

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.

## **QUESTIONS ANSWERED:**

### **Question 5**

#### **ANSWER:**

I am uncomfortable with the ethics behind giving payments for involvement in clinical trials, particularly first-in-human trials, when little might be known generally about the side effects of the drug in humans. I think people who volunteer for this may not be fully aware of the potential risk they are taking (despite adequate counselling beforehand), and the remuneration may be too tempting an inducement for someone who is struggling financially.

### **Question 12**

#### **ANSWER:**

No. I think this must remain a free choice. While someone may feel it is 'morally right' to donate, I don't think as a society we should describe any tissue donation as a duty. However, I think presumed consent is the appropriate way forward for organ donation, with the ability for the deceased's loved ones to stop donation if they have strong feelings that way. If the deceased had 'opted out', that decision should not be over-ruled, however.

### **Question 13**

#### **ANSWER:**

It should NEVER be a moral duty to participate in first-in-human trials.

### **Question 14**

#### **ANSWER:**

We should always strive to meet demand. Certainly, life-saving or life-prolonging demands should take precedence over life-giving.

### **Question 16**

#### **ANSWER:**

I find all financial rewards (other than travel expenses and very minor gratuities) distasteful and unethical as an incentive. It clouds the donor's judgement. This decision should be made solely on an individual's assessment of the benefits/risks to them individually and to society as a whole, not on the financial implications.

### **Question 21**

#### **ANSWER:**

Yes. Financial incentives.

### **Question 22**

#### **ANSWER:**

This is difficult. Only with skilled questioning of the potential donor on their own

could this be addressed.

**Question 23**

**ANSWER:**

No. Even if the material is anonymous/anonymised, I would argue that it remains the patient's property and should not be used for any purpose for which they have not explicitly consented.

**Question 25**

**ANSWER:**

I firmly believe that presumed consent is the best approach. Families should, however, have the right to withdraw consent for organs to be used if they so wish, over-ruling the donor's wishes. However, they should not ordinarily be permitted to allow donation against the wishes of the donor. The surviving family have to live with the consequences of the decision, so we cannot ignore their concerns. There is an important problem with the current system; Some organs (notably the bowel) are missing from the donor card. This means that if the subject, for example, does not allow his corneas to be used, he is also not allowing his bowel to be used, as there is no tick box to allow permission for this. Effectively, only those who tick 'any part of my body' can donate their small bowel. Although bowel transplants are relatively rare, these patients' needs are also important and should be catered for.

**Question 26**

**ANSWER:**

They belong to the donor. However, by donating the organ or body part, the donor may transfer ownership to the NHS. This allows the NHS to benefit financially from, for example, the supply of eggs or sperm to the private sector. I think it is important that the donor does not get financially rewarded, but I see no problem with the NHS as a whole benefiting from such procedures.

**Question 27**

**ANSWER:**

No.

**Question 29**

**ANSWER:**

They should consent to specific uses of the material, but it would be inappropriate for the donor to specify preconditions. This would open up the possibility for racist donors to specify an ethnic group to receive their tissue, or for a donor to deny their liver to a patient with alcoholic liver disease. As a society, we perhaps need to make judgements on whether, for example, alcoholics who are unable to stop drinking or unwilling to comply with abstinence medication/counselling should be prioritised for organs. But this is not a decision for the donors themselves.

