

# UK Government DoH Consultation on introducing 'opt-out' consent for organ and tissue donation in England

Closing date 6 March 2018

## Submission on behalf of the Christian Medical Fellowship

### Introduction

Our main concern is that the altruistic ethos of 'donation as a free gift' would be endangered by an ill-judged if well-intentioned proposal to move from voluntary donation to presumed consent.

Organs taken without consent are not donated but confiscated. 'Presumed consent' is not equivalent to consent. Presuming upon consent turns volunteer carrying a donor cards into conscripts. If organs are taken for transplantation without explicit consent there is no giving, there is only taking without asking.

Obtaining explicit written consent is required by law for medical treatment because it ensures that consent is valid and that people have thought about the implications. For example, written consent is required for fertility treatment, storing sperm, eggs and embryos, donation, surrogacy, disclosure of information and, where applicable, parenthood and withdrawing consent.

(<https://www.hfea.gov.uk/about-us/how-we-regulate/>)

Silence is not consent. It cannot be taken to imply 'no objection' to the 'opt out' message. It cannot guarantee that those who have not opted out are aware of the implications of their non-decision. Transplantation presupposes a prior, explicit, free and conscious decision on the part of the donor (or their legitimate representative). Many will be unaware that they are on a donor register because it is virtually impossible to cover everyone in a public information campaign, to be sure that everyone has access to the message, hears or sees the message, understands the message, has considered the message and made a positive choice not to opt out. Relying on a lack of stated objection to imply agreement is therefore not safe. Presumed consent will, on those occasions, amount to imposed consent. To remove organs under these conditions is immoral because it violates a person's autonomous wishes about what should happen to their body after death.<sup>1</sup>

Our other concern is a pragmatic one - the belief that presumed consent would itself increase the number of organs available for transplantation is not supported by the available evidence (see answer to Q9).

Nothing in this submission should be interpreted as a rejection of the practice of donation of organs after death where this is done with due sensitivity to medical, cultural and ethical considerations. As an organisation that represents Christian doctors and other healthcare professionals, we take our starting point from Christ who healed the sick and who gave Himself for the good of others, and welcome the benefits that have come through organ transplantation.

### Question 1

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<sup>1</sup> Veatch RM and Pitt JB. 1995. The myth of presumed consent: ethical problems in organ procurement strategies, *Transplantation Proceedings*, 27:1889-9.

**The government wants to look at different ways for people to register their decision under the new system. This could happen through government processes such as driving licence applications, and health settings such as dental surgeries and opticians.**

**Do you think people should have more ways to record a decision about organ and tissue donation?**

Yes. There would have to be as many ways as possible to hear about any change in policy and to make a positive response, either to agree to donate or to opt out. The process must not rely solely on internet access or any other single means. Not should opportunities to record their decision pressurise people into a decision either way. Information must be presented in a balanced, unbiased way.

We contend that, in practice it would be impossible to ensure that everyone has been made aware and has made a deliberate decision not to opt out.

### **Question 3**

**If the new rules come into force we need to make sure that everyone understands how the system has changed. We would like to know what you think are the best ways of telling people what the changes are, so they can decide what they want to do.**

**How can we make people more aware of the new rules on organ donation?**

All possible means should be enlisted. These might include:

- Direct mailings, both postal and electronic
- When collecting pensions or benefits
- When applying for allowances, car tax, passports, TV licenses etc from Government
- When receiving reminders about renewals (car tax, TV license), electoral role/voting rights changes, tax returns
- Advertising on TV, via social media, billboards, buses, reverse sides of train and bus tickets, in GP surgeries, jobcentres, libraries, museums and other public buildings
- Distribution through home care services, meals on wheels

People would need repeated prompting; one encounter with the message would not suffice, and the awareness programme would have to continue indefinitely. The cost of a continuing programme to raise and maintain public awareness should not be overlooked; the cost of training specialist nurses/transplant coordinators might be no greater, especially when taking into account the money saved on dialysis programmes as more organs are donated as a result.

### **Question 4**

**If the law changes, would this affect your decision about organ donation?**

When presumed consent is introduced, a proportion of the public will always withdraw from donation and sign the opt-out register because they do not like the idea of the state presuming upon their consent. In Wales, over 180,000 people have withdrawn from donation in response to the introduction of the new system. Yet before the introduction of presumed consent those 180,000

people were potential donors in the event that they died in an intensive care unit and their families agreed to donation. Opting out has therefore led to a drop in potential donor numbers. Under presumed consent their families cannot be asked about donation because the person concerned has specifically opted out. All their organs are lost.

#### **Question 5**

**A person's faith or background can play an important part in deciding whether to be an organ donor.**

**If the law changes, people would be considered willing to be organ donors unless they have opted out. Do you think this change could have a negative impact on people from some religious groups or ethnic backgrounds?**

Yes. Some cultures have traditional rituals following death that are essential aspects of showing respect for the dead body and grief by the living. Such cultures are resistant to anything that interferes with their traditions. Whilst changing the law would not have any direct impact on those traditions, the imposition of deemed consent most certainly would.

The use of neurological criteria to diagnose death is unacceptable to some people, though this may not necessarily be a faith-related stance.

It should also go without saying that a dissenting clinician, who for reasons of belief cannot participate in organ retrieval or transplantation, should enjoy freedom of conscience.

#### **Question 6**

**If someone is going to die and it is possible for them to donate their organs, medical staff always talk to their family or a long-standing friend to find out if they wanted to be a donor. In many cases, families find it easier to support organ donation if they know that was what their loved one wanted.**

**If the law changes, and someone has died and they have not opted out of organ donation, should their family be able to make the final decision?**

Always.

The state should not take ownership of a deceased person's body. Under the law as it stands, it is the family who takes custody of the body and this should not change. They are the ones best placed to know how the deceased would most likely have felt about donation and this fact should weight the responsibility for decision-making towards them. Medical staff and/or transplant coordinators should have the opportunity to broker an agreement with them but the final decision should be the family's to take. To require clinicians to retrieve organs against the stated wishes of the family would put them in an invidious position. The care of the family will be their concern, as much as the care of those needing a transplant.

#### **Question 7**

**Do you think someone's family should be able to decide if their organs are donated, if it is different to the decision they made when they were alive?**

Sometimes.

Under normal circumstances, the decision reached and properly recorded in life by a person should be respected after their death. If unforeseen circumstances arise, or if the family have reason to believe that the deceased was not in their right mind, or was not fully informed or aware of the need to opt-out, or was in some way under duress when making their decision, then the family should be able to revisit the decision.

It is likely that, at the time of agreeing to donate organs after death, many donors do not fully understand the practical consequences for family members (see further comment on this point under Q.9 para 4). In their grief, relatives may not be able to come to terms with them and wise clinicians will not press ahead with retrieval where in their judgment it would cause overwhelming distress to the family.

### **Question 8**

**The government thinks there are some people who should not be included in the new rules. This is either because they are too young, they're not able to make a decision about organ donation, or they don't usually live in England. It means they would still need to 'opt-in' to be an organ donor when they were alive.**

**Which of the following should not be included in the proposed new rules about organ donation? (please tick all those that apply)**

All the above categories of people should be excluded from having their consent presumed; similarly, a deceased person whose identity is not known.

Also excluded should be those who may have been long-term residents in England who have not opted out but whose families are not available for consultation and who belong to ethnic or religious groups known to be averse to organ donation (eg Japanese people with Confucian beliefs)

### **Question 9**

**Please tell us about any opinions or evidence you have about opting out of organ donation.**

#### **1. Opt-out schemes don't work**

Spain is often cited as an example of how successful an opt-out scheme can be, yet this does not bear closer examination. Spain changed to an opt-out scheme in 1979 and donation-rates did not increase. After a decade of disappointment, Spain invested in staff training, the appointment of transplant coordinators to talk with families at the crucial time, and supportive infrastructure changes. It was these changes that made the difference.<sup>2</sup>

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<sup>2</sup> Matesanz r et al. Spanish experience as a leading country: what kind of measures were taken? *Transplant Int*, 24, 2011. Pp 339-340.

Wales introduced an opt-out scheme in 2015 and to-date there is no sign of increasing donation-rates.<sup>3</sup> Moreover, the same data reports a shrinking pool of potential donors in that six percent have already opted out.

Other countries with opt-out systems include Sweden, Bulgaria and Luxembourg, all countries with lower donation-rates than England. Schemes with variations on presumed consent in France and Brazil actually led to falling numbers of organ 'donations'. Countries in which opt-out schemes appear to have led to increased donation-rates are those that have adopted so-called 'hard' schemes in which families of the deceased are given no say.<sup>4</sup> In multicultural England a culturally-insensitive, hard opt-out scheme is very unlikely such is the concern to avoid causing offence or attracting the change of intolerance or prejudice.

An interesting exception, at first sight, appears to be Belgium. Within five years of introducing an opt-out scheme, in 1986, donation-rates rose by 55 percent. But even here, it seems that success is due to factors other than a simple change in the law. Doctors there are encouraged to approach relatives in all cases and do not proceed with organ retrieval if, in their opinion, it would cause distress to the family. In practice, less than 10 percent of families do object, compared with 20-30 per cent elsewhere in Europe.<sup>5</sup> The training and deployment of skilled medical staff is the key.

Boyarsky has shown that countries with the highest rates of deceased donation have 'national and local initiatives, independent of presumed consent, designed to attenuate the organ shortage'.<sup>6</sup> **The single most influential factor so far identified is ensuring that clinicians specifically trained for the purpose routinely approach the families of potential donors.** Fabre believes that 'the highest levels of organ donation can be obtained while respecting the autonomy of the individual and [the] family and without presumed consent'.<sup>7</sup>

While there is no evidence that presumed consent *per se* works to increase donation rates, the Nuffield Council on Bioethics has shown that UK rates of family consent or authorisation were 69% when a Specialist Nurse in Organ Donation approached the family, but just 28% when the approach was made by other staff without the specialised training. Investing in the provision of more such nurses to talk to the families of potential donors makes the difference, *not* presumed consent laws. These nurses parallel the role of the transplant coordinators in Spain. (<http://nuffieldbioethics.org/news/2017/ethics-tank-calls-discussion-wishes-organ-donation-death>)

## 2. Opt-out schemes capitalise on inertia

There is a desperate need for organs for transplantation. Rather than follow the example of Spain by investing in training and infrastructure, the Government appears to be setting its hope on the assumption that most people will not opt-out of the proposed scheme. Instead of investing in schemes to promote altruistic donation and providing more Specialist Nurses as Transplant Coordinators in every acute hospital across the country, it is willing to **gamble the lives of those on**

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<sup>3</sup> *Organ Donation and Transplantation Activity Data: WALES*, NHS Blood and Transplant, 2018, Summary figures, page 1.

<sup>4</sup> *BBC News Online*, 10.09.17, see <http://www.bbc.co.uk/news/health-41199918> (accessed 21/02/2018)

<sup>5</sup> Michelsen P. 1996. Presumed consent to organ donation: ten years experience in Belgium. *J R Soc Med*, 89:663-66.

<sup>6</sup> Boyarsky BJ et al. 2012. Potential limitations of presumed consent legislation. *Transplantation*, 93:139.

<sup>7</sup> Fabre J et al. 2010. Presumed consent is unnecessary. *BMJ*, 341, 7779:923

**transplant waiting lists on the inertia of unintentional donors.** And this despite evidence from other jurisdictions that such a strategy will fail. The Government wants to follow an ideology that consistently has been shown to lack a credible evidence-base and, as the experiment in Wales illustrates, leads to an overall fall in the number of potential donors as people (whose organs might have become available) register their objection to presumed consent by deliberately opting out.

### 3. Opt-in schemes are not future-proof

In every area of life, the trend is towards greater protection of data. The law around data sharing is being strengthened; permission to share personal information has to be explicit and affirmative. Consent cannot be assumed or presumed. It will not be possible in the future to allow pre-ticked boxes on forms. The whole emphasis of modern life is towards the rights of privacy and the need to have express and informed consent before sharing a person's details. **An opt-out scheme for organ donation takes the most personal of property – our organs – and makes them liable to a pre-ticked box, essentially.** There is a very real risk that, in today's UK culture, such a move will be met by a significant reaction, and some of those who would have been willing to become organ donors will instead be outraged by the presumption and deliberately opt-out. The losers will be those on waiting-lists.

### 4. Opt-out schemes undermine the care of the dying and the grieving of the living

Were an opt-out scheme to be adopted in England, it is hard to see how it would not also undermine the care of dying patients or those with severe brain injury or abnormality. Such patients would inevitably be seen as 'organ resources' by professionals wanting to acquire scarce organs for transplantation. One of the reasons given by people for not carrying a donor card is the fear that organs might be removed before death. Another stated concern is that staff may over-readily apply a DNAR (do not attempt resuscitation) order in such circumstances, to provide organs for donation. Such fears need not be well-founded to have an effect.<sup>18</sup>

The thought of a brain-dead body being kept artificially ventilated and perfused, warm and pink and apparently 'alive' whilst their family is asked urgently for permission to whisk the body away to theatre for organ retrieval, hovers in the public consciousness. Even worse, the fear that organs might be removed from a person before they were clinically truly dead was cited among reasons given for the abolition of the presumed consent law in Brazil.<sup>9</sup>

The body of the deceased tangibly connects him to his family. To mourn together in the presence of that body, unites family members in a common farewell and 'marks simultaneously the connection to, and final separation from, family flesh'.<sup>10</sup> At the very moment of loss, to have to put on hold their natural instincts to gather around a peaceful corpse to say their unhurried goodbyes, all the time knowing that the still-warm body of their loved one is undergoing eviscerating surgery, will be too much for some to face. At best, a 'high-tech' death followed by the delay for retrieval, will disallow a period of quiet reflection and a family farewell in the minutes immediately following the death.

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<sup>8</sup> BMA. *Organ donation in the 21<sup>st</sup> century: Time for a consolidated approach*. London. BMA. 2000:9

<sup>9</sup> Csillag C. 1998. Brazil abolishes presumed consent in organ donation. *Lancet* 352:1367

<sup>10</sup> Kass L. *Life, Liberty and the Defence of Dignity*. San Francisco, CA: Encounter Books. 2002:136.