

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 1**

#### **ANSWER:**

No.

### **Question 2**

#### **ANSWER:**

Yes - Sperm & Eggs etc because the subsequent life has rights & needs to know their biological background...

### **Question 3**

#### **ANSWER:**

Yes - During life donations could back fire should the donor subsequently have problems & need the donated organ themselves.

### **Question 4**

#### **ANSWER:**

Birth material - Doubts/wondering is that my nephew, niece, grandchild? Organs - Doubts/wondering has this person got xxx's heart, lungs etc.? Blood - Generally accepted & not really thought about because it's been established for so long. Plus, the body replaces it within a short amount of time, unlike organs.

### **Question 5**

#### **ANSWER:**

First-in-human trials can seriously back fire & bring the whole ethics into question if a participant becomes seriously ill or has severe reactions/side effects. This could become a media circus if the extended family become involved or more than one or two participants become affected. This can seriously affect a hospital's running & affect other patients attending said hospital.

### **Question 6**

#### **ANSWER:**

No.

### **Question 7**

#### **ANSWER:**

Yes - I'd rather my organs etc go to an "innocent" patient rather than one that has inflicted the condition on themselves - Alcoholism, smoking etc. I'd also be heart broken if I discovered that my loved one's organs had been used for helping someone that inflicted the condition on themselves because I'd see it as a waste of

my loved one's organs & a betrayal by the NHS. I'd restrict an alcoholic that fell down drunk in front of a car to blood transfusion(s) & not waste a perfectly good organ on them. However, if the same alcoholic had a totally unrelated condition, I'd be happy for that person to receive a loved one's organ IF, the organ wouldn't suffer abuse & the alcoholic was rehabilitated.

### **Question 8**

#### **ANSWER:**

No - I'd be happy to participate in any trials regardless of the purpose of the trial. My only conditions are (1) That I'm convinced that the trial is as safe as it can be (2) There is a medical need rather than a financial "need" for the treatment & (3) I had faith in the team running the trial.

### **Question 9**

#### **ANSWER:**

No - presuming that the trial team are professionally motivated & not blinkered by a desire or driving force...

### **Question 10**

#### **ANSWER:**

I believe that priorities are individual to the trial participant. You can't legislate for how an individual feels about priorities following their life experiences & family medical histories...

### **Question 11**

#### **ANSWER:**

No matter what the trial, I believe that all participants should be compensated for travel & parking etc. Loss of earnings is a totally separate issue. If someone wants to participate in a trial, they can always arrange to take "holiday" / leave with or without pay to do so. That said, I don't see why a pharmaceutical company shouldn't pay participants considering the millions that they'd make from the resulting drug(s).

### **Question 12**

#### **ANSWER:**

I believe that this is a legal nightmare because I believe that relatives should be able to benefit from a loved one's NATURAL death. However, there's an ethical problem with the few that might be tempted to murder a relative for a better quality of life or for their own life to continue... I'd like families to have the right to life following a loved one's natural death - if a parent, son or daughter dies, their next of kin should be able to have their heart & lungs etc (should they be necessary). After all, we get chopped up & messed about with during a post mortem, so harvesting organs is a natural step - Kidneys weigh X grams, are in good condition, no obvious

disease etc transplant rather than stuff them back in the dead person's body. If someone is completely opposed to organ transplantation, they should have to carry a card, medallion etc instead of donors having to carry the card... If there is no family need for organs, the public at large should have the opportunity of a transplant - eyes can be closed & harvesting/post mortem incisions sewn up to make the body presentable &/or remove any trauma associated with the harvesting.

### **Question 13**

#### **ANSWER:**

No - any legal obligation would be equivalent to Hitler's medical trials during WW2.

### **Question 14**

#### **ANSWER:**

We should always strive to meet the demand for organs etc. An unharvested healthy organ is a wasted organ, a wasted opportunity to help a living person & a wasted opportunity to restore a family's way of life. Not to mention an opportunity to release NHS staff so that they can treat the next patient needing their attention.

### **Question 15**

#### **ANSWER:**

I think that offering T-shirts or mugs with, "I donated my kidney" are a waste of time & NHS funds. I used to donate blood (until regular medication became necessary & prevented me from donating), but I'd never want key rings etc. I'd much rather the NHS used the money on clinical needs. As for first-in-human trials, a T-shirt might interest students, but I don't think that business men would be tempted by one. I'd rather see "bumper stickers" & "car stickers" advertising blood donations, marrow donations or organ donations...

### **Question 16**

#### **ANSWER:**

Incentives are all well & good. However, there is a serious risk of the poor selling organs in order to live or have a better quality of life. This is unacceptable & opens the system up to abuse including "children" being pressured into donating organs for the good of the family.

### **Question 17**

#### **ANSWER:**

I don't think that incentives would discourage me, but I'd certainly think less favourably about the NHS because it would be a waste of NHS resources to provide key rings that get thrown into a draw & collect dust. NHS funds are limited & should be used on treatments rather than tat & too many bosses.

### **Question 18**

#### **ANSWER:**

Yes - indirect compensation may not be claimed & therefore has a potential of saving NHS funds. Previous organ donation should be considered, but clinical need should over ride everything. Funeral expenses doesn't do anything for me. If anything, it would put me off doing a second trial because there would be no incentive. As for free treatment, we effectively have that with the NHS. I think everyone in the UK expects the NHS to fund treatment without regard to the cost & that's simply not possible. Therefore, forcing the NHS to fund certain treatments will hit other treatments & be detrimental to the NHS. I put it to you, that the NHS should concentrate on a "Your NHS needs you" campaign rather than mugs & T-shirts etc.

### **Question 19**

#### **ANSWER:**

Yes - It's only fair to repay out of pocket expenses. However, lost earnings can be avoided by using holiday entitlement, should the participant wish. Trials for gain should be for pharmaceutical companies to fund at minimum wage or participant's established wage rate (if higher). Such funding should only cover time spent travelling to/from test establishment & time spent at said test establishment.

### **Question 20**

#### **ANSWER:**

Non.

### **Question 21**

#### **ANSWER:**

Safe guards need to be in place to prevent the poorest, the mentally challenged or most vulnerable from being exploited as their free will may be questionable & therefore should prevent their right to participate in certain trials. Each case needs to be independently checked.

### **Question 22**

#### **ANSWER:**

This can only be achieved by observations & psychiatric evaluations.

### **Question 23**

#### **ANSWER:**

No - this would be an abuse of trust and undermine any future trials.

### **Question 24**

**ANSWER:**

Yes - extra care needs to be taken in cases where someone takes the decision for someone else. My parents made a decision when I was 10 years old. They thought it was the right thing to do at the time. As a result, a decade later I was forced to deal with two TIAs (mini strokes) & the physiotherapy to regain the use of my left hand side. I have also had to live with disability for many years. Their decision was right for them & has devastated my life for over 30 years. Therefore, I can speak from personal experience that every care needs to be taken when parents or others make life changing decisions, albeit with the best intentions.

**Question 25****ANSWER:**

a & b can be treated the same if the policy is to opt out of donation. The family can state that Joe Bloggs always wore a pendant stating not to harvest, but if there is no pendant or proof that a pendant existed, organs should be harvested with the surgeon's discretion.

**Question 26****ANSWER:**

The body shouldn't belong to anyone. However, as the family become responsible for the body's disposal, they should have some input about wishes. The ultimate decision should be down to the harvesting team & the need for the organs. We should never get into a position where organs are harvested for the sake of harvesting.

**Question 27****ANSWER:**

The law should allow it subject to ethics & safe guards.

**Question 28****ANSWER:**

No - companies that deal with these issues should be nonprofit with top salaries capped to avoid abuse.

**Question 29****ANSWER:**

I believe that organ donations should comply with the desires of the donor as far as humanly possible. In life, the donor should have ultimate control & in death reasonable steps should be taken to meet the wishes of the donor. Apart from family ties being paramount, clinical need should over ride some wishes of the donor.

**Question 30**

**ANSWER:**

No.