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- ▶ We should consider paying kidney donors (*BMJ* 2011;343:d4867)
- ▶ Organ donation rates in Spain for British residents are higher than in UK (*BMJ* 2011;343:d4948)
- ▶ NICE consults on improving consent rates for organ donation (*BMJ* 2011;342:d1113)

A nudge in the right direction for organ donation—but is it enough?

Applicants for a UK driving licence are now asked to decide whether to join the NHS Organ Donor Register. **Hugo Wellesey** argues that although this should boost the number of people on the register, the number of people who ultimately donate organs will not rise unless we increase people's underlying willingness to donate

As part of attempts to increase the number of registered organ donors, the UK government has introduced “prompted choice” about donation for driving licence applications online, and the Welsh Assembly is considering adopting presumed consent.^{1 2} In this article, I examine the likely effect of these strategies on actual rates of donation and what we can do to increase people's willingness to donate.

Prompted choice

Since August everyone who applies for a UK driving licence online has to complete a question asking whether they wish to join the NHS Organ Donor Register.¹ There are three options: “Yes, I would like to register”; “I am already registered”; or “I do not want to answer this question now.” The last response was chosen to prevent a potential legal challenge resulting from mandating a response during an unrelated transaction.³ Mandated choice (where people are obliged to answer the question) would require new legislation.

People cannot declare a preference not to donate because this would require the creation of a “No” registry. It is not clear, however, why people shouldn't be given the option to say, “No, I do not want to register” (rather than, “I do not want to donate”), which would allow them to opt out of registration without requiring a separate registry. To have, “I do not want to answer this question now” as the only way to say “no” represents an artificial constraint of free choice and risks making people feel manipulated. This could potentially alienate people (including some who might otherwise agree to register) and reduce the number who sign up.

Nevertheless, prompted choice should help close the gap between the 62% of surveyed adults who say they would be willing to donate their organs for transplant⁴ and the 29% on the donor

register.⁵ As such it should be welcomed. However, the difference this change will make to the availability of organs should not be overestimated.

Panacea for organ procurement?

NHS Blood and Transplant expect the new system to attract a maximum of 375 000 potential new entrants to the register each year,³ although not all of these people will want to join. If the 62% who say they are willing to donate actually sign up then that will give an increase of 130 000 people a year over and above the 100 000 who were already coming through driver licensing (from a question that could be ignored).

However, since people feel the need to respond to survey questions in a socially desirable manner the real proportion of those who agree to donate may be lower than 62%. Also, many applicants may simply tick “I do not want to answer this question now” as a quick way to move to the next page without having to engage with the issue of organ donation. When Texas introduced a similar system in the 1990s, 80% of people answered either undecided or no, and it was subsequently withdrawn.⁶

It therefore seems likely that the number of new entries to the donor register brought by prompted choice will be relatively small—fewer than 130 000 a year. As this represents less than 1% of the number of people already registered, prompted choice is certainly no panacea. Indeed, a recent report from the House of Lords Science and Technology Select Committee concluded that attempts to nudge people into changing behaviour (of which prompted choice is an example) are

unlikely to have a serious effect,⁷ and the committee's chairman, Baroness Neuberger, argues that the government needs to be braver.

Presumed consent: brave or rash?

The Welsh Assembly is already doing this by attempting to introduce an opt-out system. Under this system, often referred to as presumed consent, anyone who doesn't opt out during their lifetime is presumed to have given their consent for organ donation. In the proposed version (a soft opt-out), families would be asked if they are aware of any unregistered objection held by the potential donor (whereas they are currently asked for consent).

This seems like a pragmatic solution, and the British Medical Association has recently reaffirmed its support. However, presumed consent is not

without its problems and was rejected by the Organ

Donation Taskforce in its review for the UK government in 2008.⁸

As well as the risk that organs are taken from people who would not have consented (but didn't register that objection), there is a risk that people will reject what they may perceive as state interference in their autonomous choices.

Those who regard it as an unacceptable expansion of state power may try to encourage others to boycott the scheme by opting out. Negative publicity has the potential to be very damaging; in France, corneal donations fell by 37% over two



years after a highly publicised event in which the corneas of a 19 year old boy were removed without consent.⁹

A recent meta-analysis showed an association between opt-out systems and increased donation but recognised that this does not signify a causal relation.¹⁰ Donation rates fell in Sweden after the introduction of a soft opt-out system in 1996,¹¹ which is thought to be because of public suspicion about the system. Advocates of an opt-out system in the UK admit that organ donor numbers could fall,¹² but if there are campaigns against the system then the result for organ procurement could be devastating.

Introducing an opt-out system is thus an expensive and risky experiment. The advantage of Wales introducing it alone is that it could work as a pilot scheme. Should it fail, Welsh patients will still be eligible for organs from the rest of the UK.

The elephant in the room

The biggest problem with prompted choice, opting out, and mandated choice is that they are unlikely to substantially increase the number of organs donated—as opposed to the number of people registered as potential donors, most of whom will not die in a way that allows them to donate their organs. Despite only 29% of the population being on the NHS organ donor register, when families are asked if they will offer their deceased relative's organs for donation, 59% agree.¹³ This figure is remarkably similar to the 62% of adults who say they would be happy to donate their organs. There doesn't appear to be a significant gap between the proportion of people who actually donate and those who say they are willing to do so.

If an opt-out system is able to achieve donation rates higher than 62% then it must be taking organs from unwilling donors. Given that consent rates are already 59%, we do not need a radical overhaul of the system; we need ways of encouraging people to want to donate.

Encouraging decisions to donate

When asking about organ donation, it is likely that the way choices are presented is important. There is some evidence that asking people if they would accept a transplant to save their life (in a non-binding format) before asking them if they would be willing to donate, substantially increases the proportion who agree.¹⁴ Another way to increase willingness to donate may be to allow potential donors to let their organs be offered to other registered donors first, so disadvantaging free riders (those who would be happy to accept an organ but refuse to donate) and enhancing reciprocal altruism. Lifesharers is a group that does this in the United States, although organs are offered first to

other members of Lifesharers rather than to anyone on the organ donor register.

The Nuffield Council on Bioethics is currently considering the role of incentives for organ donation, including a contribution towards funeral expenses (as in Spain),¹⁵ priority for organs being given to registered donors (as in Israel),¹⁶ and even payments to live donors (as in Iran, the only country to eradicate waiting lists for kidney transplants).¹⁷ The council's report is due in October, and any recommendations it makes should be seriously considered.

Prompted choice should not be seen as a way of reducing expenditure on promoting organ donation. It is a way of capturing people's choices, which is not the same as encouraging people to donate. A recent study has shown a dose-response relation between exposure to information on organ donation in the six months preceding a relative's death and rates of consent for donation.¹⁸ Given this and the 40% drop in new donor registrations after the freeze on marketing communications last year,³ it is important to continue to highlight the positive aspects of donation and to encourage people to donate.

More could also be done to prevent misleading information. Although most newspaper articles focus on the positive aspects of donation,¹⁹ a study from the United States showed that most television programmes frame organ donation in mainly negative terms,²⁰ with storylines focusing on corruption (such as gaming of the system in *House*), manipulation of a live donor (in *Lost*), doctors eagerly awaiting the death of a potential donor, and doctors wanting to remove organs from a live patient (both in *Grey's Anatomy*). These stories play to people's fears of organ donation and could reduce their willingness to donate. Organ procurement organisations should work with television and film production companies to encourage "education entertainment" and minimise the irresponsible portrayal of organ donation.

The extent to which this negative framing (along with graphic images of postmortem examinations in programmes like *CSI: Crime Scene Investigation*) has affected attitudes to organ donation is not clear, but the proportion of families who agree to donate fell from 70% in 1989²¹ to 59% in 2006.¹³ Events such as those at Alder Hey, where tissue and organs were removed from the bodies of children without their parents' consent, damaged public confidence in doctors and may also have reduced people's willingness to donate. This seems especially pertinent given that concern about "the level of respect given to a deceased person's body" and "whether doctors make every possible effort to help patients identified as potential donors" are two of the most commonly cited reasons for not wanting to register as a donor.²²

The recent decrease in the family consent rate highlights the need to work towards encouraging people to donate by tackling misconceptions and considering the role of incentives. We should not let prompted choice and opt-out systems distract us.

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