



Official Response

SUBJECT: Consultation response: Proposed Organ and Tissue Donation (Scotland) Bill

REQUESTED BY: Anne McTaggart, MSP

REFERENCE: OR-2014/07

DATE: 24 September 2014

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The following response to the Consultation on the proposed “Organ and Tissue Donation (Scotland) Bill”, presented to the Scottish parliament by Anne McTaggart, MSP, is from the Church and Society Council of the Church of Scotland.

Consultation questions

1. The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move? Please indicate “yes/no/undecided” and explain the reasons for your response.

While being supportive of 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.

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. The implementation of the *Human Tissue (Scotland) Act 2006* allows for organs and tissues to be removed for transplantation following death without the explicit prior consent of the donor (see section 7 of the Act). Indeed, between 2008 and 2013, 62% of all donations came from donors who were not on the donation register at the time of their death¹. 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.

2. How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

¹ A Donation and Transplantation Plan For Scotland 2013-2020, <http://www.scotland.gov.uk/Publications/2013/07/7461/4>

As stated above, we believe that the legislative provision in Scotland is sufficiently permissive as it currently stands.

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.

3. I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree? Please indicate “yes/no/undecided” and explain the reasons for your response.

We disagree. We believe that the current system does not have any effective facility to allow a person to register an objection to post mortem donation, and that there may be many reasons why the family may be unaware of such objections. These may include family breakdown and estrangement, which may mean that, for even the “closest” family, discerning the wishes of the deceased is little more than guesswork.

We would argue that there is a case, rather than seeking to move more quickly to an “opt-out” system as proposed by this Bill, to be seeking to strengthen the safeguards around the current legislation.

4. Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf? Please indicate “yes/no/undecided” and explain the reasons for your response.

Yes. 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.

5. My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree? Please indicate “yes/no/undecided” and explain the reasons for your response.

It is necessary at all times to ensure the protection of minors and those without the capacity to give consent for themselves. Thus, we agree with the necessity for explicit consent for children and young people to be included in any automatic opt-in system.

6. Do you agree the age limit for an adult should be set at 16 years old? Please indicate “yes/no/undecided” and explain the reasons for your response. If you answered no, what would you consider a more appropriate age?

We would agree that a lower age limit of 16 would be appropriate for any opt- out system which was introduced

7. Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death? Please indicate “yes/no/undecided” and explain the reasons for your response.

We agree that for donation to occur, there should be a requirement for a minimum period of residence in Scotland prior to death, and that 1 year seems an appropriate length of time for this.

8. If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?

See above

9. Do you think 6 months is a long enough period to run a campaign prior to change over?

We would prefer a longer campaign of up to a year, but accept that there would cost implications for this. However, every effort must be made to ensure that all citizens are aware of the implications of any change.

10. What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

It is important, in considering changes to the law, that ethical issues be taken into account, and that financial implications not be the primary driver of our decisions. A person’s wishes as to whether or not to donate their tissues or organs for transplantation must be paramount.

11. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

We would be concerned that an opt-out system could be discriminatory in that those with better education and resources might be more likely to be able to opt-out if they wish and that others – for instance the homeless, those with learning difficulties or poor command of English, even the young (just over 16 but not got round to it) might not opt out as easily, and thus end up making up a disproportionate number of ‘donors’.

12. Do you have any other comments on or suggestions relevant to the proposal?

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.

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"²

In addition, 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 fetuses, be explicitly excluded in any new legislation.

² House of Lords, European Committee, Increasing the supply of donor organs within the European Union, Vol. 1: Report, 2008, The Stationery Office, p. 59.