

**Response to the Australian Senate Community Affairs References
Committee inquiry into the Science of mitochondrial donation and
related matters**

May 2018

Introduction

- 1 The Nuffield Council on Bioethics is an independent organisation in the United Kingdom that examines and reports on ethical issues arising from developments in biological and medical research that concern the public interest.
- 2 In 2012, the Nuffield Council on Bioethics conducted a review of the ethical issues raised by novel techniques for the prevention of mitochondrial disorders. The Council's report, *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review* is available at:
<http://nuffieldbioethics.org/project/mitochondrial-dna-disorders>

Background

- 3 The conclusions of this review informed public and parliamentary debates surrounding the acceptability of the techniques. They were fed into the UK Government's consultation process, before the UK became the first country in the world to permit the use of these techniques in treatments, following Parliamentary approval, in 2015.
- 4 In March 2017, the UK Human Fertilisation and Embryology Authority (HFEA) confirmed that it has granted the first licence to use the pronuclear transfer technique for mitochondrial replacement in treatment. The licence was granted to the Newcastle Fertility Centre at Life.
- 5 In February 2018, doctors at Newcastle Fertility Centre successfully applied to treat two women at risk of passing on the neurodegenerative genetic condition, MERFF syndrome. They now have permission to create embryos by combining fertilised eggs created through IVF with mitochondrial DNA from a female donor. The resulting embryos will be implanted in the two women.

Key findings of the Council's report

- 6 Our report concluded that provided the techniques are shown to be sufficiently 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.

- 7 We also concluded that it is ethical to gather further information about these techniques through ongoing research so that they can be considered for use in treatment.
- 8 Donors of mitochondrial material 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.

We made a number of recommendations for policy makers to consider regarding the circumstances in which the techniques, if approved, should be used. These include that:

- 9 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.
- 10 Treatments should only be offered as part of a research trial in centres specialising in mitochondrial disorders, and consent to follow up would need to be included as a mandatory part of parental consent to participation in the trial.
- 11 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.

For further information, please see the Council's report, available at <http://nuffieldbioethics.org/project/mitochondrial-dna-disorders>.