



Committee Secretary
Legal Affairs and Safety Committee
Parliament House
George Street
BRISBANE QLD 4000

Via email: lasc@parliament.qld.gov.au

Dear Legal Affairs and Safety Committee

Inquiry into matters relating to donor conception information in Queensland

Thank you for the opportunity to make a submission to the Legal Affairs and Safety Committee Inquiry into matters relating to donor conception information in Queensland. I am pleased to provide the attached submission to the inquiry on behalf of the National Health and Medical Research Council (NHMRC).

I also give permission for NHMRC's submission be published in full.

Yours sincerely

Professor Anne Kelso AO
Chief Executive Officer

21 April 2022



Submission to the Legal Affairs and Safety Committee (LAS Committee) Inquiry into matters relating to donor conception information (Qld)

The National Health and Medical Research Council (NHMRC) is Australia's leading expert body for supporting health and medical research; for developing health advice for the Australian community, health professionals and governments; and for providing advice on ethical behaviour in health care and in the conduct of health and medical research.

Through the work of the Embryo Research Licensing Committee, NHMRC is responsible for administering the *Research Involving Human Embryos Act 2002* and *Prohibition of Human Cloning for Reproduction Act 2002*. These Acts prohibit certain practices, including human cloning for reproduction. They also regulate the use of excess human embryos created through assisted reproductive technology, the creation of embryos by other means and the use of such embryos in research.

Ethical guidelines on the use of assisted reproductive technology in clinical practice and research

NHMRC has had a long-standing role in the provision of ethical advice for the conduct of assisted reproductive technology (ART), including guidance relating to donor conception information. NHMRC's [*Ethical guidelines on the use of assisted reproductive technology in clinical practice and research, 2017*](#)¹ (ART Guidelines) are relevant to the work of the LAS Committee.

Developed by the [Australian Health Ethics Committee](#)² (AHEC), the ART Guidelines provide an overarching framework for the conduct of ART in both clinical practice and research. The ART Guidelines identify guiding principles to inform the conduct of clinicians and researchers. The guiding principles are in line with community expectations that ART activities will be conducted in a manner that shows respect, minimises potential harms and supports the ongoing wellbeing of all parties, including persons born as a result of ART. The guiding principles are supported by practical guidelines that are to be followed unless there is an effective alternative option that is consistent with the relevant principle, or unless otherwise specified by law.

The ART Guidelines highlight the importance of a voluntary exchange of information between the person born, the gamete donor(s) and the intending parent(s), with the valid consent of all parties, and provide the minimum level of information that should be accessible to all relevant parties. In this context, good record keeping is essential for short and long-term follow-up of procedures and to facilitate the sharing of information between relevant parties. Of particular relevance to the LAS Committee's review are paragraphs 4.2.3 – 4.2.4, 4.4.1 – 4.4.4, 5.6 – 5.10, chapter 6 and chapter 9 of the ART Guidelines.

¹ <https://www.nhmrc.gov.au/guidelines-publications/e79>

² <https://www.nhmrc.gov.au/about-us/leadership-and-governance/committees/australian-health-ethics-committee-ahec>
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The ART Guidelines form an integral part of the robust framework for the conduct of ART in Australia. The accreditation of ART clinics by the Reproductive Technology Accreditation Committee (RTAC) requires clinics to comply with government laws and guidelines concerning the practice of ART, including the ART Guidelines.

Upcoming changes to Australian legislation

The *Mitochondrial Donation Law Reform (Maeve's Law) Act 2022* amends the *Prohibition of Human Cloning for Reproduction Act 2002*, *Research Involving Human Embryos Act 2002* and *Research Involving Human Embryos Regulations 2017* to allow for the use of permitted mitochondrial donation techniques under a specified mitochondrial donation licence for the purposes of certain research and training, and in clinical settings. This Act passed both Houses of the Australian Parliament on 30 March 2022, received Royal Assent on 1 April 2022 and will come into effect on 2 October 2022, unless proclaimed at an earlier date.

The revised legislation includes provisions, in the context of mitochondrial donation, relating to the collection, storage and disclosure of information about donors and donor conceived persons. It may also be relevant for the LAS Committee to consider the impact of this legislation, particularly in relation to records and access to information.

Following the passage of this Act, AHEC will be undertaking a limited and focused review of the ART Guidelines to incorporate guidance specifically on the use of mitochondrial donation in Australian clinical practice. AHEC will be commencing this review shortly, with a view to finalising any amendments to the ART Guidelines by the end of 2022.

Further information

Further information about the ART Guidelines is available on [NHMRC's website](https://www.nhmrc.gov.au/art)³.

³ <https://www.nhmrc.gov.au/art>
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