

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 1

ANSWER:

Hair shaved for surgical procedures.

Question 2

ANSWER:

Anything related to children or babies, including aborted or miscarried material.

Question 3

ANSWER:

Possibly, depending on the religious/ethnic background/beliefs of the donor.

Question 4

ANSWER:

The cost would be the thought of disfiguration of a loved one & the incompleteness of the person at burial/cremation. Not knowing if material was being looked after/handled sensitively. Benefit would be knowing that another had benefited either by receiving material or that material was helping research from which others would benefit. I also understand that material for eg. heart transplant has to be removed while the body is still on life support (although clinically dead)& the issue of awareness/pain is a worry.

Question 5

ANSWER:

Obviously, the main risk is not knowing how the trial will work out eg. unknown severe reactions or long term health damage. Benefit for a person with a currently "incurable" condition is that the trial may lead to improved health or longer life expectancy. Benefit could be improved health or the knowledge that contributing to understanding may help others in the future. This could be a factor in allowing individuals/families live with an incurable/terminal condition.

Question 6

ANSWER:

Potential use within a commercial environment would not be acceptable to me. Use of material in the future for as yet unknown purposes could cause concern for people with certain religious/ethnic backgrounds.

Question 7

ANSWER:

Yes. Priority would be for explainable purposes. I would not donate material for

commercial purposes.

Question 8

ANSWER:

No it would not be affected.

Question 9

ANSWER:

No, the list seems comprehensive

Question 10

ANSWER:

Altruism & Dignity should be prioritised. Altruism should always take precedence.

Question 11

ANSWER:

I think that the lure of compensation could cloud judgement. I do not think that it is intrinsically "better" to participate for free but I do think that it can be "wiser".

Question 12

ANSWER:

Yes, for example, I have a rare blood group & I would consider it a moral duty to donate extra blood if asked to do so eg. after a major accident.

Question 13

ANSWER:

Yes. If for example a terminally ill person were asked to participate in such a trial which would lead to eg. increased life expectancy for others in the future then I would consider it their moral duty to take part.

Question 14

ANSWER:

No it is not. There should never be a need to respond to "tourism" or commercial demands.

Question 15

ANSWER:

No.

Question 16

ANSWER:

Yes, I am disturbed by the idea of using eggs from dead donors & the idea of

"benefit sharing". There have been previous cases of people wanting to use eggs/sperm from dead donors & it does not seem to me that the issue of demonstrating the dead person's consent has ever been satisfactorily addressed. I do not like the idea of eg. donating a kidney only to eg. become a priority for another organ at an unspecified later date. For example, a sober person donates a kidney. Some years later they, having become an alcoholic, & need a liver transplant. Does this mean that they would then have priority over someone at the head of the liver transplant queue who had a liver problem not caused by alcohol abuse?

Question 17

ANSWER:

I would not accept an offered incentive but the offer would not make me less likely to agree. For example, I have been donating blood for many years & am not going to stop because I get offered silly stickers & strangely coloured donation cards at intervals.

Question 18

ANSWER:

Depends on the person being offered the compensation & their circumstances.

Question 19

ANSWER:

Yes. Lack of travel expenses & compensation for lost earnings might make it impossible for someone to participate.

Question 20

ANSWER:

I am vaguely aware of these developments but don't have enough knowledge to comment further.

Question 21

ANSWER:

Yes, if somebody was desperate for money, a financial incentive could lead them to participate when it was not in their best interests to do so.

Question 22

ANSWER:

I think that it would be very difficult to distinguish, particularly in the case of a child being asked to help a sibling. This is something that only careful questioning by a professional trained to recognise the signs of coercion would identify, hence it is an area where extreme caution about consent should be exercised.

Question 23**ANSWER:**

Yes, for example if a new disease or variant of a disease appeared & the bodily material could help with developing a cure. Also, if the material could cast light on a previous epidemic because scientific developments meant that better tests could now be carried out. As an example, I believe that research into one of the early twentieth century 'flu pandemics was aided by taking tissue from the frozen bodies of sailors buried in the permafrost.

Question 24**ANSWER:**

Yes

Question 25**ANSWER:**

If the deceased person's wishes are known, they should be respected & the family should not have right of veto. If the deceased person's wishes are unknown then family members should be given the opportunity to discuss the donation. If the family could demonstrate that the deceased was opposed to donation then that should be respected. If the family cannot so demonstrate then the bodily material should be sued.

Question 26**ANSWER:**

If someone has donated their body to science then the body should belong to the institution that has accepted it. If they have not then their body should not "belong" to anyone.

Question 27**ANSWER:**

No

Question 28**ANSWER:**

No

Question 29**ANSWER:**

If the bodily material being donated could lead to the creation of another life (eg. egg donation) then the donor should have control over future use. If the material being donated might, in the future, be used for commercial purposes then the

donor should have the right to veto that use. If there was the possibility that, in the future, the donated material might be put on public display then the donor should be able to debar that use. Otherwise, the donated material should be used freely.

Question 30

ANSWER:

I would like to see discussion about the idea of carrying "I do not wish to donate" cards rather than the current system of "I want to donate" cards. My understanding is that this would greatly increase the amount of bodily material that could potentially be available.