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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Give and take?
Human bodies in medicine and research
The response to the consultation

1. Among the types of human bodily materials that could raise some ethical concerns I would like to mention about using bodily material from embryos, fetuses from miscarriage and from stillborn infants in the purpose of research. Retrieving gametes from dead (brain-dead, cardiac dead) donors is also ethically disapproved.

2. I think reproductive material should be singled out as special in some way. Although in many countries operate special banks providing reproductive materials (eggs and sperm) from anonymous donors, I think the use of this material, which results in a birth of a child genetically related to a donor of this material, might cause various conflicts (psychological).

3. Yes, there are significant differences between providing human bodily material during life and after death. Living donor can control the process of donation, can withdraw the decision about the donation, might suffer from physical pain, anxious and other mental costs. Providing bodily material after death is believed not to have mentioned costs of donation. In donation after death psychological costs are on the side of the deceased family. Donation from living or from dead donor has also a big difference for the recipient (might have a feeling of guilt, if organs are from dead donor).

4.
1) Donation of blood: low costs for a donor (mental, physical); quite a small risk (possible an infection); the benefits: self-satisfaction from donation, becoming an honorary blood donor, small tokens of gratitude.
2) Donation of whole organs after brain death: high psychological costs on the side of family of the deceased, we should not talk about the categories of cost, risk and benefits on the side of donor.
Donation of organs from living donors: very high psychological costs both for donor and his/her family, very high risk of health complications after organ donation, benefit: self-satisfaction of saving someone's life.
3) Donation of partial organs: high physical and mental costs of donor, high risk of health complications, benefit: self-satisfaction from helping others.
4) Donation of tissues: for donor – moderate health/mental costs and risk, benefit: self-satisfaction from helping others.

5) Donation of sperm/eggs: moderate health/mental costs and risk, financial benefit for donor.
6) Embryo/ fetuses from miscarriage – does not apply in this case
7) The whole body after death for medical students – does not apply in this case, it should not be talked about the costs, risk and benefits for donor.

5. Participation in first-in-human trials depends on the will of a concrete person. S/he has to consider the potential risk and benefits. However, these considerations have to include person's family/relatives. The physical costs of such participation are unknown. Because of this the mental costs of the participation might be higher (it is difficult to expect potential influence of the trial on the body). Researchers tend to say that the risk of such trial is small. Financial benefits seem to be the most important incentives to participate in trials.

6. Such controversial purpose which can raise ethical concerns might be processing of human bodily material for research the cosmetics industry; using gametes of dead donors in the research (retrieved from dead donors or retrieved from living donors, but used after the death of these people).

7. Yes, I would provide body material for life-saving purposes only, not for any other purposes.

8. I do not want to participate in first-in human trials. Maybe I would give a priority only to trials which can contribute to inventing life-saving medicines.

9. In some religions very crucial is the value of mercy towards other people. In other religions it might be the value of compassion. In general, the matter of organ donation (from living donors or decision to donate after death) might be considered in the categories of a free, absolutely unpaid gift of life (*non omnis moriar*, I can built something which cannot be measured by money or self-satisfaction) or self-sacrifice (Greater love has no one than this, that someone lay down his life for his friends; John 15, 13). We can also mention about the transcendental values (we donate the organs in the name of the good, the truth and the beauty) and virtue of heroic deed. Participating in first-in-human trials might be considered in the categories of a contribution to welfare of the future generations.

10. If one value is the most important for the certain person, there should not be any conflicts between other values. However, the choice of the most important value depends on the personal hierarchy. We cannot make any universal paradigm of values for everyone. And we cannot press anybody to act according to such paradigm. I cannot say which value should be at the first place. But I would like to underline that the value of autonomy should not be overused and value of dignity of a person should <u>not only</u> be something, which has to be protected, but first of

all something, which has to be promoted (and this approach makes a difference). Value of community should be recalled and reviewed again.

11. First-in-human trials can be paid (small money) as probably not too many volunteers are willing to participate in such trials in the name of medical progress. Type and purpose of using bodily material or medicine being tested make a big difference.
People are willing to help for free to save others lives. This type and purpose is lofty.
However, enhancing and reproductive purpose (donating tissues and gametes) might be considered as a kind of "extraordinary" treatment. And to encourage potential donors medical/research organizations have to give some incentives (financial benefits). Otherwise people might not want to share their bodily material.

12. A moral duty to provide bodily material might arise in the case of mother and child: mother might feel a moral (maternal) duty to provide the organs, tissues, blood to save own child. Mother might feel that she has such duty (to provide organs/tissues for child/ children) also in the case her death (she should make a decision in advance to donate her organs to her children in need).. Such duty might involve other family members. And this feeling of moral duty might be mixed with some kind of moral "pressure" or coercion to donate bodily material to family member in need (conflict between moral duty and personal will).

13. A moral duty to participate in first-in-humans trials might arise in the case of parents/family/relatives of a child (or other family member), who is suffering from a certain disease and such participation in the trials can contribute to invention of an effective medicine, which can save his/her life.

14. Of course, all demands cannot and should not be meet. It is easy to reject the demand for tissue for research, but it is extremely difficult to reject the demand of organ transplantations which are saving human lives. Maybe this is strange, but development of medical science is pressing the society. Here is a mechanism of this pressure: "one hundred years ago we didn't have such possibilities to save peoples` lives by organ transplantations, but now we can, so we should use every means to do so. And this is a lofty aim. However, maybe after one hundred years the head transplantation would be possible to perform. So should we meet the demands of people and do such transplantations, just because it is possible to do?" The "possible" doesn't mean "should" be done.

Most pressing (psychologically) demands are organ donation for waiting ill children.
15. Yes, that is natural. Different incentives should be applied to different kinds of donation of bodily material. Participation in first-in-human trials is closest to selling-buying relation. There is no direct saving lives. Researchers might receive a result, which might/might not contribute to development of medical treatment.

16. Unethical way of using incentives can be easily distinguished: when donor treat incentives as an ultimate aim in itself. Incentives can be positive (money, health care benefits, discounts, love of family members, other positive feelings/benefits/proud) or negative (threatens, blackmails, negative feelings, guilty, shame). Incentives offered by relatives and friends might by based on keeping a positive feelings/ relations with them. In this meaning it is more difficult to refrain from them. The incentives on an official basis are taken directly for themselves and are easier to reject. But they also can be closer to a bargain (who will offer "higher" incentives/ price).

17. A counter-productive incentive personally for me is an idea of covering the funeral expenses. Even after taking organs from a brain-dead donor offering to cover the funeral expenses seems like distaste. Good incentive might be a discount (discount, not free) for medical treatment in the future for donor (and donor's family).

18. There is a difference: the direct financial compensation is too easy, and makes selling-buying relation between donor and the medical/research organization. It might humiliate the donor (direct payment for donation might also be a counter-productive incentive for some people). As I mention, not free, but discounts for medical treatment for donor and donor's family might be better solution. Please, forget the covering of the funeral expenses, although they are quite high indeed. It seems like a quintessence of a black sense of humor: "well, we could not help you in full recovery, but do not worry, if you decide to donate the bodily material, we can promise to sponsor your last journey to the graveyard in the future". Both donor and recipient cannot be humiliated. It is a great art to give a gift and not humiliate and take a gift and properly express the gratitude. Health/research organizations want to have the bodily materials and will pay various "prices" (included in simply money). Much better is to offer discount tickets for health treatment, medicines, visit in rehabilitation/ training place, sanatorium, than providing money for bodily donation.

19. Yes, there is a difference between compensation for economic looses (traveling expenses, actual lost earnings) and compensation for time, discomfort, inconvenience. The answer is simple: if you do not have a time (or you think this is a waste of your precious time), if you do not want to feel discomfort/inconvenience, do not come to donate the bodily material. Why medical/research organizations have to pay for your subjective feelings and grumble? Such behavior has no any trait of gift. This is an awful, non-human calculation.

20. Some inventors of artificial organs say that it will be possible to use such artificial organs maybe after 20 or 30 years. This kind of development might reduce the current demand for organs and might be very effective. However, implantation

of artificial organs might also pose many additional questions (who can be given such artificial organs, a person who can afford for it, or should it be refunded and similar questions). Now we cannot say too much about this matter. But implementation of artificial organs might be a great revolution in health care system. Another way is implementation of organs from animals. However, this kind of implementation is not popular (particularly ideas of using a heart from a pig).

21. A person's consent can be invalidated by various methods of encouragement. The problem: who is this person, what is his/her material status and what are the motivations for donating bodily materials.
If a donor and recipient are the members of one family the encouragement or rather the pressure from the family can invalidate the consent (causing the feeling of guilt, feeling of anxious, shame, threaten of physical abandoning, emotional abandoning, betraying, blackmailing and similar).
If a donor have symptoms of mental disorders, affect disorders or some incurable disease (s/he thinks that there is no point in living) then his/her consent can be invalidated.
If a donor is in a very difficult financial situation, in debts or generally has a permanent low status of living, then even small money incentives for providing bodily materials or for participating in first-in-human trials can invalidate the consent.
Donor has to be asked about the motivations of his action (sometimes it is good to use the projective methods in psychological interview, as donor might not answer to direct question about the motivation). As I wrote above, the consent might be invalidated both by positive and negative stimuli.

22. Distinction between coercion and the voluntary acceptance of some form of duty to help another family member is quite hard for ordinary person.
However, psychologist using some projective techniques and by interviewing a donor and his/her family can easily recognize the coercion. But I must underline that a different thing is consequent keeping the promise of decision about donation. If for example someone, after deep consideration, decided to be a living donor (for example registered as a bone marrow donor), then s/he should keep this promise and donate bodily material (if the person in need is found). Once decided, it is unethical to withdraw the consent. The most important is the moment of decision – there psychologists should try to seek for any evidence of coercion (physical, mental, inner, external).

23. There are circumstances in which it is ethically acceptable to use human bodily material for additional purposes for which explicit consent was not given, for example in the case when the second purpose and method of research is similar to previous one.

24. Certainly, this is not only a difference, this is a great responsibility to make decision on behalf of somebody else, particularly child (or an adult who lacks the capacity to make own decision). Here is a danger of projecting person's own will/ feelings/ worldview/ thinking way about the best interests to the potential donor of bodily material. It is hard to decide on behalf of child, as some emotional obstacles of deciding person might block the clear vision of the situation. While making a decision on behalf of child we should think that the physical and mental capacity of children is very different than adults (they can recover from heavy conditions more easily than adults).

25. A donor is surrounded by his/her family (if not orphan) and it means s/he is not some isolated individual, but emotionally connected with the family. Then it is very natural that the family of donor has to have the deciding role when the wish of the deceased is unknown. When this wish is known, family should respect the will of the deceased. In such a case the right of veto has no raison d'être. Family members should not invalidate the will of the deceased even if they disapprove it.

26. A dead body cannot belong to anyone, even family. A concrete person should leave a will (if possible rather written than oral) with the information concerned to organ donation and with instructions what should be done with his/her body, whether it can be used for research/ for medical students.

27. Neither law in the UK, nor the law in other countries should permit anyone to sell the bodily materials. Moreover this is not (not only) the matter of laws/ethics/religion/moral system. This is the matter of a good taste, gut feeling and something which cannot be perfectly verbalized/ explained.

28. According to my understanding of this issue, the companies who benefit commercially from others` willingness to donate human bodily material or volunteer in a trial should not share/ provide any proceeds of those gains. Such procedure might lead to deepening the "commercialization", "commodification", "reification" of the human bodily materials, which might be treated as a "product" which can bring a financial, long-term profit for a donor. Donors cannot "invest" their bodily materials in order to receive long-term profits from certain companies. And moreover such "long-term sharing of the profits" between companies and donors of bodily materials might lead to creation of some gaps for illegal business.

29. A person who decided to donate some bodily material should precisely state for what purposes his/her material cannot be used now and in the future (after his/her death).
The situation is clear when a donor agreed for using bodily materials for saving peoples` lives only.
Situation is not clear in the case of research. A donor should be informed for what kind of research his/her material will be used and how it will be utilized. Here a

donor can withdraw his decision about using his/her material if s/he doesn't approve the purpose of research.
The degree of the control is not the same and depends on the nature of bodily material. The hierarchy is made from the smallest to the highest degree of control:
1) A material that is removed from a body in the course of another procedure and treated as a "waste", after giving consent to use for ethical research or medical treatment (this is not a rare/ specific material);
2) Materials such as blood, bone marrow, if used in ethical way (not rare material). However, I will repeat, quite a different thing is a situation of giving consent in this case. For example, people, who registered as a potential donor of bone marrow, sometimes withdraw their consent, when the recipient is found. They are afraid or simply change their mind. Such "control" and withdrawing of consent might be very harmful for the recipient and is very irresponsible behavior);
3) Reproductive materials that might result in the birth of a child genetically related to the person providing the material (very specific material, however, many people, who knowingly decided to donate sperm/eggs to banks, renounced the right to control this bodily material);
4) Non-regenerative material – organs - priority should be given to the members of family, if they are in need. This kind of material, which can save the human lives is in shortage so that a donor should have a possibility to give the priority to own family (the highest degree of control, when a donor can designate a concrete recipient).

30. At the end of my response to your paper, I would like to underline that one important thing. It is essential that qualified psychologist could make interviews with people (and if possible with their families) who express the will of donating bodily material, particularly organs (now or after death). This procedure will not only show the state of mind and motivations of donors. It can also provide important information about the degree, in which the decision about donation is made voluntarily. Work with psychologist can improve the contact between medical team and donors (donors` families).

I am sorry for mistakes and inappropriate using of English.
Yours sincerely,
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