

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.

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CONSULTATION Paper – Give and take? Human bodies in medicine and research

Thank you for the opportunity to respond to this consultation paper. The instigation of such a consultation indicates a recognition and awareness that there are moral boundaries that have to be respected.

As Christians, believers on our Lord Jesus Christ, we hold our bodies as belonging to Him, as stated in the Holy Scriptures – “ and ye are not your own , for ye have been bought with a price; therefore glorify God in your body”. 1 Corinthians 6, verses 19-20.

Where a person feels guided by their conscience to donate their body, parts, organs or tissue for research that is entirely their own personal decision and what cannot be accepted and should be resisted at all cost is the attempt to introduce Presumed Consent. The State cannot assume ownership of the human body.

We have previously made submissions stating these convictions to The retained Organs Commission, and in response to consultations on The reform of the Coroners System and Death Certification, The Human Tissue Bill and The Human Fertilization and Embryology Bill.

The answers to the questions are provided in the light of our feelings as stated.

Part 1.

Questions :

1. Are there any additional types of human bodily material that could raise ethical concerns?
2. Should any particular type(s) of human bodily material be singled out as 'special' in some way?
3. Are there any significant differences between providing human bodily material during life and after death?
4. What do you consider the costs, risks or benefits (to the individual concerned, their relatives or others close to them) of providing bodily material? Please distinguish between different kinds of bodily material if appropriate.
5. What do you consider the costs, risks or benefits (to the individual concerned, their relatives or others close to them) of participating in a first-in-human clinical trial?

Answers :

Questions 1 & 2. The area of reproduction and conception should be regarded as 'special' – God grants conception.

Questions 3, 4 & 5. No Comment

Part 2.

Questions:

6. Are there any additional purposes for which human bodily material may be provided that raise ethical concerns for the person providing the material?

7. Would you be willing to provide bodily material for some purposes but not for others? How would you priorities purposes?

8. Would your willingness to participate in a first-in-human trial be affected by the purpose of the medicine being tested? How would you priorities purposes?

Answers:

Question 6. No comment

Question 7. Material taken for diagnostic purpose, excluding the reproductive areas, could be used for medical research.

Question 8. No comment.

Part 3.

Questions:

9. Are there any other values you think should be taken into consideration?

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

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?

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?

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?

Answers:

Questions 9, 10 & 11. The true value is seen in the principle of a Gift. The human body is not a commercial commodity.

Question 12. There is no moral duty, it must be the person's expressed wish. For example if my wife required a bone marrow transplant and we were advised that siblings would be the best donors.

Question 13. No comment.

Part 4.

Questions:

14. Is it right to always try to meet demand? Are some 'needs' or 'demands' more pressing than others?

15. Should different forms of incentive, compensation or recognition be used to encourage people to provide different forms of bodily material or to participate in a first-in-human trial?

16. Are there forms of incentive that are unethical in themselves, even if they are effective? Does it make any difference if the incentive is offered by family or friends, rather than on an 'official' basis?

17. Is there any kind of incentive that would make you *less* likely to agree to provide material or participate in a trial? Why?

18. Is there a difference between indirect compensation (such as free treatment or funeral expenses) and direct financial compensation?

19. Is there a difference between compensation for economic losses (such as travelling expenses and actual lost earnings) and compensation/payment for other factors such as time, discomfort or inconvenience?

20. Are you aware of any developments (scientific or policy) which may replace or significantly reduce the current demand for any particular form of bodily material or for first-in-human volunteers? How effective do you think they will be?

Answers:

Question 14. No comment

Question 15. We feel the most urgent need is to raise public awareness.

Questions 16-19. As stated previously, The human body is not a commercial commodity , the value is in the Gift.

Question 20. No comment.

Part 5.

Questions:

21. In your opinion are there any forms of encouragement or incentive to provide bodily material or to participate in first-in-human research that could invalidate a person's consent?

22. How can coercion within the family be distinguished from the voluntary acceptance of some form of duty to help another family member?

23. Are there circumstances in which it is ethically acceptable to use human bodily material for additional purposes for which explicit consent was not given?

24. Is there a difference between making a decision on behalf of yourself and making a decision on behalf of somebody else: for example for your child, or for an adult who lacks the capacity to make the decision for themselves?

25. What part should family members play in deciding whether bodily material may be used after death

(a) where the deceased person's wishes are known and (b) where they are unknown? Should family members have any right of veto?

Answers:

Questions 21 & 22. Fully Informed Consent must be the principle that governs every decision. Advice may be given but not incentives and encouragement.

Question 23. From our own experience – when some material was taken from my wife for diagnostic purposes she was first asked as to further use. We would suggest that there could be some form of 'tick-box' system as there would be some material we would not wish to be used in medical research as outlined previously, for example, in reproductive areas.

Question 24. A Child or an Adult lacking capacity should always be protected and no permission should be granted.

Question 25 (a) There should be provision for a moral viewpoint to be respected.

(b) There should be provision for a request for there to be no interference with the body, to be respected.

Part 6.

Questions:

26. To whom, if anyone, should a dead body or its parts belong?

27. Should the laws in the UK permit a person to sell their bodily material for all or any purposes?

28. Should companies who benefit commercially from others' willingness to donate human bodily material or volunteer in a trial share the proceeds of those gains in any way? If so, how?

29. What degree of control should a person providing bodily material (either during life or after death) have over its future use? If your answer would depend on the nature or purpose of the bodily material, please say so and explain why.

Answers:

Question 26. The wishes of the next of kin or the bereaved should be acknowledged and respected – see the provision in the Coroners & Justice Bill – The Charter for the bereaved.

Questions 27 & 28. The UK should not make this legal and any commercial gain should be totally removed from the principle of a 'Gift'.

Question 29. The person should have total and absolute control and given the means to record or register their wishes should their material be wanted after their death.

Part 7.

Question :

30. Are there any other issue, connected with our Terms of reference, that you would like to draw to our attention?

Question 30. Our conviction is that the 'Gold Standard' is enshrined in the Human Tissue Act – the principle of Informed Consent. This is safe and ethically sound, providing the foundation for medical research.

We are responding personally and are willing to have our names included in the list of respondents that will be published in the report and we are happy for the response to be included in the report and made available on the Council's website.

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