HFEA consultation on Mitochondrial Replacement.

Consultation questions (in red)

1. Permissibility of new techniques

Having read the information on this website about the two mitochondria replacement techniques, 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.

The Anscombe Bioethics Centre is opposed to both techniques: neither pronuclear transfer (PNT) nor maternal spindle transfer (MST) is justified in view of their risks and harms, including to future generations. Such risks and harms are created in the course of germ-line genetic manipulation which is not needed and is carried out simply because some form of genetic connection is desired by the woman with faulty mitochondria with the child she wants to have.

We are particularly opposed to PNT, which destroys two human embryos and is a form of reproductive embryo cloning: cloning from one embryo, using a second donor embryo, to create a third embryo who will be a clone (i.e. a partial copy) of the first. Cloning from an embryo – in this case, to create a baby - should be prohibited, whether the embryo copied consists of one cell or of more than one cell.

We are also strongly opposed to MST, which does not involve cloning or inherent embryo destruction, but does fragment the child’s genetic parentage, with all the physical and emotional risks and harms this will create.

2. Changing the germ line

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?

If alteration of the germline is allowed for mitochondrial disease then it will certainly be requested for other diseases and other reasons. Any change will affect future generations in ways that are impossible to predict, while the risk of mitochondrial disease can be avoided simply by avoiding conception (for example, choosing to adopt). Germ-line alterations are illegal in many countries for good reasons: we simply do not know what harm we may be doing, and such harm may extend indefinitely to many generations.

3. Implications for identity

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?

Though MST tries to erase the identity of the egg donor mother, the egg will still bear traces of her identity and the child will be able to trace her maternal ancestry through
her. If MST is allowed, which it should not be, it should be the children who are born from it who should decide whether they wish to contact their egg mothers. It is patronising to claim in advance that the egg donor mother is not a “real” mother.

The attempt to erase the egg donor mother’s identity may cause more identity problems for the child, not fewer. In the case of PNT, identity problems may be more severe, as the child will be a clone formed from “spare parts” of two deliberately destroyed embryos.

4. The status of the mitochondria donor

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.

When an egg donor is used in standard IVF, this avoids passing on mitochondrial disease. What is new in MST or PNT is that the donor egg or donor embryo would be genetically modified to partially erase the contribution of the egg donor mother (in the case of MST) or the donor embryo (in the case of PNT).

Standard egg donation does not involve an egg from which many genes have been erased before fertilisation (in the case of MST). Nor does it involve the total replacement of fertilisation by cloning (in the case of PNT). While we believe there are profound ethical problems with all gamete donation, in that it involves the deliberate conception of children one does not intend to parent, we believe these problems are merely compounded by MST and PNT.

The child resulting, even if healthy, would be no more healthy than children conceived using standard egg donation. Moreover, the child would be at greater physical risk from the new procedure, and might well have more serious problems of identity, particularly in the case of PNT where the child is deliberately constructed from other embryos who are used and destroyed for their parts. These techniques cross an important ethical line for no good medical reason.

The egg donor in the case of MST is more than a mitochondria donor. The names maternal spindle transfer and pronuclear transfer show that it is not the mitochondria themselves that are transferred but the nuclear genes (the spindle or the pro-nuclei) that are transferred into a second egg or embryo. The spindle is not an egg and without an
egg there is no embryo. The egg donor is a kind of partial mother, just as the spindle donor is a kind of partial mother.

In contrast, in the case of PNT the egg donor is not the mother directly of the final embryo created, but of an embryo who is destroyed to create that final embryo. This is something potential egg donors may not realise. Many people have concerns about the existing exploitation of egg donors, who may be paid or offered fertility treatment as payment for their eggs. We should not be encouraging this kind of exploitation, particularly in cases where the donor’s own genetic child is destined not for birth but for destruction.

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

- The child should get no information
- The child should be able to get medical and personal information about the mitochondria donor, but never know their identity
- The child should be able to get medical and personal information about the mitochondria donor and be able to contact them once the child reaches the age of 18
- Other
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

MST and PNT should not be permitted in treatment at all (or, we believe, in research, given that such research involves creating and destroying embryos). However, if MST is legalised and children are born from it, such children should not be deprived of knowledge of their egg donor mother. They should have no fewer rights than other children conceived using donor eggs or sperm.

In PNT there will be up to four parents involved in the conceiving of the original two IVF embryos, and the PNT child will then be a clone constructed from those two embryos, who are destroyed in the process. However, its mitochondrial DNA will be derived from the egg donor, via the second, donor embryo. Given his or her likely state of parental confusion, any child born from this destructive procedure should, at very least, be offered full knowledge of the woman who donated the second egg and of the man whose
sperm was used to create the donor embryo with that second egg (if this man is different from the child's social father).

By only allowing one box to tick, this consultation does not allow those opposed to these techniques adequately to express a view about how to mitigate the bad effects.

5. Regulation of mitochondria replacement

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)

- Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases
- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases
- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

MST and PNT should not be permitted. History has shown that, if such techniques are legalised, the regulator will not be an effective safeguard against ever-expanding use of the techniques. The only practical safeguard is a clear rule as to which techniques are prohibited. Such rules are best set by Parliament, not by the regulator.

By only allowing one box to tick, this consultation does not allow those opposed to these techniques adequately to express a view about how to mitigate the bad effects.

6. Should the law be changed?

In Question 1, we asked for your views on these techniques. 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? You may wish to address the two techniques separately.
For reasons stated above, MST and PNT should not be permitted and the regulations should not be created to allow them.

PNT is much worse than MST as it involves cloning and the creation and destruction of embryos on every occasion it is used. So if the government is determined to permit “mitochondrial replacement” - which we believe would be a serious error - at least it should not permit PNT.

7. Further considerations

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

Both techniques are forms of laboratory conception that use an egg donor at some point of the process. Neither MST nor PNT would be safer or more efficient than standard egg donation, nor would they do any more than standard egg donation to avoid the transmission of mitochondrial disease (which does not happen with standard egg donation), nor would they avoid the need for an egg donor (an egg mother, in the case of MST). The aim of MST and PNT is to satisfy the wish for a genetically related child, and this wish does not justify cloning, embryo destruction, genetically modifying the child or altering the germline.