

NUFFIELD COUNCIL ON BIOETHICS

Response to the Human Tissue Authority Consultation on Code of Practice F:
Donation of solid organs and tissue for transplantation

September 2019

Introduction

The [Nuffield Council on Bioethics](#) is an independent body that examines and reports on the ethical issues in biology and medicine. Our comments on this Code of Practice are drawn from the approach and recommendations set out in our 2011 report [Human bodies: donation for medicine and research](#). We welcome the opportunity to respond to the draft Code of Practice.

As we do not have a view on all of the questions set out in your consultation, we have answered only those that are pertinent to our work in this area. If you would like to discuss any of this response further, we would be happy to help. Please contact Richella Logan: rlogan@nuffieldbioethics.org.

Comments

Q 10. Role of the Family (paragraphs 48-54) Is the role of the family clear within the Code of Practice?

We welcome this point made at paragraph 45: “*The existence of appropriate consent permits an activity to proceed, but does not mandate that it must*”, and similar points made at paragraph 68, and 80. This is very important because it recognises that there may be circumstances where even if there is appropriate consent, it is not appropriate to go ahead with donation. One example of such circumstances would be where there is significant family distress.

We especially welcome the emphasis on the family being at the centre of decision making, such as at paragraph 49 “*The family plays a key role in the donation process*” and para 50 “*sensitive communication and engagement with the family play an essential role*”. Appropriate support for families to remain central to the organ donation process is one of the key factors needed to ensure that an opt-out system for organ donation can proceed ethically.

Q 18. Are the steps that the Specialist Nurses for Organ Donation /Specialist Requesters would need to take to assess the information clear?

Paragraph 100 of the code states “*In England, if the SNOD/SR is not satisfied that the information presented to them constitutes the decision of the potential donor, or is informed that the potential donor had not made a decision, then consent can be deemed unless the potential donor is a child or an excepted adult.*” This is problematic because the ethical argument for ‘deemed consent’ is that a person, by not opting out, wishes (or at least is willing) to donate: - i.e. they have made an *active decision* not to

opt out. If the person concerned has never given anyone any reason to believe that they would be willing to donate, or ever expressed any views about donation in general, then surely their consent cannot be 'deemed' (this would be acting on the basis of the person's ignorance or apathy).

Q 21. Is there anything you else to which you would like to specifically draw our attention?

At paragraph 110 the code states "*In a situation in which the list is ranked and agreement cannot be reached between people of the same rank, it is lawful to proceed with the consent of just one of those people. This does not mean that the consent of one person must be acted on, and the SNOD/SR will need to carefully consider the emotional impact of any decision on family and friends.*" We welcome the careful reference to considering emotional impact in these circumstances.

In paragraph 157, the code states: "*Information that the potential donor was not aware that deemed consent affected them is not sufficient, on its own, to lead a reasonable person to conclude that the potential donor would not have consented to organ donation*". Here again, the ethical arguments underpinning deemed consent (see above response to Q18) are relevant. For an opt-out system to work ethically, the deemed consent should be based on knowledge of an active decision by the potential donor or a reasonable belief that a person would have been positive about donation. We would therefore argue that if it is known that a person was genuinely unaware that they were affected, from an ethical point of view they should be excluded on the same basis as those who aren't ordinarily resident.

In circumstances where it is problematic to deem consent (for the reasons given above, e.g. the wishes of the potential donor are not known), consent should be sought from family members, just as it is now.