

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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## **Questions**

### **2. Should any particular type(s) of human bodily material be singled out as 'special' in some way?**

Any non-regenerative material should be put in a separate class from another. (I would also include livers in this category)

Reproductive material should be put into a separate class.

### **3. Are there significant differences between providing human bodily material during life and after death?**

Considerable concerns over bodily autonomy. During life informed consent can be given. The donor may benefit in various ways. Unless consent is given in lifetime (by donor) as to what happens after death, bodily material should not be interfered with.

### **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.**

Risks of healthcare include potential death whether we are looking at organ donation or gamete donation. However, there tends not to be the same emotional roller coaster for those donating gametes or blood, unless donating ova is in exchange for reduced fee fertility treatment. These women have to be counselled as to the potential pregnancy in the recipient but the failure for themselves.

Those who donate organs have to really consider the potential for morbidity, or the feelings of guilt if the organ doesn't take.

### **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?**

Considerable!

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

Beneficence & malfeasance

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

Autonomy & beneficence, malfeasance in that order,

### **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?**

No I don't think it is morally better, I think that this is up to the individual's conscience, not to accept the compensation. For example, I fully support the offering of a financial incentive, in certain cases. I don't support a large financial incentive, as that might very well encourage participation from unwilling quarters, a large financial incentive could well lead to undue influence in some quarters.

**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?**

I don't support the notion that there should ever be a duty to provide such material either whilst alive or dead.

**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?**

No & No

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

No I think that it is impossible to meet demand.

**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?**

I have mixed feelings regarding donors. Some rewards are appropriate.

I think it essential to compensate (in a variety of ways) those who are undergoing first-in-human trials. I'm sure that Neil Armstrong was paid exceptionally well to go to the Moon. That doesn't mean to say that his wages outdid the '*giant leap for mankind*' he took.

It would be difficult though to reward medical guinea pigs with the offer of such fame. The rare occasion that experiments reach the headlines are when they go wrong.

**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?**

There is a potential for abuse if rewards are offered to family members, depending on the nature of the requirement of course. At one end of the spectrum blood would be relatively mild in operation, at the other end lies the right-lobe of the liver.

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

No I don't believe so, but I have no problem with financial reimbursement *per se*.

**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?**

All should be compensated for.

**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?**

I am aware of synthetic organs. I understand that artificial hearts are a future apparatus. I think money should be ploughed into this research to ensure that they are effective

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

Yes family involvement

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

I don't believe it can. We are all simple creatures at heart. Guilt is the undoing of most of us and there is nothing like a family to allow guilt to kick in, making us feel (rightly or wrongly) that it is our moral duty to look after family members.

**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?**

If consent to 'and any future developments as yet unknown' was given then that would be satisfied, otherwise no.

**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?**

Yes, I am unhappy with the idea of an individual making decisions on behalf of anyone else where they did not know what the other truly wanted.

**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 (no part) and (b) where they are unknown (families should be approached)? Should family members have any right of veto?**

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

To the beneficiary under the will or the Crown if *bona vacantia*

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

Yes provided that it is thoroughly regulated.

**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?**

Yes although they provide the skill, but the volunteer should have some of the proceeds.

**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.**

This so much depends on what material has been provided and the initial purpose of the donation. It should only be used for that which informed consent was obtained, unless a general and anything else, was added to the consent form.