



CEO Statement: Should Australia introduce mitochondrial donation?

5 June 2020: Two reports issued to inform discussion

Today, NHMRC is releasing two reports to inform discussion in Australia about mitochondrial donation.

Mitochondrial donation is an assisted reproductive technology that might help prevent certain rare mitochondrial diseases. As with all new medical technologies, it is important to look at the underlying science and whether the technology is effective and safe. There are also social and ethical issues to consider.

The reports released today are the:

- *Report on NHMRC's public consultation on the social and ethical issues raised by mitochondrial donation* (Consultation Report), and
- *Mitochondrial Donation Expert Working Committee Statement to the NHMRC CEO on the science of mitochondrial donation* (Expert Statement).

These reports are the result of expert advice and community consultation undertaken by NHMRC in 2019 and 2020.

I would like to thank the hundreds of people who contributed to NHMRC's consultation, especially the members of the Mitochondrial Donation Expert Working Committee and the Citizens' Panel.

I encourage the Australian community and interested stakeholders to read the Consultation Report and Expert Statement and continue contributing to the national conversation about this issue. The documents can be accessed from www.nhmrc.gov.au/mito.

Mitochondrial disease is a group of inherited conditions that can cause serious health issues. In severe cases, life expectancy is reduced. Currently, there is no known cure, and treatment options are limited largely to management of symptoms. Between one in 5,000 and one in 10,000 Australians are estimated to develop severe mitochondrial disease during their lifetime.

Mitochondrial donation seeks to reduce the risk of a child inheriting mitochondrial disease from a woman carrying genes that cause the condition. Mitochondrial donation involves using mitochondrial DNA from a donor egg and nuclear DNA from the mother. It would need to be performed at fertility clinics. However, clinical use of mitochondrial donation for reproductive purposes is currently prohibited in Australia.

The Mitochondrial Donation Expert Working Committee considered the science of mitochondrial donation over a series of meetings from March 2019 to March 2020. The experts agreed that further research into mitochondrial donation would help further our understanding of the safety and effectiveness of the technology. However, they did not agree on whether more research must be done before using mitochondrial donation in Australia or whether the technology could be introduced safely now, with more research undertaken during and after its introduction.

From September to November 2019, NHMRC asked the Australian community to consider the social and ethical issues raised by mitochondrial donation. The Consultation Report outlines the views of the Australian community on issues such as: the rights and wellbeing of the child and the donor, the importance of genetic kinship, the genetic composition of embryos, and who should have access to the technology.

Many Australians participated in the community consultation through various events and online. The Citizens' Panel met over two weekends to consider and reach a position on mitochondrial donation. I thank everyone who participated for their strong engagement and for their contribution in expressing their views on these important issues. It is vital that the Government continues to engage with the Australian community about the possible introduction of emerging technologies like mitochondrial donation.

The reports released today respond to the Senate Community Affairs References Committee *2018 Inquiry into the science of mitochondrial donation and related matters*.

The Mitochondrial Donation Expert Working Committee was comprised of Australia's leading experts in mitochondrial donation and consumer issues. The Committee informed the development of the Expert Statement and the consultation process and I thank the members for their care and dedication.

For further information about mitochondrial donation, including an issues paper, video and the consultation process, please visit www.nhmrc.gov.au/mito.

If you have further enquiries please email embryo.research@nhmrc.gov.au.