

Proposed Organ and Tissue Donation (Scotland) Bill

Anne McTaggart MSP

“A proposal for a Bill 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”

Response to Consultation

Free Church of Scotland

Consultation questions and our responses

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.**

No

We support organ donation and transplantation, but we believe the donation should always be on the basis of a deliberate, well-informed, voluntary decision. ‘Presumed consent’ in an opt-out system is based on the unfounded assumption that every single person who has not opted out was aware of the opt-out provision and has consciously taken a decision not to opt out. This is no consent at all and a donation on this basis is not a donation but something akin to a tax imposed by the State. It means that the State claims to have ownership of our bodies after death unless we consciously reject this while alive.

The system in Scotland, since the Human Tissue (Scotland) Act 2006, is not entirely opt-in. This is because a nearest relative may (1) add to the list of body parts that can be removed and transplanted without knowing the donor’s wishes on these body parts and (2) give permission for removal of body parts even if they do not know if the person was in favour of this (section 7 of the Act).

There are several problems with this:

- This is a type of ‘presumed consent’, which, as we have argued, is no consent at all.
- The definition of ‘nearest relative’ (section 50 (1) (k)) is rather wide, including ‘friend of long standing’, and gives no confidence that they would know the deceased person’s wishes with regard to organ donation and transplantation.
- With the present state of increasing family breakdown and mobility, it might become more difficult to identify a sufficiently informed ‘nearest relative’.
- Following the Alder Hey Children’s Hospital scandal, the public is suspicious about removal of organs post mortem and this type of law might only increase that suspicion and could be counterproductive.

The aim of this proposal, to increase the number of organs available for transplantation, is worthy, but such a law would be ethically unacceptable and should be rejected.

- 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?**

We believe the proposed change in the law is unnecessary as well as ethically unacceptable. The current law should be amended to eliminate any element of 'presumed consent'. Research published in *Transplantation*, the journal of the Transplantation Society, on 27 June 2012, showed that there was no conclusive evidence that changing from an opt-in to an opt-out system had increased donor rates in countries where this had taken place. Other factors may well be more important.

Better education of the public, beginning in schools, and more sympathetic handling of relatives at the time of death will be more effective in the long run.

- 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.**

No

The family should have the right to refuse permission for removal of organs whether or not they know if the person objected to it. They should also be able to give permission for organ removal and transplantation if they have certain knowledge that the deceased person was willing for this, even where there is no written record. This is why it is so important that the 'nearest relative' is someone who knew the deceased person well.

Usually organs are taken from those who die in intensive care units following severe trauma or some other catastrophic medical incident. This is a very emotional time for the relatives. It would only antagonise the public more if relatives felt they were being ignored or bypassed when it came to organ donation.

An important factor in the rise in donor rates is the appointment of specially trained nurses, who liaise with the relatives of patients who are potential donors. By removing misunderstandings and giving emotional support at a difficult time, relatives are helped to see the benefits of organ donation for those in need and more readily agree to the procedure. The declared wishes of the deceased person are paramount and the relatives should not be able to go against these.

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

This could be catered for by encouraging people to appoint someone whom they trust to have power of attorney including the matter of organ/tissue donation.

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.

Yes, if this proposal were to become law, although we oppose it in principle.

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?

No

Although we disagree with the proposed Bill on principle, if it were to be introduced 18 should be the age limit, until the results of the implementation of the Welsh Act have been analysed.

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.

N/A

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?

N/A

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

NO

While we oppose the measure in principle, if it were to become law at least a year should allowed for informing and educating the populace.

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?

N/A

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?

YES - largely negative

Disadvantaged groups and ethnic minorities are more liable to be affected, because they would be more difficult to inform adequately about changes in the law. As they are at present underrepresented as donors, the best course is to inform them in a positive way about the benefits of an informed opt-in system. To introduce the opt-out system would make it even more difficult to inform such people about the need for voluntary donations and lead to greater mistrust.

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

Since this Bill is controversial, it should not be pursued in this form at the present time, especially since a similar Act will come into force in 2015 in Wales. Its effects should be studied there before any similar change is considered in Scotland. If the Bill was altered to rectify the weaknesses of the 2006 Act mentioned above, it would be more acceptable.

Since the types of tissues and organs which may be transplanted are increasing, this should be recognised in any revision of the 2006 law. Permission to donate should specify which tissues and organs are covered and which are not.

Transplantation of reproductive organs, tissues and cells and embryonic organs, tissues and cells from a deceased person should be prohibited.

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