

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.

Anonymous 20

- Ethical concerns around producing “three parent babies” are sensationalist and unfounded.
- It would be unethical to continue to ban these emerging techniques.
- These emerging techniques should be treated no differently from a legal or ethical perspective than egg and sperm donation.
- A donor record should be kept and maintained and consent forms signed by the parents and donor. The consent of the embryo should be deemed as it is in respect of emergency caesareans and incubators for premature babies.
- The existing and lawful techniques of PGD and PND are not sufficient.

1. Ethical concerns around producing “three parent babies” are sensationalist and unfounded. As noted in the Call for Evidence Paper dated January 2012, the 13 mitochondrial genes govern the function of mitochondria (i.e. the batteries of cells) and not personality or physical traits and, as such, any donor of mDNA (or any part thereof) would not be a “parent” of the resultant child (neither ethically nor legally according to the terms of s47 of the Human Fertilisation and Embryology Act 2008 (the “HFE Act”). The emerging techniques are largely akin to replacing the faulty battery of a cell.

2. There are no known cures for mitochondrial diseases. These emerging techniques are expected to prevent (i) the resulting children from inheriting mitochondrial diseases; and (ii) the resulting female children from passing mitochondrial diseases onto their children. It would be unethical to continue to illegalise these techniques because (a) society and the government is then implicitly advocating that certain individuals should have no right to bear their own children; and (b) we would be allowing children to continue to be born with mitochondrial diseases (thereby potentially suffering from premature death, blindness, deafness, dementia and being wheelchair bound) when the science is in place to prevent this.

3. Regarding the ethics of using experimental techniques on unborn children, this should be lawful if consent is given freely by the mother, father and mDNA donor. Any argument that we should not allow an unborn child to be the subject of an experiment because it cannot give its consent is flawed because the technique is in the child’s favour and should therefore be treated as deemed consent. If this flawed argument is taken to its logical conclusion, then we should illegalise emergency caesareans and incubators (which are beneficial for the child but carry associated risks like most medical procedures) because a child cannot consent to these procedures. The rules to be introduced regarding mDNA donation should be similar to the existing rules regarding egg donation (e.g. reasonable expenses for the donor should be paid on request but there should be no “egg-bidding” on the internet in order to protect vulnerable women from being exploited).

4. Any argument that we are seeking to play God by legalising these techniques is flawed. Whether you are religious, humanist, agnostic or atheist, what “God” or what sort of society or government would choose to continue to inflict the symptoms of these debilitating diseases on families and their unborn children and grandchildren?

5. These emerging techniques should be treated no differently from a legal or ethical perspective than egg and sperm donation using IVF. How can it be lawful for a female to donate one of her eggs in its entirety but not lawful for a female to donate a part of her egg? There needs to be consistency from the government.

6. It would be desirable for records of donations to be kept and managed by the relevant authorities setting out the names and addresses of the parents, the donor and the date of birth of the resulting child. The information on this register should only be made available on request to (i) the parents; (ii) the donor; and (iii) the resulting child and any successors of the resulting child.

7. The existing and lawful techniques of PGD and PND are not sufficient because (a) neither of them prevent a female child born via either of these techniques from passing on mitochondrial diseases to

her children; (b) PGD is not a suitable technique for all types of mitochondrial diseases; and (c) if PND uncovers an embryo with a mitochondrial health disorder, we are forcing the parents into the devastating position of having to choose between an abortion or having a potentially disabled child.

8. It is suggested that the risks of these emerging techniques could be mitigated by (i) all practitioners of this technique requiring a licence; (ii) a body being set up to regulate the provision of licences and the acts and omissions all practitioners; (iii) any parents and donors signing consent forms in advance setting out the potential risks; and (iv) all participants being encouraged to partake in an ongoing analysis of the resulting children and the children of their future generations.

9. The existing wording in the HFE Act prohibiting “genetically modified embryos or embryos created by cloning” from being placed into a woman’s body was surely intended to alleviate public concern over genetic cloning and the selection of hair colour, eye colour or sex. The emerging techniques fall into a completely different category from these aforementioned examples and I implore the government to introduce supplemental regulations to make these new techniques lawful.