

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.

University of Leicester Medical School - group 22

### **Question 9**

We are a group of first year medical students at Leicester Medical School, and have debated these questions within our facility. The first issue that would come into consideration would be respect. As someone has donated a part of their body to improve your life you must hold utmost respect for their decision and the beneficial impact it will have on your life. One of the issues we raised was the example of George Best, who failed to respect his liver donations and continually abused his own body and the donors' organ. To combat this issue, we would recommend a statement of intentions prior to receiving the organ or body part, to live as healthy a life as possible. Failure to comply with this after the donation ought to result in limitations to future organ transplants and donations of human bodily material. Another value discussed was the issue of donor choice. As the bodily material belongs to the donor, a question raised was whether every donor should have the choice of who their organs can or cannot be donated to. Additionally, our group questioned whether this freedom could lead to discrimination, and also impact upon the donor register, in that those most at need may be denied by others preferences. However, it also raises the question - are preferences bad? Is it fair to donate human bodily material to a person who may abuse the opportunity of receiving the material, or may not need it as much as someone who has developed a condition through illness instead of lifestyle? An interesting issue that was raised was that of reciprocity. As reciprocity is defined as "providing benefits or services to another as part of a mutual exchange", it raised the query about what the donor receives in exchange for their organ. Since the donor list is anonymous, how does this mutual exchange occur? Furthermore, the exchange could involve money for human bodily material, thus raises the question - how much is an organ actually worth? Where the issue of money or incentives are concerned, this negates the idea of organ donation being an altruistic act of good will and takes it into the realms of coercion. Most exchanges involve some form of consent from both parties, thus are legally binding. However, this may cause problems in the future if an individual decides they no longer want to take part in the exchange, so we therefore must consider the legal implications of such an act.

### **Question 10**

One of the main priorities that we should consider is that of human rights. Our group discussed how each individual should have the right to autonomy, i.e. the ability to chose to donate bodily material or not. However, this contrasts with the idea of solidarity, which suggests that we all have 'mutual obligations' to be part of such a donation, and confers a requirement to all individuals. In the case of organ donation, we would therefore suggest that these distinctions between autonomy

and solidarity be recognised separately for those willing to become a donor to avoid any conflicts of interest. We would also suggest that autonomy and solidarity be balanced, and not discriminative of those who do not wish to donate. As previously discussed, one of the issues we thought to consider was respect. Respect however is a difficult concept, it cannot be prioritised or balanced, yet depends on the understanding between individuals. It should be considered, however cannot be forced, as people have the freedom to think as they like, thus do not necessarily have to take it into consideration, although it would be strongly suggested. In the case of donor choice, we feel that this should be a significant priority to consider. Donor choice as discussed has many connotations assigned with it, both negative and positive. To avoid those in need not receiving human bodily material due to opinion, we would suggest that donors do not have a choice as to who their material goes to.

### **Question 11**

To state that either participation in first-in-human trials or donation of human bodily material is better than receiving compensation is entirely down to individual perception. There are a number of ethical issues that can be raised from either party. There is a risk from both providing human bodily material and first-in-human trials that there may not be very many willing participants or donors. With first-in-human trials, we do not know the implications of testing on humans prior to animals and the consequences that could occur due to this. Is it morally right to test on a human without lowering their standards or rights? And, by volunteering for such a procedure, what would your rights be? In this case we would need to think of compliance, and indeed if an individual were allowed to drop out of the trial. We would also need to think of what rights they would be signing away, therefore what rights they would indeed be entitled to. Another issue would be if the volunteers would actually have ownership of their own body, or if they would be signing their rights away to making any decisions on what indeed they will be put through. Providing human bodily material on the other hand, was agreed upon as being morally better, despite certain negative aspects. However, in terms of compensation, is it right to offer money if people did not want to volunteer for trials, or, indeed if they did not want to donate human bodily material? Would this not then raise the question of the value of life, and the value of the constituents that make our bodies function? Is it right to even put a price on life? Taking into consideration that there may be a high loss of candidates participating in the trials, money may be seen as a way to ensure individuals stay on the trial and participate. Although this may be the case, it does not make it ethically viable or correct. The type or purpose of bodily material or medicine being tested again comes down to perception, and in some cases religion. Where it may be seen that a bodily material such as blood should be donated, it may impose individuals beliefs, thus we must not assume that what may seem acceptable to donate may not be for everyone. Also, if for example, cancer treatments would need to be tested on certain individuals, it may at first seem a duty for people to participate as it is a major

disease affecting our populations. Yet if the risk of participation could in fact be death as a result of side effects, this would indeed change the circumstances of the situation and public opinion. Therefore, there is no guarantee that something that appears to be viable and a moral obligation could not have endangering aspects.

### **Question 12**

Within our group we discussed that there should be an "opt out" scheme, in which everyone is entitled to provide human bodily material unless they choose to opt out of the process for personal reasons. We see that opting out would be a basic human right in the fact an individual has control of their body as it is their own. Not only will this be fair to society, it also respects autonomy as there is no moral duty to donate organs or human bodily material. Providing human bodily material during life is slightly different to that after death, as after death there is uncertainty as to who has rights to your body as you are no longer alive. Also, after death an individual has no say on whether they believe it is indeed a moral duty to provide human bodily material. During life it is beneficial to provide human bodily material yet it is not a moral obligation, and merely comes down to perception and religion as to whether people will donate. However, concerning religion, some individuals will not know in detail if their religion permits them to donate human bodily material, thus may follow the influence of their family in such a case, thus not donate. There are a few cases where there may be a moral duty to provide human bodily material, in the instance of rare diseases. If an individual has an extremely rare disease that can only be cured or managed by a donation of a certain specific human bodily material that only a small minority possesses, we feel there would be a duty to provide the human bodily material.

### **Question 13**

This question brought great discussion and debate from our group. The NHS provides us all with free medical care, so if we receive free treatment, should we be prepared to contribute in these trials? Some say that there may be a moral duty to participate in first-in-human trials as to receive treatment, we must contribute to its development. On the other hand, should we be risking our personal safety for unseen circumstances that could pose a detriment? First-in-human trials have many negative connotations, mainly that we do not know treatment efficacy and safety on human subjects. Not only is this a concern, therapeutic doses will not be accurate, so too little or too much could be administered, posing a threat to health. With some circumstances associated with these trials, is it right to put all individuals through this without threatening the health of the population as a whole? In this case, the question of solidarity needs to be raised. If participation in first-in-human trials becomes an obligation or moral duty, solidarity will be taken to an extreme. This could have a number of impacts - it could involve members of the population coming together and supporting each other, or could create clear divisions in society with those that do participate and those that do not. This

however would then raise the issue of religion - would those that are religious and do not believe in such a trial being undertaken on themselves be allowed to opt out? This could in fact contradict altruism, by making donation a duty instead of a gift.