

Proposed Organ and Tissue Donation (Scotland) Bill

#46



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Q1: 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.

Yes,

Please give your reasons for your response:
I believe that many people would agree to organ donation but for various reasons do not get round to registering as a donor. When asked they are quite prepared to be a donor. Opting out would focus the minds of those who specifically do not want to be a donor. Such people are likely to have strong views and would make a point of opting out.

Q2: 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?

It is essential to change the law and to have in place an effective strategy. Decision makers would have no doubt about this if they had a child in their family who required an organ in order to survive. Currently the publicity and awareness raising is shockingly poor. I discovered some time ago that UK transplant no longer took a proactive position to ensure that public places had leaflets available. Instead they relied on individual GP surgeries etc requesting leaflets. In reality very few took this initiative and availability/visibility dwindled. I think opting out would be a more cost effective system rather than spending huge sums on an ineffective system that tries to encourage people to register as a donor.

Q3: 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.

Yes,

Please give reasons for your response:
Families are not always able to make the best decision at the time that a loved one dies. It would be easier for families if the decision was clearly that of their loved one and there was less ambiguity about the families role as decision makers. Also I would like to note that not all doctors are good at approaching families. When a relative of mine died no-one approached our family about organ donation. This was something one family member raised and by doing so two people were given the gift of sight. However, the person who raised the issue of donation has been left with a strong sense of guilt and worry that other members of the family may have seen this as insensitive and may not have wanted this outcome. If consent is assumed unless otherwise stated (opt out) there is less of a burden on families and less risk of family disagreement.

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Q4: 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.

No,

Please give reasons for your response:
I think that there should be protection for those in our society who are not able to make the decision to opt out e.g those with learning disabilities or mental health issues and that the decision should not be given to someone else. This is a difficult question but on balance I feel that in some cases where the person does not have the ability to make an informed choice organ donation should not go ahead.

Q5: 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,

Please give reasons for your response:
This allows for discussion within the family. There should always be informed choice and the ability to make the choice is affected by age/maturity. However, this should only be until age 16 and then the person should be expected to opt out if they don't want to be a donor.

Q6: 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.

Yes,

If you answered no, what would you consider a more appropriate age?
At 16 you are old enough to marry and now to vote, therefore I believe that you are old enough to consider your position on organ donation. In fact many young people are clear about this at a younger age but I think age 16 is a good age limit.

Q7: 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.

No,

Please give reasons for your response:
I think that a shorter period of time would be more appropriate. When someone registers at a doctors they could be informed that we have an opt out system in Scotland and would have enough time to opt out with a 3 month period.

Q8: 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?

3 months see above.

Q9: Do you think 6 months is a long enough period to run a campaign prior to change over?

Yes - a campaign that is longer is not going to be any more effective. However, it is important to have systems working well or this will undermine the opt out system.

Q10: 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?

I think that there is every possibility that this will save money. Firstly on an ineffective system that works to persuade people to become a donor (saving will be made if we no longer require UK transplant) Also, people will not have to be supported long term with expensive medical treatments while they wait for long periods for an organ.

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Q11: 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?

I don't know.

Q12: Do you have any other comments on or suggestions relevant to the proposal?

I cannot understand why there would be resistance to this. Provided there were safeguards to ensure dignity and safe procedures to make sure that any organ removed was genuinely required. Also it should be easy to opt out so that anyone who does not want to be a donor should not find any unnecessary barriers to this.

PAGE 3: Contact Details

Q13: If you wish your response, or any part of it, to be treated as anonymous or confidential, please check the appropriate box and state the reason for this. If not, then please go to question 14. If I accept the reasons, I will publish it as "anonymous response" or only publish the non-confidential parts of the response. If I do not accept the reasons, I will let you know and give you the option of withdrawing it or submitting it on the normal attributable basis.

Respondent skipped this question

Q14: Thank you for completing this survey. For the purposes of the consultation, it would be helpful if you could provide your contact details.

Name

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

