



Australian Government

Department of Health

Consultation Summary Report

Public consultation on the approach to
introduce mitochondrial donation in Australia



Overview

The Australian Government is seeking to introduce mitochondrial donation to Australia in a staged and closely monitored way.

Mitochondrial donation is an IVF-based assisted reproductive technology. It has the potential to prevent mitochondrial disease in babies born to mothers who may otherwise pass on the disease.

The aim is to give impacted families greater reproductive choices and reduce the burden of disease for future generations. The Government plans to proceed slowly, through a 2-Stage implementation approach.

A public consultation process conducted by the Department of Health was held from 5 February 2021 to 15 March 2021, to provide the community with the opportunity to comment on the 2-Stage approach to implementation being proposed by the Government.

As part of this process, a Public Consultation Paper explaining the proposed approach to introduce mitochondrial donation in Australia, and Q&As were available through the Department of Health (the Department) website. The Department also met with interested stakeholders including representatives of advocacy and religious groups, and some State and Territory Government officials.

The science and ethics of mitochondrial donation are complex. In Australia, mitochondrial donation has been the subject of two previous national consultation processes; a Senate Inquiry in 2018 and a public consultation process and consideration by an expert committee established by the National Health and Medical Research Council (NHMRC) in 2019-20.

Both found support for mitochondrial donation. Proponents base their support on:

- the right of a child to the enjoyment of the highest attainable standard of health
- the prevention of disease and disability
- the promotion of choice and reproductive freedom, and
- reduced burden of disease for the community.

There are, however, a number of ethical issues associated with mitochondrial donation, the foremost being the creation and destruction of embryos. For some in the community these issues are highly significant and are seen to cross ethical lines, preventing them from supporting mitochondrial donation, despite its potential benefits. Some believe that it creates children with three parents or is a form of genetic modification.

While the public consultation process held in February and March 2021 sought feedback on the 2-Stage approach to introducing mitochondrial donation in Australia, the majority of feedback reflected the responses provided through the Senate Inquiry and National Health and Medical Research Council (NHMRC) consultation process.

Those individuals and groups supporting the introduction of mitochondrial donation in Australia largely supported the cautious 2-Stage approach being proposed. A small number advocated for a faster move to Stage-two, or for more organisations to be funded to deliver mitochondrial donation under trial conditions in Stage-one.

Those individuals and groups not supporting the introduction of mitochondrial donation in Australia sometimes suggested other options for families seeking to have children such as adoption. Other suggestions were for a much longer public consultation period prior to introduction, and complete transparency regarding the impacts and risks being described to those people considering undertaking mitochondrial donation.

Summary of feedback

The consultation process invited individuals and groups to respond to a short 'survey' of two questions, and/or to make a more detailed written submission. The survey questions were:

- 1) Why are you interested in providing feedback /comments on the consultation paper?
- 2) What is your feedback or comments on the Government's staged approach to legalising mitochondrial donation in Australia?

In total, 74 survey responses were received and 27 written submissions were made. Some individuals and groups responded to the survey and also provided a written submission.

Many who responded to the survey questions, were individuals who have had direct experience with mitochondrial disease. The message from those individuals was of support for introducing mitochondrial donation in Australia, including the two-stage approach being proposed.

A small number of individuals who responded to the survey raised concerns over the introduction of mitochondrial donation in Australia. In this context, the key issues raised related to the use of mitochondrial donation due to the newness of the science, ethical concerns about using the technique and the appropriateness of publicly funding the technology. In relation to the way introduction is proposed, concerns were centered on the length of the public consultation period, and that proper oversight and regulation should occur if the technique is introduced.

The written submissions were provided by individuals with direct experience with mitochondrial disease, persons representing religious and ethics organisations, professional and medical organisations, research and academic institutes, and mitochondrial disease advocacy groups.

Those received from religious and ethics organisations raised a variety of concerns about mitochondrial donation, reflecting the feedback received as part of the 2018 Senate Inquiry and 2019-2020 NHMRC consultation process, as discussed above. Some of the key issues raised related to whether the use of this technology constitutes genetic modification, the creation and destruction of embryos, how to ensure privacy of individuals undertaking mitochondrial donation and whether there is a risk that financial incentives could be used to attract female donors.

Medical organisations and professional bodies were generally supportive of the proposal to introduce mitochondrial donation, as proposed. Some made suggestions about the proposed implementation process, for example, proposing movement to Stage-two more quickly.

Research and academic institutes were supportive of the Government's approach to the introduction of mitochondrial donation as proposed. Some made suggestions that part of the Australian approach should involve monitoring the progress in the UK closely and ensuring the NHMRC are integrated into the decision-making process. There were some concerns raised about instituting safeguards to secure the long-term safety of mitochondrial donation, a feature of which would be ensuring sufficient training of embryologists before mitochondrial donation can be introduced.

Individuals with lived experience of mitochondrial disease were supportive of the overall approach to legalising mitochondrial donation. Many individuals shared their individual stories and hopes for Stage-one to begin as soon as possible.

Next Steps

All comments and submissions will be considered carefully by the Australian Government.

The Australian Government is grateful to those who took the time to provide feedback as part of the consultation process.