

Dear colleague,

Briefing on the Organ Donation (Deemed Consent) Bill

Second Reading – House of Lords, 23 November 2018

The Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues in biology and medicine. The Nuffield Council on Bioethics strongly supports organ donation where this aligns with the wishes of the individual.

Ahead of the second reading of the Organ Donation (Deemed Consent) Bill this week and following the Government's plans to change the system of consent for organ donation from spring 2020, we are writing to draw to your attention some of the ethical considerations which may affect how this change is implemented.

In 2011, we published a report, *Human bodies: donation for medicine and research*,¹ the culmination of a two-year inquiry, in which we address ethical questions regarding consent for organ donation. We argue that the taking of bodily material after death should be based on the clearest possible wishes of the donor.

In our report, we take the view that opt-out systems can be ethical if people are well-informed, families are appropriately involved (well-supported and not pressured), and trust in the organ donation system is not compromised.

When we published our report, we did not, however, recommend a change to an opt-out system. This was both because of a lack of evidence that such a change would, in itself, increase donation rates; and because of concerns that the requirements to ensure that any such system continues to operate ethically are very onerous. We do not believe this situation has changed in the intervening time.

Given that a policy decision has been taken to move to an opt-out system of consent, we would like to reiterate the need to pay serious attention to **three key points** in order to avoid a loss of trust in the system or a detrimental effect on the good work that has been done in recent years to increase the number of donated organs:

Chair
Professor David Archard

Deputy Chair
Professor Julian Hughes

Members
Professor Simon Caney
Dr Tara Clancy
Professor Jeanette Edwards
Professor Ann Gallagher
Dr Andy Greenfield
Professor Erica Haines
Sir Roland Jackson
David Lawrence
Professor Shaun Pattinson
Professor Christine Watson
Professor Robin Weiss
Professor Heather Widdows
Adam Wishart
Dr Paquita de Zulueta

Director
Hugh Whittall

Assistant Directors
Catherine Joynson
Dr Peter Mills
Katharine Wright

NUFFIELD
COUNCIL
ON
BIOETHICS

¹ Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, available at: <http://nuffieldbioethics.org/project/donation>.

1. A well-informed public and the importance of discussing wishes

If an opt-out system is introduced, **it is vital to have measures in place that encourage people to express and document their wishes about organ donation during their lifetime**. Otherwise, it is very hard indeed to claim that donation is in line with the wishes of the donor, or that consent can be ‘deemed’. An active choice not to opt-out can certainly be described as consent. However, such an active choice can *only* be made where people are well informed and aware of the significance of making or not making this choice.

Information about the donation process must be easily accessible, and it must always be clear that more information is available if desired. It is not enough to focus on a public information campaign at the point when the law changes: effort (and resource) will be required on an ongoing basis to ensure that the public *remains* well-informed. The first impact assessment of the change to ‘deemed consent’ in Wales showed how public awareness could quickly drop, after an initial surge at the point of legislative change.²

2. Family involvement and support

Families must stay at the heart of the decision-making system, recognising that even if the law permits donation against family wishes (as it does at present), in practice, professionals rightly recognise the central role of the family at the moment of bereavement. This is particularly important, given that the question of organ donation often arises in the context of sudden and traumatic bereavement, and those close to the deceased have their own stake in how the body of their loved one is treated.

The possibility of refusal by the family of the deceased should therefore be recognised and respected, even where the deceased has left clear evidence of their wishes to donate. In practice, it appears that when families are aware of deceased relatives’ wishes, then they are very unlikely to refuse consent to organ donation, especially when they are well-supported. The annual audits conducted by NHS Blood and Transplant make clear that a decisive factor in family decision-making on organ donation is the support available through specialist nurses: family consent rates rise from as low as 22% where no such support is available, to 70% when a specialist nurse for organ donation is present for the approach to a family for a formal organ donation discussion.³ **We highlight the importance of investing further in the network of specialist nurses for organ donation, given their proven value both in supporting bereaved families, and in enabling others to benefit from the gift of organ donation.**

² Welsh Government (2017) *Evaluation of the Human Transplantation (Wales) Act: impact evaluation report*, available at <http://gov.wales/docs/caecd/research/2017/171130-evaluation-human-transplantation-wales-act-impact-en.pdf>.

³ NBSBT (2018) *Organ donation and transplantation: activity report 2017/18*, available at: <https://nhsbtde.blob.core.windows.net/umbraco-assets/1848/transplant-activity-report-2017-2018.pdf>, at Table 13.12.

3. Trust in the organ donation system

Trust plays a central role in creating systems in which people are willing to donate. **Any change to the donation system therefore needs to be designed in such a way as to minimise the risk of any loss of trust.** We would like to draw the House's attention to this overriding need to maintain trust in the organ donation system, in particular by being cautious as to what is promised about the effect of opt-out, on the basis of the current evidence (which is described in the Department of Health's own impact assessment as "ambiguous"⁴). Such ambiguity contrasts with the very clear evidence emerging from NHS Blood and Transplant audits as to the decisive role played in decision-making about organ donation by clear knowledge about the deceased's wishes, and access to specialist family support for those left bereaved.

We would welcome the opportunity to meet with you to discuss our hopes for an ethical way forward, if you would find that useful. If you would like any further information in advance of second reading, please contact our Public Affairs Manager, Richella Logan at rlogan@nuffieldbioethics.org or on 07768 999 828.

Yours sincerely,



Hugh Whittall
Director
Nuffield Council on Bioethics

⁴ Department of Health (2017) *Impact assessment: consultation on an opt-out system of organ and tissue donation*, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/666518/Organ_Donation_Opt-Out_Consultation_Impact_Assessment.pdf.