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.

Submission by H+UK (the UK Transhumanist Association)

- We shouldn't shy away from removing a known danger because of the theoretical possibility of adverse side effects
- We look forward to a time when an individual will be able to decide how to enhance his or her own DNA
- The banning of medical technologies drives patients to countries that offer them
- Selection of healthy genes that will be inherited by future generations is acceptable if necessary to provide a healthy life
- Maternal Spindle Transfer and Pronuclear Transfer raise fewer ethical concerns than preimplantation genetic screening
- The modification of the nuclear DNA of an embryo would raise even fewer ethical concerns
- The relationship between mitochondrial donor and recipient can be roughly compared with that of organ donors/recipients
- Mitochrondria donation should be regulated in a way similar to sperm and organ donation

1. By modifying an embryo's DNA we are obviously taking decisions on behalf of the unborn and, indeed, future generations. This puts on our shoulders additional ethical responsibilities, but we shouldn't shy away from removing a known danger because of the theoretical possibility of adverse side effects that might or might not present themselves.

2. Every new drug or treatment would be considered experimental in the early stages of treatment and mitochondrial transfer is no exception. If it was not approved in the UK on these or other grounds, the strong desire of many couples to have (biological) children would drive them to obtain such or similar techniques in those countries that, inevitably, will offer them.

3. The children resulting from the use of these techniques could be described as having three parents, and indeed this has been the facile headline of many newspapers. However, this is misleading. The overwhelming disproportion between nuclear DNA and mtDNA makes receiving the latter akin to receiving an organ donation. Consequently, there's no particular reason why the child would have to have any relationship with the mitochondrial donor, unless he or she expressed a desire in that direction, once grown up. But such relationship could be roughly compared with that of the recipient of a living kidney donation and the relative donor.

4. In the context of preventing inherited mitochondrial disorders, the selection of healthy genes that will be inherited by future generations is acceptable on the grounds that those future generations' healthy life itself would not have been possible without it.

5. Both Maternal Spindle Transfer and Pronuclear Transfer would raise fewer ethical concerns than preimplantation genetic screening, if they imply the creation, and subsequent destruction, of fewer embryos. In this optic, Maternal Spindle Transfer would raise fewer ethical concerns than Pronuclear Transfer, as it doesn't imply the removal of the nucleus from the donor egg.

6. The modification of the nuclear DNA of an embryo would raise fewer ethical concerns of one type (embryo destruction), but would raise different ones as, unlike mitochondrial DNA, nuclear DNA

controls the overwhelming majority of an individual's phenotype.

7. As transhumanists (a growing movement that affirms the desirability of improving the human condition by developing technology), we look forward to a time when an individual will be able to decide how to enhance his or her own DNA, but the modification of the genetic material of the unborn raises different ethical concerns.

8. Just as it would be obviously unethical to modify an embryo's DNA so that a child would be born suffering of a condition that he/she would not have otherwise suffered from, it would be equally unethical to commit a sin of omission by not modifying the DNA of an embryo that we know would result in a sick, suffering, child. We extend this concept to include the enhancement of the embryo and of future generations: if, in the future, we had a safe and affordable technique that offered some form of generally-accepted-as-desirable enhancement (increased resistance to disease, for example), it would be a moral imperative to make it available to all the parents that desire it for their children.

9. We do not see the urgent need to use pre-implantation sex selection (preferring male embryos) in order to prevent passing mtDNA on to subsequent generations. The ethical benefit of a precautionary approach is in this case counterbalanced by the inevitable destruction of additional embryos implicit in sex selection. However, some parents might be allowed to take this course of action if they expressed particular concern, mostly on psychological well-being grounds.

10. Mitochrondria donation should be regulated in a way similar to sperm and organ donation. The donor's privacy should be protected up to a point, but records should be retained and made available for inspection for the purposes of medical research or the curiosity of the resulting child.

11. It might be desirable to keep a record of donations as a precautionary measure, just in case it might be necessary, at some future stage, to further investigate the donor's health or family history. Such information should be made available, on request, to the medical authorities treating the recipient for (currently hypothetical) adverse effects. Some recipients might express a desire to know more about their donor and/or to contact her. The donor should be given the option whether to allow this or not.