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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Question 1
Fetuses (either spontaneously or voluntarily aborted; stillborn children) Human uteruses (as in gestational surrogacy)

Question 2
Gametes and embryos are different, in my view, than organs or tissue. Gametes and embryos produce new life, with the genetic makeup of the donor. Organs and tissues prolong life, but without genetic perpetuation of the donor's DNA. There is a major difference.

Question 3
The issue of consent is most important here. During life, a donor who is mentally competent can decide about the disposition of his/her body parts. This includes decisions about donation of these parts after his/her death. If a person dies without having consented to donation, then posthumous donation is ethically problematic, in my view.

Question 4
The benefits of all forms of donation are the feelings of altruism and saving or creating human life. This is especially compelling when the life of a loved one is at stake. The risks of donation are (a) impairment of the donor's own health as a result of the donation, (b) the possibility of coercion, especially if the donor is under age, mentally incompetent, socially marginalized in some way, and donating explicitly for economic compensation. In areas of the world where gross economic disparities exist and compensation for bodily materials is offered (eg, Iran, Egypt, South Asia), issues of social justice and health equity become of paramount concern.

Question 5
Clinical trials of pharmaceuticals, medical devices, and other forms of therapy are obviously required to measure the safety and efficacy of life-saving therapies and medical techniques. Without these trials, medical sciences could not advance, and people around the world would be without various life-saving therapies. On the other hand, there are clear risks of (a) bodily harm to those who volunteer for these trials, and (b) the possibility of coercion, because of payment for participation in such trials. This is especially true in parts of the world where clinical trials are being "off-shored" (eg, South Asia, Eastern Europe). It is also clear that people in those places sign up for clinical trials believing that it is their only hope for obtaining life-saving medication. Thus, issues of social justice and health equity come into play.

Question 6
Embryo disposition raises ethical concerns for many infertile couples. Currently, there are millions of embryos in cold storage around the world, because fertility clinics are loathe to destroy the embryos, as are the infertile couples who have produced them. In places like India, these embryos are routinely "donated" to the burgeoning stem cell industry, where they are being used to produce "therapeutic" stem cell lines. The question is: Do couples realize and voluntarily "donate" their embryos to stem-cell research? Are they fully aware of and properly consented? Gestational surrogacy raises similar troubling issues of "true" consent in areas of the world where surrogates are financially compensated. This is true especially of India, which is the current global hub of surrogacy-for-hire. It is also true in parts of the U.S., where American surrogates receive minimally $25,000 for their services, and the contracting couples pay as much as $150,000 for the surrogacy arrangement.

Question 7
Personally, I would be willing to donate most of my body parts posthumously. I have indicated this on my US driver's license, which asks all individuals to indicate their donation preferences and consent. My husband is aware of my willingness to donate, and he is willing to donate posthumously also. If I had a seriously ill child or natal family member (and keep evil away!), I would consider becoming a live tissue/organ donor. I would do this for a loved one. I would guess that most Americans would as well. I accept men's and women's decisions to donate and receive gametes and embryos. I have seen the joy of these decisions in my own research on assisted reproduction in the Middle East. Personally, I have some ambivalence about donating my own gametes or embryos (or my husband's), in the sense of having a biologically related child "out there" somewhere, and not knowing its life circumstances. On the other hand, if I were in need, I believe that I could accept a donated embryo or gamete (including from a sperm donor). I had once considered this before marriage (i.e., single motherhood of a donor sperm child). My willingness to accept third-party donation is very much akin to my willingness to parent an adopted child. I have also considered this possibility quite seriously. In general, these issues of gamete/embryo donation/receipt invoke issues of rightful and righteous parenting. Namely, are the children to be born of these techniques well parented? If there is parental ambivalence, then the effects may be devastating for the child. Furthermore, the move toward "openness" in donation, like openness in adoption, has drastically diminished gamete donation in places like the UK. It seems that many donors, especially men, have no desire to "know" their potential biological offspring. They donate because of financial compensation, and also the egotistical belief that they are good biological progenitors. Altruism may be a subsidiary consideration. Thus, anonymity of donation is becoming a more and more contested ethical issue around the world, especially in Euro-American settings.

Question 8
My own willingness would be based on my concern over bodily harm. If there was a substantial risk to my own health, I would probably not be willing to participate in a clinical trial. In terms of priority, there are three major "global killer" infectious diseases: HIV/AIDS, tuberculosis, and malaria. In my view, these should be prioritized. Then, there are the growing global chronic diseases, namely, diabetes, hypertension, stroke, myocardial infarction. First, I would like to see these diseases PREVENTED. But, because not all cases of disease can be prevented, these chronic diseases, affecting millions of people worldwide, should be prioritized as well in terms of treatment.

Question 9
Maximizing health and welfare, one of the values listed on p. 16, is the value underlying public health. It does not receive enough attention in discussions of life-saving and life-prolonging therapies. Many life-saving techniques, such as organ transplantation, would, in fact, be much less necessary if society placed more emphasis on PREVENTION of the kinds of diseases that lead to the need for organs (eg, cirrhosis of the liver from alcoholism, kidney failure from diabetes, lung disease from smoking). I will say more on this later, but this is a very important value that needs further discussion in these kinds of debates.

Question 10
Autonomy--the right to control one's own body and the disposition of body parts--seems to be the most important value when it comes to donation. No human being should be compelled to donate a body part without consent and full capacity to determine what is right for his/her own body and future. In terms of receipt of bodily materials, saving the lives of young people--those with many future years to live--seems to be of special importance. Some kind of system for indicating need based on age and what are called "disability adjusted life years" (DALYs) in public health needs to be put in place in discussions of organ receipt. Finally, social justice considerations are very important. Distribution of organs/body parts needs to be done fairly and without discrimination based on race, social class, and so on. In parts of the world where organ donation is taking place for compensation, it is generally the poor who "donate" and the wealthy who "receive the gift." In the developed countries, minority populations are at an extreme disadvantage in terms of poorer health (thereby the greater need for organs). But their cases may not be prioritized based on either overt or subtle discrimination. These are major concerns for all societies marked by race, class, gender, and other forms of oppression/discrimination.

Question 11
Compensation for donation is inherently problematic, in that it may be a way for the poor and marginalized to make ends meet, or even to survive. This has been shown in a few ethnographic studies from around the world (eg, Egypt, India).

There is true concern over the global "traffick in organs," which have been taken from paid donors or from non-paid donors against their wishes or without their knowledge. On the other hand, when there is no compensation for provision of bodily materials, then the underlying value for donation is altruism. In purely "altruistic" settings, not enough people will freely consent to provide their organs and body parts. This is as true for organs as it is for gametes, I believe. In general, I have ethical objections against compensation for the provision of bodily materials. On the other hand, knowing that this leads to "supply" problems, I would reemphasize the need for PREVENTION of all of those problems leading to the "demand" for organs. More on this in a later question.

Question 12
I do not believe that any human being has an absolute moral duty to provide human bodily material. For example, there are religious traditions where donation is unacceptable, and these traditions should be respected. On a personal level, I would feel a true moral duty to donate bodily material to a close family member, even at the risk of my own life. This would be especially true for my children. Many parents probably feel this moral duty, although again, it cannot be made absolute. Finally, on a personal level, I feel a moral obligation to donate any healthy body parts after my own death. Knowing that there is unmet "demand" for body organs and tissues, I would hope that my body parts go to good use. I also prefer post-donation cremation over burial. This is becoming increasingly popular in the United States.

Question 13
Again, I cannot imagine an absolute moral duty to participate in a clinical trial. On the other hand, if there was a global, life-threatening pandemic, I would hope that many global citizens would participate in vaccine trials to prevent the wipeout of the human population. I would!

Question 14
As suggested in my earlier responses, I value public health measures to reduce demand, rather than therapeutic measures such as organ donation to meet demand. The high demand for organs and other body parts is being created by preventable public health problems. These include, inter alia: 1) increasing overweight and obesity, leading to diabetes and organ failure, cardiac disease and organ failure, retinopathies and blindness, hypertension and cardiovascular disease, etc, etc. 2) increasing alcoholism in some parts of the world and cirrhosis of the liver, as well as esophageal disease and a host of other problems 3) increasing blood-borne infections, such as hepatitis C, which is leading to cirrhosis of the liver. The hugely fashionable tattoo-ing craze is of major concern in this regard. So is injection drug use. Egypt has the highest rates of hepatitis C in the world because of syringe use as a preferred route of delivery for medications. 4) tobacco-related conditions, of which there are many, and particularly all sorts of lung

diseases 5) injuries, intentional and nonintentional, which lead to the need for human skin (eg, in burn victims, car accident victims) and organs 6) infertility from polycystic ovary syndrome, a major part of the metabolic syndrome of diabetes, which leads to the need for human oocytes; PCOS could be prevented through the same public health measure to control overweight and obesity Of course, there are many genetic and other conditions that are not "preventable," per se, which require human bodily materials through transplantation. But, MUCH of the "demand" for these body parts could be eliminated with better public health measures and simply healthier societies around the world. Personally, I blame the United States and its tobacco industry, as well as its multinational food companies, for promoting American unhealthy lifestyles around the world. This has been documented in a number of important documentaries (eg, Supersize Me, Food Inc), as well as in public health work on the tobacco and obesity "epidemics" in the US.

Question 15

In the United States, all citizens who are issued drivers' licenses are asked on the back of the license to indicate their consent for posthumous organ and tissue donation. At the point of reaching adulthood (i.e., at age 16, when most Americans first pass their drivers' tests), US citizens are asked to think through and make a decision about this issue. It serves as a useful "incentive" toward altruism for many, but not all, people. There are particular ethnic and religious groups in the US that are less willing to donate bodily materials. In particular, African Americans have had a very sad history in the US medical system, where they have been "used" without consent as "guinea pigs" in all kinds of medical research. The ongoing suspicion of US medicine within the African-American community has made organ donation less likely. Sadly, however, African-Americans are also in great "need" of organs, because of poor health and health care, leading to a higher rate of preventable conditions. In short, there is a vicious cycle of high "demand" and low "supply" within this minority community in the US. The same may be true in Britain to some degree.

Question 16

Children should not be "incentivized" to donate organs or other bodily materials (eg, bone marrow). The "saviour sibling" issue is a difficult one, ethically speaking, because parents may be so desperate to save one child that they are willing to inflict pain and suffering on another living child (eg, bone marrow transplants). There is a current movie, "Sisters" (?), which deals with this ethically contentious issue. An older sister is dying of cancer, and her younger sister is her major supplier of body parts, under pressure from the parents (especially the mother).

Question 17

Financial compensation

Question 18

Yes, direct financial compensation may be sought by the poor, by those with an addiction, or by those in some kind of desperate situation. Indirect compensation is more likely among the actual community "in need" of the treatment. So it is likely to generate a very different pool of participants. This is true in "egg-sharing" arrangements in UK infertility settings. In the US, most egg donation is done for significant amounts of compensation, making it ethically questionable.

Question 19

Yes, compensation beyond the actual economic losses may be attractive to those in economic need. It raises a different set of ethical issues, as suggested earlier.

Question 20

I feel very strongly about implementing public health policies that will dramatically reduce the need for donors, transplants, and human gametes. In an earlier section, I outlined some of the preventable conditions that are leading to high "demand" in places like the US and UK. Every effort should be made by public health authorities to prevent chronic and infectious diseases that lead to the "need" for human body parts. This means reducing tobacco consumption, reducing alcohol consumption, reducing overweight/obesity, reducing needle sharing (as in drug use and tattooing), and promoting healthy lifestyles in general. This is true for all sectors of society, but especially those that are structurally disadvantaged or in other ways oppressed. Even in the world of infertility, much of the need for human oocytes could be prevented through better public health education. Young women need to be educated about the human reproductive life cycle and when human fertility naturally begins to decline. Much effort is now being made to freeze human oocytes as a method of fertility preservation among career women. This seems like a high-cost "solution" to an issue that could be addressed in another manner.

Question 21

Not sure.

Question 22

As suggested in a previous answer, this is a serious concern, especially of parents coercing a child to save a sibling. In general, minors are incapable of giving truly informed consent, and parental consent is ethically questionable in the "saviour sibling" situation. Such cases probably need to be dealt with on an individual basis, and involve both psychological assessment/counseling as well as ethical review boards. Even in cases of adult consent within the family, psychological evaluation and ethical review board decisions seem necessary.

Question 23

In my view, consent is always necessary.

Question 24

Yes, as suggested in earlier responses, there is a huge difference between giving personal consent and giving consent for a dependent. Some sort of regulatory body needs to oversee this process, as suggested earlier.

Question 25
Ideally, all adults should have some sort of living will, which makes clear end-of-life decision-making, including the disposition of body parts. If a person's wishes are known, then these should be respected, and family members should not have the right to veto power. The more difficult matter is when the deceased person's wishes are NOT known. Family members will be in a heightened emotional state, and may be subject to coercion (eg, a transplant team making an appeal for body parts). These kinds of difficult situations can be avoided by policy measures, such as the one in the US involving donation decisions on the back of drivers' licenses. Fewer cases of "unknown wishes" will then occur.

Question 26
Again, through living wills, adults can state very explicitly the instructions about the disposition of their bodies after death. Some persons may want to donate their bodies to research, for example. In cases where bodily disposition instructions are not available, closest living relatives will have to make these decisions. If a person dies without any known close relatives, then I suppose that the body belongs to the state. In the US, many cadavers used in medical research have been of dead indigent persons, with no known relatives.

Question 27
Donation over sale is always ethically preferable, in my view. Selling organs is more ethically egregious than selling blood or gametes (such as sperm), based on potential abuses that have been documented in ethnographic research.

Question 28
Those who donate their body materials could be given "royalties," just as authors and artists are given royalties by their publishers/companies.

Question 29
A high degree of control (if not absolute). Bodily autonomy is a very, very important ethical principle.

Question 30
None.