



Official Response

SUBJECT: Call for views: Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill

REQUESTED BY: Health and Sport Committee
(HealthandSport@scottish.parliament.uk)

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The following response to the Call for views on the “Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill”, presented to the Scottish parliament by Anne McTaggart, MSP, is from the Church and Society Council of the Church of Scotland.

Questions

Do you support the Bill?

The Church of Scotland, along with many other Christian and faith groups, supports the practice of organ and tissue donation.¹ We believe that this is part of humanity’s commitment to healing and, with the real potential for the death of one person to prolong or greatly improve the quality of the life of another, an action with strong symbolic Christian resonance. The Council has supported the current strategy and the activities of the Scottish Government and NHS Blood and Transplant to increase the number of people registering for organ donation, for example through promotion of the *fleshandblood* campaign.

While being supportive of a desire to see an increase in tissue and organ donation in Scotland, we do not believe that the proposed legislation is necessary or represents the best way forward. It is the view of the Church and Society Council that there is not yet evidence

¹ In the report of the Church and Society Council to the 2015 General Assembly of the Church of Scotland, the Assembly agreed the following *Deliverance*:

26. Urge the Scottish Government to promote organ donation on the present system of consent and to monitor developments elsewhere.
27. Encourage congregations to consider promoting the *fleshandblood* campaign (<http://fleshandblood.org/about/associates/churchofscotland/>).
28. Urge members to join the Organ Donor Register, to advise their families and close friends of this decision, and to encourage them also to join.

that such a change would necessarily significantly increase the number of organs available for transplantation.

1. Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland? Please provide an explanation for your answer.

We believe that the current legislative position already accomplishes much of what the proposed legislation seeks to achieve- most particularly the “soft opt- out” option. Between 2008 and 2013, 62% of all donations came from donors who were not on the donation register at the time of their death². In these cases, consent for donation was given by relatives (or, in some cases, close friends), many of whom may not have had clear prior knowledge of the views of the deceased with regard to tissue and/ or organ donation. Thus a Spanish- style “opt- out” system is already largely operating in Scotland. There is evidence to suggest that the better funding and regional organisation is more important in increasing donation rates than simply introducing presumed consent.

In addition, there are examples where a change to an opt-out policy has had detrimental effects on the number of organs retrieved for transplantation; for example, in Brazil, where the law had to be repealed because of mistrust in the government and accusations of body snatching, and in France where a specific case, although fully compliant with the law, caused a great deal of negative press and a fall in donor numbers.

The primary purpose of a legislative change to increase the numbers of organs available for transplantation would only be of overall benefit to society if the gain in terms of lives saved or prolonged outweighed any harm done by an ‘opt-out system’ of donation. The likelihood of a significant increase in transplantation has yet to be established, but before going down this legislative path, it is also worth considering some of the potential harms from an opt-out system of organ donation.

- **Equality:** The rights of the person who has not explicitly opted in as a donor must be carefully considered. Not all persons who fail to opt out will have wished to give consent for retrieval and transplantation of their organs in the event of death. We consider that there is a risk of inequality in accessing the means of opting out of organ retrieval. Some people will never want to address the concept of their death

² A Donation and Transplantation Plan For Scotland 2013-2020,
<http://www.scotland.gov.uk/Publications/2013/07/7461/4>

and therefore will not make a decision about organ donation. People with social or emotional stresses or less family support may find it harder to have hypothetical discussions about dying and therefore to make their wishes about organ donation known to those who may be consulted in the event of their deaths. Some may not have the education, capacity or social circumstances needed to allow them to engage with health or legal organisations responsible for compiling the opt-out register. Those with learning difficulties, homeless people or mentally ill people are among the groups who may be, or who may perceive themselves to be, less able to opt out. Those with supportive families and better resources may be more readily able to make choices about organ donation and to opt out if that is their wish. There is therefore a danger that, in the long run, the pool of donors will be drawn disproportionately from the 'voiceless'.

- **Loss of trust:** There is also a risk of a loss of trust between families of critically ill patients and medical staff. What happens to the body after death may be important to the deceased, but perhaps more often, the handling of the body is not as relevant to the one who has died as to the bereaved family and friends. Many of us might wish consideration for the feelings of our loved ones to take precedence over our own wishes after our deaths, and therefore even if we had failed to opt out of organ donation, we may not strongly wish it to proceed if, in traumatic circumstances, the donation was likely to cause distress to a loved one. With an opt-out system, the default position may be to retrieve the organs of a recently deceased person, without requiring the authorisation of the person's family. There is a potential for harm to the bereaved, if they do not want organ donation to proceed, but feel that they cannot refuse in the absence of an opt-out order by the deceased. If the family feel removed from decision making by the absence of an opt-out directive, then we can foresee distress and loss of trust which could be harmful to the bereaved and to medical teams alike.
- **Reduced public support for transplantation:** At present there is broad general public support for those people on transplant waiting lists and also for those who, sometimes tragically, become organ donors. In Scotland, over 40% of the population are on the organ donor register, and over 90% of Scottish people support organ

donation.³ However, there is the potential for an opt-out system to lead to cases where the bereaved family later resent the taking of organs and complain that their wishes were not considered or that they were pressurised into agreeing to organ retrieval. In the event of such cases being publicised, it may be that the general public becomes less supportive of the medical teams seen as the takers of the organs and perhaps even of the recipients of the organs. It is likely that a new policy such as this one would receive much publicity and be the subject of news interest. We are concerned that there could be sensationalised reporting of any cases of bereaved families who felt that organ retrieval proceeded against their wishes. There have been previous examples of prominent media attention leading to a reduction in the support for transplantation.⁴

2. Do you support the proposal of appointing a proxy? Please provide an explanation for your answer

Provided that the proxy is fully apprised of the views of the deceased prior to their death as regards donation of tissue and/ or organs for transplantation, we would be of the view that this has the potential to strengthen the safeguards to ensure that a person's wishes in this regard are always respected.

However, for this to work effectively, it is essential that there is a mechanism to ensure that the correct proxy is appointed, and that they are always acting according to the instructions of the deceased individual. For example, it may be possible to envisage a scenario where the relationship between a person and the individual they have appointed as their proxy deteriorates to the extent that they should be removed from that responsibility. To help prevent this, we would recommend that the name of the proxy should be reviewed regularly e.g. every 3 years.

3. Do you have any comments on the role of "authorised investigating persons" as provided for in the Bill?

³ Ms. A. McTaggart MSP, Proposed Organ and Tissue Donation (Scotland) Bill Consultation Document, 2014, p.11.

⁴ For example, the Alder Hey Hospital scandal involved children's organs which were retained following post mortem examination for scientific research without the permission of parents. Although the tissues in question were not being used for transplantation, there was enough of a link in the public mind for this to lead to a temporary dip in rates of organ transplantation. (see <http://news.bbc.co.uk/1/hi/health/1475676.stm> and <http://news.bbc.co.uk/1/hi/health/1150951.stm>)

Clause 57 of the Explanatory Notes⁵ accompanying the Bill states that the role of the authorised investigating person (AIP) would be to “**obtain a single decisive answer to the questions he or she must ask of a nearest relative, even if there are two or more equally-ranked relatives to choose from, who may have differing views**”

It must always be remembered that a deceased person remains loved and cherished by their family, even following death. We would be concerned that, in the situation where two or more equally ranked relatives are in disagreement about whether or not organs should be available for donation, every effort should be made to ensure that all relatives are happy with the decision. We feel that the default position should be that organs are NOT available for donation, unless all relatives of equal rank are in agreement. If an AIP has the capacity to overrule the decision of a relative, this raises the possibility that families will feel that the organs have been taken under duress, rather than freely donated.

In addition, there does not appear to be anything in the proposed legislation to prevent a legal challenge against the decision made by an AIP: we would also have some concerns as to whether there would be adequate support for the AIP in this situation, or would they be “on their own”?

4. Is there anything in the Bill you would change? If yes, please provide more details.

Scope of the Proposed Bill: given the rate of progress in many aspects of transplantation technology, we have some concerns at the lack of specificity as to the scope of organs for transplantation covered by the proposed Bill. Specifically, we would urge that the transplantation of reproductive organs, tissues or cells, or the equivalent organs, tissues or cells from embryos or foetuses, be explicitly excluded in any new legislation

Conclusion:

As John Wesley, the famous 18th Century preacher said, part of our responsibility as Christians is to “Do all the good you can. By all the means you can. In all the ways you can. In all the places you can. At all the times you can. To all the people you can. As long as ever you can”. With the availability of tissue and organ donation, the ability to share the gift of life now goes beyond death.

⁵ See

[http://www.scottish.parliament.uk/S4_Bills/\(1\)Transplantation%20\(Authorisation%20of%20Removal%20of%20Organs%20etc.\)%20\(Scotland\)%20Bill/b72s4-introd-en.pdf](http://www.scottish.parliament.uk/S4_Bills/(1)Transplantation%20(Authorisation%20of%20Removal%20of%20Organs%20etc.)%20(Scotland)%20Bill/b72s4-introd-en.pdf), p12

However, we are also aware that, in order for donation to be donation in the fullest sense, it must always be with the fully informed consent of the person concerned. Any legislative changes must always seek to ensure that this is the case.

It has been argued that:

“Presumed consent would turn us from volunteers into conscripts—unless we register as conscientious objectors ... Such a system would make the term ‘donation’ redundant. A donation is something freely gifted, not taken by default”⁶

As Christians, the Church and Society Council of the Church of Scotland supports the life-giving practice of organ transplantation and therefore the Council is keen to see promotion of donation of organs and a reduction in the suffering of those waiting for the chance of transplant surgery. However, the Council also recognises that many organ transplants involve the death of another, equally valued human being, often prematurely and in stressful circumstances in hospital. If an opt-out system of organ donation could significantly increase the numbers of organs available for transplant without harming those persons and families involved in the donation, then it might be justifiable and welcomed by the people of Scotland. The Council considers that further evidence of benefit without harm of such a system is needed before supporting the proposal for change in Scotland.

We are of the view that no further legislative change should take place in Scotland until a proper assessment has been made of the impact of the implementation of the Human Transplantation (Wales) Bill. Although the implementation of this legislation is not due to begin until December 2015, and it will be some years before the impact of this on the levels of organs and tissues becoming available for donation is able to be fully assessed, we believe this to be the best and most responsible approach.

⁶ House of Lords, European Committee, Increasing the supply of donor organs within the European Union, Vol. 1: Report, 2008, The Stationery Office, p. 59.