

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.

## Responses to questions

2) The donation of reproductive material such as eggs or sperm after death (in cases such as brain stem dead organ donors) for use within marriage / long term relationships requires further inspection as currently only possible with specific written consent such as in a will, which many people are unaware of.

3) Theoretically no, if there is informed consent for the provision. However donation of the same materials before and after death are viewed very differently by the public.

7) & 8) I would prioritise depending on the ability to save or change the lives of others, so organ donation would be a priority following my death, followed by tissue donation and then blood while alive. The provision on any other materials would depend on the use/outcome, and the risk/benefit to myself. For example, unless i was terminally ill and would be accessing potentially beneficial medication, i wouldnt be willing to enter a 1<sup>st</sup> in human pharmaceutical trial.

9) Beneficence – Doing good and Non-maleficence – Not doing harm.

10) Over-riding principles of autonomy, dignity and non-maleficance should be priority as these should protect any individuals providing any materials.

11) Morally it is far better to be entering a 1<sup>st</sup> in human trial for free. The decision to take such a risk should not be influenced by compensation.

12) One could say that there is a moral duty to provide materials which may save the lives of others such as blood when alive and organs/tissues when dead, however this should not come at the cost of autonomous decision making.

13) I could never see a moral right to participate in 1<sup>st</sup> in human trial as there may be more of a significant risk to health than in the donation of blood while alive. This should be a fully informed decision, completely up to the individual concerned.

14) If the demand means that people suffer harm, such as organ donation or blood donation, as long as ethical principles are adhered to then it is clear within todays society that there has to be an active attempt to meet demand. The meeting of sperm for commercial uses is far less pressing than organ/ blood donation.

15) & 16) Not for bodily materials, but i think that compensation for 1<sup>st</sup> in human trials is necessary due to time spent in trial, however how this is used to actually

'recruit' people could potentially be unethical. i.e. seeing advertisements for clinical trials at universities and job centres. If the compensation for time etc is mentioned once someone has shown an interest in participating, then that is fine, but if the money is used as an initial incentive then this is very different.

17) & 18) Apart from non-cash incentives such as mugs etc for blood donation, all other direct and non-direct incentives are completely equal. Paying for someone's funeral is only saving someone from paying it themselves, so indirectly giving them cash.

19) I don't see a difference between the two and both should be factored in together.

20) The development and use of synthetic blood, however this is only in development at the moment and would require rigorous clinical trials.

21) Amounts of compensation/ payment significantly higher than usual could be coercive and make someone willing to accept higher risks.

22) Depends on the presence of any external coercion on the individual. Moral duty should be something which is felt by the individual.

23) No, although as mentioned, i would like the issue regarding use of reproductive materials following an individuals death to be examined more closely (solely for the use within a marriage/long term relationship).

24) Depends on the situation and relationship. I don't think there is much difference as in most cases if you are in a position to make a decision for someone then would be family etc so you would balance the risk/benefit for them, as you would yourself. Also, their level of comprehension may make the difference far less i.e. they fully comprehend the decision and can indicate this decision to you.

25) Where the individual's wishes are indicated legally, with sufficiently fully informed consent, then there shouldnt be an occasion where members of family could change this. In cases where the wish is unknown, then family members should make every decision regarding use of materials. Many individuals on organ donor register are surprised that their families could potentially stop their organ donation if they want to.

26) In the case of an individual having a next of kin, then to them. In cases of none, then possibly the closest hospital or coroner.

27) No.

28) Yes there should be some willingness to share. Unsure how though. Shares of profits? But then this just adds further compensation/ payment which has further ethical issues. I think the difference would be whether the material was donated voluntarily i.e. tissues from a deceased patient, not suitable for donation/transplant but which is entered into commercial research, compared to someone already having been paid for the material.

29) An individual should have complete control over its future use, or in the cases of deceased people, their next of kin should have this say.

30) Unaware of any.