

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.

1. A significant concern of mine currently are efforts to conceive children specifically so that their bodily materials (bone marrow, for instance) may be used to save an existing child. Thus, it is not so much about the item itself as it is from whom the substance is acquired, and how it is acquired.
2. I believe significant categories include 1) the taking of non-renewable substances from living persons and 2) medically invasive procedures that are necessary for acquiring substances from living people.
3. It is unclear whether or not all medical personnel (not to mention the lay public) agree on what counts as 'death,' making it especially difficult to answer this question. What processes are involved in determining death (cardiac arrest? brain death? apnea test? for how long should the person be unable to breathe on their own or sustain a heartbeat, for instance). It is disturbing that methods employed for determining death are not standardized (at least in the U.S.)—you can be dead in Pennsylvania but still alive in Oklahoma, or dead in the U.S. but still alive in Canada, for that matter. Also, we must be very cautious indeed about what we do to bodies before the declaration of death, and before we have acquired consent. Sometimes procedures are initiated that are designed to preserve organs (rather than lives that are seen as irretrievable). This is a common practice in Spain and sectors of the U.S.
4. I think that the final 'consent' should rest with the potential donor's survivors to determine. Even if one has self-identified as a 'donor,' surviving kin must live with the memory of what was done. It is also important to ask these sorts of questions along the full chain of participation. For instance, who, in the end, will profit (medically, commercially, psychologically)? Where financial gain is concerned, transparency is essential if one wishes to garner trust. It is my personal opinion that bodily substances should not be patentable. Instead, open/free access is key for research; the commons should be privileged over private enterprise, and we should encourage strict regulation of pharmaceutical corporations, which have emerged as the new transnational giants of the 21st century.
5. This is a very complicated question, especially when read with the previous section in mind. Several key points emerge here: drug trials, when run by private pharmaceutical industries, have increasingly moved 'offshore'—that is, whereas the market for the drugs themselves may be understood to lie within wealthier countries (especially in North America and Western and Northern Europe), the testing of potential drugs has moved to countries that often lack a basic, working healthcare infrastructure. Thus, drug trials are now increasingly the only source of any quality health care at all in some countries, or for some populations (in for instance S Africa, Uganda, Ukraine, New Zealand). Drug companies want 'naïve' patients—those who are not taking other drugs that would cause counterindications and those who are 'naïve', too, in their knowledge of their rights as test subjects. Although presumed consent procedures might be followed to the letter, these subjects may well be willing take greater risks with their health because they are already ill and receive no treatment. Participating in a drug trial, then, is a reasonable (yet potentially very harmful) gamble. This practice strikes me as blatantly unethical:

they exploit the desperate, and, further, once the trial has ended, the team may well retreat to another context, leaving people with no follow up health care at all, even when faced with serious side effects. Drug trials should not stand in for standard health care.

I do not know what the procedures are in the U.K.—I am based in the U.S.—but drug companies should not be permitted to run their own trials or hire their own testing firms. Because these firms are increasingly multinational, though, it becomes very difficult to regulate them. These processes nevertheless need to be regulated with care by government(s) so that honest reporting of trial procedures and outcomes are available. (The coverup of the dangers of Vioxx being a prime example of the latter.)

6 'Life enhancing' should perhaps also include cosmetic surgical uses—sometimes this involves 'restorative' surgery; in others it is purely cosmetic/aesthetic, and it is in this domain where tissues for profit are pervasive (and when donated perhaps not imagined in this way). Why should we speak, for instance, of bodily substances as being 'used non-commercially' at the exclusion of commercial use? Key ethical concerns should also address the fact that those who give tissues may not realize that their body parts are used commercially—transparency should characterize the consent process. Some people may prefer not to give if corporate entities stand to gain from their donations; for others, this will not matter because they view certain parts as medical waste that they are happy to recycle, for instance. I should note that I found the commentary on how bodily substances may be 'potentially used within a commercial environment' a bit brief; as such, it struck me as potentially intentional that it was skirting relevant issues and widespread practices; perhaps, though this happened simply in an effort to economize on space so that readers would not experience fatigue in reading subsequent sections. (Many of the relevant issues do in fact surface later.)

Perhaps bone marrow harvesting should be included as another category of 'directed' donations.

7. As for where I stand—most important to me would be HOW my body parts are acquired; I willingly donated my placenta when I gave birth, knowing full well that its use in "research" most likely meant it would go to commercial use in the cosmetics industry. I understood 'my' placenta as medical waste and I was happy to have it put to use—it began as mine, but was no longer once I signed the consent form. Parts acquired through techniques that may harm me (live kidney donation, for instance) I would most likely only give if I could direct where they went. I am fully in favor of full body donation at death, and organ donation as well; I myself, however, am uncomfortable with the first (the fantasy that a former student might dissect me is too great a fear), and I have instructed close kin to consent to organ donation only if they themselves are comfortable with the decision. Criteria for determination of death matter here as well—I am uncomfortable with the growing practice of acquiring organs from non-brain dead donors where the timing of cardiac death is orchestrated within the operating theater.

8. I have been asked in the past (when I was in my early 20s) to participate in a drug trial, and I refused. Adequate medical care was withheld by the physician as a punitive measure as a result (I then shifted to another physician). This has colored my willingness to do so even now (30 years later). I would most likely only participate in a drug trials if it were the only option I had

when faced with imminent death from injury or fatal illness, although even then my consent would be dependant on my age, the nature of my illness, and, most importantly, the needs of my dependants. I expect the same standards to be possible for people living in nations or communities underserved by quality medical care facilities/professionals. Drug trials should not take the place of adequate medical care.

9. I don't think that autonomy is always about body ownership. These should be handled separately. I believe autonomy is first and foremost about personal will—consider, for instance, cases where parents make decisions for underaged children—the child 'owns' the body and can express desires that one hopes parents/guardians will do their best to consider or honor, but the autonomous decision is made by the adult caretaker.

I found the definition of dignity a bit odd here—why is it framed by the theme of commodification? Death with dignity, for example, has little to do with the commodification of the body. Dignity seems far more about honoring the desires/wishes/concerns/fears of the person who is affected, and the body itself should not be desecrated (however the individual himself/herself understands this). Dignity is slippery—one imagines there might be a universal understanding of this (no body should be hacked apart as if it is a piece of meat), but it requires a strong dedication to relativism, too—my sense of dignity may not be the same as yours, yet I ask you to respect it, nevertheless.

Also, why is justice anchored to recompense?

As for maximizing health and welfare: what worries me here is that if we can promise the greatest good to the greatest number, what happens to the outliers? "Maximizing" strikes me as a rather dangerous term. Why not instead striving for health and welfare for all (even if this is an ideal and not perhaps an attainable reality)?

Regarding reciprocity: within the realm of organ donation (at least as practice in the U.S.) organs are given willingly (altruistically) without the expectation of reciprocation. Reciprocity nevertheless occurs, *and is widespread*, although this assumes forms that fall outside 'benefits or services': for instance, the surviving kin of deceased donors and organ recipients may locate one another and redefine their relationships as those of kin, where the 'payback' so to speak is a sentimental one (of warmth, caring, hospitality, etc.)

10. Among the more troubling values are those that assume that market principles are a natural and convenient way to pay back, reciprocate, etc. Generally, paying people for their body parts or willingness to participate in studies inevitably corrupts the relationship between provider and patient. Thus, although I have no clear answers as to how all values listed here should be prioritized, I would argue that commercialization should fall at the bottom (or be of lowest priority).

11. As noted in my answer to #10, I believe that the market corrupts. I think with caution some categories of reimbursement (with receipts) makes sense: for instance, for travel to and

from the research site. But involvement in drug trials should not be a way in which to earn wages. Similarly, it worries me that drug trials in some countries stand in place of general medical care, and this strikes me as criminal. I also believe that anyone who participates in a drug trial should be guaranteed free medical care for several years afterwards in case the procedures or drugs prove harmful in the long- and short-term. This is less of a problem in a country with a national health plan. Elsewhere trials are inevitably exploitative/predatory.

12. There is no such thing as a universally imagined moral duty to provide human body materials at the time of death. There are a few countries where this is very much the national ethos (as in Sweden, where there is a strong sense that the body belongs to the state); in Spain, mandatory organ donation has been legislated, but this is not the same as a widely accepted cultural notion that it is a moral duty to participate.

13. I can imagine no context where there is a moral duty to participate in human trials, except on an individual basis (that is, one believes, as an individual, that one must do this). As citizens of individual nations we should have the right to say yes/no. I believe this is a universal right, and it is the moral duty of the state to protect this right (to say yes or no).

14. In the best of all possible worlds, it would be wonderful if the supply could meet the demand. I believe this is an ideal, but probably not possible. The reasons for increased demand are complex: the expansion of medical knowledge and techniques; an increase in medical professionals who can refer patients for procedures that require human material or who are capable of practicing such surgeries etc. themselves; the fact that we can no longer simply die of “natural causes” or “old age” but must beat the odds and try all procedures possible rather than accepting death.

15. Should different incentives exist? If lost wages are provided in some instances for existing forms of body donation, what happens with those who are unemployed? I can think of no forms of incentive or compensation in addition to those listed. I am a strong supporter of non financial tokens of gratitude (certificates, medals, T-shirts, etc.) that are not a form of payment but often ingenious promotional strategy (both of these are mentioned in the subsequent section). **What if, for instance, a lump sum were donated in the person’s name to a charity that mattered to them?** This could be a revolutionary approach—there is a significant award made but no single individual profits.

Other remarks/notes:

--I believe it is important to separate sperm from egg donation, and that the discussion on compensation should be separate for each. Whereas sperm donation (as far as we know) causes no harm to the donor, the marketing of egg procurement from young/university aged women may prove in the longrun to be quite dangerous to these ‘donors’ who undergo numerous treatments of very potent fertility drugs (as do the to-be mothers paying tens of thousands of dollars for these services). This practice needs to be curtailed and carefully regulated. U.S. practices are out of control.

--I do not support opt-out or mandated choice systems. I believe this will erode the now frankly impressive number of people willing to 'merely' donate organs. Opt-out systems are coercive. On funeral expenses: perhaps a token amount only, but not paying for the full funeral. Perhaps, for instance, the cost for cremation or embalment might be offered because the body is inevitably marred by procurement procedures.

--Also, one's priority on a waiting list (should one later need an organ) seems only fair—you endangered your life when healthy to help someone else who was ill.

--If researchers were to have freer access to discarded materials, this implies that the person of origin was unaware that researchers needed their materials (or they did not consent, but we are nevertheless going to give their medical waste to someone who wants it? This seems to go against rules of consent)

--Eggs from deceased donors? really? Does this really happen all that often?

--'Uncontrolled' donation after cardiac death should still require consent. In fact, it is hardly 'uncontrolled'—this procedure requires special ambulances and local trauma centers with staff at the ready to sustain bodies in stasis until the organs can be retrieved. This is often referred to as 'the Spanish model.' In Spain, surviving kin are approached and asked for consent only after the body is being perfused in anticipation of taking the organs. These practices rest within a grey zone of ethical/unethical medical behavior.

16. No one should not be paid wages or lump sums of money that go beyond basic costs for organs or other body parts where retrieval is invasive and potentially life threatening (limited to travel expenses, for instance, with receipts). Organs should be given willingly and not bought.

17. As stated earlier, I probably would not be willing to participate in a trial.

18. Yes, there is a difference between indirect compensation and wages, although the former expression is often applied as a euphemism for the latter. These expressions/terms thus need to be defined with care and legally.

19. I am wary of paying for lost wages. What if one isn't employed? Do the employed get paid but unemployed do not? If we paid the unemployed, would this be an incentive that would allow for greater exploitation of the poor? I think so. What would it mean to pay for discomfort or inconvenience? I find questions 17-19 troubling because they imply that we could augment the (presumably low?) supply of body parts by offering compensation. ***This would most likely replace but not augment the current supply that is donated***—that is, it would shift the supply of body parts to a different pool of people, rather than increase the current supply. In other words, yes, I believe that such strategies would be counter-productive (and my own research data from working with organ donor families in the U.S. suggests this outcome).

21. Just as there is an assumption within the medical scientific communities that rewarding people financially will influence decisions to participate (as organ/tissue donors or as research subjects), in all likelihood subjects will be affected by the 'lure' of cash, allowing the desire for money (especially if they are in desperate financial straits) to overshadow caution. Other rewards may have a similar effect (what if, for instance, various services are promised to the

subject to which they normally has no access?). If the decision is made that some reward is necessary then it should be something of little monetary value that is thus potentially of equal *emotional* value to all subjects, regardless of socioeconomic standing.

22. It is extraordinarily difficult to determine whether family coercion is at work. Perhaps the best strategy is to employ a third party who is, say, a family counselor or social worker, to conduct interviews with all involved parties prior to making a decision whether or not to include the subject in the study/procedure.

23. Among the thorniest cases involving the acquisition of bodily materials for which future use was unknown have involved those where genetic material has been extracted and subsequently marketed. Perhaps subjects should be asked additional questions about generic use where commercialization is possible. I personally wouldn't really care if this happened with 'my own' bodily material if offered under this generic standard (and subsequently marketed). The principle at work here is as follows: "I don't need it, I consider it medical waste, and others are welcome to make use of it; hopefully their efforts will assist someone else, although I realize this may be an idealized wish." This is, however, a personal point of view and I do not know how widespread this sentiment would be.

24. Is there a difference between making a decision for another rather than yourself? I'm not sure how to answer this question. I would assume so, yes—assuming the person wishes to behave ethically and protect the individual under question, the emotional burden would potentially be heavier when determining someone else's fate. There may be a desire to go to extraordinary measures to save a child, even if it means they might suffer during treatments administered as a last-ditch effort to save a life; or it may be driven by a desire to withhold care in order to allow a feeble adult (who may be perceived as having experienced enough suffering already) to grow increasingly ill and die. I believe it is generally easier to make these sorts of decisions for oneself. Also, when deciding for others, one generally does not (and can't) do this alone—there are always other parties involved who disrupt a smooth transition to making a clear decision.

25. Although the law would allow medical staff to remove bodily material after death if the deceased had consented to this whereas surviving kin oppose it (as is the case in many states in the U.S., too), I believe that it would severely undermine any sort of trust people have in the health professions if we were to do so. The effort in the U.S. and U.K. to transform donation decisions from an expression of desire to a medical mandate is flawed to the core, because it overlooks the fact that it is the living who must 'live' with a range of decisions made at the time of another's death. For instance, we might well outline in advance how we wish to be buried, but funerals are, by and large, for the living and not for the dead. Similarly with donation. Some surviving kin might well be haunted by images of the partitioning of the body for research or organ donation and, thus, it is important to honor their needs and desires. Medical concerns for the scarcity of reusable human parts must be secondary to this. Frequently, however, several family members are involved in the decision making process, and they don't all agree on what to do; also, people change their minds over time once their acceptance of death sets in, they've

talked to others whom they respect, and they learn more about the process involved. Clarity and transparency are important when talking to family members—under such circumstances they may well reach consensus and honor the deceased’s wishes. This takes more time and effort, but in the end it’s a better approach than simply taking what one believes one is entitled to take under the law. In short, I do not think that allowing for a medical ‘veto’ would be anything but counter-productive.

26. The question on ownership seems to depend on whether the question is asked before or after it is donated. Personally, I would not want to be the one making a legal determination in a case where ownership was contested! This is because it is so difficult to determine whether the agency involved in using the material was indeed honest about its intentions at the onset. (Or even knew what the potential was at the time.) It is here where *informed* consent at time of donation strikes me as extraordinarily important. As noted in an earlier answer, where ‘my own’ bodily substances are concerned, once I give them to someone I do not care what happens with them, regardless of the number of agencies and middlemen/brokers who handle these before something is ‘done’ or accomplished with them. My knowledge of the processes involved, however, is relatively sophisticated because I read and write about these sorts of things. Among the most deeply troubling issues at hand right now, in my opinion, concern the extraction of genetic material from individuals and groups of people that are then transformed into marketable substances or knowledge. Thus, at the very least, close attention must be given to both poles of the process: the nature of the information provided at the time of consent, and the handling of materials within the marketplace. We must also always ask who emerges as the most vulnerable and thus the easiest to exploit? Is this dependant on literacy? education level? socioeconomic standing? ethnicity? nationality?

27. In my personal opinion, we’re probably better off prohibiting the sale of body substances of any kind—blood, sperm, ova, organs, etc. included. If other agencies later make a profit off these substances, perhaps a portion of the profits should circle back into funds that assist those in need?

28. Ah, this question anticipated my answer to 27. Yes, I believe it would be a better world indeed if commercial success would then feed into programs of social value that would help people with a range of needs.

29. I am in favor of the ability to limit the use of one’s bodily substances (for medical use but not research, for instance). Not all people would be equally comfortable with the range of possible uses—some would not care, whereas others would view certain practices as exploitative or unethical. We should honor these differences, even though it requires the ability to manage a complex accounting system. As for directed donation (e.g., I will donate my kidneys on death but only if they go to my sister) does not strike me as particularly troubling, although it would be helpful if the potential donor would also consider the needs of others, too. Again, much of this hinges on honoring what the donor, or surviving kin, can ‘live’ with—donation of body parts often imposes an emotional burden on people that persists over time. We want involved parties

to feel they made the right decision under often very trying circumstances. In the future they will then promote the practice among others.

30. No other comments. Thank you—this was a thought-provoking exercise.