



Official Response

SUBJECT: HFEA Consultation: Medical Frontiers
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These are the recorded submissions for Session 1. Only sections to which responses have been recorded are listed below.

Permissibility of new techniques

Q1: Having read the information on this website about the two mitochondria replacement techniques – maternal spindle transfer and pro-nuclear transfer, what are your views on offering (one or both of) these techniques to people at risk of passing on mitochondrial disease to their child? You may wish to address the two techniques separately.

Your response:

We would oppose the development of both these techniques, for a number of reasons. In addition to some for the specific concerns explored more fully below, we feel that such developments represent an effective downgrading of the special respect which UK law is supposed to afford the early human embryo. Particularly in relation to pro- nuclear transfer, such technology would involve the creation of embryos specifically with a view to destruction as a part of the process: the church would wish to express its opposition to this.

The Church of Scotland has in the past argued that ethical concerns are important in the development of technologies. For example, in relation to stem cells, our report in 2006 advocated the development of sources other than human embryos for stem cells. It should be noted that technologies to ameliorate problems with dysfunctional mitochondria without resorting to the manipulation of early embryos are already being developed (e.g. <http://www.pnas.org/content/109/13/4840.full.pdf>). We would urge further exploration of these, rather than the technologies being proposed.

Only a few years ago, the Human Fertilisation and Embryology Act 2008 placed limits on the gestation of human embryos which had been manipulated, such that no manipulated embryo would be allowed to develop beyond 14 days. Allowing these technologies to enter routine clinical use would mean that such limits would be removed .

It should also be noted that during the debate on the HFEA Act 2008 it was argued strongly that it was necessary to allow for the creation of human- animal hybrid embryos, for the generation of

stem cells. These have proven to be technically impractical and essentially a waste of time and effort. We fear that the techniques described here would be a similarly futile waste of energy and resources.

A recent study indicated that children conceived using IVF are 25% more likely than naturally conceived children to suffer from birth defects (<http://www.uclahealth.org/body.cfm?id=561&action=detail&ref=2039>). Given the greater trauma inflicted on the egg or embryo in carrying out the techniques described here, it is probable that unacceptably high rates of birth defects would result. In addition, it is possible that the shear forces involved in the manipulation of the pro- nuclei or maternal spindle complex may result in physical damage to the chromosomes (e.g. chromosome breakage), with potentially disastrous consequences for any resultant child.

Changing the germ line

Q2: Do you think there are social and ethical implications to changing the germ line in the way the techniques do? If so, what are they?

Your response:

The technologies described have profound social and ethical implications. Such technologies are very similar to those used in somatic cell nuclear transfer (SCNT), which is the basis of the mammalian cloning techniques which lead to the reproductive cloning of Dolly the Sheep. As such, these technologies would represent technical developments which would lend themselves to the development of human reproductive cloning, as well as to the manipulation of genetic material in the nucleus, taking us towards “designer babies”. These are developments which are not permitted in any country, and which many jurisdictions have moved to explicitly outlaw.

Although some may argue that these techniques do not alter the germ line (as they do not involve changing the genetic material in the nucleus), it remains the case that changes introduced will be passed on to future generations. In addition, as the functioning of mitochondria is dependent not only on genes in the mitochondria themselves, but also on genes in the nucleus, many of the clinically identified “mitochondrial diseases” are in fact caused by defects in the genes in the nucleus, and so would not be amenable to treatments using these techniques. Thus, if we were to allow the techniques currently under discussion, it could be argued that it would be unfair or illegal to disallow manipulation of nuclear genes in order to ameliorate mitochondrial diseases. The long term consequences, for the individual and for society, of moving towards germ line manipulation are potentially very profound and should in our view be resisted.

Implications for identity

Q3: Considering the possible impact of mitochondria replacement on a person’s sense of identity, do you think there are social and ethical implications? If so, what are they?

Your response:

There is considerable research around the psychological effects on donor conceived individuals, some of which indicates that donor conceived individuals experience profound psychological effects (see, for example, My Daddy’s Name is Donor: A New Study of Young Adults Conceived through Sperm Donation. Commission on Parenthood's Future (E Marquardt et al (2010)). Available to

download here: http://www.familyscholars.org/assets/Donor_FINAL.pdf). These effects seem to be accentuated if the parents hide from the children the fact that they were donor conceived, as is the case with the majority of parents who use donor conception (See, for example, "Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy" (J Readings et al (2011) Reproductive BioMedicine Online 22, 485-495). We would consider that it is probable that any individuals conceived using these techniques would also be prone to such effects.

The status of the mitochondria donor

Q4 (a) In your view how does the donation of mitochondria compare to existing types of donation? Please specify what you think this means for the status of a mitochondria donor.

Your response:

This type of donation differs fundamentally from many other existing types of donation. Such donation as would be required for the proposed techniques involves the donating not simply of mitochondria, but of mature eggs. Not only is the harvesting of eggs in itself an invasive, difficult and potentially risky procedure, but the clinical over-stimulation of the ovaries in order to maximise the number of eggs harvested per procedure also carries risks. The numbers of egg donors in the UK remains low for these reasons; the clinical development of such techniques as described in this consultation would necessitate a significant increase in the rate of egg donation. We would be concerned that, in order to overcome such a shortfall, vulnerable women may be offered unethical inducement to "donate" eggs.

In addition, the donation of gametes differs from other forms of donation, in that the material donated is passed on into future generations.

Q4 (b): Thinking about your response to 4 (a), what information about the mitochondria donor do you think a child should have? (Choose one response only)

Your response:

Option5

Please explain your choice

Your response:

For reasons enumerated, we would be opposed to the development of clinical mitochondrial replacement therapies as described here.

Regulation of mitochondria replacement

Q5: If the law changed to allow mitochondria replacement to take place in a specialist clinic regulated by the HFEA, how should decisions be made on who can access this treatment? (Choose one response only)

Your response:

Option4

Please explain your choice

Your response:

For reasons enumerated, we would be opposed to the development of clinical mitochondrial replacement therapies as described here.

Should the law be changed?

Q6: In Question 1, we asked for your views on the mitochondria replacement techniques MST and PNT. Please could you now tell us if you think the law should be changed to allow (one or both of) these techniques to be made available to people who are at risk of passing on mitochondrial disease to their child?

Your response:

We would consider that the potential risks involved, the moral and ethical implications, and the availability of alternative approaches to solving this problem, mean that to change the law to allow these techniques to develop would be wrong.

Further considerations

Q7: Are there any other considerations you think decision makers should take into account when deciding whether or not to permit mitochondria replacement?

Your response:

The Church of Scotland welcomes the opportunity to comment on these proposed technologies. As indicated above, we are concerned not only about the specifics of these techniques, but also about the general direction in which this will drive society, and also the effective downgrading of the special status of the early human embryo.

We would advocate the development of alternative forms of therapy which do not carry the ethical problems associated with these techniques. We would strongly urge that these technologies not be developed for clinical use.
