

NUFFIELD COUNCIL ^{ON} BIOETHICS

Human Tissue (Authorisation) (Scotland) Bill: ethical issues

As you may be aware the Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues in biology and medicine.

We are writing to you ahead of the of the first reading of the Human Tissue (Authorisation) (Scotland) Bill on 26 February 2019 to raise a few ethical concerns we have around plans to change the system of consent for organ donations.

The Nuffield Council on Bioethics strongly supports organ donation where this aligns with the wishes of the individual. However, we also believe there are some important ethical considerations which may affect how the system of consent for organ donation will be implemented.

In our 2011 report, *Human Bodies: donation for medicine and research*, we argued that opt-out systems can be ethical if people are well informed, families are appropriately involved and supported, and vitally, trust in the system is not compromised. When we published our report, we did not recommend a change to an opt-out system because of a lack of evidence that a change would, in itself, increase donation rates and because of our concerns that the requirements to ensure such a system operates ethically are potentially onerous.

Whatever legal system you have in place the evidence is clear that the public needs constant awareness to support intra-family discussion; and infrastructure and resources are needed to support sensitive conversations at the point of bereavement.

We have worked closely with parliamentarians in England on the Organ Donation (Deemed Consent) Bill and pushed hard for families to remain at the heart of the system. Health Minister, Jackie Doyle-Price wrote to us to reassure us that; “in practice, there will always be a discussion with the deceased’s family about donation. Clinicians have a duty of care to the family, and no family will be forced to agree to 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 difficult 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.¹

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 clearly recognised in the Spanish system (which has very high donation rates), and indeed the Director of the Spanish transplantation service describes the question of opt-in/out as a 'distraction', ascribing the successes of the Spanish system to the infrastructure for family support. This aspect 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. In practice, it appears that when families are aware of deceased relatives' wishes, 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.² **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.**

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 welcome the opportunity to further discuss our hopes for an ethical way forward. Please get in touch if you would like any further information.

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¹ 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>.

² NHSBT (2018) *Organ donation and transplantation: activity report 2017/18*, available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1848/transplant-activity-report-2017-2018.pdf>, at Table 13.12.