Royal College of Physicians of Edinburgh

Response to the Proposed Organ and Tissue Donation (Scotland) Bill

The Royal College of Physicians of Edinburgh (the College) is pleased to respond to the Proposed Organ and Tissue Donation (Scotland) Bill. The College has sought the input of Fellows in a variety of medical specialties as well as the view of our Lay Advisory Committee to contribute to this consultation response. A wide range of views have been submitted and unanimity has not been reached on several issues.

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.

Yes. The College supports this move provided there is a parallel process of public education about the benefits of organ donation and improved infrastructure to support families and clinical teams at the time of organ donation.

Some Fellows have expressed the view that there are a number of individuals who would be donors but have not made that view known before their death. The move to a soft opt-out system would therefore likely make a small but real difference to the number of organs donated in Scotland.

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?

Scotland currently has a voluntary 'opt-in' system, encouraging people through educational campaigns to register as donors on the Organ Donor Register. Following investment and publicity about this register, around 40% of the population of Scotland have registered as donors.

In practice, consent for organ donation is always sought from the next of kin. Unfortunately, approximately 40% of families approached refuse consent for organ donation. If someone has previously registered their desire to be a donor then the refusal rate is lower (approximately 10% v. 50%).

The available international evidence supports the fact that 'opt-out' legislation is associated with increased rates of deceased organ donation. However, the **legislation itself may not be the major determining factor for organ donation** as some countries with "opt-in" systems still have higher organ donation rates than countries which have adopted "opt-out" legislation.

There are differing opinions within the medical profession and society at large regarding an 'opt-out' system. Some believe that "opt-out" legislation effectively means acquisition by the State of organs, and removal of the altruistic aspect of donation is of real concern to some of our Fellows, who feel that bereaved families take great solace from an active act of giving. These and other ethical issues have prevented the global adoption of presumed consent legislation.

However, the higher rate of organ donation in 'opt-out' jurisdictions persists even when the next of kin are still asked for their approval before retrieval (this is termed 'soft' opt-out as opposed to 'hard' opt-out when the relatives are not consulted).

A higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure.

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. Public confidence in a soft opt-out system would be quickly undermined if family did not continue to play a key role in decision making. Clinicians could be placed in the very difficult position of harvesting organs in the face of explicit opposition from immediate family members, which could undermine confidence in medical teams. The family should always be consulted about the request to harvest organs and asked about the expressed wishes of the deceased.

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

Undecided. Fellows have mixed views on this proposal.

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.

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?

Undecided. There are shades of opinion on this issue, given that patients under 18 are able to give informed consent for other medical procedures. However, a more explicit "opt-in" approach may be helpful for those under 18, particularly as it is likely to be their parents who are asked for consent to harvest organs.

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.

Yes. This should be long enough to allow health records to be available and for the deceased to have had an opportunity to opt out.

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?

Yes; providing this includes extensive publicity and promotion of educational information about organ donation. Improved infrastructure (including training) to support clinicians and families may take longer to put into place, however, and this **must** be prioritised in order for the introduction of a soft opt-out system to have a meaningful impact.

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?

No specific comment.

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?

No specific comment.

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

None.

All College responses are published on the College website

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