

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.

Question 1

Products of conception should also include the naturally wasted material such as the placenta or even the umbilical cord. Research recently has suggested that the current medical practice of cutting the cord occurs too soon and this can have a detrimental effect upon the newborn baby's blood levels (leading to anaemia amongst other complications). If material that is considered "waste" appears to have an important impact upon the health of the child/person, this would warrant ethical considerations if that "waste" were used for medical research or treatment. Waste may have therapeutic effects for other patients or useful for experimentation but should not be removed at the detriment of the health of the person. Genetic material is also present in much of this waste and so if ownership is related to whose DNA belongs to whom (see later questions) then waste must also be included.

Question 2

Yes, material that can be used to produce viable offspring should be used with ethical consideration to the life that will be conceived. There should not be any distinction between a life that is distinct genetically to the cells that produce it or to those which are cloned. The reasoning for this is related to the fact that clones (genetically identical twins, triplets and so on) appear in nature and are afforded the same rights, so the same should be extended to those cloned cells produced artificially. Producing life from cells that are not reproductive cells needs careful consideration in experiments. Reproductive cells act differently to other cells so to experiment with creating life from cells not designed in nature to result in viable offspring seems at best futile and at worst abhorrent. I personally do not have a problem with the use of 3 cells to produce a viable egg where the mitochondrial DNA has been used from a third donor. To me, this donation is not distinct to the donor as it is not specific reproductive genetic material like that found in the egg/sperm nucleus. Many people share the same genetic code for mitochondrial DNA so I see this as a process of repairing the cell. Ethical considerations though should be explored if the problems with the mitochondrial DNA are passed down the generations. A part of me considers this medical intervention to be similar to those we make regularly for diabetics by giving insulin; it is repairing a fault. However, not having insulin will result in death, whereas to not produce a child does not. Another distinction should be made between tissue that can be gained readily without the need for an operation, such as sperm, blood and perhaps even the material discarded after birth (a natural process!) whereas to obtain organs or eggs require specific medical procedures and can have an effect upon the donor - see next question.

Question 3

Yes, material given through life (other than through tissue that can be readily collected such as sperm and blood - see question 2) could have an effect upon the giver. Simply put to use a living donor for organs creates two patients whereas donation after death only has one patient. I have never had a problem with the idea of donating my organs after death. However, I do not wish to donate my reproductive cells (eggs) after my death. I do not wish to donate my eggs whilst alive or after death as I have not yet been convinced that the child(ren) produced from a donation are not affected by the knowledge that their parents are not biologically related to them. I have had no experience of the benefits or disadvantages of reproductive cell donation and whilst I have personal objections, unless there is evidence that this has a proven detrimental effect upon children, I do not wish to see a general prohibition of this practice.

Question 4

I have never questioned my desire to donate my organs after death and I have even donated blood a couple of times (I am now unable as I have had borderline cancer). I have always felt that it is an appropriate thing to want to do; once I am dead I will have no further need of my body and someone (perhaps more than one person) could live a longer and more fulfilling life as a result of the donation. After death I could not possibly feel any pain, it won't cost me anything and it seems illogical that the completeness of my body after death will have any effect on an afterlife (if such a thing occurs). I have also always made my intentions clear to my family so that they would not have to worry about making a decision whether or not to use my organs. I would also hope that they understand that life, no matter whose that may be, is important and if I can give one last thing it is to donate something I can no longer use. I do worry that if my relatives die and I have to make a decision over their organs that I would choose the wrong thing to do. However, I hope that because my family know how strongly I feel about donating my own organs that they would not be surprised that I would give permission for their organs to be donated. Currently though there is no way for my family to tell me that they have any objections to donating their organs unless they tell me, as the current system is only an affirmation of wishing to donate. Many people just do not get around to opting-in; it is an absence of a decision. I fully understand other people's concerns about organ donation, either for religious reasons or the feeling that this is an unnatural thing to do. However, I do struggle with those that have not even taken the time to consider donating or are ignorant of its benefits to patients. For this reason I would like to see a change from an opt-in system to an opt-out. I do worry about my reproductive cells being donated as this no longer just affects me but potential children. I worry about how they would feel about being the product of a donation and being brought up with family who are not biologically related to them. My concerns are not so different from adoption for similar reasons. However, I think it is still a magnanimous act, and perhaps one that I am just not brave enough to do.

Question 5

Ethical research is a difficult thing to achieve I think. To be able to get to the point where things can be tested on humans systems may have been used with are ethically dubious, such as testing on animals. Whilst thorough testing always occurs, the reaction a human will have could differ dramatically and so there is always a risk to the person. I am less concerned about medication being used on a patient with the condition the medication is designed to treat if this is the patient's last hope and to not go on the trial would mean a decreased life span. In these occasions the patients consent and are aware of the consequences. Often too they are aware that successes may be slim for them but that the trial could benefit future patients. The people who I think do not consider fully the consequences to their involvement in first-in human trials are the healthy individuals. I think it is harder for a healthy person to visualise and understand the consequences of a trial even when these are explicitly described. It may not be possible to dispense with trials but what I would say is that the attraction to them should not be financial as this will cloud the motivation and perhaps judgement of the volunteer.

Question 12

I worry about the pressure being put upon living donors as there are not enough donated organs after death. If a relative requires an organ, say a kidney, and I am a close enough match to them, then I feel obliged to seriously consider undergoing a surgery, with all of the risk involved, to donate my organ. To say no to the operation seems to be morally wrong as it would be threatening the life of a loved one. This is a dreadfully regrettable situation which should only be occurring in the rarest of occasions. Some people may say this is similar to the process by which a child is born to save a sibling. However, I do not think it is the same as an operation to remove a healthy organ puts a strain on the body, whereas if a child is born for their stem cells they undergo no operation and would be as welcomed into the family as the child who they have now saved.

Question 15

I do not like the idea of using money to encourage donation (through life or after death) as this is encouraging the health service to become part of the free market trade. Once money is exchanged for donated bodily material it will be very difficult to stop and given the current financial climate this should be a consideration. I do not agree with the idea that a person who donates their organ could be a priority for an organ in the future, unless by donating their organ they have health implications as a result. For example, after donating a kidney the remaining kidney starts to fail, then yes, they should be a priority. But this should not happen. Why should it be morally right that healthy individuals risk their health and their lives to be living donors (unless in extreme circumstances) when there are many organs that are disposed of after death as people have not considered or had the time to opt-in to donating their organs. It seems incredulous that instead of trying an opt-out system, thus allowing those with strong objections to do so, we consider using

financial incentives to achieve the same goals. I am happy for my blood and tissue samples 'left-over' to be used, again so long as there is no financial gain to be had and any benefits of research can be used by the health service. I would wish for any blood or tissue that is taken in any hospital, NHS or private, to be the property of the NHS.

Question 23

I do not have a problem with non reproductive human bodily material being used for additional purposes for which explicit consent has not been given so long as there is no monetary gain. I do not agree with patenting of genetic material as can be seen through HeRa. Reproductive material, by its nature of potentially producing life should not be used without prior consent of the donor. If consent is sought it should be explicit and consent sought for every act and experiment proposed.

Question 25

I think that where a person has expressed their wishes these must be supported as far as reasonable and as the law permits, so in effect it is an extension to the Last Will and Testament. If the wishes of the person are unknown this puts the family in a difficult position. Either they impose their own beliefs on what can happen or they make a decision based on what they hope the person would have wanted. Without any reference to what the deceased person may have wished many will err on the side of the caution which would be to refuse the use of bodily material. The other difficulty in asking the relatives for the use of bodily material is it comes at a very emotional and distressing time which will have an impact on the decision made. If the system were to be opt out rather than opt in the default position would be the allowing of organ donations at death. Nevertheless, I am concerned that with opt out it is a method of non-action. So if I allow the default to donate but I have family who are strongly opposed to donation, they could object upon my death and there would be no reference to my wish for donation of organs; I have not had a way to actively confirm my intention. To this I would suggest that there is also a mechanism, using the current system, to note active intention for donations after death (opt out default and opt in reinforcement). However, this could of course be administratively burdensome and may not be enough of a widespread problem to warrant these measures.

Question 26

In the first instance a dead body or its parts belong to the person (for circumstances such as donation of organs, medical research and wishes in disposal such as types of burial). Where a person has not expressed wishes or is incapable (such as children or people with learning disabilities), as is currently, the next of kin would have the right to determine what happens to the body and its parts. Where a person does not have any next of kin, the body should be respected in the same manner as the first two circumstances but in this scenario I would suggest that the responsibility lies with the healthcare system and the local authority (as is

currently, the latter are responsible for disposal i.e. burial). Currently our systems err on the side of caution by not using organs that have not been specifically approved for donation and a body for medical research would not be used without consent. If the systems were changed to be opt out for donating organs, perhaps this should be extended to medical research too.

Question 27

An individual should be modestly (with the emphasis on modestly) compensated for their involvement, either for loss of income and inconvenience as part of a trial or contributions to the destruction/burial of bodily waste if their body is donated for research. However, I feel strongly that free market principles should not be extended to donation or "any purpose" as there is a danger that people could jeopardise their health and wellbeing by donating or volunteering for money. This attracts those that need money the most and who are the most desperate. I do not agree with patenting of genetic material and I believe that if any discoveries are made, such as the cells HeRa, there would be no financial gain to naturally occurring material. Any royalties (as would occur in the UK) should default to the healthcare system and no commercial enterprise should effectively "own" genetic material.

Question 28

Companies that benefit commercially from specifically donated human bodily material should share the proceeds with the wider community by providing the medication and treatment at a lower cost to the NHS (or other healthcare systems). I realise that profits are to be used by these companies for R&D however they do make a degree of profit which supports shareholders and could sustain some discount to healthcare systems.