Why Scotland should not presume authorisation without evidence

The change in the law in Wales

Scotland and England are both currently considering following Wales which in 2013 passed legislation to switch to a “deemed consent” system beginning in December 2015. In a press statement released just prior to the system coming into effect, the Welsh government claimed that this “could lead to a 25% increase in the number of organ donors”.

No robust evidence of benefit

There is no robust evidence that a change on the law on consent / authorisation will increase rates of organ transplantation. Comparison even with fellow European countries such as Spain is difficult because of the many differences of culture, history and medical practice between countries. Even when transplantation rates change within a country it is difficult to distinguish the extent this reflects increased public discussion, simultaneous changes in medical practice or funding, or the change in the law itself. Perhaps the best opportunity to generate a meaningful comparison among countries with a common health service is provided by Wales operating a different consent/ authorisation system to the rest of the United Kingdom. However, the results so far give no evidence of benefit on rates of transplantation or reduction in waiting lists.

In 2017 after the first full year of the opt out system in Wales, post mortem organ donors rose in Scotland (103 to 137) and rose in England (from 1134 to 1157) but decreased in Wales (75 to 68). Similarly, the most recent report of NHSBT shows that between 2016/17 and 2017/18 the kidney transplant waiting list was reduced in Scotland (from 437 to 430) and England (from 4463 to 4298) but increased in Wales (from 185 to 189). These figures vary from year to year and depend on many factors but there is no evidence from Wales of the dramatic benefits that were promised.

The results from Wales are in line with the comprehensive review by the Organ Donation Task Force in 2008 which concluded that it was “not confident that the introduction of opt-out legislation would increase organ donor numbers, and there is evidence that donor numbers may go down.”

All across the United Kingdom there is a steady rise in organ donation and reduction in the waiting list for organs. Ironically Scotland and England are making better progress than Wales with its system of “deemed” consent. Deemed authorisation is not a “magic bullet” but is a distraction from changes that are known to increase donation rates (such as being on the organ donation register or the presence of a specialist nurse for organ donation).
In most cases in Wales deemed consent does not reflect the wishes of the deceased person

In surveys throughout the UK most people voice support for organ donation (between 65% and 80% depending on the question). Similarly, most people, assuming it would increase the organs available, are in favour of a system of deemed authorisation or consent. The SPICe briefing notes that a survey commissioned by the Health and Sport Committee found 68.8% in favour of a move to deemed authorisation. This is higher than the percentage of people on the organ donation register (currently 46% in Scotland). However, if people are not on the register it may also be because they do not wish to donate or because they have not decided either way.

In preparation for the change in the law, and subsequent to the change, the Welsh government has asked about attitudes to organ donation. They found that, after the change in the law, in 65% of cases people were either already on the register or had “done nothing – as were happy for deemed consent to apply”, a clear majority. However, 38% of people in Wales were at that time on the donation register and 6% had opted out. Thus, among those who are not in the opt-in or opt-out register less than half were “happy for deemed consent to apply”. In most cases in Wales where deemed consent is used this does not reflect what the person would have wanted. Taking organs where a person neither authorised it nor was happy for deemed authorisation to apply is not donation. To move to a system of organ transplantation by deemed authorisation is to undermine the very concept of organ donation.

In this context it should be noted that a form of opt out system already exists in Scotland. An opt out register was established in 2006. Opting in by signing the organ donation register provides legal authorisation so that authorisation by the nearest relative is not needed and transplantation could take place, legally, over the objections of the nearest relative. In the absence of authorisation by the person, the current law enables the relative to authorise donation on his or her behalf. The only effect of the change in the law is therefore to allow transplantation over the objection of the nearest relative in cases where the deceased is not on the organ donation register and the doctor can have no reasonable confidence of what the person wanted. Doctors are reluctant to take organs under these conditions, and if they did, it would not be “donation”.

The undermining of donation was a key argument that united Roman Catholic and Church in Wales bishops (and a representative of the Orthodox Church in Wales) in opposing the change to an opt-out system. A copy of the churches’ joint submission is given in an appendix to a report on the ethics of organ transplantation produced by the Anscombe Bioethics Centre (which also discusses many other ethical questions in this area). http://bioethics.org.uk/Ontheethicsoforганtransplantationfinal.pdf

The sensitivities of religious and ethnic minorities

Members of Black, Asian and Minority Ethnic communities have, on average, a greater need to receive an organ but are less likely to register as an organ donor and less likely to consent to donation of a relative. Faith communities have diverse views
about the determination of death and/or about the proper treatment of human remains. Successive governments have therefore had a policy to engage positively with minority communities on organ donation. However, this work requires great sensitivity and the system relies on trust. It only takes one case where the family feels they were misled or not properly consulted, or it emerges that the person was opposed to organ retrieval on religious grounds, for “deemed authorisation” to become a lightning rod.

Around the same time as Scotland has had its consultation a very similar consultation has occurred in England. With due respect to the differences between the countries, there may still be something to learn by looking at the results of this consultation which attracted over 17,000 submissions including 987 from Jewish or Muslim respondents. The English consultation asked explicitly whether a change to a deemed consent system could have a negative impact on those from certain faith groups or ethnic backgrounds. The view from the majority community was mixed, with 32% saying it could have a negative impact, 44% saying that it would not and 24% uncertain. However, the view from minority faith communities was clearer and much more negative, with 85% of Jewish and 79% of Muslim respondents stating that it could have a negative impact.

In summary there is no robust evidence that a change to deemed authorisation would increase rates of organ transplantation in Scotland and there is good reason to think that it would undermine the concept of transplantation as donation and that it could have a negative impact on religious minorities. At the very least the Scottish government should defer any change until there is clear evidence from Wales that such a change could bring significant, positive and measurable benefits.