

Australian Genomics Submission on Legalising Mitochondrial Donation in Australia Public Consultation Paper

Australian Genomics is an Australian Government initiative to support genomic research and its translation into clinical practice by broad engagement and a collaborative national approach. By interfacing with state and federal governments, industry and global genomics initiatives, Australian Genomics drives policy and practice and facilitates growth of the sector. Australian Genomics previously participated in the ELSI consultation workshop and provided a submission on the “Mitochondrial Donation Issues Paper – Ethical and Social Issues for Community Consultation”. The purpose of this note is to affirm support for the Government proposal on legalising mitochondrial donation in Australia. We base our support on the following:

- 1) The proposed model is evidence based and derived in consultation with medical specialists and robust scientific review. By incorporating the UK model, the 2-stage approach will both allow Australians immediate access to the technology and allow for improvement based on the evidence base of both the UK and Australia’s own experiences of implementation. The model also facilitates prompt implementation directly into clinical practice, whilst providing appropriate medical safeguards.
- 2) Introduction will have an immediate and highly positive impact on individuals and families affected by mitochondrial disease. For some Australians with mitochondrial disease, the proposed IVF-based assisted reproductive technology is their only option to have a biologically related child without mitochondrial disease. We also stress the importance of having this technology available in an equitable way to all Australians, which could be supported by prioritising the pathway to an MBS item number.
- 3) There is good evidence of significant cost savings to health care. The UK Department of Health assessed that 20 healthy births per year using mitochondrial donation would equate to a savings of GB 33.5 million pounds. As mentioned in the consultation paper, one child a week is born in Australia with a severe form of mitochondrial disease.
- 4) The proposal is in line with both Australia’s Long Term National Health Plan (potentially intersecting Pillar 3: ‘Mental health and preventive health’ and Pillar 4: ‘Medical research to save lives and boost our economy’), and the Draft National Preventive Health Strategy including Aim 1 that ‘Australians have the best start to life’. Importantly, the proposal is consistent with Section 2.4.1.5 of the National Strategic Action Plan for Rare Diseases, concerning ongoing review of health technology policy.
- 5) The mitochondrial donation proposal is the culmination of a long and rigorous consultation process including interrogation of the ethical and social issues, a senate committee report, and input from relevant patient advocacy groups such as the Mito Foundation.

Collectively considered, Australian Genomics supports the legislation for Mitochondrial Donation in Australia, and the 2-stage approach outlined in the public consultation paper. This will allow for a measured introduction of the technology within a regulated framework. We believe this legislation will dramatically improve the reproductive options of individuals with mitochondrial disease. Additionally, the legislation will be an important step forward for implementation of genomic technologies into Australian health care.