

A consultation on:

**Proposed Organ and Tissue
Donation (Scotland) Bill**

Response by:

**Christian Concern
Christian Legal Centre**

Consultation:
PROPOSED ORGAN AND TISSUE DONATION (Scotland) BILL

Closing date: 25 September 2014

Send Response to:
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Would you like acknowledgement of your response? Yes.

If you are a representative of a group, please tell us the name of the group and give a summary of the people or organisation that you represent.

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Christian Concern is linked to a sister and separate organisation, the Christian Legal Centre, which takes up cases affecting Christian freedoms. www.christianlegalcentre.com

CONSULTATION RESPONSES

Question 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.

1.1 No, we do not support the move to an opt-out system - even a soft opt-out system.

1.2 The proposed system presumes consent of every person over sixteen. This is problematic because:

- If consent is presumed, then by definition consent is not present. The decision to donate should be informed, voluntary and autonomous. Silence does not amount to consent.
- Organ donation is an altruistic act and should involve the voluntary giving – not taking – of organs as a free gift in the context of fully informed consent. A system based on presumed consent undermines altruism as a core ethical value underlying organ donation and opens the path to government, doctors and others taking a more consumerist view of the human body: as an item which the State has an inherent right to and which has value as a physical resource. This is a potentially dangerous mind-set and an unnecessary one to promote. We need to work at improving organ donation rates by raising awareness, increasing opportunities to opt-in, harnessing new technologies such as social media, and promoting a culture of altruism and self-sacrifice which encourages voluntary giving.
- Eliminating the need for consent creates the potential for conflict between family members and clinical staff, and risks undermining public trust in the medical profession (particularly in relation to those who are caring for patients reaching the end of their lives). The Organ Donation Taskforce of 2008 advised against the introduction of soft opt-out laws, citing as one of its reasons the “potential to erode the trust between clinicians and families at a distressing time.”¹

1.2 The proposed system does not give due regard to the wishes of bereaved family members for whom the death of a loved one is often a trying and traumatic time. The Alder Hey inquiry into the use of children’s organs demonstrated the importance of the body to loved ones, and the need to refrain from causing additional distress to grieving friends and family members. Whilst the proposed soft opt-out system mentions family involvement, it is unclear as to the degree to which their wishes will actually influence a doctor’s final decision. Our concerns are heightened by the obligation placed on health care professionals to proceed even if relatives manifest strong objections or distress.

1.3 There is no clear evidence to suggest that soft opt-out laws in fact lead to an increase in organ donation rates. Spain, which introduced a scheme based on presumed consent in 1979, did not see an improvement in organ donation rates until the implementation of a comprehensive national procurement system in the 1990s. The British Medical Journal noted: “Advocates of presumed consent often cite the Spanish organ donation system as an example of the success of presumed consent legislation. In fact, what Spain has shown is that the highest levels of organ donation can be obtained

¹ <http://www.odt.nhs.uk/pdf/the-potential-impact-of-an-opt-out-system-for-organ-donation-in-the-UK.pdf>

while respecting the autonomy of the individual and family, and without presumed consent.² The article also noted that the US, which has opt-in systems in place, has an “excellent deceased donor rate” which can be attributed to a ‘positive attitude to organ donation on the part of those approaching families of potential donors.’³ A report by the UK’s NHS Blood Transplant body noted that Sweden, which introduced opt-out laws in 1979, has a lower organ donation rate than the UK.⁴

1.4 There is a real concern that if the Government adopts a scheme based on presumed consent, people will feel that the State is placing a greater imposition on them which could lead to individuals turning away from organ donation entirely.

1.6 A soft-out system presumes that every individual is aware of the legal requirement to register their objections, and that a failure to do so is simply indicative of consent. However, this is unlikely to be the case in practice, and it is inevitable that organs will be unethically removed from individuals who failed to opt-out because they were unaware of the new system.

Question 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 measures that could achieve similar outcomes without the need for legislation?

2.1 We would argue that it is not essential to change the law.

2.2 Though the number of deaths resulting from a shortage of donated organs is concerning and action is urgently needed, there is no clear evidence to show that changing to an opt-out system will produce the desired result. Sweden introduced presumed consent laws in 1979 and still has one of the lowest levels of organ availability in the developed world. Spain also introduced opt-out laws in 1979 but the legislation has had no impact on organ availability. The United States and Ireland have opt-in systems and have very high rates of organ donation.

2.3 It has not been shown that having an opt-out system with presumed consent makes a key difference to organ donation rates. Statistics from Spain, Ireland and the US demonstrate that a substantial increase in organ donation rates can be achieved within the current legislative framework by diverting resources to other more effective measures. These alternative measures include raising awareness through government campaigns and advertising, and increasing transplant coordinators, intensive care beds and organ retrieval teams. The Government could consider for instance replicating the catchy slogan of Canadian Blood Services advertisements: “Blood. It’s in you to give”. This campaign would be far less costly than switching to an opt-in system and would draw on the concept of altruism to encourage voluntary donation.

² One of the BMJ authors, Prof Rafael Matesanz, is founder of the world’s most successful transplantation service in Spain. Fabre, P Murphy, R Matesanz. 2010. ‘Presumed consent: a distraction in the quest for increasing rates of organ donation’. BMJ. 341 doi: 10.1136/bmj.c4973 <http://bit.ly/vmzenx>

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⁴ http://www.organdonation.nhs.uk/newsroom/statements_and_stances/statements/opt_in_or_out.asp

2.4 The Organ Donation Taskforce of 2008 advised against implementing an opt-out system, saying it had the “potential to erode the trust between clinicians and families at a distressing time.” The taskforce also “found no convincing evidence that [an opt-out system] would deliver significant increases in the number of donated organs.”⁵

2.5 Should the government decide to move away from an opt-in system, we propose “Mandated Choice” as an alternative. This would require legislation, but would not present any problems beyond those entailed in switching to an opt-out system.

2.6 “Mandated Choice” brings with it no comparable ethical concerns and is a system where, by law, individuals are required to make a decision about organ donation, but are completely free to choose whether or not to donate. There is no compulsion about the content of the decision - it is necessary only that a decision be made and recorded.

2.7 This choice can be revisited at any time and remains on file with the rest of the individual's National Insurance information.

Question 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.

3.1 We do not agree with the introduction of a soft opt-out system.

However, should the Government press ahead with its proposals:

3.2 We do not agree that the role of the family should be limited to being consulted only on unregistered objections. It would be detrimental to the practice of medicine, and the relationship between doctors and patients, if doctors were encouraged to disregard consent in dealing with the immediate family in the context of death.

3.3 Those closest to the deceased should have an important role to play in the decision-making process, not just in determining whether a registered objection had been made by the deceased. This is especially true for children under the age of 16.

3.4 Where a decision was not clearly expressed by the deceased, it should not be possible for clinicians to remove organs where loved ones express an objection. Ignoring the objections of family members would only serve to increase the pressure on loved ones at a distressing time.

Question 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.

⁵ http://www.nhsbt.nhs.uk/download/board_papers/nov08/potential_impact_ODTF_08_103.pdf

4.1 We do not agree with changing to an opt-out system for organ donation.

However, should the Government press ahead with its proposals:

4.2 We do not agree that a proxy should be permitted to make the final decision on behalf of the deceased. An individual who objects to organ donation would not appoint a proxy, but would simply register their objection.

Question 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.

5.1 We do not support the move away from an opt-in system.

However, should the Government decide to press ahead with its proposals:

5.2 We agree that only adults should be registered as donors automatically. Younger persons should be required to opt-in.

5.3 The best way to safeguard children and young people is to require parental consent before registration. This would ensure that both children and parents fully understand the implications of the decision to donate, and would eliminate the potential for conflict and confusion later on.

Question 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?

6.1 We do not support the move away from an opt-in system.

However, should the Government decide to press ahead with its proposals:

6.2 We do not agree that the automatic opt-in age should be sixteen.

6.3 Whilst sixteen is the age set for health card registration, it is not the age at which most people are considered to be mature, independent-thinking adults. Sixteen year-olds are still in school, usually still live at home, cannot serve in the military and cannot vote. If the Government is unwilling to permit sixteen-year olds to take decisions in matters of military and voting, why should organ donation be any different?

6.4 A more appropriate age would be eighteen, as this is considered the age of maturity for other important life decisions.

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

7.1 We do not support the move away from an opt-in system.

However, should the Government decide to press ahead with amending the law:

7.2 We do not agree that a one year minimum period is sufficiently long as this would encompass people who are residing in Scotland temporarily, including students and long-term visitors. Temporary residents may not be aware of the need to opt-out and yet would be considered as having ‘consented’ to organ donation if they fail to do so. The law should only apply to those who have been in the country for five years or more.

Question 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.

8.1 We do not support the move away from an opt-in system.

However, should the Government decide to press ahead with its proposals:

8.2 The residency period should be five years.

8.3 The residency should be for a continuous period.

8.4 The requirement for five years of continuous residency would help ensure that temporary students, workers and visitors - who are unlikely to be aware of the new system - would not be considered by the State as having ‘consented’ to organ donation. The removal of organs from those who are visiting the country temporarily is likely to cause great distress to friends and relatives abroad and will only serve to damage public confidence in the medical profession.

8.5 Five years is long enough to cover students only living in Scotland for the three or four years of school.

8.6 Requiring the residency to be continuous protects the frequent traveler from being caught off guard by automatic inclusion.

8.7 Having a continuous period would be increasingly important as the minimum time requirement decreases.

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

9.1 We do not support the move away from an opt-in system.

However, should the government decide to press ahead with amending the law:

9.2 No, we do not agree that 6 months is a long enough period. The campaign prior to change-over should be at least a year – 18 months long, followed by a further one year - 18 month transition period during which individuals are encouraged to make their final decision. Each individual should be provided with time to discuss their options, make an informed decision, communicate their decisions to their family and register their decision with the Government.

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

10.1 There may be financial implications of the proposals to our organisation. Should families' wishes or individuals' choices be misconstrued, the Christian Legal Centre may be required to provide legal representation to families who take legal action against the NHS, individual doctors and the Government. Many families will not have the resources to afford such litigation, and this would be costly to our organisation.

10.2 The proposed system will be costly and have financial implications for the NHS. In order to provide an opt-out system that is not corrupt, the Government will need to ensure that the right financial incentives are in place for a successful move to opt-out. This will include financial means to pay for campaigns and an adequate system of recording the wishes of people who choose to opt-out of the scheme. This would be complicated and costly for the Government.

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

11.1 We do not support the move away from an opt-in system.

However, should the Government press ahead with amending the law, safeguards should be in place to protect vulnerable groups:

11.2 The disabled

- We are concerned that those with severe physical disabilities may have trouble registering their objections with the Government. This group, in particular, would need family members to play a strong role in indicating their wishes regarding consent to medical professionals.
- We are also concerned that the disabled may be at risk of premature harvesting of their organs.

11.3 Minorities

- As mentioned above, the best way to safeguard children and young people is to require parental consent before registration (please see 5.3 above).
- We are concerned that the scarcity of donated organs from children may put minors at greater risk. Under a presumed consent system, doctors may face undue pressure to prematurely harvest organs from minority groups.

11.4 Those Experiencing Mental Health Challenges

- We agree that presumed consent laws should not apply to mentally ill patients as they would not have the capacity to register their decision.

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

We strongly oppose the move away from an opt-in system. It presents a fundamental ethical shift and opens the path to possible abuse, coercion and distress. The proposed system does not involve 'consent' by an individual, and fails to protect the fundamental dignity and autonomy of every human being. An increase in organ donations can, and should, be achieved within the current legislative framework by diverting resources to other more effective measures.