

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.

QUESTIONS ANSWERED:

Question 3 During life donating may involve or result in inconvenience, actual monetary loss, discomfort and medical risk. After death none of the above can occur but relatives may feel they have a right to override the wishes of the deceased donor to allow for cultural reasons or to aid grieving.

Question 4 For after death donation the only costs involved are additional charges by undertakers for a non-standard service. There may be psychological risks to relatives who hold cultural or religious views on the disposing or handling of the body.

Question 5 For the majority of healthy volunteers the only benefit is the provision of "expenses" which they may consider to be easily earned money and worth the clinical risk. This is likely to be strongest in the un-waged or low paid population. For the non-healthy volunteer there may be benefits from the belief that they are helping others and possibly themselves by assisting research in their condition.

Question 7 I would be more likely to provide directed donations where there is a significant medical risk or discomfort to myself. Otherwise I would be willing to provide material for any purpose which need not be specified in advance.

Question 8 I would be more willing to participate if as a non-healthy volunteer 1) I thought I might personally benefit medically 2) I thought other sufferers might benefit If terminally ill I might consider participating in any first-in-human trial which would accept me.

Question 12 During life - there is a moral duty to provide blood or renewable material to benefit others on the basis of reciprocity. Excess materials i.e biopsy and material removed during surgery should be regarded as freely available for any purpose without specific permission.

Question 13 No

Question 15 Payment in recognition of "inconvenience" and discomfort should be possible. Compare the compensation payments made for discomfort etc caused by negligence claims. By limiting payments by linking to minimum wage a large pool of possible donors or participants are probably lost. For 1st-in-human trials linkage to risk should be allowed.

Question 16 Incentives should, except in exceptional circumstances, be on an official basis only.

Question 18 No

Question 19 Most people will value their free or non-working time. Therefore compensation or payment for time or inconvenience is really no different than compensation for economic loss. Similar discomfort results in "lost" time to do as one pleases and should be compensated for.

Question 21 Extremely excessive generous payments in relation to a person's financial status could result in invalidating consent. However the level of risk

involved and the compensation available if the volunteer suffered harm are relevant factors to be considered when deciding what is excessive.

Question 22 With difficulty. The screening procedure should be completely confidential and include tests for coercion. The outcome result should be a simple accepted/rejected with no reasoning attached. This would give a coerced family member a route to withdraw without losing face.

Question 23 The only test should be approval by an Ethics Committee. It is difficult to see what harm can come to a donor if bodily material is used for other purposes without explicit consent.

Question 25 In a) family members should play no part and should NOT be consulted. For a hospital to be influenced by the contrary wishes of relatives degrades the decision the deceased has already taken.

Question 26 Estate of the dead person unless gifted prior to death

Question 27 no

Question 28 Although I believe that companies should not benefit excessively from use of donated material or volunteer trials - I cannot see anyway easy way of controlling the issue except possibly via a windfall tax in exceptional circumstances.

Question 29 After death control should be limited to broad categories of use, ie research, transplantation. Except for gametes, during lifetime control over donations of excess or surplus material should again be limited to broad categories.