

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.

Miss N. Sethi, AHRC/SCRIPT Centre, School of Law, University of Edinburgh

## **Question 2**

It could be argued that reproductive material should be treated 'differently', because, unlike the use of other body parts which is dedicated to saving lives either directly or indirectly, the use of reproductive material has life creating potential. It could be argued that vital organs such as kidneys and hearts are 'special' because of their life saving potential.

## **Question 3**

Depending on which material we refer to, there can be a difference. If the removal of certain bodily material for example, whole organs such as kidneys would seriously put the individuals health at risk, there is an obvious difference. Further, if reproductive material is used for the creation of life and the donor is no longer alive, where consent for the use has not been granted by the donor in their lifetime, serious ethical concerns exist.

## **Question 4**

Financially, the provision of bodily materials can prove costly for individuals and their families, particularly where a prolonged recovery period/resulting illness from procedures leads to time of work and loss of earnings. Emotionally, both the costs and benefits of providing bodily material can be immeasurable for example, where an individual donates a kidney to another family member, the joy of being able to help may exist on one side, and on the other side feelings of resentment due to pressure from family members or a donors' own feeling of obligation may be present. The potential guilt of the recipient should also be considered in the instance that the transplant is not successful, or where the donor falls ill as a result (directly or indirectly) of the donation. In terms of provision of bodily materials after death, relatives of the deceased are particularly vulnerable when questions of organ donation are raised, conflicts might arise where relatives are unaware of the intentions of the deceased, they might feel pressured into donation. In particular, where the decision to withdraw life-sustaining treatment has been made, families must consider permitting donation of organs from a family member who is still alive, but won't be for much longer.

## **Question 5**

Potential benefits may be particularly high where treatment proves beneficial to patients with serious illnesses. However, coercion may exist from the families side, pressurising their ill relative to agree to participate. On the other hand, the patient may be fully willing however their family might be more wary of the potential unknown side effects of the drugs, the risks to the individual's health, such

feelings may cause tension between an already stressed group of people. An individual may also feel pressure external to that applied from those around them, they might consider participation as a moral obligation, someone has to participate in such trials, and if they would expect to benefit from such pre-tested drugs, then it might be argued that they should be willing to participate in the trial process in return

### **Question 7**

Yes, I would prioritise purposes of providing bodily material as follows- 1) life saving purposes 2) life prolonging 3) life enhancing I would not consider providing life creating bodily material for egg donation for an infertile couple as it can be argued that this is something to be treated differently to other purposes. It could be argued that the provision of bodily material should be provided in order to save pre-existing lives (because there are at present, no feasible alternatives to the assistance which bodily material from other humans can provide). Where a couple is unable to conceive, alternatives to the creation of life (i.e. adoption) do exist.

### **Question 10**

Balancing the different ethical considerations at stake in this context is a difficult exercise. One might be tempted to place autonomy at the top of the list of values, due to the human rights based society in which we live, where the individual's right to self-determination is central. However, if this right was to be absolute in nature, we would be unable to stop someone from donating their heart to another, because it would be argued that this was their autonomous wish and right. Thus, while we must respect the individuals autonomous right, we must balance this with other rights and obligations, that is, a duty to protect individuals from harming themselves. However, even this balance is misleading, how much harm is too much harm? For society accepts that the harm involved in donating a kidney to another individual is acceptable.

### **Question 14**

This depends on how the demand is met, and by whom. For example, in developing countries such as India, the black market in kidney trade is rife, such organs are often sold for minimal amounts of cash, the standards to which procedures are performed often result in kidneys not being screened, as well as donors lacking the necessary aftercare and developing infections which they are unable to afford medication for. Thus attempts to meet demand here are clearly not without their dangers. In terms of needs and demands in the UK, patients requiring transplants can either wait on long lists in the hope they will receive an organ, or, those who can afford to and who are willing to, may travel abroad for illegal purchasing of organs. Thus, not trying to meet domestic demands may result in propelling travel tourism, driving patients to other countries. The key is international cooperation. In terms of demands for reproductive bodily materials e.g. egg or sperm donation,

demands to preserve or enhance pre-existing life would appear more pressing than reproductive needs which involve creating life.

### **Question 18**

There are those morally opposed to the commodification of body parts out right, whether this is through direct or indirect compensation. However, there are also those who whilst not opposed to 'compensation', reject the idea of 'payment'. For example, I would draw a distinction between compensating a donor for time off work and medical costs incurred directly as a result of their donation and paying them a sum of money directly due to their donation.

### **Question 19**

It could be argued that there is a difference between the two, however it is difficult to envisage how factors such as 'discomfort' and 'inconvenience' can be measured and attributed a monetary value. The Council of Europe Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin (2006) does not categorically reject all forms of monetary compensation for losses incurred to the donor as a result of donation, Article 21 provides that certain payments do not constitute 'financial gain or comparable advantage, these include compensation for loss of earnings, payment for related medical fees the donor incurred and for damage resulting from the removal of the organ.' Thus perhaps it depends on whether 'inconvenience and discomfort' are interpreted as 'damage resulting from the removal of the organ'.

### **Question 20**

Eurotransplant (the Eurotransplant International Foundation) is 'responsible for the mediation and allocation of organ donation procedures in Austria, Belgium, Croatia, Germany, Luxemburg, the Netherlands and Slovenia. In this international collaborative framework, the participants include all transplant hospitals, tissue-typing laboratories and hospitals where organ donations take place.' Whilst this consultation focuses on the UK approach, the importance of international cooperation cannot be ignored. With regards to kidney donation, in the Iranian model, financial award for kidney donation as well as health insurance are offered, affording donors both short term and long-term compensation. However, Ghods and Savaj point out: 'the financial incentives to kidney donors in the Iranian model neither has enough life-changing potential nor has enough long-term compensatory effect, resulting in long-term dissatisfaction of some donors.'

### **Question 23**

It can be argued that the purpose of the use of the material might determine the acceptability of use without consent. Where material is being used for certain types of medical research then I think that it is ethically acceptable to use the material without consent. Often, future uses of bodily material cannot be envisaged when consent is being obtained for a particular use/study and additional uses are

discovered some time after it has been used for its original purpose. It might not be possible or practical to obtain explicit consent for a new use. However, where there is a reasonable risk of identification of an individual (especially when dealing with genetic information) then this material should not be used without obtaining consent. Where identification is not possible (or more accurately, where the risk of identification is minimal) then REC approval is a must.