

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.

Miss E. J. Toogood

Question 1

Face, reproductive organs, especially the uterus

Question 2

Yes. Those capable of creating new life, since some uses of bodily material may have some impact on that new life, whether it be good, bad or neutral. In addition, since humans can be characterised as 'somatic' beings, (from the Greek somatos, meaning 'body') perhaps aspects of the body that are most directly connected to identity should be classified as being somehow 'special'. Examples might include the face, eyes, skin and perhaps reproductive organs. That is not to say they should be used differently from material that is not considered 'special', necessarily. In identifying an approach for our epoch it is culturally important and not least, interesting, to consider what types of human bodily material are thought to be 'special'. Recognising 'special' types of bodily material may be particularly important for understanding approaches to the use of human bodily material. After all, there is a sense that many inclinations against use of certain organs are irrational (albeit perfectly legitimate). Understanding reluctance to consent to donation of particular bodily material may break down the irrationality and lead to greater peace of mind and consequently greater willingness to donate. That is, understanding and accepting 'special' may be of benefit, since society accepts that bodily material as being particularly special. The sacrifice or 'gift' of such 'special' human bodily material may even be thought to be all the more important and therefore people may be more willing to donate what they might otherwise 'irrationally' withhold. ('somatic' beings in Rose, N. Politics of life itself : biomedicine, power and subjectivity in the twenty-first century (Princeton: Princeton University Press, 2006)

Question 3

It is not clear whether 'death' refers to brain stem death or non-heart beating donor. However, it is assumed that it means brain stem death, which is currently accepted as being synonymous with death. Yes, there are significant differences, especially in the consent process i.e. informed/ appropriate consent. Whether or not this is ethically important is another matter. There may be an element of coercion, duty, desperation or fear involved in donating bodily material during life. We also know that bone marrow donation, for example, is extremely painful. Also, the role of saviour siblings, etc. comes into play. I think that paired donation after death should be permitted as it is during life.

Question 4

There can be emotional benefit (this is supported in the cases of 'saviour siblings')

who lack capacity e.g. Re Y). There can be horrendous disappointment and a sense of failure too. That is why informed consent is so important. Costs are financial and somatic, potentially affecting future health. There are also costs, risks and benefits to not providing bodily material, and to not in the first place seeking bodily material.

Question 5

Benefit: social contract - those benefiting from medicine have a duty to contribute to it. All due financial expenses may encourage people to take part, whereas in donating an organ in life, one saves a loved one or someone dependent on them - it is a personal contract. Human self experimentation has a long history, especially amongst clinicians themselves. If the participant is not a clinician and takes a passive role in the trial, the benefit is felt by the individual who may learn about medicine, about their body and about an exciting innovation that may benefit mankind. It is a gift to humanity rather than a gift to a man. However, if the participant has a condition that may be resolved or improved by participation, the trial offers hope and potentially relief to relatives and others. Although this cannot be stated at the outset as there is presumption that the person does not stand to gain from the trial in this way.

Question 6

Saviour siblings - a child born with useful bodily material.

Question 7

A utilitarian view! For potentially life saving treatment. I think procedures offering the highest likelihood of immediate success for the greatest number should be prioritised whether or not that leads to the extension of life. The extension of life is less important. In the context of research, the quality of the trial, the scope of the trial and the opportunity for success should be paramount. The donation of bodily material to save a loved one would be my first priority, though.

Question 8

Yes. I would consider what medicine is currently available to those with the condition in question, what the side effects of that medicine are and what the likely outcome of the medicine being tested is perceived to be. I may prioritise participation in a trial for a medicine that cures or improves a condition that I have experienced either first or second hand. The scope of the purpose would not matter to me. That is, participating in a trial to test a medicine intended for use in the context of a very rare condition would be just as worthy of my participation as one that could potentially rid Africa of Aids.

Question 9

Family values - the impact of taking part in trials on family members. The time, money and emotional involvement. Duty to oneself to protect and enhance somatic existence. The values of the organisations involved - the drug companies v

charitable organisations. I would be more likely to participate in a trial for the Alzheimer's Society, say.

Question 10

Duty to oneself, and willing volunteers should be advised accordingly.

Question 11

It makes no difference, morally to the undertaking of the volunteer, but it does make a difference, morally to the procurement of volunteers. I.e. some form of compensation may unduly coerce or result in contributions of necessity. That is not to rule it out - the motivation for contribution must be thoroughly examined, rather as it is in marriage! People should be encouraged to give adequate reasons to justify their participation.

Question 12

Social contract. If one is to benefit either potentially or actually from the acts of others in providing bodily material. However, this does not mean that donation amounts to a 'moral duty'. The social contract makes it morally acceptable to donate, but by no means obligatory. It is not morally 'wrong' to accept another's organs, but to decline donation oneself, because it is morally right to preserve and strive for one's life. It may be socially uncomfortable to adopt that position though.

Question 13

No, not a moral 'duty', but it is a morally acceptable activity because man benefits from participation.

Question 14

Demand for food is more pressing than demand for bodily materials in a hospitalised setting. It is an exaggeration that the perceived shortage of organs is 'critical', since there is no 'right' to organs. It is a matter of the judgment of the donor and the luck of the recipient. With greater judgment about the benefits of organ donation, we may in turn celebrate more recipients. Judgment should not be clouded by the impression that the demand for organs is critical and that people will die if organs are not donated. It reduces humans from a number to an amount, and the concept is highly unsettling, if unintentional and well-meaning. Blood is certainly a more pressing demand than the demand for organs, since blood can be procured and used at reasonably low cost, with little inconvenience and appears not to adversely affect the donor. Its use can be life saving.

Question 15

Incentivise by offering comprehensive and interesting participation taking full advantage of technology with journals, videos, encouraging a wealth of artistic and scientific involvement. Compensate by dedication to innovation and medical

advancement within a culturally tangible, albeit diverse, context, and recognise the decision and judgement of potential participants by providing adequate information, forums and public discussion on the topic. There seems to be a culture of 'nudge' behavioural economics in NHS Blood and Transplant and a deficit model of engagement. A deliberative and democratic approach would be most welcome and exciting, even.

Question 16

No, providing the interests of the donor are put first. Incentives should be offered on an 'official' basis and should be standardised.

Question 17

No, although I'd prefer not to have the opportunity to donate for money.

Question 18

Yes. Incentives should be standardised and entirely practical.

Question 19

Yes - it is difficult to fix a price on the latter.

Question 20

Xenotransplantation.

Question 21

At the moment, financial incentives invalidate a person's consent. I do not believe that financial incentives should invalidate consent, even though I do not think that financial incentives need be implemented. Consent in my opinion need only be voluntary and informed for those with capacity. However, in the context of donors who lack capacity, encouragement and incentive should not be employed.

Question 22

Crucial factors are capacity, age, proximity of relationship and nature of the relationship. However, in most cases it is too subtle to be distinguished, and as long as voluntary acceptance is established, there is no issue.

Question 23

If the purpose is related in spirit to the purpose for which it was first offered, it is ethically acceptable to use human bodily material for additional purposes. Also, the new purpose should require the same organ, or bodily material as the old.

Question 24

Depends on the relationship between the two - it should be a proximate relationship. There is a difference, but that doesn't mean the same conclusion can't

be drawn either way. I.e. if you are the carer of your child with learning disabilities and you would be comfortable donating your own organs, it is not a necessity to preclude the participation of the child in a practice that you believe to have sound moral and ethical value.

Question 25

As Margaret Lock argues in *Twice Dead* (2002), the donation of a loved one's organs can have great impact on family members. Given that limited/no information is available at the time of signing up to the organ donation register, it is reasonable to give family members a right of veto. It is right that family members should contribute to the decision, and discussion of organ donation between family members is to be encouraged. It would be useful to have an opt out AND opt in system, so that individuals can say either that they do or do not want their organs to be donation. If such a system were to exist, family members would have a more legitimate role in deciding whether to authorise donation.

Question 26

John Harris argues that the dead body belongs to society. I believe that there is no reason to assign property rights automatically, unless the individual has bequeathed their body to an academic institution, say. The body should then belong to the institution regardless of whether the institution has 'done' anything to the body.

Question 27

I see no useful reason to permit this (based on evidence of sales in India and Pakistan), but at the same time I would not see fit to deny a person the right to make an autonomous decision to sell his or her organs in a fully regulated and safe system. I think it would be a shame, but nothing more than that. In the UK it may be socially frowned upon, rather like tabloid modelling, which would be of no benefit to the donation of bodily materials at all.

Question 28

Any gains should be offered to charitable causes or a great cultural venture such as a new music hall or a beautiful garden.

Question 29

None, providing that the material goes to an organisation approved of by the HTA. Once a type of bodily material has been specified and removed from the body, there need not be any restriction. Potential donors should be given an idea of the scope of usage. Restriction could lead to unnecessary suspicion, and there is possibly no need for it at this stage. The need for restriction may need to be reviewed at a later date, however. Bodily material used and monitored whilst the body is brain dead or broadly speaking intact, may be worthy of separate consideration.

Question 30

The anticipation of public concern, whilst it is important, should not affect the content of the information available. I would like to see a much more collaborative approach to gathering bodily material for research and donation. For example, a charitable body separate from the organisation that uses the material may improve participation. After all, whilst it is recognised that for example the procurement and allocation of organs under one roof is beneficial to the process of matching, it is not necessarily the most ethical approach. As there is such a great emphasis on patient choice in healthcare, why not form a body that allows one to make interesting and informed decision on the use of one's body for public health purposes? It would be a boon for public health to engage people in this way. Rather than asking banal questions about the cleanliness of a hospital or the kind and caring nature of its staff, or impress on them the dearth of organs available, it would be wonderful to encourage people to engage creatively. Donation and research allows donors to engage in a quest for health, not necessarily to become a solution to a need or [insert hopeless] drought. The point is that the latter is merely a reality of the human condition; the former is an enlightened and considered approach to life. An ongoing recruitment of people to provide bodily materials as a form of 'plug' on 'tragedy' is neither ethical nor beneficial. More focus on information, consent, design and philosophy in, say, NHS Blood and Transplant campaigns and far less on numbers, social contract, 'moral duty' and guilt would, I guess, work.