This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

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**Introductory remarks**

As I noted in my introductory remarks, in preparation I considered some of the publicly available documents mostly produced in the last year or so, and including the HFEA’s existing work on scientific and the ethical issues. I am not going to comment here on the "standard" ethical issues of safety of procedure, moral status of the embryo, or getting informed consent for experimental technology. I was asked to focus on issues of identity, which I do, but I also add some extra comments on areas that seem to me to have been neglected or missed in the literature I’ve looked at.

(NB: ‘mt’ throughout means mitochondri(on)(a)(al).)

**A. Identity issues**

Note that the technology is effectively a manipulative rather than selective technology, and involves transmission of modification to subsequent generations – both of these are new.

What might be the impact of mt transfer technology, so that children are born without mt disorder, on the children themselves, their descendants (germ line change), the ‘community of people with mt disorders’, and also on those who continue to be born with mt disorders because parents could not/would not use technology.

**1. Children**

One paper (by the HFEA) which I looked at structures its discussion of this around distinguishing between personal and social identity, and then within personal identity distinguishing between models that say ‘identity is about the consciousness you have’ and those that say ‘identity is about the body you come in’ which in that paper seems to be equated with ‘the DNA that makes the body you come in’. So the question is what effect might the presence of donor mt DNA have on any of this.
**Personal identity:** The document I’ve already referred to (HFEA Ethics and Law) states explicitly that only if you take the ‘body’ approach to identity does the presence of extra DNA have any implications for a child’s personal identity. If personal identity (sense of self) is something that results principally or solely from genes, then it’s hard to see what effect donor mt DNA might have directly (due to the small number), unless it turns out that mt DNA has some kind of unexpected influence, e.g. as master gene. There’s no evidence for this but since so little is known about the exact role and function of mt DNA, while it may seem implausible it would be unwise to rule it out entirely.

This question is unlikely to be resolved unless or until the technology is actually used. There is some sort of precedent in that children produced through a range of ARTs have all been very ‘normal’ as far as we can tell in terms of their personal identity. On the other hand it could be argued that none of these involved actual manipulation of genome.

Another line (following standard non-identity philosophical arguments) is that no personal identity can be changed, since what is altered is not yet a person with an identity anyway.

What seems to be missing in this discussion is that dominant contemporary theories of identity don’t look on personal identity as something that is read off your genes, but rather as *who you think you are*, which is to do with how you experience yourself – and that in turn is partly about your embodied, experienced reality and partly about *what other people tell you, explicitly or implicitly, you are*. This can be called **intersubjective personal identity**, as distinct from **social identity** which is more about what kinds of social positions or roles an individual has, or about family lineages and kinship.

Having 3 parents is not unusual; being born as a result of ‘generative input’ from 3 parents these days is unusual but not unprecedented; but being genetically related to 3 people is novel. In my opinion this aspect is most likely to affect the child’s sense of self, not through any influence of the DNA but through intersubjective and through
creation of unusual family lineages and social relationships. Here the question is whether families and societies have the capacity to accommodate to this as a “new kind of normal”, and if not, to what extent that lack of accommodation will be problematic.

(An additional question was asked about whether mt DNA contributes to identity only when it’s abnormal. In principle of course, not; in practice, bearing in mind what I’ve just said, it does because what is normal to a community is often not recognized as being a particular ‘identity’ – analogies here with, say, Black or Muslim being discussed as ‘identities’ within British society in a way that white or Christian rarely is.)

2. Identity of family/mt disease ‘community’
A question is likely to be raised the ethics of screening for disease/disability in general, and it’s hard to say anything sensible about something so complex and diverse. However, since we allow PND and PGD there is a general societal consensus that selecting against at least some diseases and disabling conditions is morally acceptable. Mt treatment poses different questions, not about selection but about modification/manipulation. But mt diseases themselves seem too diverse to make universal pronouncements about the permissibility of either selection or manipulation.

Likewise there is not much that can be said with 100% confidence about what a potential mt treatment will do to family identities. We know from precedent and research that impacts of genetic diagnosis within families can be complex and unexpected, eg the way in which the uptake of predictive testing for Huntington’s disease has been lower than anticipated; see also recent research by Lorraine Cowley (PhD student at PEALS) about the effect of decisions to test or not within families with rare genetic conditions. So: yes, there may be issues to do with older siblings who have the disease feeling estranged from/resentful of younger (treated) sibs, or feeling stigmatised, or descendants, post-mt treatment, reacting to the disjuncture in the family – both negatively and positively, for example thinking “now the family is free to be what it is without being this disease as well”. If mt disease is drastically reduced then along the way there may be issues about reduction in dedicated services, professional expertise, public acceptance and resulting isolation of affected families.
These are all arguments for doing solid and extensive social scientific research to accompany the treated families, without having too many presumptions about what findings will be. But note here also the ethical problem of long-term follow-up of the ‘pioneer’ families being a burden on them or stigmatizing them further – there is a recognized problem here already with groups of disabled people, who also feel exploited as research guinea pigs.

3. Collective/political identity

There are some disability groups who challenge selection (and now modification) on the grounds that a particular condition creates a collective identity (almost an ethnicity): there are a restricted number of these but in my opinion their argument is often compelling. However this is unlikely to be a strong argument for most mt diseases – speaking cautiously bcs of the clear diversity of mt diseases, but they seem not to be of the kind that generate a coherent political identity around themselves.

4. Identity of donor

Questions about the Identity (or categorization) of the mt donor also arise, and I haven’t seen these discussed elsewhere. The question is whether donors they get classified (in legal terms) as equivalent to tissue/organ donors, with the rights and responsibilities that go along with that, or as gamete/embryo donors who are now generally associated with different set of rights, responsibilities, legal protections. Faced by novel social roles and acts, people will tend to draw heavily on what law “tells” them they should think. Hence categorization here has additional identity effect, beyond the strictly legal one, eg whether an mt donor without her own children acquires the social (or even personal) identity of a mother.

Drawing parallels with other forms of donation in biomedicine is probably not helpful. There are distinct differences in that mt donor DNA is donated in the ‘generation’ of a new person, rather than to provide treatment for an already existing one. (In fact it might be worth considering the point that, if we do accept the model that says individual identity is a product of experiences as much as of DNA, then a ‘conventional’ transplant ought to raise more concern about impact on identity because of the distinctive experience of hospitalization.)
In my opinion mt donors are like but also unlike both organ donors and gamete
 donors, and I’d argue that some new classification needs be devised for mt donors that
 reflects this. Clearly it will take some work both to craft this, and to convey it to the
 public.

B. Issues not strictly about identity

1. Gender

Gender issues may be to do with

a) supply of donor mitochondria: donor mt are in donor cytoplasm which
 comes from donor oocytes. This ought to raise the question of where donor
 oocytes will come from, both in treatment and prior to that in research. Are
 they going to be volunteers? In IVF or altruistic? Paid? If in treatment,
 related to patients? If there is an inadequate supply, how to manage that?
 There are statements by clinicians in some of the documents along the
 lines of “we need to increase supply of donated oocytes” – what are the
 implications of that need, in terms of financial/emotional inducement, etc?
 Similar questions have come up around egg donation/stem cell research
 and thinking through the mt donation case can draw on these.

b) public perception of disease: the nature of mt inheritance means that it is a
 gendered condition, but in quite a complex way. It is difficult to predict how this will
 play out in either patients’ or the public mind as knowledge increases with public
 debate. Will there be stigmatization? What about the positioning of women in the
 affected family, or in society, as ‘problem causers’?

2. Thin end of the wedge

It has been argued that mt modification is the thin end of the wedge towards heritable
 manipulations – and I think that may well be true. While it is theoretically possible to
 place blocks against it, eg by stipulating that only mt but not nuclear genes can be
 changed, in practice it is going to be hard when faced with real patients to explain that
 because the cause of their condition lies on ‘the wrong kind of DNA’ you can’t
intervene. So almost inevitable I think that there will be pressure to move towards other forms of genetic manipulation, especially if/when a particular case is taken up by the media (there is a precedent for this in the ‘saviour siblings’ arena).

C. Broader (too broad for NCoB remit?) issues

1. The implied importance of genetic relatedness in families
This is to do with the message sent out by particular policy decisions.

I argue that ironically, the more that an ethical concern associated with a technology to prevent or cure a condition is given rigorous public scrutiny, the more likely it is that subsequent adoption of the technology (if that’s what you do) inadvertently sends out a set of messages (about the condition, but also about areas) that may or may not be accurate.

In the mt donation case, the message sent out could be that we are moved to cross the stringent moral bar against genetic manipulation in humans that we have held for a long time, because a) the condition is intolerable; and less obviously and more contentiously, b) the getting of ‘a genetic child of one’s own’ is important enough to justify it. I consider that a) may well be true for some but not all mt conditions; I am much less convinced about b). I don’t think it is the case that either message is deliberately intended, but that point b) needs to be examined more rigorously than I have yet seen in this debate.

2. Does only an expert standpoint count?
There is a problem of what you might call democratic epistemology: where regulation of a technology is based on degrees of technical detail that may not be comprehended by or be irrelevant to the people most affected, and where at the same time there is no expert consensus on whether these details are morally relevant either. Put another way, this is the difference between specialist and public understandings, and whether regulation ought to reflect specialist expertise or something we might think of as a common moral understanding. Who is the regulation actually for (on whose behalf is it operating, whose moral understanding does it take as superior)?
Final comment on public perception and reception: It should be clear from all that above that I think the major problems of nt donation will arise from the public perception and reception of children and families involved, particularly whether they are seen as normal children who have undergone some medical treatment early on, or conversely as as "monster kid with two mothers". This necessarily places a lot of responsibility for carefully thought through (and not just accurate) information and reporting about. So this is where bodies like the NCoB have an important role in helping to steer the kind of explanations and media presence that develops.