

Response to Consultation on Proposed Organ and Tissue Donation (Scotland) Bill

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, I do not support such a move. The paper presents a considerably simplified discussion of the highly complex issue of the relationship between donation rates and opt-out legislation.

The paper rightly notes that international comparisons are difficult to interpret and that it is problematic to assess the exact contribution of ‘presumed consent’ legislation alone to achieving increases in donation levels. It also acknowledges that there can be no certainty that a change in the system would alter family refusal rates. These issues are however discounted in favour of assertions, lacking a robust evidence base, that a soft opt-out system will help increase the availability of organs, and the paper can summon up no more than a ‘hope’ that a soft opt-out system will in fact encourage more people to make decisions about donation during their lifetime.

Given that the proposal has been triggered by the legislation passed by the Welsh Assembly, it is surprising that the consultation paper says nothing about the recent trend in organ donation numbers in Wales. The figures on the NHS Blood & Transplant (NHSBT) website show that the total number of deceased donors in Wales fell from 66 in 2010-11 to 54 in 2013-14. That is in spite of the strenuous efforts made over several years to raise awareness in Wales of organ donation in advance of the new legislation. By contrast, during the same period the number of deceased donors in Scotland has increased from 67 to 106. These data alone fully justify the Scottish Government’s stance of continuing with its present range of activities based on the current legislation and waiting until the true effect of the Welsh legislation can be assessed some time after it has come into operation.

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 transplantation rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

No change to the law is needed. The consultation paper gives an inadequate account of the present legislation and the current arrangements relating to organ donation, in order to exaggerate the supposed effect of the proposed new legislation. In fact, however, the differences are slight, and generally not for the better. Under the present arrangements, people have the right to decide whether they wish to donate or not. An increase in the number of organs available for transplantation, thereby saving some of the lives of those who would otherwise die on the waiting list, is more likely through continuing with the existing arrangements. Families are currently consulted at the time of death about their understanding of the deceased person’s wishes. Their role is made easier in every case where it is clear that the deceased had expressed a positive wish to donate. This is because the 2006 Act is based on the concept of authorisation, which embodies people’s right to make such decisions of their own volition, and gives legal backing to the honouring of those wishes. The NHS Organ Donor Register is already being revised to

allow for the recording of objections to donation, as well as positive wishes in favour of donation. The claim that changing to a system of opt-out removes the onus on the family cannot be sustained. As the paper acknowledges, the absence of an entry on the opt-out register would create a degree of uncertainty about the deceased's wishes, so expecting the family to rely on an absence of objection in fact would make their role harder.

The present legislation could be enforced more strictly, in cases where the deceased has expressed a positive wish to donate but where the family seek to veto those wishes. According to its most recent organ donation strategy, the Scottish Government intends to consult on public attitudes to such an approach, and the UK Donation Ethics Committee is intends to work on guidance on the role of the family in relation to organ donation decisions.

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.

I agree that the focus should be on establishing, and honouring, the wishes of the deceased. The role of the family should be to clarify these where the deceased left no formal expression of wishes, rather than attempting to impose their own wishes. As argued in the answer to Question 2, the family's position is made easier when they know they are supporting a positive wish on the part of the deceased in favour of donation.

4. Do you think that 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.

No. This seems an unnecessary complication. The focus should remain on encouraging people themselves to make a positive decision during their lifetime regarding donation. Where no such decision has been taken, the hierarchy of 'nearest relatives', as set out in section 50 of the 2006 Act, provides a sufficient alternative in terms of decision-making responsibility.

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. Please indicate "yes/no/undecided" and explain the reasons for your response.

Any system of organ donation must of course include safeguards for children and young people. By treating all children under 16 in the same way, the proposed approach is less nuanced than the present arrangements, and is therefore a retrograde step. The 2006 Act recognises that children over the age of 12 have the capacity to make decisions about organ donation, and to expect those decisions to be honoured by their parents. The age of 12 is in line with general legislation about the age of children's ability to make decisions in a medical context, as set out in the Age of Legal Capacity (Scotland) Act 1991. It is only children under 12 who are regarded as lacking the capacity to make such decisions.

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, the age limit for an adult should be set at 16 years old (presumably as opposed to the age of 18, as included in the Welsh legislation). That is in tune with Scots legislation generally.

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.*

This seems a purely arbitrary length of time, and is a further indication of the problems inherent in a move to a system of opting-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?*

No comment, other than to note this is yet another manifestation of the tangle that would be produced by the introduction of the proposed legislation.

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

No, it seems a quite inadequate period in which to make every adult in the country aware of a proposed change of such significance as the use to which their organs would be put after their death. The Welsh legislation stipulates an initial 2 year campaign. Nor could a one-off campaign be regarded as adequate in ensuring that at any given time the whole adult population was aware of the approach enshrined in opt-out legislation. This is a further requirement of the Welsh legislation.

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?*

It is interesting that the consultation paper offers no information on the estimated costs of public awareness campaigns in Wales. The opportunity costs of running these are considerable, and raise the question of whether such funding might be put to much more effective use for other purposes, such as underpinning the organ donation and transplantation infrastructure.

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?*

The UK Organ Donation Taskforce in its report on the potential impact of an opt-out system recorded concerns that such a move had serious implications for human rights. Many people felt that such a system, under which, as a result of apathy, donation would become the default position, would remove individual choice. Senior figures from faith and belief groups interviewed as part of Taskforce work did not support change, on the basis that opt-in represents individual choice and avoids potentially negative presumptions about a shift in balance between individuals and the state. They also felt that there would need to be much more engagement with 'hard to reach' groups such as faith and BME groups.

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

One very important issue not touched on at all in the consultation paper is the potential impact of the proposed change on the clinicians in intensive care who look after those who go on to become organ donors. Almost all the increase in Scotland's organ donation numbers in recent years has come from programmes of Donation following Circulatory Death (DCD). DCD donors are patients for whom further treatment is regarded as futile and which should therefore be withdrawn. Where such patients have expressed a wish to donate organs after death (ie they have given authorisation under the 2006 Act), steps can be taken to realise that intention. The steps currently permissible within the provisions of the Adults with Incapacity (Scotland) Act 2000, are set out in CMO Letter (SGHD/CMO(2010)11 of 3 May 2010. It makes matters much easier for ICU staff, as well as families, if they can be confident that they are making possible the positive donation wishes expressed by the person in their care. In this highly sensitive area, it cannot be certain that ICU staff would regard a presumed consent as giving them as strong a mandate. This view was endorsed in April this year by the UK Donation Ethics Committee (UKDEC), which had been asked by the Welsh Government for an opinion, amongst other things, on whether 'deemed consent' (the expression used in the Welsh legislation) represented equally strong evidence of a person's wish to be a donor as did express consent. Most members of the Committee felt that, intrinsically, deemed consent could not be so regarded, since express consent constitutes positive evidence of a wish, while deemed consent is the absence of evidence.

The significance of this point is that the UK Organ Donation Taskforce heard strong views from clinicians that a presumption of consent might make families feel they were being pressured, and therefore erode the relationship of trust between clinician and family. The Taskforce concluded that a system of decision-making based on respecting the known wishes of the patient is the one that is most likely to maintain the integrity of the relationship between doctors and patients, and between doctors and the wider public, thereby maintaining trust and confidence in the donation system (paragraph 8.2 of report).

The Taskforce also heard strong evidence from recipients of transplants who underlined how important it was for them to know that organs had been given freely. The concept of organ donation as a gift matters greatly to both donor families and recipients, and there would be significant concerns that an opt-out system might undermine that principle (paragraph 8.5 of the Taskforce report).

The current legislation was a response to the revelations about retention of organs at post-mortem, and showed very clearly the problems that can arise when presumptions are made about what people or their families actually want. Assuming consent from silence could

be thought to belong to a more paternalistic era. Those concerns are still all-too-valid, as the issue of the disposal of children's ashes has brought home. There must therefore be considerable risks to public confidence if the arrangements for organ donation and transplantation were to be based on a foundation of presumed consent.

The move to a system of opting-out is therefore a considerable leap in the dark, and carries with it the risk of jeopardising the continuation of the excellent progress in donor numbers made in Scotland in recent years. It would therefore be altogether prudent to wait until a proper assessment can be made of the impact of the Welsh legislation before considering whether a similar legislative change is needed in Scotland.