

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

University of Leicester Medical School - group 21

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Ethical Values at Stake

- 9. Are there any other values (apart from altruism, autonomy, dignity, justice, maximising health and welfare, reciprocity, and solidarity) you think should be taken into consideration?**

Practitioners of religion and members of cultural groups derive values from religion and culture, and therefore such values must be considered. Beneficence, non-maleficence, and sanctity of life values, for instance, may be derived from personal beliefs and/or religious teaching and must be respected if in conflict with the process of donation of human bodily material – for instance a desire to protect the body from mutilation or avoiding ‘playing God’. In the significant case of Jehovah’s Witnesses, blood transfusions are not accepted on the basis of Biblical teaching.

Article 9 of the Human Rights Act states that individuals have a right to Freedom of Religion, therefore expression of religious values concerning donation must be as respected as any other. It is noted that other areas of medicine acknowledge religious and cultural values, for instance patients being able to request to see a male or female doctor, and this area of medicine should be no different. Religious and cultural beliefs and values can intrinsically relate to identity of an individual and choice should therefore be respected. We believe these values to be subtly different from autonomy.

Another important issue that should be considered is the feelings of the donor’s relatives. This is already mentioned in the Human Tissue Act, as relatives can override the dead donor’s decision to donate bodily material, and we feel this is still an important issue that should not be overlooked.

- 10. How should these values be prioritised, or balanced against each other? Is there one value that should always take precedence over the others?**

We suggest that autonomy should take precedence over the other values since it infers ultimate control to the individual in any decision making process. Each of the

other values are considered of equal importance, since they may aid the decision process, and should therefore be balanced against each other consequentially – seeking the best possible outcome.

- 11. Do you think that it is in any way better, morally speaking, to provide human bodily material or volunteer for a first-in-human trial for free, rather than for some form of compensation? Does the type or purpose of bodily material or medicine being tested make a difference?**

To provide human bodily material for free, without any hope of, or desire for recompense, is an altruistic behaviour that could, therefore, be considered morally 'better'. Adding compensation as some form of reward removes the altruism of the act, though it may indeed be argued that no act is truly altruistic. Perhaps the giving of human bodily material comes with expectation that the donor would receive donated material at a future date if circumstance prescribed such a need. For instance, an individual who has donated a kidney may expect to have a greater priority for receipt of a donor kidney in the future if his or her remaining kidney fails. Arguably, the act then becomes rather more based more on reciprocity than altruism and also adds pressure to the health service to have a ready supply of material.

Financial, or other, compensation could remove this expectation and may be considered more 'just' though this raises further questions regarding the commoditisation of the body and its parts. It is recognised that some form of compensation is likely to increase the response of donors, implying a utilitarian 'greater good', but this could open the system to potential abuse; where can the line be drawn before there becomes a market for the buying and selling of organs? While compensation may be relative to the material provided or the procedure undertaken for retrieval we do not think that there should be intrinsic difference in the compensation of different material donated. We recognise, however that a difference already exists in practice, since donation of sperm/eggs is generally rewarded financially. First-in-human drug trials are also heavily compensated.

- 12. Can there be a moral duty to provide human bodily material, either during life or after death? If so, could you give examples of when such a duty might arise?**

Since we have prioritised autonomy above reciprocity, solidarity, and maximising of health and welfare, provision of human bodily material cannot be considered one's obligatory duty in deontological terms. Mandatory organ donation would relinquish individual autonomy and potentially impinge Article 5 of the Human Rights Act: The right to liberty and security of person.

We identify certain groups of individuals, however, who could be approached specifically, where appropriate to do so, for instance: individuals with a rare disease, whose bodily material may be pivotal in medical research and therefore helping of future patients with the same condition, or individuals with rare tissue types (underpinned by values of *maximising health and welfare*); individuals who have family members who are ill when there is a possibility for tissue matching of live donations (underpinned by the value of *solidarity*); individuals who have been recipients of bodily material themselves, providing they had other healthy organs available for donation (underpinned by the value of *reciprocity*). Consultations should clearly be free of coercion, insensitivity, or incentive in order to respect autonomy and protect basic Human Rights.

The only instance in which we feel there may be a moral duty to provide human bodily material is in the circumstance where material is required from a deceased person for forensic examination, in order to clear the deceased individuals name of a crime, or to correctly convict a guilty individual.

13. Can there be a moral duty to participate in first-in-human trials? If so, could you give examples of when such a duty might arise?

As above, with due respect to autonomy of the individual, it cannot be ethically acceptable to enforce mandatory participation in first-in-human trials, nor expected that individuals are duty bound to such participation. Trials do not come without risk – as seen in the 2006 Rheumatoid Arthritis trial at Northwick Park Hospital, where many participants developed debilitating side effects from the tested treatment. Participation in such trials due to moral obligation would therefore also risk breach of Article 3 of the Human Rights Act – Freedom from inhumane and degrading treatments. Doctors have a duty of non-maleficence and initiating such treatment against the will of a participant (assuming duty to participate) would therefore not be acceptable.

A duty-based ethic removes freedom from individuals but increasing awareness of trials and their necessity in terms of benefit to the population and better treatments for the future could encourage greater participation. It is recognised, however, that particularly by values of justice, maximising health and welfare, reciprocity, and solidarity, a utilitarian ethic (greater good of the greater number) could also provoke participation. In a country where we receive free healthcare and benefit from the trials of drugs, perhaps there are some grounds for moral responsibility, of able individuals, to participate and contribute towards improving healthcare of the future.

We suggest that there may be grounds for participation in trials to be considered mandatory, or duty-bound, in the occurrence of an epidemic, or pandemic, in order that drugs and treatments can be tested quickly to protect the wider population –

again by consequentialist, utilitarian ethics. In the recent swine flu pandemic, however, general panic within the population ensured that places on trials were rapidly filled voluntarily: moral obligations to participate may not be relevant in these situations anyway.

Although we do not feel there to be a moral duty to participate in first-in-human trials, we suggest that the opportunity to donate bodily material for research is made more widely available. For example, individuals could be given the opportunity to donate to a tissue bank, from which researchers take samples for future research, on the understanding that at the time of consent, the type of research is not yet determined. This may be a way in which supply and demand issues can be combated.