

# LEGAL AFFAIRS AND SAFETY COMMITTEE

## Report No. 33, 57<sup>th</sup> Parliament

### Inquiry into matters relating to donor conception information

#### FINAL QUEENSLAND GOVERNMENT RESPONSE

On 24 February 2022, the Legislative Assembly referred an inquiry into matters in relation to donor conception information to the Legal Affairs and Safety Committee (the Committee).

The Committee received 71 written submissions and held a public hearing on 13 May 2022 attended by 17 individuals and organisations.

On 31 August 2022, the Committee tabled in the Legislative Assembly its Report (No. 33, 57<sup>th</sup> Parliament - Inquiry into matters relating to donor conception information), containing six recommendations.

The Queensland Government tabled an interim response to the Committee on 29 November 2022.

#### **Queensland Government response to the Committee's six recommendations**

The Queensland Government supports all recommendations in principle noting that implementation will be subject to further consideration of resourcing and operational needs as well as ongoing targeted consultation.

The Queensland Government acknowledges the importance of a donor-conceived person knowing their genetic origins to establish a sense of identity, enhance wellbeing, have access to medical information and avoid the risk of establishing consanguineous relationships.

Queensland does not have legislation in place to regulate donor conception practices or assisted reproductive technology (ART) services generally, including access to donor conception information. Fertility clinics in Queensland are accredited through the Reproductive Treatment Accreditation Council and adhere to the National Health and Medical Research Council's (NHMRC) *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research* (Guidelines). The Guidelines commenced in 2004 and provide a framework for the collection, storage and provision of information about donor conception practices. Prior to 2004, there were no requirements for clinics in Queensland to obtain consent of the donor to release identifying information to persons conceived from their donation.

The Queensland Government supports in principle that all donor-conceived persons be legislatively provided with the right to know the identity of their donor and siblings, when they reach the age of 18 years, regardless of when they were born as well as donors having access to information about donor-conceived persons.

To ensure the provision of accurate and timely information, it is essential to establish a central donor conception register in Queensland. The Queensland Government supports in principle the establishment of a register to facilitate access to this

information, subject to further consideration of the practical requirements of implementing such a register.

Further consideration is required regarding the implementation, funding and resourcing implications to establish and maintain a register including:

- development of IT systems;
- digitising historical records;
- development of policies and procedures for staff;
- undertaking communication campaigns; and
- developing guidance and web materials and forms for users.

Other considerations that are required to ensure accurate and timely access to information include:

- the implications for fertility clinics to retrieve, check and submit all donor information to a central register, particularly historical information where clinics no longer operate or due to poor practices in record keeping;
- the best way to obtain contact preferences of the persons involved particularly for historical donor conception procedures;
- the need for adequate funding of counselling and support services that are independent of the fertility industry; and
- a communication campaign to inform all past, current and future donors of any changes to the law.

Effective implementation will depend on working through these operational and implementation issues. During 2023, the Government will conduct targeted consultation to inform effective implementation of the recommendations. Timing for introduction of legislation to establish the register and related matters will be subject to the outcomes of this targeted consultation and working through the operational and implementation issues.

The Final Queensland Government response to each recommendation contained in the Committee Report is provided below.

No.	Recommendation	Position	Response
<b>Recommendation 1: Rights of donor conceived persons, including to know their genetic origins</b>			
1	The Committee recommends that all donor-conceived persons be legislatively provided with the right to know the identity of their donor when they reach the age of 18 years, regardless of when they were born.	<b>Support in principle</b>	<p>The Queensland Government supports this recommendation in principle, but notes implementation is subject to establishment of a central donor conception register (see <b>recommendation 5</b>).</p> <p>The Queensland Government acknowledges the importance of a donor-conceived person knowing their genetic origins to establish a sense of identity, enhance wellbeing, have access to medical information and avoid the risk of establishing consanguineous relationships.</p>
<b>Recommendation 2: Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors</b>			
The committee recommends that:			
2.1	Identifying information about donors, including their medical history, be made available on request to all donor-conceived persons when they reach the age of 18 years.	<b>Support in principle</b>	The Queensland Government supports in principle these recommendations to ensure donor-conceived persons have access to identifying information about their donor and any siblings; and donors also have access to information about the gender and year of birth of donor-conceived persons.
2.2	Information about the gender and year of birth of donor-conceived persons born from their donation be made available on request to all donors	<b>Support in principle</b>	

No.	Recommendation	Position	Response
2.3	Information about the gender and year of birth of donor-conceived siblings be made available on request to donor-conceived persons	<b>Support in principle</b>	The Queensland supports in principle the establishment of a register to facilitate access to this information.
2.4	Requests from donors for contact with donor-conceived persons be facilitated subject to the consent of the donor-conceived person	<b>Support in principle</b>	The Queensland Government acknowledges the importance of obtaining a person's consent before contact is facilitated between donors, donor-conceived persons and donor siblings.  Further consideration and consultation is required to determine the best way to obtain consent of the persons involved, particularly for historical donor conception procedures, and the provision of appropriate support services (see <b>recommendation 4</b> ).
2.5	Requests from donor-conceived persons for contact with their donor be facilitated subject to the consent of the donor.	<b>Support in principle</b>	
2.5	Requests from donor-conceived persons for contact with their donor siblings be facilitated subject to the consent of both parties	<b>Support in principle</b>	
<b>Recommendation 3: Access to historical clinical records and implications of retrospectivity</b>			
The Committee recommends that the Queensland Government introduces legislation to:			
3.1	Prohibit the deliberate destruction of historical donor records	<b>Support in principle</b>	To ensure all donor-conceived persons have access to information, no matter when the donor conception occurred, the Queensland Government supports in principle access to historical clinical records for all donor-conceived persons and to prevent the destruction of any historical records.  Further consideration and consultation is required on the implications for fertility clinics to retrieve, check and submit all donor information to a central register, particularly historical information where clinics no longer operate or due to poor practices in record keeping; noting that unlike other jurisdictions that
3..2	Require clinics involved now and historically with donor conception to retrieve, check and submit all donor information to a central register within a reasonable timeframe	<b>Support in principle</b>	

No.	Recommendation	Position	Response
			have a donor conception register, Queensland does not regulate fertility clinics.
3.3	Provide that birth certificates of donor-conceived persons be annotated to note the fact of donor conception	<b>Support in principle</b>	The Queensland Government supports this recommendation in principle and will consider how best to give effect to this recommendation to ensure birth certificates of donor-conceived people reflect their donor conception.
3.4	Provide that birth certificates of donor-conceived persons already born be amended to note the fact of donor conception	<b>Support in principle</b>	
<b>Recommendation 4: Access to support and counselling for donor-conceived persons, recipient parents and donors</b>			
The Committee recommends that:			
4.1	The Queensland Government considers funding counselling and support services for donor conceived persons, recipient parents and donors to facilitate positive outcomes from recommendations in this report, utilising services with relevant and lived experience	<b>Support in principle</b>	The Queensland Government acknowledges the importance of counselling and support services being in place to support the experience and wellbeing of donor-conceived persons, recipient parents and donors.
4.2	Such counselling and support services should be independent of the fertility industry		The Queensland Government supports this recommendation in principle noting the need for adequate funding of counselling and support services that are independent of the fertility industry.
<b>Recommendation 5: Whether a register should be established</b>			
The committee recommends, as a matter of urgency, that;			
5.1	A central donor conception register be established within the Registry of Births, Deaths and Marriages	<b>Support in principle</b>	The Queensland supports in principle the establishment of a register that collects and provides access to current and historical donor conception information.

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			<p>Further consideration is also required regarding the funding and resourcing implications to establish and maintain a register including:</p> <ul style="list-style-type: none"> <li>• development of IT systems;</li> <li>• digitising historical records;</li> <li>• development of policies and procedures and upskilling for staff;</li> <li>• undertaking communication campaigns;</li> <li>• developing guidance and web materials and forms for users.</li> </ul> <p>During 2023, the Government will conduct targeted consultation to inform effective implementation of the recommendations. Timing for introduction of legislation will be subject to the outcomes of this targeted consultation and working through the operational and implementation issues.</p>
5.2	This register be mandatory in relation to donor conception achieved within a fertility clinic	<b>Support in principle</b>	<p>The Queensland Government supports the register being mandatory for fertility clinics to ensure accurate recording keeping and having access to accurate donor conception information.</p> <p>Further consideration and consultation is required on the implications for fertility clinics in providing donor conception information in a timely way, including historical information.</p>
5.3	This register be available voluntarily to those who have pursued donor conception in private arrangements	<b>Support in principle</b>	<p>The Queensland Government supports donor-conceived persons having access to information about their donors.</p>

No.	Recommendation	Position	Response
5.4	The Queensland Government undertake an investigation to determine how to a) encourage participants in private donor conception arrangements to lodge donor conception information on the central donor conception register and b) ensure the information is accurate	<b>Support in principle</b>	<p>However, acknowledging the difficulties in enforcing a mandatory requirement for those who pursued donor conception in private arrangements, the Queensland Government supports that the collection of information from private arrangements be voluntary.</p> <p>Further consideration is required on how best to encourage participants in private donor conception arrangements to provide donor conception information and to ensure the information is accurate given there is no verification of the records by clinics.</p>
5.5	The staff who operate this register to actively contact previously anonymous donors about relevant changes to the law and available support services, and permit them to lodge contact preference	<b>Support in principle</b>	The Queensland Government supports this recommendation in principle noting that further consideration is required on any law changes and the implications in actively contacting all previous anonymous donors about changes to the law, available support and how to lodge contact preferences.
5.6	The Queensland Government works with states and territories to investigate the linking of donor conception registers across jurisdictions and any potential implications.	<b>Support in principle</b>	<p>The Queensland Government supports this recommendation in principle recognising the importance for people to access donor conception information and understand their genetic origins.</p> <p>Further consideration will be given to how to most effectively and appropriately work with states and territories and the Australian Government including considering the different approaches taken in those</p>

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			jurisdictions that have established a register including the variations in how information is collected and accessed; and taking into account that not all jurisdictions have established a donor conception register.
<b>Recommendation 6: Benefits, risks and implications on donor conception practices arising from any recommendations</b>			
6	The committee recommends that all past, current and future donors be fully informed of relevant changes to the law and that they will be identifiable to those born from their donation.	<b>Support in principle</b>	The Queensland Government supports this recommendation in principle noting that further consideration is required on any law changes and the implications in undertaking a communication campaign to inform all past, current and future donors of any changes to the law, particularly for donors who made donations prior to the introduction of the 2004 Guidelines.

End