



Mitochondrial Donation Community Consultation Citizens' Panel Position Statement



For further information on NHMRC's
work on Mitochondrial Donation,
visit

www.nhmrc.gov.au

Foreword

In 2019, the National Health and Medical Research Council (NHMRC) was tasked by the Australian Government to undertake a public consultation seeking the community's views on the possible introduction of mitochondrial donation, to prevent the transmission of mitochondrial disease, into Australian clinical practice. This work was in response to the Senate Community Affairs References Committee report of its Inquiry into the Science of Mitochondrial Donation and Related Matters.

NHMRC developed a consultation process that aimed to obtain the views from across the community. An important part of this approach was the formation of the Citizens' Panel and this resultant statement.

The Citizens' Panel was established to provide an opportunity for a group of people to assist the Government in making decisions about whether to change the law to allow mitochondrial donation in Australia. It brought together a diverse group of Australians, with different backgrounds and experiences, but minimal knowledge about mitochondrial donation. As a group, they were provided with information and formulated a position statement in response to the overarching question:

What are the views of the broader Australian community on the possible introduction of mitochondrial donation into clinical practice, once the scientific, ethical and social issues are generally understood?

The Citizens' Panel met over two weekends. The first weekend (19–20 October 2019) was held in Adelaide and included presentations from several experts in the fields of science and medicine, law and ethics, as well as patient advocacy representatives. The focus was on participants learning about issues related to mitochondrial donation and engaging with the experts, and each other, to develop their understanding of the issues and formulate initial viewpoints. The second weekend (9–10 November 2019) was held in Brisbane and focused on answering the participants' questions, strengthening their understanding of mitochondrial donation and developing this statement from the participants that summarised the Panel's position on the overarching question. Participants were encouraged to discuss the overarching question with their communities and to incorporate their learnings from those discussions into the development of the statement.

Both weekends were managed by a neutral facilitator to enable participants to ask questions, learn and share their views – and their reasons for those views – in a safe and supportive environment.

This statement has been written by the members of the Citizens' Panel. It expresses their expectations, concerns and recommendations about mitochondrial donation, and outlines points of agreement and disagreement among the participants. It is designed to help inform policy makers and researchers on the views and attitudes likely to be held by members of the Australian community if these members were sufficiently informed about mitochondrial donation and able to explore the technology and issues at length. It demonstrates to the Australian public that a broad range of issues was canvassed during the Citizens' Panel process and that ordinary citizens drove the process and final outcomes.

NHMRC wishes to thank the Citizens' Panel and the experts who joined their meetings for their contribution to this important process.

Statement of citizens' panel on mitochondrial donation

This statement was written by the 2019 citizens' panel on mitochondrial donation.

1. Having the option of mitochondrial donation

We see a number of reasons why it is important for people who are at risk of passing on mitochondrial disease to their children to have the option of mitochondrial donation. The main reasons are:

- It could help prevent children being born with mitochondrial disease, which is a horrible disease with no cure currently available. So mitochondrial donation would help prevent this suffering and untimely death, with the aim of improving quality of life.
- In addition, it could give people at risk of passing on mitochondrial disease an opportunity to have healthy children who are genetically related to both parents.
- Potentially, it could help break the cycle of mitochondrial disease in families, reduce their emotional trauma and improve their mental health and wellbeing.
- Economically, it would reduce costs to the community of providing healthcare and disability support to people affected by mitochondrial disease and their families.

We are aware of the unknowns related to mitochondrial donation, but the majority have the view that mitochondrial donation should be permitted.

In coming to this view, we took into account the following:

- Any negative impacts on the child are likely to be less than if child was born to their parents without mitochondrial donation being used.
- Risks to the child can be minimised by gathering more information:
 - More data about outcomes for children born of mitochondrial donation in other countries will become available by the time any changes in Australian law were passed and an Australian clinic was ready to accept its first prospective parents, and

- o This period of time would also allow for more studies on large animals to be conducted.
- The unknown impact on future generations can be also minimised with further research.

A small minority of us feel that mitochondrial donation should not be permitted, because of unresolved concerns. These are:

- Too many unknowns about the process and outcomes.
- Impacts on the life of the child to be born, both health and privacy implications.
- Impact on future generations.

2. Who needs to be considered in making mitochondrial donation legally permissible

We agree that the following people need to be taken into account when deciding how to change the law, and put mitochondrial donation into clinical practice.

The child

We recognise that there could be negative effects on the child born of mitochondrial donation, particularly:

- That the child could still develop mitochondrial disease – there is not a guarantee of success.
- The unknown level of risk that mitochondrial disease might re-appear in the next generation (by a healthy female born from mitochondrial donation going on to have a child who then gets mitochondrial disease).
- Medicalisation of the child, because of follow-up testing.
- Risk to the child's privacy from media and social scrutiny.
- Follow up of children should be actively encouraged, especially as part of regular health checks, but not mandatory.

We feel that people wanting to use mitochondrial donation should be made of aware of the risks to the child, and also that attention should be given to finding ways to reduce the risks.

The donor

We think there would need to be safeguards to protect egg donors from various harms or risks, including exploitation, coercion, and loss of privacy. Specifically, we agree that attention should be given to the following aspects of the process of egg donation:

- Egg donors should come under existing frameworks that protect the rights of egg donors in Assisted Reproductive Technologies (ART) (including privacy, free choice, counselling and informed consent).
- Donors should be screened to ensure healthy viable eggs.
- Egg donors should have the right to withdraw up until their eggs have been collected.
- Women should not be excluded from being egg donors just because they have not had children of their own yet.
- Women should be compensated for all costs of being an egg donor, including loss of income.

We are also concerned to make sure potential egg donors are not put off by the process. We have mixed views on payment to donors and whether donors should have the option to remain anonymous to the child if they want to.

The prospective parents

We feel that the following issues about prospective parents should be taken into account:

- Affordability - mitochondrial donation should be available to everyone who needs it, not just to those who can afford to pay. Various forms of financial subsidy should be considered.
- Methods for increasing availability of egg donors, such as egg sharing schemes, should be considered.
- Counselling for prospective parents, which they could have on-going access to, would be very important.

3. Considerations in changing the law

We agree that these considerations should be taken into account when designing the change in law:

- Oversight by an independent body with scientific expertise.
- Protection against possible misuses of the science, including cloning and creation of designer babies. This needs to be kept in mind when changing law about cloning.
- Mitochondrial donation should only be available for the avoidance of mitochondrial disease, not for other purposes.
- Regular review of outcomes to promote progress in research and clinical practice.
- Protection for everyone involved if something goes wrong.
- Potential positive impact including possibility of more research and funding leading to new medical discoveries.
- Importance of long-term monitoring of outcomes for the next generation.

We also discussed whether mitochondrial donation should be accessible to Australian residents only in the initial stages. We have mixed views on this.

We appreciate being involved in this process and would like to come to Canberra if this issue is debated in Parliament.



