

Nuffield Council on Bioethics

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Consultation Coordinator
Human Tissue Authority
151 Buckingham Palace Road
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Dear Sir / Madam

Consultation on the Code of Practice on living and deceased organ and tissue donation for transplantation - Wales

I am pleased to enclose a submission from the Nuffield Council on Bioethics, an independent body that examines and reports on ethical issues in biology and medicine.

Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely



Hugh Whittall
Director

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Professor Jonathan Montgomery

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Response from the Nuffield Council on Bioethics on the Human Tissue Authority Consultation on the Code of Practice on living and deceased organ and tissue donation for transplantation - Wales

- 1 The Nuffield Council on Bioethics is an independent, not-for-profit, UK organisation that explores and reports on ethical issues in science and medicine. This response is based on conclusions and recommendations of the Nuffield Council on Bioethics report 'Human bodies: donation for medicine and research', published in October 2011. The full report is available to download at <http://nuffieldbioethics.org/donation>
- 2 In our report, we argue that the taking of bodily material after death should be based on the **clearest possible information as to the person's wishes**. Only in these circumstances can it be described as 'donation' (paragraph 5.61 of the Council's report). We further strongly emphasise the central role of **trust** in maintaining and developing a donation system (paragraph 5.82), and highlight the importance of any opt-out system being designed in such a way as to minimise the risk of any loss of trust (paragraph 6.50). Finally, we argue for recognition of the **needs of the relatives** of the deceased to be taken into account too: while family refusal to donate may be based on their knowledge of the deceased's preferences, it may also at times be understood as an expression of their own needs as bereaved family members, and this should be respected (paragraph 6.58).
- 3 In the light of the approach taken in our report, we therefore strongly endorse the distinction made in paragraph 12: that while the law may permit donation in certain circumstances on the basis of deemed consent, it does not *mandate* donation. This emphasis on professional discretion is very welcome. We similarly welcome the specific emphasis on professionals (such as the SNOD) using their discretion when making a decision about whether to go ahead with donation in cases where there is disagreement between persons with parental responsibility (paragraphs 93-94) or other members of the family or friends (paragraphs 173-174). It seems likely that this will promote trust both in the healthcare system and in professionals involved with donation.
- 4 We further endorse the CoP's emphasis on the need for express consent if there is any doubt about whether the legal requirements for deemed consent are met (such as where there is uncertainty whether or not the 12 *month* residency requirement has been met, as at paragraph 104).
- 5 In general, the Code seems to us to be clear, helpful and laid out in a logical order. There were, however, two points that we found confusing:

Paragraph 87: "*Organ donation remains a possibility for people under the age of 18 who die in Wales. If the young person had competence and made a decision to donate or not to donate during their life then this constitutes express consent (or express non-refusal)*".

Should 'express non-refusal' in this paragraph be replaced by 'express refusal', reflecting the reference to a decision made not to donate during life?

Paragraph 139: *“If the SNOD accepts that the person has changed their mind, having previously recorded a decision not to consent on the ODR, then donation should not go ahead”*

Following on from paragraph 138, this seems to imply that donation should not go ahead *despite* the SNOD accepting evidence provided by family indicating that the person wanted to donate (having recorded a wish not to donate, but changed their mind since). If this were the case then it is not clear why the family should be asked to provide evidence. Should the final phrase read “then the donation should go ahead”?