

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 ANSWERED:

Question 1

ANSWER:

Facial transplants, brain transplants

Question 2

ANSWER:

face transplants and in the future, possibly brain transplants. When the first face transplants were carried out, people seemed to have problems with this maybe because a face is such a personal thing (it is the visible 'you'. Also, were brain transplants possible in the future, such a transplant would change the person receiving it.

Question 3

ANSWER:

A person has no control over what happens to their human bodily material after death since even if they have signed a donor register or donor card, their wishes can be over-ruled by the family. Before death, the person makes the decision that they wish to donate and that decision is honoured. Apart from that, human bodily material such as organs tend to have a better outcome when transplanted than organs retrieved from a cadaver. From a monetary cost perspective, this is a better value option. A living person donating bodily material will derive satisfaction from donating to help another.

Question 4

ANSWER:

costs/risks of donating organs - possible decreased health risk - that person may donate kidney and then require a transplant themselves when their remaining kidney fails
costs of donating organs - time spent in operative process, earnings loss
benefits of donating organs - satisfaction with being able to help another individual, making a sick and possibly dependent relative well so that they are no longer reliant on help

Question 5

ANSWER:

cost/risk: possible medical and health repercussions should there be an adverse side effect
cost: time spent in taking part in trial
benefits: personal satisfaction that they may have helped the development of medication that may help a lot of other people
Cost to relatives: concern about side-effects and possible harm to their family member
benefit to relative: none

Question 6**ANSWER:**

none that I can think of.

Question 7**ANSWER:**

I would be willing to provide bodily material for any of the purposes stated (other than first trial medical research) were I able to do so as long as it did not affect my own health/quality of life. My reasons for not providing bodily material for first trial medical research/taking part in first-trial medical research are that it is not possible to quantify the risk to myself.

Question 8**ANSWER:**

No. I would not be prepared to participate in a first-in-human trial.

Question 9**ANSWER:**

None that I can think of.

Question 10**ANSWER:**

I believe that autonomy is of the utmost importance. To take that away would likely make people unwilling to donate. People should have the ultimate say in what happens to their own body. In addition, so long as it is done in a regulated way, people should be recompensed in a monetary form for the donation that they make.

Question 11**ANSWER:**

I do not feel that morally speaking that there is any difference to provide bodily material or volunteer for a first-in human trial for free, rather than for some form of compensation, as long as the process is tightly regulated to avoid pressure on a person to do so. However, I do believe that morally speaking there is a difference when people purchase organs from people who are only selling them in order to provide for essential items such as food, e.g. organ donation tourism. the type or purpose should not make a difference.

Question 12**ANSWER:**

I do not believe that there should be a moral duty during life, but in some circumstances, there should be, after death. For example, someone who has committed a serious crime, eg. murder, should be morally obliged to provide human

bodily material after death. this would to some extent, redress the balance from the wrong that they did in life.

Question 13

ANSWER:

It could be argued that someone in the population who will benefit from the development of a medication could have a moral duty to participate in first-in-human trials. However, I do not believe that there should be a moral duty since it takes away the principle of autonomy.

Question 14

ANSWER:

It is not always right to try to meet demand if the cost of meeting that demand exceeds the benefits. Some demands are more pressing than others, for example, an organ transplant which will save a life or significantly improve that health of the person receiving it (the latter applies to kidney transplants where the person can be kept alive by dialysis which is costly and allows slow deterioration of health) V. for example, the demands for sperm/eggs which do not save a life.

Question 15

ANSWER:

yes but I suspect that most people would settle for money

Question 16

ANSWER:

No. I do believe that there is a difference if the incentive is offered by family or friends rather than on an official basis. I feel that that former allows for extortion and pressure on an individual. If done on an official basis, it allows for a set amount of recompense for a particular donation and also for the process to be regulated to prevent extortion and pressure on an individual to donate.

Question 17

ANSWER:

No.

Question 18

ANSWER:

Not in my view.

Question 20

ANSWER:

No. Perhaps, methods aimed at reducing diabetes and high blood pressure and

obesity thus reducing the failure of organs. The introduction of a paired donor scheme has been a good development in increasing transplants. However, it seems to me that when a family member is willing to donate, it may be better to pair the donation so that each person receiving a transplant will have a better graft survival rate, thus reducing demand.

Question 21

ANSWER:

a person avoiding a prison sentence, otherwise no.

Question 22

ANSWER:

I'm not sure that it can. Maybe all donated organs should be pooled so that a person can receive the best match, not just because their family member is willing to donate.

Question 23

ANSWER:

Not if that person is under the belief that their consent only applied to that original purpose. Otherwise, if the consent is worded to allow for that eventuality, then I cannot see that this would be unethical.

Question 24

ANSWER:

Definitely. I would not think that it is ethical to consent to the removal of body parts for example, transplantation from another person who lacks the capacity to make the decision for themselves, be it adult or child.

Question 25

ANSWER:

I do not believe that family members have any right to over-ride the deceased person's wishes where their wishes are known (for example there is a written record of their wishes). Where the wishes are unknown, then it should be a considered to be a case of presumed consent and family members should not be able to prevent donation.

Question 26

ANSWER:

It should be available for the common good, with the exception where the body has a significance in religion. Unless a caveat for this were to be made in the event that the law was to be changed, then I do not believe that it would be possible to change the law because the religious backlash would be too great.

Question 27**ANSWER:**

Yes.

Question 28**ANSWER:**

Yes. the people who donate or volunteer, should receive adequate monetary recompense.

Question 29**ANSWER:**

I feel that a living person should be able to specify what their bodily material is to be used for and they should be able to state in written form if their bodily material can be used after death (opt-out) and those wishes should be upheld (no intervention by relatives should be allowed to veto their wishes after death).

Question 30**ANSWER:**

I am a kidney patient who has been waiting for a kidney transplant now for 7 years. The reason for my long wait has been a high antibody level received from my last transplant. I am essentially waiting for a perfect match. I am concerned that organs are being donated by family members to a person in need of a transplant where the match is less than optimal, but the transplant goes ahead anyway. Surely it would be better to pool these organs so that donor pairs could be established giving rise to a better match which would thus lead to a longer graft survival, thus reducing the numbers of second-time transplantation and thus the demand.