



ROYAL COLLEGE OF
PHYSICIANS AND
SURGEONS OF GLASGOW

Response from the Royal College of Physicians and Surgeons of Glasgow

to the

Proposed Organ and Tissue Donation (*Scotland*) Bill

Consultation questions

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 –please see section 12

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?

There are other measures that could be used –please see section 12

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.

Undecided, please see section 12

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: We are concerned that it may be difficult to contact such a proxy and that documentation would need to be reliable and witnessed

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.

We would not support the overall proposal but would agree that it should not be assumed for children.

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?

Yes

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.

Undecided: mixed views expressed

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?

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

No –much fuller consultation would be necessary

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?

The Welsh example was associated with a significant outlay

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?

Not sure – depends on terms of opt out

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

It is evident that consent for cadaveric organ donation is a complex issue. It would appear that there is an arguable case for a system of presumed consent which has been shown to yield more organs for transplantation than informed consent or opt-in systems.¹ If such a system were to be introduced into the UK, after the appropriate changes in legislation, it would have to be at least as efficient as the current system.

However, there is also evidence that the inappropriate introduction of presumed consent legislation can have a significantly negative effect on organ donation rates, as was clearly shown in Brazil.² Brazil introduced presumed consent in 1997. However the number of citizens from all socio-economic backgrounds who choose to “opt-out” was so great that the law was repealed the following year.

Abadie and Gray, in their international study³ of 22 countries over a 10 year period, did not find a correlation between presumed consent laws and higher organ donation rates. Similar work by Nowenstein⁴ supports the observation that presumed consent laws can be associated with low donation rates. Closer to home, the significant fall in organ donation rates in Wales during the recent period of public consultation on the Human Transplantation (Wales) Bill is also important to note.⁵

The current informed consent system has been substantially improved over the last five years by means of better co-ordination. These changes have resulted in a 50% increase in the number of deceased organ donors over that period.⁶ It is important that such a level of donation is maintained and increased over time in order to further reduce the organ supply deficit. The Organ Donation Taskforce in its plan for 2013-2020 outlines the continued introduction of organisational changes to increase rates of donation, with added emphasis on information technology systems.⁷

A key consideration is the wording of the Human Tissue Act 2004 which emphasises “appropriate consent” and clearly defines the term. The wishes of the deceased are given primacy in the order of those who can give “appropriate consent.” Therefore the wishes of a registered organ donor should be respected. In this regard, an opt-out system, as described by Gill⁹ with his “fewer mistakes” claim has an appeal.

However, whatever the precise legislative environment may be, it is our strongly held view that relatives play an important role in organ donation after death. It is important that they are involved and that the wishes of the deceased should be respected where they are known. Thereby the deceased’s autonomous decision, which was made freely in life, lives on and their wish to donate, or not, is fulfilled. A presumed consent system could undermine the concept of organ donation being a gift and erode the trust in NHS professionals. We believe that there remains scope to reduce the number of family refusals of organ donations from registered donors in ways that preserve their involvement.

The current system in the UK is working and is improving. Nothing should be done which would jeopardise it, because there is too much to lose. We should not ignore the Welsh experiment, and the worrying fall in donations during the year of the consultation.

This proposal has generated significantly different opinions from members of this college. Noticeably several of our Lay Advisory Board were strongly opposed to it. We believe that a proposal to adopt an opt-out system would require widespread public approval for it to operate in a manner that did not contradict the principles of the Human Tissue Act and for it to generate the desired increase in donations rather than a potential fall, as in Brazil. We believe that attention to the organizational systems that support donation and to the communication with family members may result in increased donation without the risks involved in a system of presumed consent.

Overall there does not seem to be sufficient compelling evidence of the benefits of a change to a system of presumed consent to justify endangering the current system of informed consent for cadaveric organ donation in the UK.

- 1) Michelson, P. "Presumed consent to organ donation: ten years experience in Belgium." (1996) 89 *Journal of the Royal Society of Medicine* 663-6 at p 664.
- 2) Csillag, C. Brazil Abolishes "Presumed Consent" in Organ Donation. (1998) 352 *Lancet* 1367.
- 3) Abadie, A and Gay, S. "The impact of presumed consent legislation on cadaveric organ donation: A cross-country study." (2006) 25 *Journal of Health Economics* 599-620.
- 4) Nowenstein, G. "Organ Procurement Rates: Does Presumed Consent Legislation Really Make a Difference?" <http://www2.warwick.ac.uk/fac/soc/law/elj/lgd/2004> last accessed 11/02/2013
- 5) Brazier, M. "Retained organs: ethics and humanity." (2002) 22 *Legal Studies* 550-569 at p 568
- 6) Organ Donation Transplantation news release – "NHS achieves ground breaking 50% increase in deceased organ donors" – 11/04/2013
- 7) <http://www.nhsbt.nhs.uk/strategicplan/download/nhsbt-strategic-plan-201318.pdf>
- 8) Gill, M.B. "Presumed Consent, Autonomy, and Organ Donation" (2004) 29:1 *Journal of Medicine and Philosophy* at p 41.