

#307

**COMPLETE**

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PAGE 2: Proposed Organ and Tissue Donation (Scotland) Bill Consultation

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.

No,

Please give your reasons for your response:
No I do not support such a move. Your paper correctly notes that international comparisons are difficult to interpret and that it is hard to assess what impact opt out systems contribute to achieving higher donation rates and notes that it is not a certainty that changing the system would alter consent rates. Much is made of the change to an opt out system in Wales so it is surprising that the paper passes no comment on the effect of that legislation on donor numbers in Wales. Figures published on the NHS Blood and Transplant Website show that the number of deceased donors in Wales has fallen from 66 in 10-11 to 54 in 13-14. Whereas in Scotland over the same period the numbers have increased from 67 to 106. Surely this justifies the Scottish Government position of continuing to implement the recommendations made in "A Donation and Transplantation Plan for Scotland 2013-2020" and waiting until the true effect of the changes in Wales can be fully assessed.

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?

There is no need to change the law. The consultation paper does not give an accurate position on the current legislation in Scotland where a system of "authorisation" rather than "consent" exists. The difference between authorisation and soft opt out is small and I cannot see how it would be better. The current NHS Register is already being rebuilt and this will allow people to register a wish to opt out so why change the legislation. Under the proposed system families will still be able to refuse permission for donation. The current legislation could be enforced in cases where the person had either joined the ODR, carried a card or made their wishes known to their loved one.

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:
However in practice it is not as simple as this. Specialist donation staff need to be able to work with families so that they can share information about the donor to ensure that the organs being donated are safe to be transplanted. For example details of sexual history, travel history and in-depth medical history are required. It is therefore not possible to limit the role of the family as suggested.

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 fail to see the point in this. It is more important to encourage people to make a positive decision during their lifetime. If they have not done this then the hierarchy of nearest relatives currently in the 2006 Act provides the way to do this.

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:
Of course the system must include suitable safeguards for children and young people however the suggestions in the paper are a retrograde step to the current legislation which states that children over the age of 12 have the capacity to make decisions about their donation wishes and to expect those wishes to be honoured by their parents. The age of 12 is in line with legislation about the age of children's ability to make decisions and only children under 12 are seen as not having the capacity to make such decisions. Scotland is internationally recognised as having addressed this matter by developing an educational resource for all children aged 12 and over which gives them the information required to make such an important decision.

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?
This is generally in line with Scottish legislation in other areas.

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:
One year seems a short period of time. Would the individual have had the opportunity to make themselves aware of the legislation in this period. I consider that 2 years would be a more suitable period of time

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?

2 years and yes it should be continuous. Not sure however how this would be able to be identified at the time of donation when time is short

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

Absolutely not. To make every adult (and perhaps children 12 and over) aware of this significant change would take much longer than six months. Wales have allowed 2 years

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?

The costs of introducing such a change would be significant. Wales have stated the costs will be circa £8 million and it is extremely likely that it would be the same if not more in Scotland given the larger population base

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?

Hard to say but it would almost definitely be seen as a negative step by some faith groups and BAME communities

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

Assuming consent from silence is a very risky strategy. Scotland has made fantastic progress in donation over the last 6 years and is currently bucking the trend of declining donation figures in the rUK. I strongly support the SG position of continuing to improve the infrastructure of organ donation and transplantation while waiting to see what happens in Wales. Opt out carries a significant risk to public confidence. Remember Alder Hey and more recently the baby ashes scandal. One headline in a tabloid newspaper about organs being "stolen" could damage all the progress which has been made in Scotland

PAGE 3: Contact Details

Q13: If you wish your response, or any part of it, to be treated as anonymous and/or confidential, please check the appropriate box. If not, then please go to question 14.

Anonymous

Q14: Thank you for completing this survey. Please provide your name and contact details below.

Name

Company

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

