed to be contacted in turn before speaking to the family.

107. The Committee heard that the process of organ donation, as it currently stands, can take between 18 to 25 hours from the conversation taking place to getting everything in place for the removal of organs to proceed.\textsuperscript{78}

108. The Royal College of Physicians of Edinburgh stated that:

\begin{itemize}
  \item If an individual may appoint up to three proxies, we need to consider the time that it will take to contact them and the reliability of the database on which the proxy information will be kept...if somebody is unaware that they are a proxy that could add to the time problem.\textsuperscript{79}
\end{itemize}

\textbf{Scottish Government}

109. The Scottish Government did not support the proposal to appoint up to three proxies.

110. The Scottish Government advised that the introduction of optional proxies would add a time-consuming layer of administration to the current time-critical organ donation process. It also has concerns that it has the potential to cause significant additional distress to the families, the proxies and to clinical staff.\textsuperscript{80}

111. The Scottish Government stated that it was unsure what problem the proxy provision was trying to solve. It also questioned whether there was a need for the provision since there was such low uptake in the rest of the countries in the UK, which enabled up to two appointed representatives to be nominated.\textsuperscript{81}
112. The Scottish Government questioned whether it was right to introduce a new law (i.e. proxy precedence over nearest relatives) if the expectation beforehand is that it will not, and should not, be followed in certain circumstances (i.e. when the family is distressed). It additionally noted that the concession to the family appears to directly conflict with the aim of having a proxy to over-ride the family.  

Member in charge

113. Anne McTaggart MSP stated that the proxy provision had been carefully designed so as not to cause additional delays to the process. Allowing up to three proxies was in fact intended to maximise the chances that at least one would be contactable within the time-limited frames involved.

114. Anne McTaggart MSP acknowledged that there had been low uptake of proxies (authorised representatives in Wales and nominated representatives in England) but did not see how this was a reason to not include them in her Bill. The Bill therefore aims to provide the option to the people in Scotland as is the case for the rest of the UK.

115. The Committee acknowledges that legislation in the rest of the UK allows for people to appoint up to two appointed representatives (proxies) but notes that the uptake for this function has been very low and not utilised to any great extent.

116. The Committee recognises that there are reasons why families may not be in contact with each other. As such the ability to appoint someone, other than a family member, who knows your wishes on organ donation could be desirable. We note the comments from the member in charge of the Bill, NHSBT and medical professionals that the decision of any proxy would never override the family wishes if that decision would cause the family significant distress.

117. However the majority of the Committee agrees that the Bill’s proposal to allow the appointment of proxies could cause unnecessary delays to an already time-sensitive process and could also result in additional stress being placed on the family of the donor at a very sensitive time. They consider that it could put at risk the receipt of information from the family, which is vital for organ donation to proceed, should the family end up marginalised due to a difference in opinion with a proxy and possible time delays.

118. A minority of the Committee agrees with the provision for a proxy to be appointed, welcoming the role that a proxy could play in situations where people did not have next of kin or did not want their family to make decisions on their behalf, such as looked-after children. That said, this minority of the Committee agrees that should this Bill proceed to Stage 2 then it would
encourage the member in charge to amend the Bill to allow for only two proxies, as is the case in the rest of the UK. This may also address some of the concerns of NHSBT regarding the importance of consistency in the organ donation process across the UK.

Requirements for registering a proxy

119. The appointment of a proxy must be made in writing but there is no requirement for the proxy to be advised of this appointment or to agree to it. They do however have the right to renounce the appointment at any time. This was raised as an area of concern by some witnesses.

120. The Law Society of Scotland found it “incomprehensible” that an individual might not even know that they were a proxy, given that it is such an important decision and such a responsibility. It suggests that this should be revisited and that a proxy should have to consent to their appointment.

121. Sally Johnson, representing NHSBT advised that without the authorisation of the nominated proxy it would be unable to hold the proxy’s personal details in the organ donor register, stating—

> My understanding and the advice that I have received is that we cannot hold data about people that has not been given to us by the person...It could not be entered without the agreement of the person who has been nominated.

122. NHS Greater Glasgow and Clyde believed that it was unwise that a proxy should be appointed without them being aware of the proposal, especially since ideally the proxy should have had the opportunity to discuss donation with the potential donor.

123. Under the Bill’s provisions if a proxy is appointed they will be a valid proxy unless they are removed or the person subsequently uses one of the other methods for noting their wishes (such as joining the opt-in register or opt-out register).

124. Some submissions questioned whether there should be a time limit on the length of appointment of a proxy.

125. The Royal College of Physicians of Edinburgh and others felt that a time limit on being a proxy would help ensure that the correct contact details were listed on the database and that the proxy was still the person that the individual wanted to be contacted.

126. The Church and Society Council of the Church of Scotland agreed and suggested every three years as a review period.
127. The Committee agrees with witnesses and considers that the process for registering a proxy must include receiving consent from the nominee.

128. This will ensure that the person being nominated will have spoken with the person about their wishes and, should they be called upon to make a decision about organ donation, is better able to make an informed decision. This approach will also address NHSBT concerns about data protection and adding proxy details to the organ donor register.

129. The Committee asks for confirmation from the member in charge of the Bill (before the Stage 1 debate on this Bill) whether she will seek to amend the Bill accordingly, should the Bill proceed to Stage 2.

130. The Committee also seeks the member in charge’s view on the proposal that the Bill should provide for a regular review period for the validity of a proxy registration.

European Convention on Human Rights issues

131. Some written submissions raised the issue of whether the Bill, under certain circumstances, could contravene the European Convention on Human Rights (ECHR). Article 8(1) of ECHR provides that “everyone has the right to respect for his private and family life, his home and correspondence”. Questions were raised by some witnesses regarding whether in circumstances where a proxy seeks to over-rule the wishes of a bereaved family member; it might be possible that the provisions of the Bill engage the Convention Rights of the family of the deceased person whose organs are removed for transplantation under the Bill, contrary to the family’s wishes.

132. The Law Society of Scotland advised that in examining rights under Article 8 it would, as normal, be looking at the autonomy of the individual, their views and whether it could build a picture of what their preference would have been. However, in the absence of any evidence as to a person’s views there could possibly be a challenge.92

133. The Scottish Council on Human Bioethics questioned whether ECHR could also be contravened if someone was not aware of the new system having come into place. In its written submission it stated that—

> if a deceased person was not aware of (1) the system of consent/authorisation in place and (2) the possible destiny of his or her body or its parts (transplantation, research, etc.), and the use of the body or its parts did go ahead without the individual having given his informed consent, there may be grounds for taking the case to the European Court of Human Rights. This is because the European Convention on Human Rights and Biomedicine requires informed consent to take place before any
intervention is envisaged. And, in this case, an intervention would also include a procedure after death under the spirit of the law.\textsuperscript{93}

**Scottish Government**

134. Concerns were raised by the Scottish Government as to whether ECHR could be contravened. Their concern was to whether the priority given to proxy decisions, and presumed consent itself, could be seen as contravening Article 8 or Article 9 rights of family members under ECHR law.

**Member in charge**

135. Anne McTaggart MSP explained that the system of ‘appointed representatives’ has been operational in the rest of the UK for almost 10 years and she is unaware of any legal challenges during this time under Article 8 of the European Convention on Human Rights.

136. The Committee notes the views of witnesses, the Scottish Government and the member in charge of the Bill on whether ECHR could be engaged by proxy provisions of this Bill.

**The role of authorised investigating persons**

137. The new provisions inserted by the Bill into the 2006 Act provides for the role of “authorised investigating person” (AIP), to be set out in regulations made by the Scottish Ministers. This allows designation to be by category (e.g. by reference to a role or level of experience within the NHS). The regulations designating AIPs will be subject to annulment by resolution of the Parliament (“the negative procedure”).\textsuperscript{94}

138. The role of the AIP is described in the Policy Memorandum as being a health professional whose role would be to determine whether or not a deceased adult’s organs can lawfully be removed and used for transplantation.\textsuperscript{95}

139. The AIP would initially have to check whether the adult was resident in Scotland at the time of death. If they were the AIP would then be required to ascertain whether six pre-conditions had been met. The pre-conditions are:

   a) checking whether the person’s wishes (to opt in, opt-out or appoint a proxy) were formally registered

   b) contacting, or attempt to contact, any proxies that have been appointed to obtain a decision (authorising or refusing authorisation for the removal of organs)
Health and Sport Committee
Stage 1 Report on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill, 3rd Report, 2016 (Session 4)

(c) where there is no proxy, or the proxy or proxies are unable or unwilling to make a decision within a reasonable time, it is for the AIP to consult the nearest relative to check:

i. whether the deceased person had a “reasonable opportunity” to opt-out

ii. whether they are aware of any (unregistered) objection that the adult had (to the removal of the organ in question for transplantation)

d) where there are no proxies or nearest relatives to advise if the deceased had objected to removal of organs for transplantation then the AIP can authorise removal by “authorisation by operation of law” 96

Views

140. The Committee received mixed views on the role of an AIP. Most of the evidence received focused on what the role of the AIP would be, who would carry the role out, whether it is a separate role from those staff already involved in the donor’s care and what a “reasonable time” is for the AIP to make a decision.

141. The British Heart Foundation Scotland, BMA Scotland and the Royal College of Physicians of Edinburgh all noted that many of the duties described as being carried out by the AIP were already tasks carried out by a specialist nurse in organ donation. All agreed however that should the specialist nurse in organ donation be identified as the person to take on the AIP role they would need additional training and it would be essential that they were available at all times. 97

142. The Scottish Government’s ‘A Donation and Transplantation Plan for Scotland 2013–2020’ states that part of the role of a specialist nurse in organ donation “is to check the individual’s wishes (by checking the NHS Organ Donor Register) and to speak to the family. The specialist nurse in organ donation has a key role in ensuring that the family or next-of-kin feel able to support donation where the deceased had made known a wish to donate, or can take an informed view in instances where the deceased had not made their wishes known. Even though the law in Scotland allows donation to proceed in the absence of family authorisation, in practice, donation would not currently proceed without this support. At all times specialist nurses in organ donation are devoted to the care and on-going support of the potential donor’s family, often many years into the future, providing families with regular updates, and including them in remembrance services”. 98

143. Others disagreed with the AIP role being carried out by a specialist nurse in organ donation. The Scottish Council on Human Bioethics did not feel that it was ethical for the specialist nurse in organ donation to carry out the role of the AIP. It considered that this would cause a conflict of interest with their role to support the family. At present a specialist nurse in organ donation does not authorise organ
removal for transplant, their role is to ask the nearest relative whether transplantation can go ahead.\textsuperscript{99}

144. NHSBT also had concerns about the AIP role being carried out by a specialist nurse in organ donation. It felt that the AIP role does not appear to be entirely consistent with supporting the family through the process of organ donation and that the legal requirements of being an authorised investigating person presents some conflicts with the specialist nurse’s role of supporting the family.\textsuperscript{100}

145. NHSBT believes that the role could only be carried out by a healthcare professional. Irene Young, a specialist nurse in organ donation, stated that—

\begin{quote}
\ldots\textit{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.}\textsuperscript{101}
\end{quote}

146. NHS Fife felt that there was no need for the role of AIP and that the system of specialist nurses in organ donation already in place should remain unchanged. It further stated that the AIP role could not be carried out by a specialist nurse in organ donation or a clinical lead on organ donation therefore if the AIP was deemed as required then a new role would be needed and they would have to be available 24/7.\textsuperscript{102}

147. The Law Society of Scotland felt that the role of an AIP would be a very onerous one stating—

\begin{quote}
\ldots\textit{not only are they interpreting, but they are looking at a cascading process, particularly in relation to proxy decision making...there is no mention of consent in the Bill...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.}\textsuperscript{103}
\end{quote}

148. It further stated that it did not believe that the individual carrying out the AIP role should be a healthcare professional as that would also seem to raise a conflict of interest.\textsuperscript{104}

149. The Delegated Powers and Law Reform Committee (DPLRC) noted that the power is drawn to permit any persons, or categories of persons, not just those within the NHS, to be so designated for the purpose of the Bill.
150. In her response of 19 November 2015 to the DPLRC\textsuperscript{105} Anne McTaggart MSP acknowledged that this power is drawn in a way that would allow Scottish Ministers to designate persons from outwith the NHS as authorised investigating persons. Anne McTaggart MSP further acknowledged that this was not her intention and that she would therefore consider lodging an amendment at Stage 2 of the Bill to draw the scope more narrowly, to only apply to relevant health professionals within the NHS.

151. Another issue by NHS National Services Scotland and others in relation to AIP was\textsuperscript{106} that there is no detail as to what a “reasonable time” would be for an AIP to contact proxies or to take a decision as to proceed with organ retrieval through authorisation by operation of law. This leaves it open to interpretation and could give rise to legal challenge which could have a detrimental effect on donation overall and lead to a loss of trust between families and those that care for them.\textsuperscript{107}

**Costs of provision of AIP**

152. The Financial Memorandum to the Bill does not identify any additional cost as being required to carry out the role of authorised investigating person. Anne McTaggart MSP explained that she did not see the AIP as being a wholly new role and that the responsibilities could be carried out by a health professional already working within the NHS such as a specialist nurse in organ donation.

153. NHSBT described the role of the AIP as “potentially the most significant financial issue relating to the Bill” and advised that should specialist nurses in organ donation be seen as the suitable candidate for such a role then they would need to be available 24 hours a day 365 days a year. They advised that to ensure such availability they would require additional funding of around £1.1 million per annum.\textsuperscript{108}

154. The Scottish Government provided the Finance Committee with a projection of the approximate costs should an AIP team have to be created. They projected, based on a similarly created role of Medical Reviewers, that the recreation of a new AIP team would cost around £120,000 in year one set up costs with annual recurring costs of £1.2 million per annum.\textsuperscript{109}

155. The Scottish Government also concluded that should the Bill be amended so that the role of AIP could be carried out by a specialist nurse in organ donation more would be required than currently exist and that this would result in additional costs.\textsuperscript{110}

156. The Scottish Government commented that even if the Bill was amended so that the role of the specialist nurse in organ donation better aligned with the role of the AIP then there would be an issue of funding as there would be a requirement for more specialist nurses in organ donation than were currently available.\textsuperscript{111}

157. Anne McTaggart MSP advised the Finance Committee that should the role of AIP be undertaken by specialist nurses in organ donation, enhanced training would be
required and this would cost approximately £500,000.\textsuperscript{112} In evidence to the Finance Committee, the member in charge noted that the Governments in Wales and Northern Ireland had adopted similar approaches to AIPs and that neither had recruited additional staff to become AIPs.

158. During oral evidence to the Health and Sport Committee, Anne McTaggart MSP noted that—

\begin{quote}
In the Bill we have set aside £0.5 million for enhancing the current role. That would be done through post-qualification experience and education. That is what is being done with the 2013 act in Wales.\textsuperscript{113}
\end{quote}

Scottish Government

159. The Scottish Government believes that the additional role of an AIP, with the additional checks required, and their legal complexities, would be more likely to slow the system down. It states that there is nothing within their role that would reduce the current administrative burden associated with organ donation.\textsuperscript{114}

160. During oral evidence the Scottish Government stated—

\begin{quote}
the process will happen after a family has been sitting with a loved one perhaps for days or hours[…] the family is then expected to wait for that further process to take place[…] we already lose donors because the process is quite long.
\end{quote}

161. Additionally it noted that the longer it takes to retrieve organs the less viable many of those organs will be.\textsuperscript{115}

162. The Scottish Government highlighted that the role of the AIP would require the person carrying out that role to make legal judgements.\textsuperscript{116}

163. The Scottish Government considered that the AIP would be personally legally accountable for decisions, noting that the terminology in the Bill talks about “his or her” decisions and judgements which could conceivably mean the AIP might have to justify decisions in court if something went wrong.\textsuperscript{117} The Scottish Government was concerned that this could result in the AIP applying high levels of caution in their investigations and decisions, which might delay or in some instances even prevent donation from proceeding where it might otherwise have gone ahead.\textsuperscript{118}

164. The Scottish Government noted that in Wales, under the new organ donation legislation, there has been no role such as the AIP introduced with specialist nurses in organ donation only carrying out fact checks and not making legal judgements.\textsuperscript{119}

165. The Scottish Government was also concerned that some specific operational aspects of the role need to be clarified such as the requirement for consistent judgements on timescales for contacting proxies. The Scottish Government raised
questions around what the possible implications on the organ donation service would be if any conflict between the AIP and the family arose.\textsuperscript{120} 

166. The Scottish Government agree with NHSBT that specialist nurses in organ donation could not carry out the role of AIP as it would result in a conflict of interest.\textsuperscript{121} It also noted that it is unsure whether a health professional could carry out the AIP role.\textsuperscript{122}

Member in charge

167. Anne McTaggart MSP stated that she did not envisage the role of the AIP being taken on by anyone other than a specialist nurse in organ donation, stating "We are not talking about two different people. The AIP is not a different person".\textsuperscript{123} She also noted that the Bill, by introducing the term "authorised investigating person", does not create a whole new role, and that it would be for the Scottish Government and the NHS to decide which staff would carry out the role.\textsuperscript{124}

168. In a letter to the Committee, Anne McTaggart MSP stated that the AIP has a procedure to follow and criteria to apply; some of these require judgements to be made, but that this is inevitable in the context, and is already part of what NHS staff do in many end of life situations.\textsuperscript{125}

169. Anne McTaggart MSP believes that a role, similar to that of the AIP, is currently carried out in Wales by the specialist nurse in organ donation and questioned other witnesses' evidence that Scotland would need someone different to do this role, thereby inventing another layer of staff.

170. In that regard the member in charge's official confirmed that—

> I do not think that we can get away from the fact that even if the authorised investigating person role is removed, judgment will still need to be exercised. The Human Transplantation (Wales) Act 2013 provides for the exercise of judgment; it is just less specific about who makes the judgments. I guess that there is a policy call about whether introducing a role for an authorised investigating person is the right way to go.\textsuperscript{126}

171. Anne McTaggart MSP noted that what amounts to a “reasonable time” is determined by the AIP taking account of the timescales in which decisions must be made if the organ is to be transplanted.\textsuperscript{127}

172. Anne McTaggart MSP confirmed that the AIP sections in this Bill are similar to the Welsh Act. She explained that the Welsh Act provides the following explanation of what “a reasonable time” is—

> …if it is not reasonably practicable to communicate with [an appointed representative] within the time available if consent is to be acted upon, the person is to be treated as being not able to give consent to an activity under the appointment”.\textsuperscript{128}
173. The Committee recognises the importance of public trust in the organ donation system that organs will only be taken when that is the wish of donors and their family. The Committee notes the level of uptake for appointed representatives elsewhere in the UK is low and that therefore in the majority of cases the family will be the first contact for AIPs in relation to organ donation. The Committee notes the important role that families play in ensuring that personal information is provided.

174. We acknowledge that the role of AIP as proposed in this Bill could play an important role in ensuring that organ donation is authorised ‘by operation of law’ thereby maintaining trust in the organ donation system.

175. However, the majority of the Committee consider that the role currently carried out by specialist nurses in organ donation and the role of AIP as proposed are so significantly different that they do not consider that the AIP role could be carried out by a specialist nurse in organ donation. We agree with witnesses that the specialist nurse in organ donation’s role of supporting families through organ donation would appear to be in conflict with the role of the AIP in ‘authorising’ organ donation when on occasion that authorisation could involve a proxy decision taking precedence over the family’s views.

176. The majority of the Committee are also concerned by possible time delays that introducing the role of the AIP may have on the organ donor process. This is given the greater range of tests which the AIP requires to apply in order to conclude that organ donation can proceed legally and that the AIP may require to contact up to three proxies, and potentially also families. Any additional time added to the already time critical process is undesirable. They also have concerns that should the family end up feeling marginalised due to a disagreement with the AIP’s decision then it could be very difficult for all the necessary information to be collated to ensure a safe transplant could take place. This could then increase the risk to any organ recipient.

177. The minority of the Committee considers that the role of the AIP is important and could be undertaken by either a specialist nurse in organ donation or other health professional. Whilst judgement will require to be exercised by whoever takes on the AIP role, the minority of the Committee considers that the Bill adequately provides for regulations to be brought forward at a later date, which would enable Scottish Ministers to identify which health professionals or categories of health professionals are most suited to undertake the AIP role.

Publicity campaign

178. The Bill requires the Scottish Government to undertake a publicity campaign to ensure the public awareness of the changes being introduced by the Bill. The
publicity campaign is required to last throughout the period between the “first appointed day”\(^\text{iv}\) and the “second appointed day”\(^\text{v}\), which must be at least 6 months apart. The Bill states that the actual duration of the publicity campaign can be longer than the minimum required, should the Scottish Government consider this appropriate.

179. The Bill’s Financial Memorandum states that should a one-year publicity campaign be considered appropriate then the estimated cost would be £2.8 million. This is based on halving the £3.3 million spent by Wales over a two year period and adjusting by a factor of 1.7 to account for Scotland’s larger population size and geographic area.\(^\text{129}\)

180. The Financial Memorandum goes on to explain that the Scottish Government has an annual advertising budget of £7.2 million, with the most recent figure for spend on health and social care campaigns (2012-13) totalling £1.2 million (gross). £527,000 (gross) of this budget was spent on organ donation.\(^\text{130}\)

181. Anne McTaggart MSP subsequently confirmed that she agreed with the Scottish Government’s estimated £3.3 million figure for publicity campaigns for the first two years.\(^\text{131}\)

182. Anne McTaggart MSP advised that costs for a recurring publicity campaign were not included in the Bill’s Financial Memorandum as under section 1(1)(b) of the Human Tissue (Scotland) Act 2006 the Scottish Government must “promote information and awareness about the donation for transplantation of parts of the human body”, and as such this cost was already accounted for.\(^\text{132}\)

**Views**

183. All the evidence the Committee received agreed that a publicity campaign as proposed by the Bill was required but that six months was seen as insufficient by most of the respondents and witnesses.

184. NHSBT advised that the Welsh Government had carried out an intensive communications campaign, which lasted two years and involved two leaflet drops to every single household, plus an additional drop to everyone approaching the age of 18. NHSBT explained that any publicity campaign had to be something that reaches all and gets everyone to understand the new law.\(^\text{133}\)

185. A number of other bodies highlighted concerns with a six month campaign, such as:

- that it was inadequate and that either a continuing publicity campaign was required or an alternative way to ensure that people were informed and that

\(^\text{iv}\) the day appointed by Scottish Ministers for the Commencement of the Bill.

\(^\text{v}\) the day it becomes lawful to remove a deceased adult’s organs for transplantation under the Bill.
any information programme must be permanent to ensure that all teenagers and new immigrants were informed of the opt-out system,\textsuperscript{134}

- that such a campaign could have the unintended consequence of actually promoting how to opt-out rather than encouraging people to opt-in which could in turn affect donation rates,\textsuperscript{135}
- whether an opt-out system could ever be ethical given for any opt-out system to be ethical everyone in the country should know about it.\textsuperscript{136}

\textbf{Scottish Government}

186. The Scottish Government believed that a six month publicity campaign would be too short a timescale and this would have to be increased to one or two years depending on the implementation schedule of the Bill.\textsuperscript{137}

187. The Scottish Government stated that there would also need to be continuing marketing and awareness raising for two main reasons:

a) the difference age limits on donation (see later section entitled Age), whether 12, 16 or 18 (in the UK), given people turning 16 could be deemed to have given consent, if they had not opted out,

b) people coming to the country for the first time, such as students and people travelling from other parts of the UK, would be new to the system so would need to be made aware of the law.

188. The Scottish Government submitted its own breakdown of what it believed the cost for publicity and awareness-raising could be. It advised that to ensure the changes were publicised well it had calculated the cost over two years, as being £3.3 million, with recurring yearly costs of £0.62 million thereafter.

189. The Scottish Government advised that there was a need for continuing publicity to—

\begin{quote}
prevent a general drop in awareness after the initial year or two. Particularly important is the need to inform those turning 16 each year that…they would now be considered to be willing to be donors unless they opt-out.\textsuperscript{138}
\end{quote}

190. The Scottish Government stated that the obligations under this Bill would differ from those under the 2006 Act, including the additional requirement to notify all of those approaching 16 years of age and students and temporary foreign contractors in the county of their right to opt-out.\textsuperscript{139}

191. The Scottish Government also noted that although the marketing spend on organ donation was £527k in 2012-13 this budget had since been halved and as such is lower than that required for the on-going publication costs of a new opt-out system.
192. The Scottish Government advised that in 2013-14 it had started a new organ donation campaign which resulted in a lot of up-front costs, such as creative development and testing, which made the budget much higher than in any other year. When it then moved to implementation of this new campaign a lot of it was online and as such costs were much lower – resulting in the budget being effectively halved.\(^{140}\)

193. This therefore meant that the £0.62 million recurring publicity costs could not be met from the existing Scottish Government budget for organ donation and would have to be viewed as additional costs.

**Member in charge**

194. The member in charge of the Bill explained that although the forecast £2.8 million spend\(^{vi}\) on publicity for organ donation arising from this Bill is a large increase from organ donation marking spend of £527,000 in 2012-13. She considers that the Scottish Government already has to decide which policy areas get priority and as such, believes that the Scottish Government could re-prioritise spend from other portfolios in favour of Health and so could prioritise this spend on organ donation resulting in no increase to their overall advertising expenditure.\(^{141}\)

195. Anne McTaggart MSP also stated that she could not understand why the Scottish Government’s recurring publicity costs would need to be more than four times higher than in Wales, and that as the £0.62 million figure was only slightly higher than the £527k Scottish Government marketing budget for organ donation then these recurring costs should be able to be absorbed within existing budgets. This would therefore leave only the cost of the initial publicity campaign as additional expenditure arising as a result of this Bill.\(^{142}\)

196. The Committee acknowledges that publicity of the changes proposed by this Bill is crucial to ensure that the high level of public trust in the organ donor system continues and that people in Scotland are fully aware of the implications of the changes to that system as a result of this Bill.

197. In that regard the Committee notes that the Welsh Government carried out a two-year intensive campaign and we consider that the Scottish Government would need to provide a similar campaign to ensure that everyone in Scotland was aware of the changes. This is especially important given people would, for the first time, be able to appoint proxies.

198. The Committee notes that the member in charge is content to extend the publicity campaign to two years and we recommend that should the Bill proceed to Stage 2 she brings forward an amendment to reflect this.

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\(^{vi}\) The member in charge subsequently agreed with the Scottish Government cost estimates of £3.3 million for a two year publicity campaign.
Persons to whom the Bill applies

Adults with incapacity

199. The Bill proposes to amend the Adults with Incapacity (Scotland) Act 2000 (2000 Act) to impose restrictions on what actions an adult’s welfare attorney or guardian may take in relation to organ donation.

200. At present, Section 16 of the 2000 Act allows a person to grant a power of attorney relating to his personal welfare that may be exercised at such time as the granter lacks the capacity to make decisions for him or herself. Various restrictions are placed on what the welfare attorney may do, and this currently includes provisions preventing the attorney giving authorisation for the removal or use of organs under various sections of the 2006 Act.

201. The new restrictions under subsection (2) prevent a welfare attorney from either appointing (or withdrawing the appointment of) a proxy, or objecting to the removal of the adult’s organs. Subsection (3) amends section 64(2) of the 2000 Act to impose the same restrictions on a guardian.\textsuperscript{143}

Views

202. The Scottish Council on Human Bioethics noted that it would not have any concerns with adults with incapacity donating their organs, stating—

\begin{quote}
People with severe mental disabilities should be able to donate their organs after their death, because they should be considered persons like you and me. They have the right to donate their organs after their death and that right should be respected.\textsuperscript{144}
\end{quote}

203. The Royal College of Physicians and Surgeons of Glasgow also agreed, noting that if a person has no supporting relatives or proxies then one would be comfortable with a presumed consent scenario for adults with incapacity.\textsuperscript{145}

204. NHS Greater Glasgow and Clyde noted that the Bill seems to imply that for adults with incapacity a welfare attorney cannot either appoint a proxy or object to donation and that this implies that authorisation by operation of law will always be possible irrespective of whether a welfare attorney knew the wishes of the organ donor.\textsuperscript{146}

Scottish Government

205. The Scottish Government raised concerns around whether adults with incapacity could in effect become “locked-in” to organ donation as neither they, nor someone acting on their behalf under the provisions of the 2000 Act, would be able to appoint a proxy, or be able to register an objection to the removal of organs.\textsuperscript{147}
206. It also noted that Section 15 of the Bill could have the effect of leaving the next of kin or guardian unable to exercise their current right (under Section 7 of the 2006 Act) to not allow organ donation to proceed.

207. The Scottish Government was not persuaded of the ability for the AIP to conclude that an adult did not have capacity, and therefore did not have reasonable opportunity to object. This is because the AIP is under no obligation to establish the adult's capacity status or take that into account when deciding whether removal of organs for donation is authorised by operation of law.  

Member in charge

208. The member in charge responded to concerns that adults with incapacity may get “locked-in” to organ donation, noting that under Section 6B, the AIP must satisfy themselves “that the adult had a reasonable opportunity to record an objection to such removal and use” of their organs. In that regard, a lack of capacity over a substantial period is the sort of factor that could lead the AIP to conclude that a person lacked a reasonable opportunity to object – and so prevent the removal of organs being authorised.

209. Anne McTaggart MSP advised that currently, the relatives, guardians and welfare attorneys of adults living with incapacity have no legal power to opt them in to organ donation. The Bill does not change that position; it merely extends the principle to cover other comparable decisions (i.e. to opt-out or to appoint or withdraw a proxy).

210. The Committee notes the differing views as to whether the Bill as proposed would provide adequately for adults with incapacity to opt-out of organ donation.

211. The Committee seeks views from the member in charge on what factors relating to incapacity AIPs should have regard to when deciding if a reasonable opportunity had been given to opt-out.

212. Given the Committee’s previous comments (see para 176) on the timescale for an AIP deciding whether organ donation is lawfully authorised, we seek the member in charge’s comments on the extent to which seeking to determine whether an adult lacks capacity might further delay any AIP decision.

Resident in Scotland

213. The Bill applies to people who were resident in Scotland at the time of their death and had been habitually resident in Scotland for a continuous six month period, beginning after their 16th birthday and after the day the opt-out register first became available.
214. Section 6(1) of the Bill proposes to insert a new section 6B(1)(a) into the 2006 Act which would exclude any adult who was not a resident in Scotland at the time of death from the proposed new opt-out system. The Policy Memorandum states that this aims to ensure adults from countries operating opt-in systems of organ donation that die in Scotland cannot have their organs removed for transplantation as they would not have had an opportunity to record an objection.\textsuperscript{151}

215. The Delegated Powers Memorandum on the delegated powers provisions in the Bill states that it might be thought unreasonable that a person dying in Scotland, who met the requirements for opt-out under their home system, should be excluded from the opt-out provisions in this Bill.\textsuperscript{152}

216. Section 16 would enable the making of regulations to modify the 2006 Act (as amended by this Bill), to make provision for these circumstances. Regulations could only modify the 2006 Act if the laws of the country of the person’s residence authorise the removal of parts of the body from a deceased adult for transplantation, either generally or in particular circumstances, in the absence of a prior objection by the adult.

Views

217. NHSBT advised that a year would be a “safer period” of time for someone to be resident in Scotland before they were eligible for the opt-out system. It noted that this would provide them time to find out about the law and become informed. It also advised that this would make it consistent with the Welsh legislation.\textsuperscript{153}

218. The Law Society of Scotland also suggested that a year seemed a more reasonable period of time.\textsuperscript{154}

219. The DPLRC raised a concern that the Scottish Ministers’ power to modify the 2006 Act where the criteria in section 16(2) are met is drawn too widely. It explained that their concern was that the requirements define the persons who would be subject to the power, rather than defining the system of organ donation which might be applied to them in future.

220. DPLRC also had concerns that Section 16 was drafted too widely and would currently allow for someone from any country with an opt-out system to be considered. It recommended that should the Bill proceed to Stage 2, an amendment should be considered so that an adult must be resident, immediately before death, in a jurisdiction in the remainder of the UK, rather than any jurisdiction other than Scotland.

Scottish Government

221. The Scottish Government noted that the Bill’s Policy Memorandum assertion that it is reasonable to assume that an adult who has an objection to donation would opt-out within a period of six months of habitual residence appears to be a subjective judgement.\textsuperscript{155}
222. The Scottish Government state that the six month residency could be expected to have additional implications and significance for international students, foreign contractors and new permanent residents in Scotland (and their next of kin), particularly if English is not their first language and/or their culture or religion does not allow for organ donation.\(^{156}\)

Member in charge

223. Anne McTaggart MSP advised that a six month period of habitual residency in Scotland was a sufficient period of time for adults to be made aware of the change to the law on organ donation and to opt-out if they wished to do so.

224. Anne McTaggart MSP also observed that moving to a foreign country carries a lot of legal consequences with it, but that it is each individual’s responsibility to familiarise themselves with the laws of the country.\(^{157}\)

225. Anne McTaggart MSP did however indicate that she would be happy to consider extending the timescale, such as to 12 months, if it was decided six months was not sufficient.\(^{158}\)

226. The Committee notes the concerns raised with the Committee that six months may not be a reasonable time for someone coming into Scotland to acquaint themselves with the organ donation process and how to opt-out as proposed by this Bill.

227. The Committee therefore welcomes the member-in-charge’s indication that she would be happy to amend the Bill to provide for 12 months habitual residence before a person, who dies in Scotland, is considered able to donate their organs.

228. The Committee notes that the member in charge responded to the DPLRC concerns confirming that she would be willing to see the provisions at section 16 amended at Stage 2 to narrow the power in section 16(2); and to restrict the application of the Bill at section 16 to include only other UK jurisdictions.

229. We invite the member in charge to confirm, before the Stage 1 debate, that she will bring forward these amendments at Stage 2, should the Bill proceed.

Age

230. The Bill’s Policy Memorandum states that the changes will only apply to adults (defined as people who are aged 16 years and above). In England and Wales people can opt in (in England) or opt-out (in Wales only) who are aged 18 years and above.
231. However, the 2006 Act, under Section 8, allows for a child who is 12 years of age or over to authorise the removal and use of a part of their body after their death for transplantation, research, education or training and audit. This means that a child who is 12 years of age or over can opt-in to the organ donor register.

Views

232. The Committee heard mixed views as to whether 16 and over was an appropriate age for this Bill.

233. The Scottish Youth Parliament believed that 16 was an appropriate age to be considered an adult for the purposes of organ donation but believed that the right to opt-in from 12 should be retained.  

234. The British Heart Foundation was also keen for the right of a 12 year-old to opt-in to be continued even if there was a change to an opt-out system, noting—

I think that our system is special and significant because we allow really young people to make an affirmative statement about their wishes and what they would like to happen. That is empowering. It enables our young people from a very young age to demonstrate what they see as being their role and potential in society even in the event of their death. I would be loath to see that lost in any new system.

235. BMA Scotland was also keen for children to be able to continue to opt-in. It felt that this really helps parents who have lost a child as it means that they knew that their child wished to donate their organs and it could then follow through on this.

236. The General Medical Council, indicated that it believed that only adults (18 years old and over) should be automatically opted-out.

237. The Law Society of Scotland noted the differing ages to opt-in to organ donation in the different jurisdictions within the UK. It explained that although 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 it is not sure that agreeing to organ donation could be considered medical treatment. It explained that if the Bill was about enabling people to make informed choices then it would probably be easier if the age limit was the same in Wales, in Scotland and any other jurisdiction in the UK.

238. NHSBT confirmed that having differing age applications across the UK would add complexity such that it would have to train their nurses to understand the law in each country. It gave the example that if a 16 year-old resident of Scotland happened to die whilst on a visit to London then the nurse would have to be aware of the differences to these two countries organ donor systems.
Scottish Government

239. The Scottish Government is unclear as to why the provision as drafted applies to only those 16 years-old and over. It does not see any reason why children aged 12 or above should not register their objection to organ donation by opting-out in the same way as it can currently opt-in.\(^{165}\)

240. It explained that children of 12 and over can already opt-in via the organ donor register and that this Bill risks removing a right that children currently have.

241. The Scottish Government commented that allowing children of 12 years and over the choice of explicitly opting-in or opting-out does, and would, provide parents or nearest relatives with a clear expression of the child’s wishes.

242. The Scottish Government recognises that the age of 16 was selected to align with certain other rights (e.g. voting and the right to get married), but questioned why that did not include the most directly similar existing legal right, which is the right to authorise donation at 12, under the Human Tissue (Scotland) Act 2006.\(^{166}\)

Member in charge

243. Anne McTaggart MSP explained that she set the age limit of 16 in the Bill as this is the age at which people acquire many other legal rights and considers that they are old enough to fully understand their legal obligations in terms of opting-out of organ donation or making no choice.\(^{167}\)

244. The member in charge noted that when putting the Bill together she took evidence from the Scottish Youth Parliament who analysed research behind age which helped her decide to propose the age of 16 years and over in the Bill.

245. Anne McTaggart MSP advised that when consulting on 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 opt-out of organ donation at that age. Whilst young people can opt-in at the age of 12 this is only with the consent of their parents or guardians.\(^{168}\) She highlighted to the Committee that 67% of people surveyed by the member in charge agreed that the age should be set at 16 and over.\(^{169}\)

246. The Committee notes the comments from some witnesses on the challenges that may arise from differing ages at which a person can legally opt in or opt-out of organ donation in different jurisdictions of the UK.

247. The Committee also notes that children of 12 years-old and above can currently opt-in to the organ donor register in Scotland under the 2006 Act.

248. The majority of the Committee agreed that, given it is currently possible to opt in to organ donation at age 12 and over, the Bill should also provide for those aged 12 and over to opt-out. This will ensure that parents are clear of their child’s views in either case.
249. The minority of the Committee considered that 16 years and over was the appropriate age at which a person could opt-out of organ donation. Given opting out of organ donation would preclude the family being consulted, these members considered that the higher age of 16 more appropriately reflected the significance of the decision.

Other provisions in the Bill

250. The Committee notes that the Bill provides for a number of other (mainly consequential) changes to the 2006 Act, which enable parts of that Act to also apply to organ donation system provided for in this Bill.

251. The Committee also notes that the Bill provides for Scottish Ministers to report annually to the Scottish Parliament on the effectiveness of the changes made by the Bill.

Consideration by other Committees

Finance Committee

252. The Finance Committee published its report on the Bill's Financial Memorandum on 2 December 2015. Some of the issues raised have been explored in the body of this report.

253. The Committee notes the Finance Committee’s report.

Delegated Powers and Law Reform Committee

254. The Delegated Powers and Law Reform Committee published its report on the Bill’s Financial Memorandum on 3 December 2015. Some of the issues raised have been explored in the body of this report.

255. The Committee notes the Delegated Powers and Law Reform Committee’s report

Petition PE1453

256. Petition PE1453 was submitted to the Scottish Parliament’s Public Petitions Committee in November 2012 by Caroline Wilson on behalf of the Evening Times & Kidney Research UK (Scotland). This petition calls on the Scottish Parliament to urge the Scottish Government to introduce an opt-out system of organ donation in Scotland to help save more lives.
257. The Public Petitions Committee initially considered this petition and it held a debate in the Chamber on the subject of the petition on 1 May 2014.

258. On the 28 October 2014 the petition was referred to the Health and Sport Committee and it considered it on the 10 March 2015 and agreed to keep the petition open.

259. In view of the Committee’s consideration of this Bill and its overall conclusions the Committee agrees to close this petition.

Overall Conclusions

260. The Committee recognises and supports the need and desire to increase organ donation rates in Scotland. The Committee heard of the transformative effects of organ donation on those who received organs and their families. The Committee also heard of the devastating impact on all aspects of family life of those who are waiting for donated organs.

261. The Committee acknowledges the passion of all those that provided evidence to increase organ donation rates in Scotland.

262. The Committee has considered each of the key provisions within the Bill as well as the Bill’s overall purpose in reaching its views on whether to agree the Bill’s general principles.

263. A majority of the Committee is not persuaded that this Bill is an effective means to increase organ donation rates in Scotland due to serious concerns over the practical implications of aspects of this Bill. A majority of members consider that there is not enough clear evidence to demonstrate that specifically changing to the opt-out system of organ donation as proposed in this Bill would, in of itself, result in an increase in donations. As a result a majority of the Committee cannot recommend the general principles of the Bill.

264. However, a majority believes that along with on-going efforts to increase organ donation rates that there may be merit in developing a workable soft opt-out system for Scotland. The Committee therefore calls on the Scottish Government to commence work in preparation for a detailed consultation on further methods to increase organ donations and transplants in Scotland, including soft opt-out, as an early priority in the next Parliament, learning from the experiences of Wales who are currently implementing their own opt-out legislation, and to consider legislating itself as appropriate.
265. A minority of the Committee considers that this Bill needs to be introduced now so that the resulting increase in organ donation rates can benefit those currently on transplantation waiting lists. They consider the opt-out system proposed in this Bill will enhance the range of other activities undertaken and will change the conversation with families at a time of loss such that there will be an increase in donation rates. As such a minority of members agree with the general principles of the Bill.
http://www.scottish.parliament.uk/S4_Bills/(1)Transplantation%20(Authorisation%20of%20Removal%20of%20Organs%20etc.)%20(Scotland)%20Bill/TRA031-Law_Society.pdf
87 Scottish Parliament Health and Sport Committee. Official Report, 1 December 2015, Col 33
88 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA006-NHSGCCC.pdf
89 British Medical Association Scotland, Church and Society Council of the Church of Scotland
91 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA017-CSC_CoS.pdf
92 Scottish Parliament Health and Sport Committee. Official Report, 1 December 2015, Col 30
93 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA015-SCHB.pdf
94 Transplantation (Authorisation of Removal of Organs) (Scotland) Bill Explanatory Notes para 12
95 Transplantation (Authorisation of Removal of Organs) (Scotland) Bill Policy Memorandum para 41
96 Transplantation (Authorisation of Removal of Organs) (Scotland) Bill Explanatory Notes para 46
98 http://www.gov.scot/Publications/2013/07/7461
100 Scottish Parliament Health and Sport Committee. Official Report, 1 December 2015, Col 24
102 http://www.scottish.parliament.uk/S4_Bills/(1)Transplantation%20(Authorisation%20of%20Removal%20of%20Organs%20etc.)%20(Scotland)%20Bill/TRA021-NHSFife.pdf
103 Scottish Parliament Health and Sport Committee. Official Report, 1 December 2015, Col 24
106 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA011-RCPs_Glasgow.pdf
107 http://www.scottish.parliament.uk/S4_Bills/(1)Transplantation%20(Authorisation%20of%20Removal%20of%20Organs%20etc.)%20(Scotland)%20Bill/TRA025-NHSGlobalServicesScotland.pdf
109 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA010-SGov.pdf
110 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 15
111 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 15
113 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 38
114 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA010-SGov.pdf
115 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/TRA010-SGov.pdf
117 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 21
119 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 14
120 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/OR's/20151612Ministerial_Response_to_McTaggart_letter_1_Dec.pdf
121 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 13
122 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 14
123 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 37
124 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/20151201AMcTaggartLetter.pdf
125 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/20151201AMcTaggartLetter.pdf
126 Scottish Parliament Health and Sport Committee. Official Report, 8 December 2015, Col 36
127 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/20151201AMcTaggartLetter.pdf
128 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/OR's/20151215AMcTaggartLetter_No_Caveated.pdf
129 http://www.scottish.parliament.uk/S4_Bills/(1)Transplantation%20(Authorisation%20of%20Removal%20of%20Organs%20etc.)%20(Scotland)%20Bill/b72s4-introd-en.pdf
130 Transplantation (Authorisation of Removal of Organs) (Scotland) Bill Financial Memorandum para 19
Annexe A

Extracts from the minutes of the Health and Sport Committee and associated written and supplementary evidence

22nd Meeting, Tuesday 1 September 2015
Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered and agreed its approach to a call for evidence on the Bill at Stage 1.

27th Meeting, Tuesday 6 October 2015
Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee agreed its approach to the scrutiny of the Bill at Stage 1.

28th Meeting, Tuesday 27 October 2015
Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee agreed to seek approval to undertake a fact finding visit.

31st Meeting, Tuesday 17 November 2015
3. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—
Dr Sue Robertson, Member of BMA Scottish Council and renal physician in Dumfries, BMA Scotland;
Jordan Linden MSYP, Chair, Scottish Youth Parliament;
Lindsay Paterson, Policy Manager, Royal College of Physicians of Edinburgh;
Dr James Cant, Director, British Heart Foundation Scotland.
4. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered the main themes arising from the oral evidence heard earlier in the meeting.

Written Evidence

BMA Scotland
32nd Meeting, Tuesday 24 November 2015

2. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—
Professor David Galloway, President Elect, Royal College of Physicians and Surgeons of Glasgow;
Dr Charles Wallis, Intensive Care Consultant, SICS Organ Donation Representative, Scottish Intensive Care Society;
Dr Calum MacKellar, Director of Research, Scottish Council on Human Bioethics.

3. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered the main themes arising from the oral evidence heard earlier in the meeting.

Written Evidence
Royal College of Physicians and Surgeons of Glasgow
Scottish Council on Human Bioethics (SCHB)
Scottish Intensive Care Society (SICS)

33rd Meeting, Tuesday 1 December 2015

3. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—
Sally Johnson, Director of Organ Donation and Transplantation, Liz Waite, Specialist Nurse – Organ Donation, and Irene Young, Specialist Nurse – Organ Donation, NHS Blood and Transplant;
Professor Alison Britton, Convener to the Society’s Health and Medical Law Committee, Law Society of Scotland;
Lorna Marson, Vice President, British Transplantation Society.

4. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered the main themes arising from the oral evidence heard earlier in the meeting.

Written Evidence
NHS Blood and Transplant
Law Society of Scotland
34th Meeting, Tuesday 8 December 2015

1. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill: The Committee took evidence on the Bill at Stage 1 from—
Maureen Watt, Minister for Public Health, and Mr Gareth Brown, Head of Health Protection Division, Population Health Improvement Directorate, Scottish Government;
Professor John Forsythe, Lead Clinician for Organ Donation and Transplantation in Scotland and Consultant Transplant Surgeon, Royal Infirmary of Edinburgh, NHS Lothian;
Anne McTaggart MSP, member in charge of the Bill, Scottish Parliament; Louise Miller, Senior Solicitor, Office of the Solicitor to the Scottish Parliament.

2. Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered the main themes arising from the oral evidence heard earlier in the meeting.

Written Evidence
Scottish Government
Anne McTaggart letter 1 December 2015

Supplementary Written Evidence
Anne McTaggart letter 15 December 2015
Minister for Public Health letter 16 December 2015

5th Meeting, Tuesday 19 January 2016

Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered a draft Stage 1 report. Various changes were agreed to, and the Committee agreed to consider a revised draft, in private, at a future meeting.

6th Meeting, Thursday 21 January 2016

Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered a draft Stage 1 report.
7th Meeting, Tuesday 26 January 2016
Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill (in private): The Committee considered a revised draft Stage 1 report. Various changes were agreed to, and the report was agreed for publication.
List of other written evidence

- NHS Forth Valley
- Revival
- NHS Lanarkshire
- RCN Scotland
- NHS Greater Glasgow and Clyde
- Scottish Ambulance Service
- General Medical Council
- Scottish Donation and Transplant Group
- Scottish Council of Jewish Communities (SCoJeC)
- Nuffield Council on Bioethics
- Church and Society Council of the Church of Scotland
- CARE Scotland
- NHS Fife
- Royal College of General Practitioners
- Free Church of Scotland
- PBC Foundation
- NHS National Services Scotland
- UK Donation Ethics Committee
- Christian Medical Fellowship
- NHS Ayrshire and Arran
- Aberdeenshire Health and Social Care Partnership
- NHS Highland

Additional Submissions

- Yvonne Prentice

Supplementary Written Evidence

- Christian Medical Fellowship

Online Survey

In addition to the call for evidence, the Committee carried out an online survey on the Bill. The results of the online survey can be found on the Scottish Parliament's website at the following webpage:

http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/SmartSurveyResults.pdf
Annexe B

Note of informal meetings

On 4 November, the Committee held an informal meeting with transplant recipients.

Note of Meeting with transplant recipients

On 11 November, the Committee held an informal meeting with organ donor families.

Note of Meeting with organ donor families

On 12 November, the Committee held an informal meeting with faith and belief groups.

Note of Meeting with faith and belief groups
Annexe C

Note by the Clerk of fact finding visit to Madrid 16 November 2015

- Note of Visit
- Slideshow Presentation
- Article 1
- Article 2
Annexe D

Report from the Delegated Powers and Law Reform Committee and Report from the Finance Committee

Report from the Delegated Powers and Law Reform Committee

The Delegated Powers and Law Reform Committee (DPLRC) report on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill can be found on the Scottish Parliament's website at the following webpage:

http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/94617.aspx

Report from the Finance Committee

The Finance Committee issued a call for evidence on the financial implications of the Bill. The evidence received can be found on the Scottish Parliament's website at the following webpage:

http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/90970.aspx

The Finance Committee report on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill's Financial Memorandum can be found on the Scottish Parliament's website at the following webpage:

http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/94566.aspx