NUFFIELD COUNCIL ON BIOETHICS

Summary of report

Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review

Published 12 June 2012

Inherited genetic disorders caused by mutations in mitochondrial DNA can cause a wide range of severely debilitating and disabling health problems including heart and other major organ failure, stroke, dementia, blindness or deafness. These progressive disorders can onset at any age from birth and can cause premature death. There is currently no cure for these conditions.

Research into techniques that could prevent the transmission of inherited mitochondrial DNA disorders is advancing, spearheaded by UK scientists. Using variations of IVF procedures, techniques such as pronuclear transfer (PNT) and maternal spindle transfer (MST) (see diagram overleaf), could make it possible for a woman carrying mitochondrial DNA mutations to have a healthy child that is genetically related to her. Both techniques rely on the use of healthy mitochondria from a donor's egg as replacements for the damaged mitochondrial DNA that would otherwise be passed on from the mother.

The Nuffield Council on Bioethics has published a report which explores the ethical issues relevant to affected families, potential donors, researchers, medical professionals and others trying to understand and respond to the possibility of using these techniques in treatment. It concludes that:

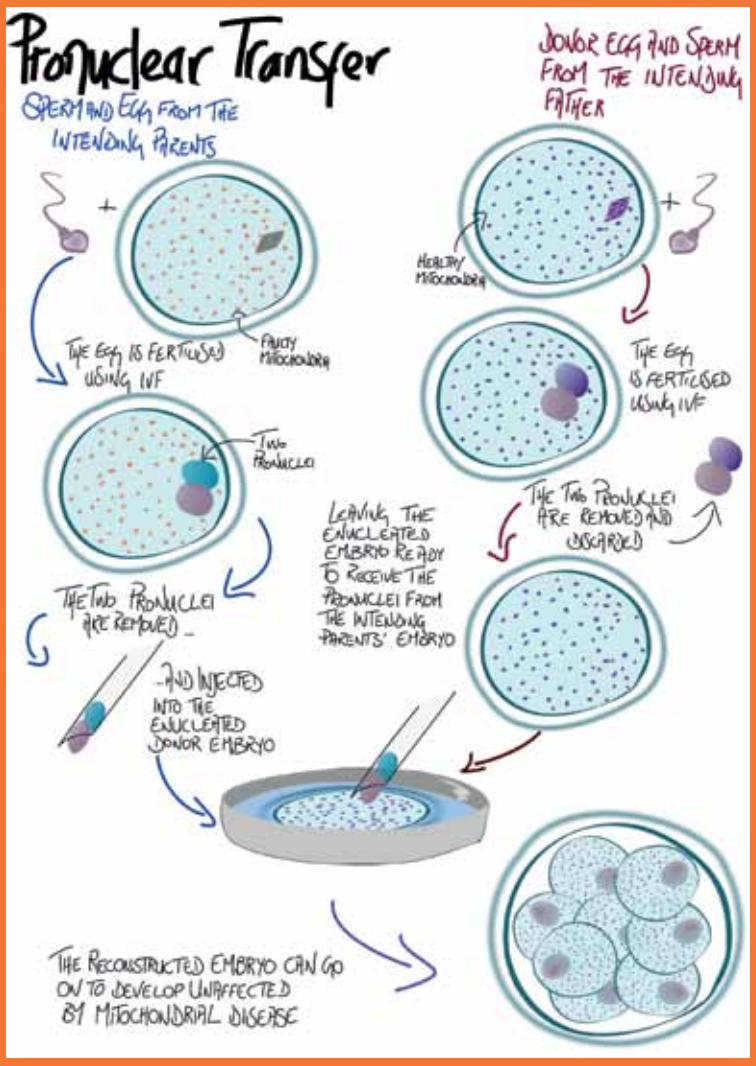
- Provided that the techniques are proved to be safe and effective, and an appropriate level of information and support is offered, it would be ethical for families to use these techniques as treatment.
- Subject to appropriate oversight, it is ethical to gather further information about these techniques, in order that they can be considered for treatment use.

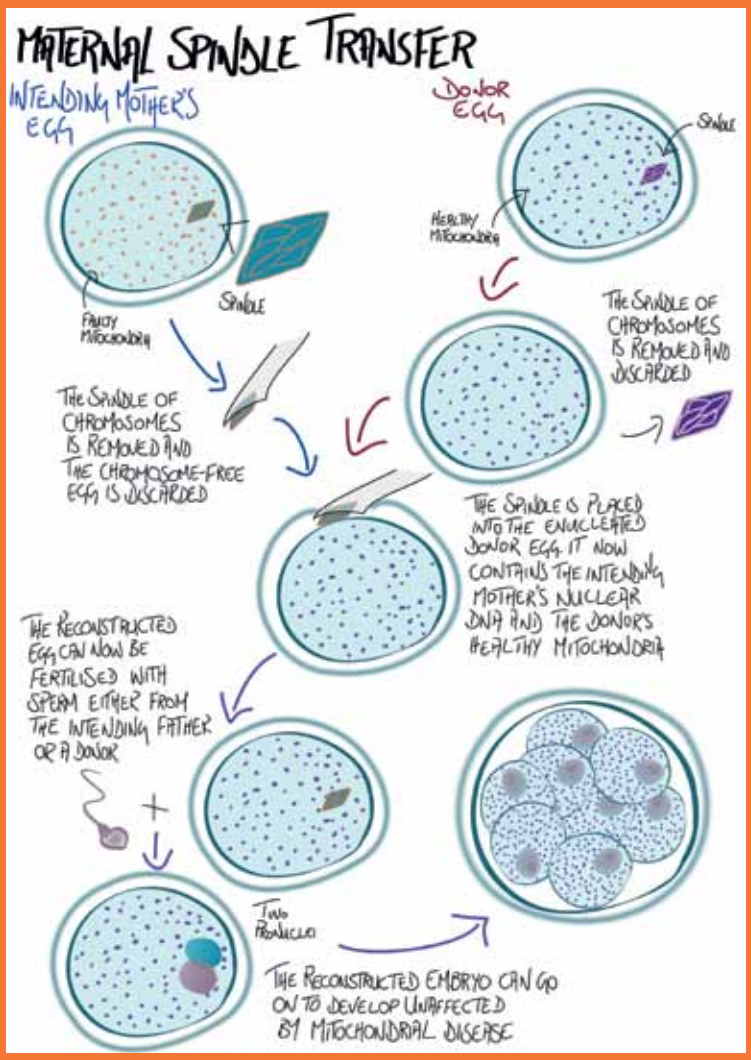
More research is needed to establish whether the techniques in question are safe and effective as treatment options. If they were approved as treatments in future, the Council makes a number of conclusions for policy makers to consider, including that:

- Information and counselling about the implications of these novel treatments must be provided to prospective parents by specialists with appropriate training and up to date information.
- Follow up and evaluation will be crucial to further knowledge about the outcome of these treatments. This could be supported by a centrally funded register of procedures performed in the UK that is available to researchers over several decades.

These developments raise significant questions, both on the status of the mitochondrial donor and possible implications for other potential gene therapies. On these issues the Council concludes:

- As only part of the donated egg is used and not its nuclear DNA, it is not legally or biologically accurate to refer to the mitochondrial donor as a mother or 'third parent' of the resulting child.
- Accordingly, mitochondrial donors in these cases should not have the same status in regulation as egg or embryo donors for reproduction. For example they should not be required to be identifiable to the adults born from their donation.
- The wider policy debate would benefit from a fuller discussion of the ethics of various possible future therapies for genetic disorders. These might include therapies acting through heritable effects on the cell nucleus, and therapies involving nuclear transfer in its various forms.





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