Dr Petra Nordqvist, University of Manchester

Question 2

I believe that distinctions should be made, like you suggest in the consultation paper, around reproductive material and non-reproductive material. While non-reproductive material raises issues to do with bodily organs and donations during/after birth, reproductive material raises wider concerns to do with the regeneration of people, parenthood, origins, biogenetic relatedness and the anonymity of donors. These questions are socially very different from those concerning non-reproductive materials.

Question 4

While I consider the benefits of for example egg and sperm donation to be high in terms of providing a means for heterosexual, lesbian and single women and gay men to become parents, I do think that there are important distinction between the donation processes involved that should be considered. While sperm donations are non-invasive procedures, egg donations are both invasive and risky for the women involved. I think with the donation of bodily material, the different physical costs and risks of donating must be considered when considering these forms of bodily material.

Question 7

I do think distinctions can be made between the donation of bodily material depending on the purpose of the donation. I believe that there are important distinctions to be made on levels of donation to a known person (can be family but can also be friends etc, where there is a match), strangers, research and commercial use. While I think that it is appropriate that if a person enters into a donation agreement because he/she wants to donate material to e.g. a family member who is ill, then that person should have a say in who the donation goes to. It is likely that the person has entered into a donation agreement precisely because he/she wants to honour a relationship with the receiver. However, I also think that in 'stranger' donation, where bodily material is donated but not to anyone in particular, it is important that the donor cannot make distinctions between the receivers. For example, I think it is important that an egg donor cannot decide whether her eggs should be given to a middle class heterosexual white couple, or a lesbian couple, single woman, mixed race couple or working class couple. I also think there are important distinctions between donating for the direct benefit of a human (known or stranger), for research and for commercial means and with possible indirect benefits of humans. I believe that tissue and materials used for commercial gains in a market economy (in the way that e.g. sperm is used in private infertility clinics) are highly problematic, while tissues used for research is

less problematic.

Question 8
I believe that willingness to participate in first-in-human trials may vary depending on the situatedness of the person. I believe that family relationships and background, along with other factors, may influence a person to take part. If the medicine being tested would further research in a particular area to which a person has a particular personal link, then her/his willingness to take part may be affected by the purpose of the medicine. Equally, I believe that persons can take moral issues with taking part depending on if they agree/disagree morally with the purpose of the medicine in question.

Question 9
I think that alongside this very useful list of the ethical values that might underpin people's willingness or motivation to take part in e.g. first-in-human trials, what also needs to be considered is the role of monetary gains and class and also globalisation. Recent research in the social sciences demonstrate that the role of class, poverty and globalisation impact on whether people are willing to donate material. For example, research indicates that poor women in Rumania can engage in egg donation procedures because this represents their only source of income. With increasing globalisation, there is an increasingly international market exchange of bodily materials and so issues to do with tissue and bodily material donation needs to be considered on a global level and not only on a national level. Issues to be reciprocity or altruism may have a very limited role in explaining patterns of motivation among different groups in different, and unequal, global economies.

Question 14
I do think that it is important to consider the issue of demand and 'needs' and look at its social and cultural specificity. Access to assisted reproduction services in reproductive health centre is increasingly coached in terms of the right to have a child. I think it is important to question this notion of 'right' to become a parent in this particular way (rather than, for example, through adoption), and the demands on provisions of donor eggs or sperm that comes with this notion. Thus, it is important to look at the social and cultural context in which specific 'demand' arises, how it changes over time and indeed. If meeting demands mean to compromise other ethical dilemmas such as reproductive tourism to poorer countries where bodily material is perhaps more readily available, then I do not think it is right to meet that demand. And so what 'demand' means has to be situated socially and contextually, and analysed from a perspective of power.

Question 15
I see different risks with compensation. First, I believe that compensation should be contextual and case-specific. For example, I believe that the differences embedded

in sperm and egg donation for the donors (with risks and invasive procedures for women who donate eggs but not for men who donate sperm) should be taken account into how differently the donors are compensated. Second, I think that there are risks associated with high compensation in the sense that it potentially raises issues to do with class, poverty and reproductive inequalities. Research from the US indicates that women who take part as surrogates in surrogate arrangements for payments are more likely to be working class women, thus some women (poor women) put themselves at risk for other (richer) women. Third, I also think that issues arise around compensation when there are commercial gains made from people's donations of bodily material. I find the power relations involved in tissue donation, donors, recipients, market economy, neoliberalism and commercialisation deeply problematic.

Question 16

I think this is a question of informed consent and what might compromise such consent. I believe that cash incentives can compromise a person's informed consent and his/her ability to say no to participation. Equally, incentive from family and friends can turn into pressure on the donor and compromise informed consent.

Question 19

Yes, I think there is a difference in incentive between compensation for loss of income and offering payment for services in the sense that you might stand to gain income from donating your bodily material (which can be problematic as a incentive).

Question 20

My research explores lesbian couples' incentive to pursue donor conception inside and also outside reproductive health clinics in England and Wales. It demonstrates that the demand among this group of lesbians to seek licensed donor sperm in reproductive health clinics is not necessarily structured by infertility by is tied in with the couples' desire to be the only two parents of the child (that is, they do not want the donor to be legally or socially recognised as a parent), and this cannot not, at the moment, be realised in donor conception outside reproductive health clinics. The couples who conceive using donor sperm outside clinics have to manage the legal risks embedded in this practice, as such donors (in contrast to clinic donors) are legally considered the parent of the child. It may be then that if the regulatory framework governing assisted conception in the UK was extended to lesbians and also single women who conceive outside clinics and giving them the choice to not have the donor recognised as the legal father of the child they hope to conceive, then the demand on licensed donor sperm from this group (in which women do not necessarily suffer from infertility problems) may be reduced.

Question 21

Yes, I believe that large sums of money may invalidate a person's consent. I also believe that encouragement from family/friends can invalidate the consent as it may not be possible for a person to choose if he/she is part of a particular set of family relationships.

Question 22
This is a very good question and requires more research into family relationships!

Question 24
I believe that it is very problematic to consent to donation of bodily material on behalf on somebody else, for example in the case of the child and in the case of an adult who lacks the capacity to decide for her/himself.

Question 25
I think on this issue that it needs to be very clearly defined what is meant by family. Are we talking about the rights of parents, children, spouses or partners? Can friends be recognised as family? Do you need to have a formalised relationship (a marriage/civil partnership) or can 'common law marriages' count? These issues are brought to the fore in the gay and lesbian communities where there has been and still is recorded conflicts between gay/lesbian partners and parents in case of death (even when the person's wishes are known), particularly in cases where a son/daughter has been in a gay/lesbian relationship for a long time but never 'come out' to his/her family. Perhaps one way of resolving this issue is to not assume who next of kin is in terms of who can make decisions, but to ask people to define it for themselves. I do not believe that family members (family in the conventional sense) should have a right to veto.

Question 26
If there are last wishes available from the person, then I would suggest that these should be followed after death. If there is a next of kin nominated, this person can be consulted.

Question 27
No, I do not agree that UK law should allow people to sell any bodily material, including bodily waste, such as sperm.

Question 28
Yes, I believe that commercial gains based on bodily material from donors are deeply problematic, and at the same time, for reasons to do with social inequalities, there are problems attached to monetary compensation for donations. I would suggest that there should be more research into alternatives to this binary model. One suggestion could be, for example, that companies who gained commercially

from bodily material pay back to a nation state or a particular community through higher taxes or investments in local/regional communities within a nation state, and in such a way make companies responsible not towards a singular person but towards a group.

Question 29

I think there is an important distinction to be made between if a person donates to a family member/friend or to a 'stranger'. If the purpose of the donation is to help a friend or someone in a person's family, then it is probably very important to secure control over the donation. However, if it is a 'stranger' donation, then I believe that it is important that people cannot choose who the donation should go to. This has for example been an important issue in the context of sperm donation where there has been discussions around whether donors should be able to control who can receive their donation. I do not believe, for example, that individual donors should be able to reject giving their donation to, for example, a lesbian couple.