

Presumed evidence in deemed consent to organ donation

David Shaw

It was recently announced that Scotland is to follow the example of Wales in introducing ‘opt-out’ legislation for consent to organ donation.¹ If implemented, this will mean that people living in Scotland will no longer have to actively register authorisation (the term used in Scotland) to donate – this will be ‘deemed’ for anyone who does not register a refusal to donate his or her organs. While this move might be welcome inasmuch as it aims to increase organ donation rates and save lives, the evidence that this change will achieve that aim is weak – and the change could increase pressure on intensive care staff.

The Scottish Government’s justification for the decision to bring forward legislation serves as a metaphor for more fundamental problems relating to evidence. The main reason cited in the announcement was that ‘82% of consultation responses supported the move... including a petition with 18,500 signatures in support of opt out’.² First, it is not clear what the criteria for defining a response as supportive were; for example, the British Transplantation Society response was supportive in principle but listed several reservations, including the suggestion that more data from Wales be gathered before making a decision.³ Second, consultations are not referenda; if the 18% of negative responses contains serious arguments against opt-out, that should potentially be given greater weight than a larger proportion of positive yet illogical responses.

The evidence regarding the effect of the introduction of deemed consent in Wales has also been overstated – not least by the Welsh Government. Only six months after the introduction of the new consent system, it was claimed that ‘dozens of lives’ had been saved by the new system.⁴ But in all cases where consent was deemed, it would otherwise have been sought from relatives, and in many cases granted. After one year, it was claimed that ‘The number of organs transplanted has increased from 120 between the 1 December 2013 and 31 October 2014, to 160 between 1 December 2015 and 2016’.⁵ This figure includes organs donated from patients outside Wales, and thus misrepresents the effect of deemed consent. Furthermore, even if there was an increase, it could be due to year-on-year fluctuation rather than any effect of deemed consent.

But more important than the misrepresentation of evidence for political ends is the potential misrepresentation of the evidence base for consent to families. Under the deemed consent system, everyone is presumed to have consented unless he or she opted out. In Wales, there was a public information campaign, which led to an increase in donation rates even before deemed consent was introduced. NHSBT and the Welsh Government (and seemingly the Scottish Government) seem to be happy assuming that everyone knows about the new consent system. Unfortunately, however, many people do not know about it. Research conducted one year after the introduction of deemed consent found that over one in four people could not describe how the system had changed.⁶ In other words, over 25% of people in Wales do not appear to know that they have to register a refusal if they do not want their organs to be removed once they die. (One can hardly ‘donate’ by accident.) But perhaps that is not so bad, as presumably most of these people would support donation in any case – generally public support for donation is at least 75%. This means that perhaps 25% of the 25% who do not know about deemed consent would not want their organs to be taken. But that still means over 6% of all those from whom organs are taken. In a worst-case scenario, this in turn means that over 1 in 20 ‘donors’ are having organs removed against their will.

Of course, under the deemed consent system, families can prevent donation going ahead if they think the patient would not have wanted to donate. This is an important safeguard, but it is questionable whether they are being given enough information to assess the balance of probabilities. Generally, they are told something like the following: everyone in Wales knows and knew about the new law, and there’s been a big information campaign, and their loved one did not register an objection, so unless the family has any

Institute for Biomedical Ethics, University of Basel, Switzerland;
Department of Health, Ethics and Society, CAPHRI Research
Institute, Maastricht University, the Netherlands

Corresponding author:

David Shaw, Institute for Biomedical Ethics, University of Basel, Basel 4056, Switzerland.
Email: david.shaw@unibas.ch

evidence of objection donation will proceed. This approach implies that there is good evidence to think it safe that consent can be deemed. What they are not told is that one in four Welsh people are unaware that they had to register a refusal and that (in cases where there is no evidence of refusal or consent) there is a one in four chance that their relative actually did not want to donate. It does not seem unreasonable to give families up to date information about public awareness of deemed consent before asking them to make a decision. Otherwise, any evidence given to families in support of deemed consent will itself be presumed.

The issue of weak evidence regarding various claims connected with deemed consent (or authorisation is augmented by the fact that deemed consent could actually increase the rate of family overrule). While the Welsh data so far are weak, they nonetheless suggest a quite high rate of overrule. This is unsurprising, for all the reasons mentioned in the previous paragraph. If a person is on the donor register, a family might object but assent when shown evidence of consent. If a person never bothered to register because of deemed consent making it unnecessary to do so, that evidence will not exist, making it tempting for families to overrule deemed consent to avoid the risk of organ removal when it was not wanted. And another vagueness is that families can and in several cases have registered refusals to donate on behalf of their relatives when those relatives are incapacitated in hospital, when only the patient him or herself is meant to do that. This could be because they do not realise that is not necessary and they could just say the

person did not want to donate, but it is unfortunate nonetheless.

The introduction of deemed authorisation in Scotland would be a bold step aiming at improving organ donation rates. But if the evidence from Wales and elsewhere is disregarded, and if families are not give transparent information, it might instead be a bold step backwards for Scotland's donation rates.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

1. www.theguardian.com/society/2017/jun/28/scotland-to-introduce-soft-opt-out-system-for-organ-donations (accessed 18 September 2017).
2. <https://news.gov.scot/news/increasing-organ-and-tissue-donation> (accessed 18 September 2017).
3. <https://bts.org.uk/bts-response-to-scottish-government/> (accessed 18 September 2017).
4. www.theguardian.com/society/2016/jun/14/wales-deemed-consent-organ-donations-increase-transplants.
5. www.itv.com/news/wales/2016-12-01/one-year-since-automatic-organ-donation-law-came-into-force-has-it-made-a-difference/ (accessed 18 September 2017).
6. www.bbc.co.uk/news/uk-wales-politics-36520627 (accessed 18 September 2017).