

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.

Yes (strongly).

An opt-out system is better for those who wish to donate, because it relieves them of the burden of registering their preferences, and for those who do not wish to donate, because it allows them to record their objection (whereas in our present system it is possible that their next of kin may authorise donation). Assuming that such a system will increase rates of donation and transplantation, it is also better for those in need of a transplant.

If there is anyone made worse off by the change, then perhaps it is those undecided whether to donate. Under the proposed opt-out system, these people will have their organs taken. However, it is not clear that they are worse off as a result. Having their organs taken is not obviously harmful to them, since a) they are dead, b) it is not against their wishes, and c) it is a morally commendable choice. It may be objected that they lose control over whether their organs are taken, but this is no more true under the proposed system than under the present system: if an individual does not make a choice then someone else must. In our present system, either their organs will not be used (which deprives others of a much needed transplant) or the decision will be left to next of kin, burdening them at a difficult time. The opt-out seems at least *no worse* for those in this group, while clearly better for the groups identified above.

I think it is important not to conflate an opt-out system with ‘presumed consent’. This is a common mistake in mainstream media reporting and debate, and the consultation document does sometimes do this: “A move to a soft opt-out system would mean that consent is presumed to have been given by everyone to whom the system applies unless they registered or expressed an objection to becoming a donor” (p. 8).

One may support an opt-out system for a variety of reasons. For instance, one may think the mere *absence of objection* (rather than positive consent) is sufficient to licence posthumous organ retrieval.¹ If this is so, then there is no need to presume that those who did not register an objection actually consent.

¹ Douglas TM and Douglas NM. (2009) Absence of significant dissent should be sufficient for deceased donor organ procurement in New Zealand. *Australian and New Zealand Journal of Public Health* 33(5): 449-454.

Moreover, a *presumption* of consent would be insufficient if *express* consent was necessary for donation. An opt-out proposal therefore assumes that express consent is not necessary. If this is so, however, then (assuming some form of consent is still required) some other, weaker form of consent – tacit or implicit consent – is presumably sufficient to licence donation. An opt-out policy can therefore be justified on the grounds that those who do not opt-out *do actually* consent, albeit tacitly.² Such tacit consent is commonly accepted in other domains.

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?

Undecided.

I'm unclear how to disambiguate this question. Is it asking 'given that we want to achieve these benefits, how essential is a change in the law for doing so?' or 'do these benefits make a change in the law essential?'

If the latter, I'm undecided. Organ transplantations clearly bring significant benefits: they not only save lives but can improve the quality of life and allow people to be contributing members of society. However, transplants are expensive. It is possible that they money could achieve greater benefits if invested elsewhere, including in preventative medicine.³ This would be an empirical question which it is beyond me to answer.

If the former, then it is again (at least in part) an empirical question. Certainly other measures, such as public education and awareness campaigns, can go some way to increasing the donation rate. They will not, however, achieve all of the benefits listed above: for instance, they will not allow those who object to donation to register their objections.

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.

Yes, with caveats.

I agree that the family should not be asked to give consent, i.e. that their role should *at most* be to report an unregistered objection on the part of the deceased. In fact, I might even go further and support a 'hard' opt-out, in which the family had no role whatsoever. (I am undecided on this.)

There is a danger that the family, if consulted, may override the individual's wishes. Suppose someone wants to be a donor, but their family object to this – under the proposed system, they can block the donation simply by saying (falsely) that the deceased individual had an unregistered objection.

² Den Hartogh G. (2011) Can consent be presumed? *Journal of Applied Philosophy* 28(3): 295-307 and Saunders B. (2012) Organ donation without presumptions. *Journal of Medical Ethics* 38(2): 69-72.

³ As the consultation document notes (p. 21), sometimes a transplant is less expensive than the alternative, e.g. lengthy dialysis. In other cases, however, there is no alternative treatment and the patient will die without a transplant. While it may seem worth spending (e.g.) £25,000 on a life-saving transplant, we must consider whether this money could save more lives if directed elsewhere.

One possible safeguard would be to retain an opt-in register alongside the register of objections. This would mean that those who did wish to donate could record the fact, removing any doubt from the mind of their family. Retaining such a register would not (I assume) be too costly in administrative terms, since an opt-in register is in any case to be retained for children (below 16). There is, however, some danger that (particularly during and immediately after transition) it would call into question the legitimacy of taking organs from those who had not opted in. If such a register were to be obtained, then it should be made clear that all non-objectors are regarded as donors – opting in only prevents family objections.

It is also important to consider what would happen if the family did object. Studies of organ retrieval in European countries that currently employ opt-out policies reveal that surgeons are often reluctant to proceed in the face of objections from next of kin, even where family consent is not necessary.⁴ There is a danger that the scheme would, in practice, operate as a 'hard' rather than soft opt-out. I do not think that medical staff should be required to proceed with transplantation if they do not wish to, in light of family objections (this would likely undermine public confidence in organ transplantation). Even though the individual will have had opportunity to register any objection s/he has, it is not clear that this will prevent family objections. Continued efforts will be needed to encourage individuals to discuss their wishes with their family.

I would note that the role of the family is somewhat orthogonal to the opt-in/opt-out question. The consultation document says: "The current system is not a "pure" opt-in system, however, as it allows organs or tissue to be removed after death in some circumstances where the person has not opted in. Where a person is not on the register, their nearest relative (or other person qualified to act on their behalf) is consulted and, so long as they are not aware that the person had an objection to transplantation, may give consent on that person's behalf" (p. 9).

This is, at best, contentious. In the present system, someone's organs cannot be taken unless they are opted in. This opting in can be done either by the individual themselves or by their family, so it is not what we may call an *individual* opt-in system, but this does not undermine the need for opting in (i.e. for someone to change the default).

Similarly, one could have an opt-out system in which either the individual or their family were entitled to veto donation. This would still be an opt-out system, though it is not, I take it, the proposal here – the family's role is only to voice an objection that the individual may have had but not recorded, rather than to voice their own objection.

So, there are two points in the proposal here: First, that the family are not asked for their own views but only those of the deceased. Second, that they are asked only whether s/he had an objection, not to give consent. Both of these I support.

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.

Yes (strongly).

I believe this is the case in Switzerland.⁵ I see no reason why, if an individual does not make his/her own decision, the law should mandate who else is to decide (according to the hierarchy on p. 19).

⁴ Neades BL. (2009) Presumed consent to organ donation in three European countries. *Nursing Ethics* 16(3): 267-82.

⁵ Shaw D. (2013) Improving the organ donor card system in Switzerland. *Swiss Medical Weekly* 143: w13835.

This raises the danger that what happens to an individual's organs may be decided by a family member from whom they are estranged. I see no reason why an individual should not be able to appoint who they want to make the decision.

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.

Undecided.

It's not clear that this is necessary. If parents are trusted to protect their children's interests, then I don't see why parents couldn't be told 'your child will also be considered a donor unless you register an objection to this'. The child, when older, can either confirm or revoke this parental objection.

Nonetheless, while I'm not sure of the necessity of this measure, it doesn't seem particularly objectionable.

Similar concerns apply to incompetent adults (p. 18). Such individuals may be unable to give an objection, but nor are they able to give consent. If the default is reasonable, why should it be different in their case? Perhaps one answer is that competent adults can be said to tacitly consent if they do not register an objection, whereas incompetent adults cannot – that would support the idea, suggested in my answer to Q. 1, that there is genuine consent (tacit, rather than express, but not merely presumed) in the proposed system. I have no firm views on how best to treat such persons.

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 (weakly).

16 seems fine, though I wouldn't object to 18 either.

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 (leaning towards yes).

There obviously needs to be clarity on this issue. I'm somewhat inclined to think a year longer than necessary and that a period as short as three months may suffice. That said, I see some merits in erring on the side of caution, so perhaps a year is a fair compromise of sorts.

I believe the period should have to be continuous and immediately prior to death. Someone who lived in Scotland between, say, 2016 and 2020 but then left, only to die in Scotland during a week's holiday in 2026 should not – I take it – be automatically considered a donor. On the other hand, someone's having taken a two week holiday within the twelve months prior to their death should not disqualify them, provided that Scotland remained their place of permanent residence.

Arrangements would have to be made for groups such as students and those who travel for work. Perhaps the matter could be tied to the electoral franchise – e.g. Scottish ex-pats who retain citizenship/voting rights might also be considered eligible donors should they die in Scotland.

For those to whom these proposals do not apply, will it be possible for them to indicate their willingness to donate? Would a rUK Donor Card be considered as consent?

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?

See above.

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

Yes.

I believe this is ample time to spread information, particularly given that there will no doubt be plenty of media coverage about the proposed Bill before it becomes law. There does, however, seem some anomaly in setting this period at 6 months, when 12 months' residency is supposedly required "in order to give [people] time to consider and understand the system in operation" (pp. 17-18). It may be wise to bring these into line; i.e. either a 12 month period prior to change or a 6 month residency requirement.

If there is any concern about certain groups, particularly the elderly, not getting the message then one solution would be to exempt them – e.g. say that the new law does not apply to those aged 65 or more at the time that it is passed.

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?

None for me or my organisation.

Obviously, as alluded to earlier, organ transplantation is costly. It will be for the NHS (or any Scottish successor) to determine whether transplantation is the most efficient use of resources. It should be borne in mind that there may be public outcry if it is found that organs are being taken but not actually transplanted, so organs should only be removed where it is expected that they will be transplanted – even if this means that organs are not taken from some eligible donors.

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?

There are some issues around children and incompetent adults, touched on above. It's hard to be sure of further effects. It's possible that members of some ethnic groups will be more likely to opt-out than others, but we currently observe different opt-in rates too, so it's hard to tell what the net effect will be compared to the status quo.

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

Nothing to add to the above – my main points being those in response to Q. 1 and Q. 3 – though I would be happy to be consulted on any ethical issues (whether addressed here or not).