

**SUBMITTING EVIDENCE TO A SCOTTISH PARLIAMENT COMMITTEE  
DATA PROTECTION FORM**

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<b>Date:</b>	<b>21 July 2018</b>
<b>Organisation: (if required)</b>	<b>Mission Board of the General Synod of the Scottish Episcopal Church</b>
<b>Topic of submission:</b>	<b>Human Tissue (Authorisation) (Scotland) Bill</b>

**I have read and understood the privacy notice about submitting evidence to a Committee. Yes**

**I am happy for my name, or that of my organisation, to be on the submission, for it to be published on the Scottish Parliament website, mentioned in any Committee report and form part of the public record.**

**I understand I will be added to the contact list to receive updates from the Committee on this and other pieces of work. I understand I can unsubscribe at any time. Yes**

Non-standard submissions

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**I would like to request that my submission be processed in a non-standard way.**

## **HEALTH AND SPORT COMMITTEE**

### **HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL**

#### **SUBMISSION FROM the Mission Board of the General Synod of the Scottish Episcopal Church**

##### **Subtitle (Arial 12, bold, left aligned)**

Body text (Arial 12, left aligned)

Please do not add any organisation logos

Question 1 What are the strengths and weaknesses of the proposal to introduce “deemed authorisation” for those who have not made clear their views?

Giving the gift of life to another person is something to be commended. It is important that organ donation should always be a precious and thoughtful gift and not a requisition. The Scottish Episcopal Church has always been in support of organ transplantation and has worked to encourage its members to sign up for organ donation. This would continue to be our view. We would wish to continue to support practical ideas for increasing the numbers of people who are able to become organ donors. We therefore welcome the current initiative by Scottish Government to encourage a public discussion of these issues. We also welcome the changes made to earlier drafts of the proposed legislation which would involve more significant discussion with the families of organ donors i.e. the move to a “Soft Opt Out”. The ability of a grieving family to have input is an important element in what will always be a difficult balance between the potential donor and their family and the potential recipients and society. As within any group within society, the views of the members of the Scottish Episcopal Church as to the importance of strengths and weaknesses will differ.

Despite our support for the concept in general we continue to have significant concerns about the introduction into Scots Law of the concept of “deemed authorisation” or “presumed consent”. We are concerned that its introduction into this area might create a precedent for its use in other areas.

In addition to this basic concern we also have the following concerns

- a) We are aware that the introduction of a similar system in Wales resulted in a decrease in the availability of organs for transplant. We are unclear as to what is the evidence that introducing this in Scotland would not have a similar negative impact.
- b) The successful running of an opt out system requires that there must be a good IT system to maintain records. The record of Government in this area is not good with most Government IT systems having had significant issues. What is the evidence that the IT system needed will ensure that no one who has opted out will be missed out and subject to deemed consent. Will those who have opted out be notified that their opt out has been

recorded? Broadband is not universally available across Scotland so it is important that electronic communication is not the default means of communication.

c) The purpose of the current bill is to increase the number of organ transplants. Have costings been done of the impact of this change and of the planned and targeted increases in the number of organs available on areas of health economics such as expenditure, available manpower and impact on other NHS services. . Given that NHS Budgets continue to be under pressure where is it expected that funds for increased number of transplants will come from? What current services will be reduced so as to pay for this? Increasing the number of transplants will need an increase in the number of surgeons and associated staff. Numbers of surgeons are currently under pressure. Where will the additional surgeons come from and what current areas of surgical activity will be negatively impacted?

d) This change to legislation risks a significant change in status for the body of a deceased person who may effectively come to be seen as owned by the state and to have value only as a source of spare parts. Individuals are more than a physical body. They have connections to family, community and a worth in relation to who they have been. What will be done to continue to value those deemed to have authorised transplants?

Question 2 What are the key strengths and weaknesses of plans for pre death procedures?

Linked to the desire to increase the number of organs becoming available for transplant must be a wish that an increasing number of transplants will be successful. This would seem to be the basis of the suggestion that treatments be administered to someone who is likely to die so as to increase the probability that organs will be in good condition for transplant. In terms of the efficiency of the process the case for this seems clear. However administering treatments to a potential donor which have no value to the donor and which may have an adverse impact on their defined period of life does cross a line and raise new issues. At the point when such treatments are begun, the donor will inevitably move from being a person of standing with health issues to someone who is seen primarily in terms of their ability to supply spare parts. In a pressured NHS, what safeguards will exist to ensure the continued priority of the needs of the donor over those of the intended recipients?

Question 3 What other comments do you have?

The potential change to the status of transplantation had limited publicity when each of the consultations was announced. We are clear from discussion with church members that most people are unaware of what is being proposed. What plans are there to increase publicity? Major decisions to be made in referenda have usually involved direct mailing to all who could be affected, essentially the whole population of Scotland. Is a major mailing programme giving information on how to opt out, other than via electronic means planned? It matters to remember that significant parts of Scotland cannot get information requiring high speed broadband. Plans currently aim to exclude those who have been in Scotland for under 12 months. How will this be known?