

# Organ donation:

## opting in or opting out?

Both Jeremy Corbyn and Theresa May have recently expressed their support for a change to the law in England to introduce an opting-out system for organ donation, and the Department of Health is consulting on the issue. This is based on the assumption that it would make a significant impact on the shortage of organs for transplantation and thus save hundreds of lives each year. It is a popular assumption, because the intention is so obviously well meaning. Sadly, though, it is an assumption that offers false hope.

### WOULD A CHANGE IN THE LAW INCREASE DECEASED DONATION?

There is no good evidence from anywhere in the world that a change in the law leads to a sustained increase in donation. Indeed, there are countries where in fact donation has decreased, and Brazil offers perhaps the best example of this. The few publications that suggest a possible benefit have important methodological flaws that make it very difficult to isolate the impact of the law.<sup>1</sup> The evidence was reviewed in great detail as part of the second Organ Donation Taskforce report in 2008,<sup>2</sup> and little has changed since then. So what is the basis for the assumption? There are at least two important misunderstandings in the case that are often made. First, there is the superficially attractive observation of the Spanish donation experience. Spain has opting-out legislation and for many years has had the highest donation rate in the world. But the Spanish authorities have stated repeatedly that their 'success' does not stem from the law.<sup>3</sup> Opting out was introduced in Spain in 1979, with no apparent effect. Ten years later, in 1989, a national transplant organisation was established with a wide-ranging brief to transform the donation system, based primarily on the employment of medically qualified donor coordinators in every hospital. The effects were immediate, and Spain has led the way since then. The Spanish model has been introduced successfully in other regions and countries, including northern Italy, Croatia, and Portugal. There were no changes in the law, but there were dramatic increases in organ donation as a result of nationally led changes in clinical practice in intensive care units (ICUs). Moreover, Spain does not in fact operate an opting-out system — there is no register for people to either opt in or

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opt out. As in England, consent for donation is explicit and comes either from the patient in life or through their family.

There is one other important factor relevant to the Spanish success: different countries have different numbers of potential donors. Very few patients die in circumstances that allow organ donation to proceed (about one in a 100 in the UK). For clinical and practical reasons the patient must die from the 'right' diseases (that is, be free of transmissible agents such as cancer and significant infections), in the 'right' place (that is, in hospital and probably in an ICU), and in the 'right' way (that is, death must be, at least to some extent, expected and predictable). Most donors have suffered a catastrophic brain injury from intracerebral bleeding, trauma, or hypoxia, and have been treated in intensive care. For many years Spain has had between two and three times as many ICU beds per capita compared with the UK. Different resources and approaches to end-of-life care result in different numbers of potential donors — and therefore of actual donors.

Second, a common misunderstanding is that under current opt-in legislation 'in order to be a donor you have to have opted in, by joining the NHS Organ Donor Register (ODR)'. Because only 36% of the population have signed up there is a false belief that the other 64% will never be donors, because they haven't opted in. In fact, in the UK last year the families of almost all brain dead potential donors were approached about donation,<sup>4</sup> regardless of whether the patient was registered on the ODR. Certainly registration is to be encouraged as it makes it so much easier for the family to know their relative's wishes, but it is absolutely not a requirement. Over 90% of families now agree to donation when the patient was registered but about 70% agree even when the patient was not registered. The suggestion that opting out would somehow add the 'missing' 64% of the population to the donor pool is quite wrong — in practice, they are there already.

The only experience of opting out in the UK comes from Wales, where legislation for what is called 'deemed consent' was introduced in December 2015. Although this still allows a role for the patient's family, this is limited to providing information about the patient's wishes, and the family's attitude to donation should not be relevant. The numbers are small and it is premature to draw conclusions but in the first full year after the new law was introduced donor numbers were almost unchanged, while in the first 6 months of the second year they have fallen (on an annualised basis) by 14% (compared with a rise of 9% in England in the same time period).<sup>5</sup>

### IS OPTING OUT A 'BETTER' FORM OF CONSENT?

There are also ethical and practical concerns about a change to the law. Opting-out laws cover a spectrum but are usually described as either 'hard' or 'soft'. Under a hard system organs will be removed after death if the individual has not opted out, and the family have no role. It is this system that leads to the frequently heard objection that the state is taking over the person's body after death, and there are major ethical concerns. Consent is an active process that cannot be 'presumed' simply because no objection is known. It is not clear that such a system would be acceptable to intensive care clinicians, who play such a vital role in the care of potential donors. Under a soft system there is a presumption in favour of donation but the family have the final say. Ethically this is far less troublesome. However, it is not always apparent that the media and the public are aware of the differences between a hard and a soft system, and the widespread objection to the former may have an adverse effect on the possible acceptability of the latter, and so have an adverse impact on donation.

### ARE THERE ANY ALTERNATIVES?

So if opting out is not the solution, what is? For nearly 20 years the UK had a poor record in organ donation, and the

numbers were falling from the start of this century. In 2008 the Organ Donation Taskforce report was published<sup>6</sup> with a series of recommendations that have all been implemented. They have transformed the donation system and overall donor numbers have increased by over 70% since then, and continue to do so — at least in England.<sup>7</sup> Key to this transformation has been tremendous work by intensive care clinicians and the specialist nurses who work with them, combined with central support from a national donation organisation, NHS Blood and Transplant. Fundamental to this has been the move to recognise donation as being in the best interests of an individual who had wished to be a donor rather than seeing potential organ donors simply as a source of organs for someone else — autonomy rather than utilitarianism, if you like. These results are spectacular but everyone concerned knows that there is much more that can and should be done — and they are working hard to do it.

These results speak for themselves and more of the same would seem to be an excellent policy. GPs and practice nurses can play a valuable role by including organ donation in any discussions about a patient's end-of-life wishes and by promoting the Organ Donor Register alongside other public health issues ('stop smoking, lose weight, and join the Organ Donor Register'). The need for more organs

for transplantation is pressing, but there seems to be little merit in pursuing a change in the law that appears to revert to the utilitarian approach that is now discredited and is unproven, controversial, expensive, ethically questionable, and possibly risky.

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**Provenance**

Commissioned; not externally peer reviewed.

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