

Proposed Organ and Tissue Donation (Scotland) Bill

#108



COMPLETE

Collector: Web Link 1 (Web Link)
Started: Sunday, August 03, 2014 12:14:55 AM
Last Modified: Sunday, August 03, 2014 1:54:32 AM
Time Spent: 01:39:37
IP Address: 86.155.168.52

PAGE 2: Proposed Organ and Tissue Donation (Scotland) Bill Consultation

Q1: 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 give your reasons for your response:
There is insufficient evidence to say such a move would actually lead to an increase in organs becoming available. Based on my understanding of organ donation, opt-out won't make a big difference and therefore I don't support it because it will be an expensive and time-consuming distraction from doing the things that will make a difference. (I would personally have no objection to living in a country with a system of opt-out so I have no ideological opposition - I just don't think it would work.)
Suggesting opt-out will increase the number of donors shows a lack of understanding of how organ donation actually work. Opt-out would only change the number of overall potential donors in the population (i.e. the number of people on the organ donor register) - but that never really has any impact on the number of donors there actually are. Your own consultation proves that point - 62% of donors in recent years were not on the Organ Donor Register - and clearly that shows that not being on the register doesn't stop people from becoming donors. The reality is the biggest rate-limiting factor on the total number of donors in Scotland is the number of people who die in intensive care. Only around 1% of deaths occur in intensive care and that's the maximum potential donors there will ever be - opt-out will do nothing to affect that. I note that your consultation is not supported by any of the clinical groups actually involved in organ donation or transplant, such as the British Transplant Society or the Scottish Intensive Care Society (BMA or Royal College of Surgeons as groups don't really count because the vast majority of members of those groups will never see a donor or a transplant recipient - it's a rare event for most doctors.) Why would you not seek the views of the clinicians and professionals actually involved in the work and who know how the organ donation pathway actually operates? I can understand why patient groups support opt-out, because they think it will make a difference, but in reality it won't. One other thing I've never understood about the arguments for opt-out is people say it would be very easy for people to register their wish to 'opt out' so nobody would have their organs taken who didn't

Proposed Organ and Tissue Donation (Scotland) Bill

actually want it. But it is incredibly easy to register your wish to opt-in at the moment, and even though 90%+ of people support organ donation only 40% have done so. So you have to be careful saying that because something is easy people will make their wishes known - they don't at the moment. At the moment the worst that could happen as a result of that inaction is that donors are lost. With a move to opt-out the worst that could happen is that someone's organs are taken against their will - just because they never got round to it. And if that happens the whole public faith in the system will collapse (as was seen in France in the 1990s). It's just not worth the risk when donation and transplant risks are going up significantly without opt-out, and not before we know it would make a difference.

Q2: 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?

Clearly not essential at all given, as the consultation points out, there has been an almost doubling in the number of donors in the last five years or so. There is no reference in the consultation to the Scottish Government's organ donation plan, which was published last year. That plan was drafted in consultation with people working in the field of organ donation and transplant, as well as donor families and transplant recipients. If you had considered that you would see there's something like 20 different actions that are going to be taken forward over the coming years right across the donation pathway. These are things which are known will make a difference (unlike opt out). A prime example is potential donors who are not referred to the specialist nurses in organ donation. These are donors who are lost simply because NHS systems do not work properly (it is nothing to do with the patient or opting in). The Government plan identifies something like 30 such potential donors who were missed in the year before that plan was published - that's double the number of donors Wales thinks opt out will deliver (which remains to be seen). That's just one action in that plan which will increase significantly the number of donors. But that plan does not include opt-out because the people working in the donation and transplant field do not think it will make a difference. Why would you not take account of the views of those experts in the way the Government has done? These are the people who have delivered the significant increase we have seen, and would have to work with the opt-out system you are proposing.

Q3: 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,

Please give reasons for your response:
No firm view on this as I don't support a move to opt-out for the reasons set out above, but if legislation were to be passed on the basis of the family being consulted on any unregistered objection by the deceased that would essentially undermine the whole principle of opt-out. A family who were against donation could simply say there was an unregistered objection. Similar issues have been raised in Wales - essentially if you defer to the family in any way the legislation does not significantly change how things work just now.

Q4: Do you think 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,

Please give reasons for your response:
Don't understand why a proxy is needed if there will be presumed consent? And why does this question refer to 'decision regarding transplantation' rather than 'decision regarding donation'?

Proposed Organ and Tissue Donation (Scotland) Bill

Q5: 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.

No,

Please give reasons for your response:
Why only adults? At the moment anyone aged 12 or over can register as a donor. If the current law allows that these children are able to consent why would opt out take an inconsistent approach? Age of capacity legislation in Scotland allows capacity from 12 in certain circumstances so any proposal to limit opt out to adults would run into conflict with that. It is also interesting that you feel 'opt out' might be a risk that children need 'safeguarding' from - what about adults with limited capacity? Do they not need safeguarding? (I don't mean adults who lack capacity, which you discuss in your consultation, I mean those who may have learning difficulties or some other condition which means they may not be able to fully understand the ins and outs of opt out)

Q6: 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.

No,

If you answered no, what would you consider a more appropriate age?
See comments above about age and capacity. Limiting to 16 years would be out of line with existing legislation in Scotland.

Q7: 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,

Please give reasons for your response:
There will be various views on this, and it will be a judgement call based on consultation and legal opinion as to when opt-out would apply. It will be important to be consistent with other parts of the UK if opt-out is being introduced, to minimise the complexity and potential for confusion in the system.

Q8: 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?

As above - it should be in line with other parts of the UK.

Q9: Do you think 6 months is a long enough period to run a campaign prior to change over?

Not in the slightest. Wales is running a campaign over a number of years. You would need at least two years to ensure sufficient awareness given you are essentially fundamentally changing how informed consent operates. If you get this wrong the whole system of donation could be undermined as the public would lose faith in the NHS.

Q10: 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?

Wales is assuming something like £7mil for the costs of opt-out over a number of years. Scotland will face similar costs (perhaps slightly lower because some of the IT work will have been done for Wales). That's a significant amount of money to spend on something where there is no good evidence it will make a difference - not the best use of public money in my view, particularly when there are other things we could do with that money which we definitely know would increase uptake.

Proposed Organ and Tissue Donation (Scotland) Bill

Q11: 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?

There are groups of people who have moral or religious objections to presumed consent. I don't share those views, I am not ideologically opposed to opt out, I just doubt it will work, but there may be negative impacts on such people. Given donation by ethnic and religious minorities is already relatively rare compared with white groups opt out might exacerbate that problem.

Q12: Do you have any other comments on or suggestions relevant to the proposal?

Some of the content of your consultation is factually incorrect or out of date. For example your graph of donation rates in countries dates from 2002. Since that time the UK has actually progressed a lot and no longer at the lower end of donation rates - we are somewhere in the middle.

The waiting list for transplants in Scotland has actually gone down year on year over the last three years or so, not up.

Some of your content presents an overly simplistic assessment of the issues. For example looking at deceased donation rates is overly simplistic. The UK has one of the best living donation rates in the world, which is never reflected in discussions about opt-out. You also need to look at more than just donation rates when comparing with other countries - Spain has very high donation rates but it also wastes a lot of donated organs. They are unable to use a lot of donated organs because they come from very elderly. Donation is not an end in itself - donation is only useful if it turns into transplants.

Your discussion of opt-out in other countries, particularly in relation to the University of York study, is somewhat selective of the evidence. The study showed there was correlation but not causation. There is no evidence that opt-out leads to higher donation rates and no country with a higher donation rate ascribes that result is due to opt-out. Spain had opt-out for a decade with no change to donation rates. Only when other changes were made did donation rates go up. The argument that Spain (or Italy or X country) has opt-out and therefore higher donation rates, therefore we should adopt opt-out, is like saying the United States has very high donation rates and has a private healthcare system, so we should adopt a private healthcare system. It is hugely simplistic and takes no account of the many other factors in play - i.e. intensive care bed capacity or mandatory brain-stem death testing as just two examples.

And the impact of many other facts is not just linked to the health service... you should map donation rates in Europe against road traffic accidents... that shows how things other than opt-out can drive donation rates... Countries with very low rates of road traffic accidents (like in northern Europe, UK or Germany) do tend to have lower donation rates as a result than in southern Europe.

I'm afraid that overall the consultation is not as well-informed as it should be on a subject of this importance; rather it regurgitates popular myths and misconceptions about opt-out without sufficient evidence or consideration of the intricacies of the donation pathway. I am afraid that this will be an expensive and time-consuming distraction from the work that the NHS in Scotland is already successfully doing to increase donation rates.

PAGE 3: Contact Details

Q13: If you wish your response, or any part of it, to be treated as anonymous and/or confidential, please check the appropriate box. If not, then please go to question 14.

Anonymous

Proposed Organ and Tissue Donation (Scotland) Bill

Q14: Thank you for completing this survey. Please provide your name and contact details below.

Name

Company

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

