

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.

Patricia Stoa, Convenor, Health and Bioethics Committee, National Board of Catholic Women

**Give and Take
Human Bodies in Medicine and Research**

A response to the Nuffield Council on Bioethics Consultation July 2010

The National Board of Catholic Women and its Health and Bioethics Committee are grateful to the Nuffield Council for instituting this consultation and for the clarity and scope of the consultation paper.

1 Nature of Bodily Materials and First-in-Human Trials

In general we think that organ and tissue donation are to be commended and represent a rare opportunity for altruism and generosity.

We also think that first-in-human trials, which are not without risk, offer opportunities to participate in a social good that many young men take up to supplement their incomes, and that people with specific conditions may be glad to contribute to, perhaps to prevent others suffering as they are suffering.

Our reservations come when we move beyond the immediate and personal and come to the question of research and the use of 'waste' materials. An important question arises about 'who has the right to decide' what happens.

1 No, we don't think so.

2 Eggs, sperm and embryos, and other material involved in the creation of new life; these are 'special' precisely because they are involved in the creation of new life and of bonds between people. They are 'relational' as other body parts are not.

3 No.

4 The donation of bodily parts offers an opportunity for altruism and generosity to the donor, with low costs and risks, and great personal satisfaction is a life is saved or enhanced. Where 'life-creating' materials are concerned the issue is less clear cut. Where the intention is to create a child, the question of the best interests of the child should be paramount, but often are not.

5 It seems to us to be relatively low risk, and an opportunity for altruistic action [and a chance to pay off student debts].

2 Purposes of providing bodily materials / volunteering in a trial

We commend the donation of bodily material to provide life-saving, life-prolonging, and life-enhancing treatments. We would not have reservations about donating for these purposes, nor about participating in first-in-human trials for these purposes.

We have ethical concerns about the question of the use of bodily materials for life-creating purposes; about the use of donated materials by commercial organizations; and about the processing of donated materials [for example, the use of 'spare' embryos for experimental work on embryonic stem cells].

We would draw attention to the dangers of:

- thinking of human reproduction in 'instrumental' terms detached from human relationships and human community,
- prioritizing the needs of adults over those of the child or children [who have no voice in any decisions that may be made before they are conceived, but who surely have an interest in such decisions], and
- treating the making of children as a matter of material production rather than loving relationship.

We think, [from our own experience as blood and kidney donors] that people will be less inclined to donate bodily materials if they think that such materials may be used at some point by a commercial organization to make profits.

We also believe that donors should be clear about what use will be made of donated material, and that informed consent depends on clarity about this. A category of 'reserve' uses might be added to consent forms, so that people could consent or not to the use of donated materials for future unspecified research. [That is, people could say what they do not want their donated materials used for, leaving all other options open].

6 We do not think so.

7 We would all be happy to donate organs for life-saving treatment, and probably for life-prolonging or life-enhancing treatment, although we had some reservations about prolonging lives for 'too long', although this was hard to define.

We are concerned that fertility treatments are making children into commodities and undermining the key role of loving relationships as the foundation of human family and community. We would not wish to donate eggs for these purposes, or permit bodily materials we had donated to be used in treatment or research of this kind – that is, where the conception of children is detached from the physical union of the parents.

8 We would be more willing to participate in first-in-human trials if the medicine being tested were life-saving, but this would not be a determining factor – level of risk would be more of a consideration.

3 Ethical values at stake

9 We thought that the question of the ‘right to decide’ – who has it, and under what circumstances – should be considered in the context of ethical values [for example, should family members be able to over-ride someone’s wish to donate their body parts after death? Who may consent to the destruction of an embryo or its use for research?]

10 Our order of priority was:

- Altruism – we think that the ‘gift relationship’ is of the essence when bodies and donations are under consideration;
- Solidarity - the demands of mutual obligation and support are the key to community and trust between people – the sense of the common good
- Dignity – this concept needs to be unpacked – one of us considers it ‘ungrounded’, able to mean whatever we want it to mean; from a Catholic perspective we take it to mean that which is due to a human being as a human being, and therefore to a human body as human – belonging to a community, a ‘body-in-relation’, not a waste product or rubbish.
- Justice - especially where it concerns access to medical treatment and its benefits, though we also recognize that fair recompense for donors may be important.

11 It seems reasonable to us that what can be given free in this context should be given free, but that people should not be placed at a disadvantage because of their generosity. So insurance in the case of first-in-human trials, expenses in the case of other donations [including loss of earnings] should be paid. What matters is that people should not be exploited or placed at unnecessary risk, and that there should be clarity and transparency.

12 We think there will always be amoral duty *to consider* providing bodily material where it may be used to save lives, or to enhance or prolong life, although we debated the question of whether all lives should be prolonged., and ‘who decides?’ We think the ‘default’ position on this question should be that there *is* a moral duty to do what we can [including donating our bodily material] to preserve and enhance life, but that this is a matter for individual decision and cannot be required of people.

13 We think there would only be a moral duty to participate in first-in-human trials where the individual was in a unique position to contribute to research because of his or her condition, for example where someone was suffering from a rare disorder.

4 Responding to demand

14 We think that where life-saving treatments are concerned it is right to try to meet demand; and so far as possible where life-enhancing and life-prolonging treatments are concerned. We are less persuaded about treatments concerned with fertility; there are concerns about whether donations are just to children, and whether the use of donations in fertility treatment tends to turn children into objects of consumption, to be bought [and sold]. We think that on balance there should be no commercial considerations involved in fertility treatments, not simply because of the risk of children being seen as something to be bought, but because of the dangers of children being seen as something to be sold, or the gift of fertility being seen as something to be sold.

15 WE think that recognition will appeal to some people, and those first-in-human trials, especially where the drug involved is likely to be profitable, should involve reasonable compensation.

16 It seems to us that the danger of offering incentives is that donors may come forward who are inappropriate, and possibly endangering their own lives or those of the recipients of their donations; and that 'altruistic' donors may be discouraged by the offer of incentives [judging from our experience as blood donors, here and in the USA]. We would be concerned about incentives such as 'egg sharing' where women unable to afford treatment are offered it on condition that they do something [donate eggs] that they might otherwise not wish to do, and that they might not regard as ethical.

17 All of us thought that straightforward financial incentives would make us less likely to donate / volunteer for a trial. We value the gift relationship and would resist any effort to turn it into a commercial deal.

18 WE think there is a difference between financial compensation and indirect compensation such as the provision of funeral expenses, in that the gift relationship is preserved – the exchange is of gifts in a context of mutuality, not of commerce. We are more concerned about free treatment, where the exchange might seem to be coercive. What matters is that people should be acting freely in accordance with their own good and that of others, on the basis of informed consent and their own conscience.

19 Not if the compensation is realistic.

20 We are aware of work being done with stem cells that may, and we hope will, mean that it will not in future be necessary to destroy human embryos in order to 'harvest' stem cells for research. We are also aware of work designed to reduce animal testing by the use of computer modeling and cell cultures that may make first-in-human testing safer [though cannot replace it entirely]. We are also aware of work on artificial organs, but we expect these to be much less efficient and safe than transplants, at least for the time being.

5 The role of consent

21 This is a very difficult question. When does an incentive become a bribe? We think that in general, provided that full and clear information is given and that the person making the decision and giving consent has the relevant capacity, the answer is no. On the other hand, there are issues of perception – the extent to which someone under pressure sees the issues clearly, the kinds of relationships involved, the question of 'who benefits'".

22 This is even more difficult, and we do not know the answer. Perhaps it is important to ensure that family donors always have an opportunity to speak in confidence with the medical team, as often as necessary, to give them the chance to say no.

23 We think that it should be possible to design a consent form which gives people the option of refusing consent to the use of their bodily material for additional purposes in general, or in specific contexts [for example for commercial research or for research involving the creation / destruction of embryos].

Role of families: Living Donation

24 Yes. When you make a decision on behalf of someone else it is necessary to consider their best interests, their priorities and their beliefs and values, not your own. This may be difficult. Might it be good practice to offer help for people making decisions about donations on behalf of others from a specialist counsellor?

Role of families: donation after death

25 Family members should have a role in deciding whether bodily material may be used after death only if the wishes of the deceased person are unknown.

6 Ownership and Control

26 The issue seems to us to be not to whom should the body belong [it is not property] but who should have the right / duty to decide to what use it may be put? And should that right be circumscribed by a requirement that the person who has the right to decide should act in accordance with the beliefs and values of the deceased?

27 We think not. The body is intimately linked to the person, to identity and the sense of self, and is not property [I may not be bought or sold by others, and I may not buy or sell myself]. We think the law should respect this, and refuse to allow the body or its parts to be commodified.

28 It seems to us that companies that benefit commercially from the donations of human bodily materials or from the bodies of volunteers should acknowledge this by a reciprocal donation of a percentage of the profits to relevant charities, or by donating a percentage of the drugs or treatments developed free to countries too poor to buy them [perhaps through medical NGOs].

29 The ideal answer to this question would be, as much control as they want. Once again the question of the 'right to decide' is important. So far as possible we think donors should be able to give or withhold specific consent; we think that they should have full information about the uses to which their donated bodily material may be put; they should be able to specify restrictions. This would be especially important in the case of 'life-creating' donations, or of restrictions on the use of tissue in research involving the creation or destruction of embryos, including nuclear cell transfer, where human life is involved.

Patricia Stoa / Health and Bioethics Committee

National Board of catholic Women

13 July 2010