RESPONSE TO NUFFIELD CONSULTATION

Membership of the Working Party.

1) I was surprised not to see any declarations of conflicts of interest of the members of the Working Party. I was thinking of Gillian Lockwood who has a high public profile regarding egg freezing and yet benefits from the rising demand for such a service (see page 21 which predicts that a large % of women will freeze their eggs – otherwise the development makes no sense as we don't know which 10-30% of women will have fertility problems). Also Alison Murdoch who benefits from paid 'donations' for research. The 'normalisation' of assisted conception techniques and alienation of the person from her own body parts along with the financial transactions (and thus doctors' financial and academic interests) is part and parcel of the ethical concerns in the field of assisted reproduction.

Questions 1-4

2) Although not directly within the remit of the working party, egg freezing is a form of 'extra-corporeal' donation even if the intention is to give it back to oneself several years older. I think another distinction should be drawn with respect to material that involves medical practitioners collecting material that is *saved for oneself.* Sperm or egg banking after cancer treatment are clearly indicated by the threat to fertility (though the former is non-invasive) as is bone marrow prior to total body irradiation in blood cancers. However, egg freezing and cord blood collection are much more speculative, and commercially driven endeavours that are not 'medically indicated'.

3) Cord or placental blood from the newborn is not explicitly put on the Human Bodily material list (page 12). It should be included as it is commonly 'donated' by parents on behalf of the infant for storage for future speculative purposes or for altruistic reasons. Similar to point (1), it is a 'donation' kept in a laboratory for a future date. The precious blood would otherwise be in the baby were it not for an obstetric intervention (clamping before umbilical pulsations cease) without evidence to support its safety. The topic might come under blood (only the baby is not a willing, consenting 'donor'), and it might come under products of conception (only the blood isn't a 'product' of conception left in the mother – it normally enters the baby's body unless there is early cord clamping before pulsations cease). It would be better to be in a category of its own. Again, this is a very important topic because (like egg freezing) there is a fast growing market building up and it is disappointing if the Nuffield Council on Bioethics has not paid attention to a highly contentious area where the ethics are less well explored.

4) Page 13. It is wrong to describe cord blood as 'waste' in the same way as amniotic membrane (see above). In physiological birth, during 'transition', blood moves from the placenta to the baby to fill the new pulmonary circulation (amongst other functions) (Dowling & Bewley 2009). Blood only remains in the placenta because of an intervention. Recent authorities are recommending that it is recognised as important to the baby and the placental transfusion should be allowed to occur physiologically. (Weeks 2007, Neilson 2010). These two products must be distinguished and not elided together. There is much more potential risk to early cord clamping than is generally realised: volumes equivalent to up to 30% of the babies total blood volume have been retrieved; paediatricians are very poor at recognising hypovolaemia; babies cannot tell us how they feel; the activity and timing of early cord clamping is not recorded and so there is little way to trace adverse outcomes to the intervention

5) Lastly the "borrowing" or "donating" of a body/uterus for surrogacy purposes, especially for money, has not been covered here. Although there is some supposedly non-commercial surrogacy in the UK, there are many arrangements where money is exchanged. Certainly, it is very easy to find out information about surrogacy abroad. Gay male couples in particular are buying/ renting wombs from poor women in the non-industrialised world, as they cannot gestate a baby between themselves. There is very little work on the effects on mothers and children born and sold in this way (especially with no prospect or possibility of breastfeeding, or removing from a mother after weaning)

Questions 6-10

6) Another distinction to be drawn is the donation that is potentially **life-threatening.** Some treatments (e.g. innovative transplants) come with a mortality risk meaning the recipient's life may be shortened. Others, e.g. the creation of pregnancy via ovum donation to older women and reproductively elderly postmenopausal women, may lead directly to maternal death, and perinatal mortality (as is being witnessed in the Confidential Enquiry into Maternal Death). Pregnancy is life enhancing (in terms of having children when it is successful) but has a huge biological resource cost that can overwhelm the unhealthy.

7) Cord blood could be added to the speculative usages within the commercial environment (page 15)

8) Purposes are justifiably distinguished by need (i.e. there is an order of priority in terms of sickness – i.e. close to death, very morbid – so the sickest are

higher priority) and by effectiveness (i.e. whether the treatment will work and for how long).

Questions 9-13

9) Solidarity is very important as 'we are all in it together' in the sense that disease is not chosen and does not strike in a moral way. As we 'are in it together' in a democratic society that taxes individuals and corporations and distributes benefits and health services, then we should be particularly wary of activities that diminish solidarity, as they diminish us all and may work to discourage the altruism that fuels donation. The commercialisation of donation to 'look after number 1' thus threatens the enterprise of donation for all. This is why egg freezing and cord blood collection (just for the 'donor' and not for anyone else) should be addressed more in this document. Also the selling of eggs may be just another abuse of women's bodies, akin to paying for sex. Slippery language like "egg-sharing" is morally corrupting as it does not recognise the desperation of women who can only afford IVF by "bartering" their eggs for other women to use.

Question 14

10) Some 'needs' and 'demands' need to be more fully understood to be ameliorated. The infertility 'epidemic' (doubling in last 20 years) is largely caused by avoidable risk factors: use of contraception and abortion through the fertile years, rising age of couples before attempting pregnancy, smoking, obesity, tubal damage from sexually transmitted diseases. A public health approach, or understanding of the lack of equality between women and men (in terms of equal opportunities, equal pay, protection for careers & needs for pensions) might address the 'problem' of childbearing and rearing.

11) It is particularly galling that there is a postcode lottery on IVF treatment and it would be very good if all infertility treatments (whether investigations, tubal surgery or IVF) were unlimited and free on the NHS up to 35 years of age for men and women (a perfectly reasonable 20 years of fertility time). They could be available in the private sector after this age. Such a policy would a) have a public health message, b) would concentrate resources when they are most effective and c) would allow more single embryo transfer and singleton pregnancies – rather than the twins which have more risk of prematurity.

Question 15

12) See earlier comment about 'egg sharing' arrangements that seem particularly cruel to the poorer party – who has to give up her egg, not knowing if another women has carried and brought up her genetic child, in order to afford her own treatment. Many women may indeed be comforted by the idea that there is another child 'out there', but many may not, and

their chances of their own pregnancy are lessened by the giving up of their eggs and their inability to pay for something so fundamental to identity

13) The HFEA and UK law is in a muddle about payment for gamete/embryo donation. This is partly because the regulator is too close to the commercial industry. Also people want to be 'politically correct' about gender, when that is not possible – it is an entirely different matter, with different risks, to donate an egg or sperm. Pregnancy (and the puerperium/ period of breast feeding) with its joys and risks is an entirely different matter for men and women, potential fathers and mothers. And lastly, gamete donation might not happen without payment. But if the 'gift' analysis is right (and might even more be so for the children who are the product of the 'gift/donation/sale'), then maybe a moratorium on non-altruistic donation is necessary (coordinated EU if not world-wide). It is only when the 'smug' fertile people in society feel solidarity with the infertile that we might get altruistic donation.

Questions 16-19

14) It is interesting to think what 'benefit-sharing' for egg donors might be, unless it was to allow them to find out whether pregnancy (or pregnancies) ensued or to have contact or some information about the child that resulted. And why not? Present policies on adoption recognise allowing children to find out about the biological parent and value honesty about their origins – in the name (and I hope evidence) of the child's best interests. We have not collectively considered whether honesty to children who may desire to know about their biological origins matters more than secrecy about the stigma of infertility and prioritising (social) parental rights to privacy.

15) There are some advantages to collecting eggs from a deceased donor. Especially if the eggs came from a woman killed young (e.g. traumatically) then they would be better quality, the relatives might obtain some comfort from knowing that there is a possibility of genetic transmission, and the consideration of fertility when signing a donor card might concentrate the minds of young people. There is no actual 'genetic mother' to contact, or for the recipient to worry about.

Question 20

16) Although there is some progress in science about creating gametes from somatic cells (i.e. men and women could have their own genetic gametes created from their own cells), this is not yet successful in animals, so unlikely to solve the dilemmas of donation of reproductive tissue as yet

Question 21

17) No doubt the women who undergo so-called "egg sharing" feel they are consenting and might even be outraged to be called non-autonomous, but infertility itself can be so overwhelming and distressing that voluntariness goes out of the window.

Question 23

18) To maintain safety and public confidence in researchers doing this, I think an additional rider has to be added, that not only does the researcher not know who the material came from, but the chain of identification must be broken (e.g. by anonymisation, mixing of samples, destroying of ledgers)

Question 24

19) Yes, there is a great difference in taking a risk on your own behalf and a vicarious risk on someone else's behalf

Question 25

20) Family members should not be able to override the deceased's wishes where known, and hospitals should feel entitled to respect the wishes even in the face of family opposition (which is rarely unanimous). Where the wishes are unknown and the family objects, then I consider it wrong to override their deeply held beliefs about the relative's body and the proposal to have 'presumed consent' by BMA and others potentially threatening to the integrity of the donor programme. It might be possible to consider a law (similar to Israel) whereby organ donation or refusal by a relative means that their name can rise or fall in any future waiting list (as it would be unfair and hypocritical to be prepared only to participate in social benefits, but not social risk).

Question 26

21) Dead bodies, and parts are "things of themselves", and should not be property belonging to anyone or any institution.

Question 27

22) In general, the law should not permit people to sell their bodily material for all or any purposes. Exceptions might be made for trivial reasons or body parts that are normally disposed of (e.g. hair for wigs).

Question 28

23) Companies who profit from people's willingness to donate bodily material or be research subjects should share the proceeds of those gains with the general public – either via taxation or some philanthropic communal fund for the specific purpose

References to cord clamping

Dowling C, Bewley S. Cord clamping and the third stage. Fetal & Maternal Medicine Review 2009;20(3):1-18
Neilson JP. Umbilical cord blood gas analysis. *BMJ* 2010;340:1720
Weeks A. Umbilical cord clamping after birth. *BMJ* 2007;335:312-3