Attendees of Ethics Forum at University Hospitals Birmingham, organised by Greg Moorlock

Question 1

Blood vessels are sometimes taken to support organs, but then not required for their intended purpose. Ethical issues arise surrounding consent for these to then be used for other people/purposes (there is perhaps an assumption on the part of the donor/donor family that the blood vessels will be used for the same person as the organ, but this might not always be the case).

Question 2

The overwhelming consensus was that all the human bodily materials listed are special, and that all require careful and considered treatment. This is not to say that all bodily materials require the same treatment, but the general feeling was that nothing should be singled out as being more special than any other, and that all should be treated and considered as being special.

Question 3

Several issues were raised here, focussing mainly on consent, different rewards and religious beliefs. Consent Order of consent – When providing human bodily material during life, the donor can ordinarily consent to this for him/herself, making an informed and considered decision. When human bodily material is provided after death, it is often up to family members to make decisions regarding consent, and these decisions will not always accord with the deceased's beliefs or wishes (even if they are known). So to this extent, the autonomy of the provider of human bodily material is given more weight during life than after death. Indeed the autonomy of the deceased is often largely disregarded; if a deceased person was known to be in favour of organ donation and had registered on the ODR, a refusal to consent to organ donation by the next-of-kin could over-rule this. It was felt that although there are pragmatic considerations at play in policies regarding this, it is still somewhat objectionable in some instances for family members to over-rule the wishes of the deceased. Rewards It was suggested that the costs/risks/benefits for people who provide human bodily material differ significantly between donations made during life and after death. The rewards for organ donation during life, for instance, are going to be greater than the rewards for cadaveric donors. Equally though, the 'cost' of donating an organ when one is dead is likely to be considered less than when one donates whilst alive (although of course one's individual beliefs might have a bearing on the extent of perceived cost). Some people's decisions to donate human bodily material will be motivated by the impact it will have on their own view of themselves – donating bodily material for research or the benefit of others allows one to feel good about oneself. Religious Beliefs It was also

suggested that different religious beliefs might entail differences between providing human bodily material during life and after death. This was discussed mostly in the context of organ donation, where views about bodily integrity and bodily ownership are particularly important in individual's decisions.

Question 4

It was generally felt that the cost of giving is more than merely the loss of that which one gives. So, for instance, if one donates a kidney to a family member, one sacrifices more than just a kidney – one agrees to undergo a degree of pain, suffering and inconvenience, along with health risks associated with surgery. If one placed importance in bodily integrity, one might also feel that one had sacrificed one's 'completeness'. In cases of living related kidney donation, it was discussed that recipients can be significantly emotionally affected if an organ transplant from a living related donor fails. The feelings associated with this failure can have a knock-on effect on the donor's emotional wellbeing. So although one 'only' donates a kidney, one also potentially risks emotional upset. It was highlighted though that the benefits from these sorts of donation can be substantial – an otherwise interrupted family life can be restored to relative normality, and the happiness associated with knowing that one has brought this about for a family member must be significant. Cadaveric donation – it was felt that the costs of cadaveric donation are dependent upon the beliefs of the donor and his/her family. A family that places value in the completeness of the body after death would be sacrificing something meaningful to them if they agree to donation. In many cases of cadaveric donation there is a feeling that the donation is 'what the deceased person would have wanted', and this provides some comfort and positivity to donor's families during difficult times. To be able to bring about something positive for other people from an otherwise horrendous situation is important to some families. This sort of positive impact can also be beneficial for the donor him/herself, since (s)he will be likely to be remembered in a positive light. However, it was noted that the families of cadaveric donors are much less likely to welcome publicity than live donors and their families.

Question 5

Events such as the Northwick Park trials highlight the potential risks involved. It seems that the risks involved, although presumably minimised and extremely well-managed, are potentially greater than many examples of donating human bodily materials. The potential benefits will vary from person to person. For someone who is already very ill, taking part in a first-in-human trial could potentially give them access to treatment that might improve their condition. In some respect it would seem that the risks involved in cases such as this are also slightly diminished, insofar as the participant is already very ill, so it's not as if a participant of this type is going to risk losing good health (although that's not to say that they don't risk becoming even more unwell). When there is no expectation of health benefit

and the participant is healthy, the potential benefits (beyond monetary) seem less significant. Although one might feel good about oneself for participating in research to further advance certain treatments, it seems unlikely that this is a decisive factor that makes people take part in these trials.

Question 7
It was felt by some of those present that some people feel differently about providing bodily materials for academic research and commercial research.

Question 9
The concept of rights was brought up, but this will be linked to many of the values detailed.

Question 10
It was felt that autonomy is, in general, a particularly important value and that it can outweigh some of the other values. Its weight is not completely over-riding though – there are some instances where autonomy has to be balanced against things such as justice (deceased organ donation, for instance. Autonomy is respected to some extent, insofar as the donor's wishes about donation are often taken into account, but this does not extend so far as to permit donor's to place restrictions on whom their organ can go to). An interesting view about the transfer of decision-making power to next of kin was raised in the context of deceased organ donation: it was suggested that when one dies, one does not automatically 'give' this power to the next of kin – it is, instead, 'taken' (and perhaps taken without good reason).

Question 11
The consensus was that this depends upon one's values. It was suggested that sometimes people do things for free, yet still gain from performing that action – someone donating blood, for instance, might feel particularly good about themselves for a short while. A general concern about payment was also raised, in that it works primarily as an incentive for those who are in less fortunate positions to start with. Financial incentives tend to appeal to people who need money, for instance – hence a relatively large amount of students wanting to participate in medical trials. This potentially results in people who are less well-off becoming society's guinea pigs, which seems morally dubious.

Question 12
Many notions of duty depend upon the cost of the supposedly required action. If one accepts that the views and beliefs of everybody are worthy of equal consideration, it seems challenging to suggest that there is a universal moral duty to provide human bodily material because different people will perceive the cost of providing human bodily material differently. It was suggested that if the perceived cost of providing human bodily material is low, then there could potentially be a

duty. So someone who places no importance in bodily integrity after death might have a moral duty to donate his organs (the cost to that person would be negligible since a) they would be dead b) they would not have lost anything valuable to them (since bodily integrity is unimportant to this person). Someone who believes in an afterlife and places great value in bodily integrity though might believe that by donating their organs they forfeit eternal life or other great reward. In this instance, it would seem that the perceived cost to them would be sufficient to prevent any moral duty from arising. Although one might argue that there is no such thing as an afterlife, if one is to respect the beliefs and values of individuals (and to some extent their autonomy) then one must consider perceived cost to be as important as 'actual' cost. In general terms a duty is perhaps more likely to exist following death, when the cost is arguably less than during life. Consensus seemed to be that the idea of there being a definite moral duty for everyone to provide human bodily material would be difficult to justify.

Question 13
It was not felt that there is a definite moral duty to participate in first-in-human trials.

Question 14
It was suggested that it might never be possible to meet demand for bodily material, and that attempting to do so might actually result in compromises to end-of-life care (perhaps in the case of organ donation) and other areas of treatment. There was a view that in cases where it is unlikely that demand can be met, efforts could be better spent elsewhere.

Question 15
The general view discussed was that there should not always be a need for incentives – open dialogue would be a better way of responding to demand. Raising awareness of the issues involved and the potential benefits to individuals, groups and medicine in general would increase rates of donation/participation.

Question 16
There was a general scepticism towards incentives, but a view that the risks and pain involved in some scenarios can go some way towards justifying them. A concern was raised that incentivising organ donation might result in perceived unfairness for those who want to donate but, for whatever reason, are unable to. On a larger scale incentivising some things could lead to people expecting incentives for many other things, and the general incentivisation of the NHS was viewed as being a bad thing. A recent incentive that was mentioned was the free taxi rides offered to Londoners if they agreed to sign up to the ODR – whilst not exactly payment for organs, some concerns were raised about the principles behind this. In cases such as this, it seems that although the incentive might encourage people to sign up to the ODR, this might not be a well-considered action and that

big decisions such as this are not the sort of thing that should be influenced by taxi-fares.

Question 17
It was suggested that some incentives could cause people to lose faith in whatever system that incentive formed a part of. This would particularly be the case if incentives were perceived as being in some way unfair. It was felt that it was difficult to give broad and definite answers to questions about incentives because the details of specific cases and specific incentives are particularly important.

Question 19
The difference was not thought to be significant.

Question 20
It was mentioned that stem-cell research is reaching the point where, relatively speaking, we are close to being able to grow livers.

Question 21
There was a concern that incentives for other family members might be coercive in some situations. An individual with little wealth might feel obliged to donate his organs when he died if he knew that in doing so his relatives would not have to pay for his funeral expenses. Similarly there was some concern that consent might not be entirely freely given if refusal to consent would result in harm to another person. The problem with providing significant incentives is that then opting to take the course of action that doesn't entail one receiving an incentive becomes effectively burdensome. If one is in a situation where one option is burdensome but yields great reward, and the other involves no burdensome action but living with the knowledge that one has foregone some great reward, one now seems to be in a situation where both options are negative to some extent.

Question 22
It was felt that unless coercion is clearly witnessed, it is practically impossible to establish with any certainty whether or not consent is given as a result of a voluntary acceptance of some form of duty or coercion.

Question 23
It was felt that there are generally no circumstances in which it is ethically acceptable to use human bodily material for additional purposes for which explicit consent was not given. However, in cases of life or death, where deviation from explicit consent was minimal, it was felt that one might feel justified in using human bodily materials for additional purposes.

Question 24

There was a general feeling that it is much more difficult for people to make decisions on behalf of somebody else. The notion of best interests was considered to be particularly important, but in complex situations it can be difficult to see whose interests are being best served. For instance when a child is a potential live organ donor his his/her sibling, there are possibly competing interests at stake. Cases with children are perhaps even more difficult because in the vast majority of cases they will go on to develop capacity to consent later in life, whereas there are some adults who will never have capacity to consent. This could be a relevant factor in considering the rightness or wrongness of consenting for others, since future capacity to consent presumably entails a future capacity to rationally resent decisions made before this capacity was established.

Question 25

There was some opposition to the right of veto, with several people present stating that they would strongly object to their family members over-ruling their own decisions. There is clearly a pragmatic reason for along family members the right of veto (it would be potentially harmful to the whole donation system if it was viewed as causing massive distress to already grieving relatives, for instance), but it does seem to ignore one of the fundamental ethical principles – autonomy. When the deceased's wishes are unknown, there is a lot of sense in consulting family members about donation decisions, because family members are ordinarily best positioned to put together a picture of the deceased's views and beliefs about donation in order to establish what it is likely that the deceased would have wanted.

Question 26

The family, or the coroner. The general view was that this aspect of law is fine as it is now.

Question 27

In general people should not be able to sell their bodily material. An obvious exception might be hair!

Question 28

There was a view that, in some way, everybody does gains from commercial benefits because this is what helps medicine to progress. Maybe there should be an agreement that a certain proportion of commercial benefits are reinvested in further research.

Question 30

The responses provided were written following discussion of the consultation document at an ethics forum held at University Hospital Birmingham. Attendees were a mixture of university staff, hospital staff, and NHSBT staff. Attendees of this forum were as follows: Rebecca Timmins - Donor co-ordinator/Specialist nurse

- organ donation Cathy Miller - Donor co-ordinator/Specialist nurse - organ donation Rachel Hodge - Specialist nurse - organ donation Janice Bayliss - Specialist nurse - organ donation Bridget Gunson - Research Manager Lisa Evans - Theatre Practitioner Elizabeth McWhirter - Theatre Practitioner Greg Moorlock - Doctoral Researcher, Centre for Biomedical Ethics