



Inquiry into matters relating to donor conception information

**Report No. 33, 57th Parliament
Legal Affairs and Safety Committee
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Legal Affairs and Safety Committee

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Abbreviations and definitions

Adoption Act	<i>Adoption Act 2009</i>
ANZARD	Australia and New Zealand Assisted Reproduction Database
ART	Assisted Reproductive Technology
ART Act	<i>Assisted Reproductive Treatment Act 2008 (Vic)</i>
ART SA	<i>Assisted Reproductive Treatment Act 1988 (SA)</i>
Committee	Legal Affairs and Safety Committee
DC	donor conceived
DCP	donor conceived person/s
DCR	Donor Conception Register
FSA	Fertility Society of Australia
HART Act	<i>Human Assisted Reproductive Technology Act 2004 (Parliament of New Zealand)</i>
HRA	<i>Human Rights Act 2019</i>
HRT Act	<i>Human Reproductive Technology Act 1991 (WA)</i>
IP Act	<i>Information Privacy Act 2009</i>
ISS	International Social Service Australia
IVF	In-vitro fertilisation
NHMRC	National Health and Medical Research Council
NHMRC Guidelines/Guidelines	National Health and Medical Research Council's <i>Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research</i>
OIC	Office of the Information Commissioner
PHCR Act	<i>Prohibition of Human Cloning Act 2022</i>
QFG	Queensland Fertility Group
RIHE Act	<i>Research Involving Human Embryos Act 2022</i>
RTCA	Reproductive Technology Accreditation Council
VARTA	Victorian Assisted Reproductive Treatment Authority
WLSQ	Women's Legal Service Queensland

Definitions

ART/assisted reproductive technology	The application of laboratory or clinical techniques to gametes and/or embryos for the purposes of reproduction.
ART activity/procedure	An assisted reproductive technology treatment or procedure which may include procedures involving the in-vitro (outside of body) handling of human eggs (also known as oocytes), sperm or embryos for the purposes of establishing a pregnancy. Donors may provide oocytes, sperm or embryos.
clinic	A person or body accredited to carry out ART by: (a) the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia; or (b) if the Research Involving Human Embryos Regulations 2003 prescribe another body or other bodies in addition to RTAC, that other body or any of those other bodies, as the case requires. [RIHE Act s 8]
consanguineous relationship	A sexual relationship between second cousins or closer.
donated embryo	Embryos given to an individual or couple for their reproductive use.
donated gamete	Sperm or egg(s) given to an individual or couple for their reproductive use.
donor conceived person/people	People that have been conceived by donor conception.
donor / gamete donor	A person who gives sperm or egg(s) for use by a person other than their spouse or partner in a reproductive procedure, or to research.
donor recipient/ donor parent	A person to whom gametes or embryos are donated.
donor sibling	Each of two or more offspring having one or both parents (genetic or social) in common.
gamete	A human sperm or egg (ovum or oocyte) and includes: (a) any cell that has resulted from a process of meiosis, or (b) tissue containing such cells (also referred to as gonadal tissue)

human embryo	A discrete entity that has arisen from either: (a) the first mitotic division when fertilisation of a human oocyte by a human sperm is complete, or (b) any other process that initiates organised development of a biological entity with a human nuclear genome or altered human nuclear genome that has the potential to develop up to, or beyond, the stage at which the primitive streak appears and has not yet reached 8 weeks of development since the first mitotic division. [RIHE Act s 7(1)]
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Sources include: NHMRC's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*; Commonwealth of Australia, The Senate, Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, p 1; Jade Newman, et al, & ANZARD, *Assisted reproductive technology in Australia and New Zealand 2019*, UNSW Sydney, p 1; Donor Conceived Australia, Submission 59; Donor Conceived Aotearoa, submission 39.

Chair's foreword

The journey to becoming a parent is different for everyone, and for those who do struggle to conceive, creating a family can come with difficulty and heartache. Assisted reproductive technology (ART) is an increasingly popular option, and it is therefore timely that the Queensland Government consider the unique needs of those who are conceived through this process.

This report presents a summary of the Legal Affairs and Safety Committee's examination of the inquiry into matters relating to donor conception information.

Children born through donor conception often have the same desire and need to know their genetic history as any other person. However, Queensland's legislative arrangements do not currently reflect these needs.

Consequently, the committee heard of donor-conceived people continually searching the faces of strangers looking for genetic similarities. We heard of people being refused records and information and of people conducting comprehensive searches through social media trying to connect with biological family. We heard from people who were so uncertain of their genetic history that they were apprehensive to embark on relationships themselves.

The recommendations in this report will make it possible for donor-conceived people to be provided with important information—including medical information—about their donor, and information about donor siblings.

As one submitter stated: 'not having knowledge of one's genetic origins is like having the first chapter missing from one's life story'. Whilst we recognise that the recommendations in this report cannot entirely correct this, our aim is that they go some way to restoring those early chapters.

There was some concern regarding the retrospective application of legislation in this area. It is important to note that DNA testing has changed the landscape, and people are able to access this information now, but without adequate support.

Ultimately, at the heart of this issue lies the central legal and ethical dilemma: does a person's right to know their genetic history outweigh a person's right to privacy? The committee has found that it does.

This was an important inquiry to have, and to be part of. On behalf of the committee, I thank those individuals and organisations who made written submissions on this important issue, and to those who provided in-person testimony to the committee. I also thank our Parliamentary Service staff for their assistance.

I commend this report to the House.



Mr Peter Russo MP

Chair

Recommendations

Recommendation 1: Rights of donor-conceived persons, including to know their genetic origins 31

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, regardless of when they were born.

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 32

The committee recommends that:

- 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
- information about the gender and year of birth of donor-conceived persons born from their donation be made available on request to all donors
- information about the gender and year of birth of donor-conceived siblings be made available on request to donor-conceived persons
- requests from donors for contact with donor-conceived persons be facilitated subject to the consent of the donor-conceived person
- requests from donor-conceived persons for contact with their donor be facilitated subject to the consent of the donor
- requests from donor-conceived persons for contact with their donor siblings be facilitated subject to the consent of both parties.

Recommendation 3: Access to historical clinical records and implications of retrospectivity 42

The committee recommends that the Queensland Government introduces legislation to:

- prohibit the deliberate destruction of historical donor records
- 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
- provide that birth certificates of donor-conceived persons be annotated to note the fact of donor conception
- provide that birth certificates of donor-conceived persons already born be amended to note the fact of donor conception.

Recommendation 4: Access to support and counselling for donor-conceived persons, recipient parents and donors 44

The committee recommends that:

- 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
- such counselling and support services should be independent of the fertility industry.

Recommendation 5: Whether a register should be established**50**

The committee recommends, as a matter of urgency, that:

- a central donor conception register be established within the Registry of Births, Deaths and Marriages
- this register be mandatory in relation to donor conception achieved within a fertility clinic
- this register be available voluntarily to those who have pursued donor conception in private arrangements
- 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
- 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 preferences
- the Queensland Government works with states and territories to investigate the linking of donor conception registers across jurisdictions and any potential implications.

Recommendation 6: Benefits, risks and implications on donor conception practices arising from any recommendations**52**

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.

1 Introduction

1.1 Role of the committee

The Legal Affairs and Safety Committee (committee) is a portfolio committee of the Legislative Assembly which commenced on 26 November 2020 under the *Parliament of Queensland Act 2001* and the Standing Rules and Orders of the Legislative Assembly.¹

The committee's primary areas of responsibility include:

- Justice and Attorney-General
- Women and the Prevention of Domestic and Family Violence
- Police and Corrective Services
- Fire and Emergency Services.

The functions of a portfolio committee include the examination of bills and subordinate legislation in its portfolio area to consider:

- the policy to be given effect by the legislation
- the application of fundamental legislative principles
- matters arising under the *Human Rights Act 2019*
- for subordinate legislation – its lawfulness.²

On 24 February 2022, the Legislative Assembly agreed:

That the Legal Affairs and Safety Committee (the committee) inquire into and report to the Legislative Assembly by 31 August 2022 on:

1. Issues relating to access to donor conception information, including:

- a) rights of donor-conceived persons, including to know their genetic origins
- b) extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors
- c) access to historical clinical records and implications of retrospectivity
- d) access to support and counselling for donor-conceived persons and donors
- e) whether a register should be established
- f) benefits, risks and implications on donor conception practices arising from any recommendations.

2. That the committee consider:

- a) views and experiences of donor-conceived people, donors and industry stakeholders of the current framework
- b) current governance/regulatory frameworks, including registers established interstate

¹ *Parliament of Queensland Act 2001*, section 88 and Standing Order 194.

² *Parliament of Queensland Act 2001*, section 93; and *Human Rights Act 2019*, sections 39, 40, 41 and 57.

- c) options to manage collection, storage, and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives
- d) whether and how to collect and disclose identifying information about donors where a donation was made on the condition of anonymity, including matters relating to consent
- e) whether any model should include information from private donor arrangements
- f) costs of any proposal including to establish and maintain any register and options for efficiencies, including a user-pays model
- g) whether regulating donor conception practices and assisted reproductive technology should also be considered as part of establishing a donor conception register
- h) human rights engaged under the *Human Rights Act 2019*.

1.2 Inquiry process

On 3 March 2022, the committee invited stakeholders and subscribers to make written submissions on the inquiry. Seventy-one submissions were received. See Appendix A for a list of submitters.

The committee held a public hearing on 13 May 2022. See Appendix B for a list of witnesses.

The submissions and transcript of the hearing are available on the committee's webpage.

1.3 Background to the inquiry

1.3.1 Definitions

The term 'donor conception' refers to reproductive techniques which involve the use of donated gametes and embryos. Donor conception relates to a range of procedures that are often collectively referred to as assisted reproductive technology (ART).³ ART procedures involve the in-vitro (outside of body) handling of human eggs (also known as oocytes), sperm or embryos for the purposes of establishing a pregnancy.⁴ Donors may provide oocytes, sperm or embryos. People that have been conceived by donor conception are commonly referred to as being donor conceived.⁵

1.3.2 Donor conception in Australia

The use of donor sperm to achieve pregnancies has existed for a significant period of time. In Australia its use became better known in the 1950s and significantly increased during the 1970s and 1980s.⁶ Technological advances further increased the occurrence of donor conception in Australia with the first in-vitro fertilisation (IVF) procedure in Australia occurring in 1979, and the first IVF baby born in June 1980. Since then numerous other ART practices have been developed (including gamete intra-

³ Commonwealth of Australia, The Senate, Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, p 1, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/report/index. NB: Footnote references relating to this report will be abbreviated as 'Senate report, 2011'.

⁴ Jade Newman, et al, & ANZARD, *Assisted reproductive technology in Australia and New Zealand 2019*, UNSW Sydney, <https://www.fertilitysociety.com.au/wp-content/uploads/Assisted-reproductive-technology-in-Australia-and-New-Zealand-2019.pdf>, p 1.

⁵ Submission 59, p 3.

⁶ Senate report, 2011, p 2.

fallopian transfer, zygote intrafallopian transfer, intracytoplasmic single sperm injection, and surrogacy).⁷

The exact number of donor-conceived persons born in Australia is unknown, as many were conceived with the assistance of general practitioners or through private arrangements outside of a formal healthcare setting. The first data publication in 1992 from the Australia and New Zealand Assisted Reproduction Database (ANZARD) reported 2,237 live births following assisted conception in that year.⁸ The use of ART in Australia continues to increase from 4,253 live births in 2000 to 12,056 in 2010, and to 16,310 in 2019.⁹

1.3.3 Online consumer DNA databases

There are a number of online direct-to-consumer DNA and family history databases available in Australia which can provide, based on a fee-based analysis from a DNA sample, information about living relatives, ancestors, family history and genetic mix sourced from many countries. The accessibility of these services, in terms of use and cost, has had implications for donor conception in Australia.¹⁰ As Professor Daniel Roos explained:

AncestryDNA, which is probably the most common direct-to-consumer DNA private company, will automatically contact individuals who are on their registry when there is a match. If another one of my donor children chooses to submit their DNA to AncestryDNA, I will get an automatic notification that I have another donor child and vice versa. That does happen. I assume that the other direct-to-consumer DNA companies operate the same way.¹¹

1.4 Governance and regulatory frameworks in Australian jurisdictions

The regulation and oversight of ART clinics in Australia occurs via general and specific laws and regulations. General regulation of all professional health practitioners in Australia require that they must be registered, adhere to the general law, and follow professional codes of conduct.¹²

States and territories are obliged to follow the National Health and Medical Research Council's (NHMRC) *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (the NHMRC Guidelines/the Guidelines). They provide for the ethical guidelines for the clinical practice of ART, and the ethical guidelines for research consistent with the Commonwealth legislation *Prohibition of Human Cloning for Reproduction Act 2002* (PHCR Act) and *Research Involving Human Embryos Act 2002* (RIHE Act).¹³

⁷ Parliament of Tasmania, House of Assembly Standing Committee on Community Development, *Inquiry into Donor Conception Practices in Tasmania*, 2017, p xii, [https://www.parliament.tas.gov.au/ctee/house/Reports/Report%20Inquiry%20into%20Donor%20Conception%20\(As%20Tabled\).pdf](https://www.parliament.tas.gov.au/ctee/house/Reports/Report%20Inquiry%20into%20Donor%20Conception%20(As%20Tabled).pdf).

⁸ ANZARD, Australia and New Zealand Assisted Reproduction Database, <https://npsu.unsw.edu.au/data-collection/australian-new-zealand-assisted-reproduction-database-anzard>.

⁹ ANZARD, Assisted reproductive technology in Australia and New Zealand, <https://npsu.unsw.edu.au/data-collection/australian-new-zealand-assisted-reproduction-database-anzard>.

¹⁰ Caitlin Macmillan, public hearing transcript, Brisbane, 13 May 2022, p 20.

¹¹ Public hearing transcript, Brisbane, 13 May 2022, p 5.

¹² Health Law Council, <https://www.healthlawcentral.com/assistedreproduction/clinicoversight/>.

¹³ NHMRC, *Ethical guidelines for Assisted Reproductive Technology*, <https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-assisted-reproductive->

a specified mitochondrial donation licence for the purposes of certain research and training, and in clinical settings.’ The *Mitochondrial Donation Law Reform (Maeve’s Law) Act 2022* 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. In relation to this inquiry, 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.²¹

1.4.1 Victoria

The Victorian Assisted Reproductive Treatment Authority (VARTA) is a statutory authority established to undertake a range of functions set out in the *Assisted Reproductive Treatment Act 2008* (Vic) (ART Act) and the Assisted Reproductive Treatment Regulations 2019 (Vic).

VARTA manages the following donor conception registers:

- Central Register - established in 1988, contains information about people involved in donor treatment procedures, including donor-conceived people, parents of donor-conceived people, and donors. Registered clinics are required to notify VARTA of births from donor treatment.
- Voluntary Register - established in 1998, enables people involved in donor conception to connect with each other and share information about themselves with mutual consent, including items such as photographs and videos that cannot be included on the Central Register. Two or more people need to add their details to the Voluntary Register for there to be a match and for communication to occur.²²

According to VARTA, the donor conception registers are used to facilitate donor linking:

Donor linking is the exchange of information between, or meeting of, people connected via donor conception treatment. Contact between parents, donor-conceived people and donors varies enormously and is based on personal preferences. It ranges from disclosure of limited information to occasional email communication, to ongoing contact. Sometimes people only update medical information so their genetic relatives can be notified about it.²³

In 2016 the *Assisted Reproductive Treatment Amendment Act 2016* (Vic) amended the ART Act to give all donor-conceived people, no matter when they were born, the right to know their genetic heritage. The ‘right to know’ amendments allow the lodging of contact preferences by all parties involved and enforce their compliance. Contact preferences permit the parties to decide on the terms of contact and whether they want contact at all. Contact, if chosen, may afford donor-conceived people the opportunity to learn more about their identity, background and medical history.²⁴ The amendments commenced on 1 March 2017. The operation of the donor registers is governed by this *Assisted Reproductive Treatment Amendment Act 2016*.

²¹ NHMRC, submission 20, p 3.

²² Victorian Assisted Reproductive Treatment Authority, *2021 Annual Report*, pp 15, 18; submission 24, p 2.

²³ Victorian Assisted Reproductive Treatment Authority, ‘Donor conception register services’, <https://www.varta.org.au/donor-conception-register-services>.

²⁴ VARTA, ‘Legislation and guidelines’, <https://www.varta.org.au/regulation/legislation-and-guidelines>; submission 24, p 2.

1.4.2 New South Wales

In New South Wales, ART is regulated under the *Assisted Reproductive Technology Act 2007* (NSW) (ART Act NSW) and the *Assisted Reproductive Technology Regulation 2014* (NSW). Prior to the ART Act NSW commencing on 1 January 2010, there was no process to support the disclosure of information about people involved in ART. The ART Act NSW establishes a Central Register which also commenced on 1 January 2010. The Central Register contains mandatory information in relation to all births resulting from ART treatment where conception occurred after 1 January 2010, and includes voluntary information about children born as a result of ART treatment where conception occurred before 1 January 2010, and donors who donated prior to the commencement of the Act.²⁵

From 1 January 2010, the ART Act NSW prohibits the anonymous donation of sperm and eggs in New South Wales. ART providers are required to collect identifying and non-identifying information about a donor at the time of the donation and, once a child has been born as a result of ART treatment using the donated gametes, the ART provider must provide information about the donor to the Central Register.²⁶

1.4.3 South Australia

The Donor Conception Register was established on 7 November 2021 as a result of amendments to section 15 of the *Assisted Reproductive Treatment Act 1988* (SA) (ART Act SA), via Schedule 1 Part 2 of the *Surrogacy Act 2019* (SA). Prior to these amendments, information regarding donor conceptions had to be sought from the fertility clinic responsible for the treatment.

Section 15 of the ART Act SA makes the establishment of the register by the Minister mandatory and sets out the information which must be contained in the register. Section 18 of the ART Act SA prohibits the disclosure of the identity of a donor except in certain circumstances, one of which is with the consent of the donor.

The Donor Conception Register may only be inspected in accordance with the *Assisted Reproductive Treatment Regulations 2010* (SA).

In 2021 the South Australian Government proposed amending legislation to ensure that all donor-conceived people have access to identifying information about their donors, regardless of when they were conceived. The yourSAy website stated, ‘... the register will apply retrospectively and prospectively; this means that the lifelong guarantee of anonymity provided to donors will be removed. This will be done without the consent of the donor’.²⁷

In October 2021, the electronic Donor Conception Register (DCR) was established in South Australia to hold information about donors and their offspring. yourSAy stated:

As part of the DCR, an online Assisted Reproductive Treatment (ART) Clinic portal was launched and donor records are now input directly into the DCR by ART Clinics via the portal. The DCR has linkages to the Births, Deaths and Marriages (BDM) Register for data verification purposes and ensures that so far as is possible, all available donor information is captured. This includes private donor arrangements made

²⁵ NSW Health, ‘The Central register’, <https://www.health.nsw.gov.au/art/Pages/the-central-register.aspx>

²⁶ NSW Health, ‘Information for donors on the Assisted Reproductive Technology Act 2007’, <https://www.health.nsw.gov.au/art/Publications/brochure-information-for-donors.pdf>.

²⁷ Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021 (SA). South Australia. Department for Health and Wellbeing, *The State of Donor Conception Records in SA Fact Sheet*, accessed 27 April 2022, p 1.

outside of the ART Clinic environment. SA Health is also working together with ART Clinics to verify available historical records and enable the progressive input of these records into the DCR.²⁸

On 12 November 2021, the yourSAy website indicated that the South Australian Government was developing a revised Bill for further consultation and introduction into Parliament in 2022 prior to enabling the retrospective aspect of the DCR.²⁹ A Bill Consultation Summary Report on yourSAy stated:

We know that access to genetic heritage information through the DCR may be life-changing for donors, donor-conceived persons and other relevant parties; and making connections with biological children, parents and relatives has the potential to be an extremely positive experience. However, consultation feedback indicated that if information is not provided in a safe, respectful and ethical way, this could have significant consequences for the mental health of those involved.³⁰

1.4.4 Western Australia

In Western Australia ART is regulated under the *Human Reproductive Technology Act 1991 (WA)* and the *Human Reproductive Technology Regulations 1993 (WA)*. The Act provides for the recording and release of information concerning donor conception via the Reproductive Technology Treatment Registers. The Reproductive Technology Treatment Registers include treatments, identifying data of participants, partners and donors and non-identifying donor descriptions. The registers have been in operation since 1993 with significant changes in legislation and content of registers occurring in 2004. Information is submitted to the registers by licensees, being people who hold a license to provide reproductive technology services in Western Australia.³¹

In terms of information access, for donor-conceived persons (conceived on or after 1 December 2004):

When a person conceived with the assistance of a donor on or after 1 December 2004 reaches 16 years of age they have a legal right to identifying information about their donor. This information, which is provided to the Department of Health by clinics licenced in WA, can only be released after the donor-conceived person has undertaken counselling.

For donor-conceived persons conceived before 1 December 2004:

The changes to the law on 1 December 2004 did not have any force on events in the past. This means that for people who were conceived through donor-assisted conception before this time have no automatic right of access to identifying information.

²⁸ South Australian Government, 'Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021', yourSAy, Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021 | YourSAy.

²⁹ South Australia, Department of Health and Wellbeing, 'Bill Consultation Summary Report', yourSAy, accessed 29 April 2022.

³⁰ South Australia, Department of Health and Wellbeing, 'Bill Consultation Summary Report', yourSAy, n.d. accessed 29 April 2022. https://yoursay.sa.gov.au/art-act-amendments/news_feed/consultation-summary.

³¹ Government of Western Australia, Department of Health, 'Reproductive Technology Treatment Registers, https://ww2.health.wa.gov.au/Articles/N_R/Reproductive-Technology-Treatment-Registers#:~:text=The%20Reproductive%20Technology%20Treatment%20Registers,of%20registers%20occurring%20in%202004.

The records from donor-conception treatment before 1993 are often incomplete as the practices were very different and parents were not encouraged to 'tell'. Therefore, there may be occasions when no information will be found.³²

1.4.4.1 *Voluntary information sharing*

JIGSAW DNA Connect is a WA service for people who are donor conceived, parents of donor-conceived children and donors. Support and intermediary services are available free of charge for voluntary information sharing and disclosure of identifying information.³³

Past donors are encouraged to join JIGSAW DNA Connect so that a donor-conceived person may know more about their genetic relatives and/or have the opportunity to access to identifying information. The donor decides the level of information that is provided.³⁴

1.4.5 **Tasmania, Australian Capital Territory and Northern Territory**

The Senate inquiry in 2011 recommended that Queensland, Tasmania, the Australian Capital Territory and the Northern Territory should, as a matter of priority, establish legislation to regulate donor conception in those jurisdictions.³⁵

The House of Assembly Standing Committee on Community Development of the Parliament of Tasmania conducted an *Inquiry into Donor Conception Practices in Tasmania* in 2017. The committee found that it would be preferable to have a legislative framework for donor conception practices rather than simply relying on the NHMRC Guidelines as the basis of regulation in Tasmania. The committee recommended that legislation be enacted to establish a central repository of all donor and donor-conceived persons, including the voluntary provision of pre-2004 information.³⁶ At the time of writing, the Tasmanian Government had not introduced this proposed legislation.

1.4.6 **New Zealand**

Donor Conceived Australia stated the rights and experiences of donor-conceived New Zealanders conceived prior to the 1990s were similar to those in Australia in that a donor's identity was often anonymous, although non-identifying information was sometimes available to recipients and donor-conceived people. The *Human Assisted Reproductive Technology Act 2004* (NZ) (HART Act) brought the most significant improvement in rights for donor-conceived people conceived using gametes or embryos donated after the HART Act's introduction, including requirements for clinics and the Registrar-General to collect and keep information about donors and 'donor offspring', and provisions (with conditions) for the access to this information by both donors and donor-conceived persons. Donor Conceived Australia stated:

³² Reproductive Technology Council, *Fact sheet: Access to information*, 30 March 2020, pp 1-2.

³³ <https://www.jigsawdna.org.au>

³⁴ <https://www.jigsawdna.org.au>

³⁵ Recommendation 1, p 103: Commonwealth of Australia, The Senate, Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, p 1, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/report/index.

³⁶ Parliament of Tasmania, House of Assembly Standing Committee on Community Development, *Inquiry into Donor Conception Practices in Tasmania*, Final Report, [https://www.parliament.tas.gov.au/ctee/house/Reports/Report%20Inquiry%20into%20Donor%20Conception%20\(As%20Tabled\).pdf](https://www.parliament.tas.gov.au/ctee/house/Reports/Report%20Inquiry%20into%20Donor%20Conception%20(As%20Tabled).pdf), p xiv.

The HART Act also introduced a voluntary register for donors and donor-conceived people conceived before the Act's introduction, and established greater controls and governance over donor conception (including additional oversight and conditions for the import or export of gametes or embryos).

Although there are significant limitations with the Act, including with the effectiveness of the voluntary register and the implementation of the Act generally (particularly as donor-conceived people to which the Act applies are reaching the age in which they can access information), the learnings from the New Zealand experience indicate that despite the Act's limitations it has led to significant improvements in the rights of donor-conceived people conceived from 2005 onwards.³⁷

³⁷ Submission 59, p 5.

2 Current legislative framework in Queensland

2.1 Donor conception information

There is no dedicated ART legislation in Queensland regulating donor conception information. The Office of the Information Commissioner (OIC) notes that accredited ART clinics in Queensland adhere to the NHMRC Guidelines, which, since 2004, prohibit clinics from using gametes in reproductive procedures unless the donor has consented to the release of their identifying information to any persons born as a result of their donation. Gametes collected before 2004 without the consent of the donor to the release of their identifying information may only be used in limited circumstances.³⁸

Through the NHMRC Guidelines, donor-conceived individuals are currently entitled to receive identifying information about their donor once they have reached the age of 18.³⁹ Donors are entitled to receive non-identifying information about the number, age and gender of any persons born as a result of their donation.⁴⁰

The *Information Privacy Act 2009* (IP Act) defines personal information as ‘information or an opinion, including information or an opinion forming part of a database, whether true or not, and whether recorded in a material for or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion’.⁴¹

ART clinics hold large volumes of sensitive personal and health information about gamete and embryo donors, recipients and individuals born as a result of ART treatments. ART clinics which qualify as private sector health services providers are bound under the *Privacy Act 1988* (Cth) as an Australian Privacy Principle entity, whereas ART clinics that operate as a public health service provider in Queensland must comply with the IP Act.⁴²

The *Adoption Act 2009* (Adoption Act) defines ‘identifying information’ as information that identifies a person. It includes information that is likely to lead to the identification of the person and information that may identify the person, if given to another person, because of other information that the other person has or is able to obtain.⁴³ The Adoption Act provides all adopted persons with the right to obtain identifying information once the adopted person is 18 years of age. This includes the birth parents’ name/s, date of birth and other names they are known by, and applies to adoptions which occurred before and after 1 June 1991.⁴⁴

The *Human Rights Act 2019* (HRA) identifies under section 15 that every person has the right to recognition as a person before the law; under section 26, that children have the same rights as adults with added protection according to their best interests; and under section 37, that everyone has the right to access health services without discrimination. Taking a different view, section 25 of the HRA also protects a person’s right not to have their privacy, family, home or correspondence unlawfully or arbitrarily interfered with and not to have their reputation unlawfully attacked.

³⁸ Submission 43, p 2.

³⁹ ART Guidelines, paragraph 5.9.1.

⁴⁰ ART Guidelines, paragraph 5.7.1.

⁴¹ Section 12.

⁴² Submission 43, p 7.

⁴³ Section 248.

⁴⁴ Section 263; the address of the birth parent can only be provided with consent.

Stakeholders acknowledged that in considering the matter of access to donor conception information, there are competing human rights: the human rights of donor-conceived people and the human rights of donors.⁴⁵

This matter is discussed in more detail in section 3.1.

2.2 Other legislative provisions relating to donor conception

The following Queensland legislation refer to ART on specific matters:

- *Status of Children Act 1978*: men and women who provide gamete material for the purposes of donor conception shall be presumed, for all purposes, not to be the father or mother of any child born as a result of the pregnancy
- *Anti-Discrimination Act 1991*: a person who supplies goods and services, including assisted reproductive technology, must not discriminate on the basis of relationship status or sexuality
- *Corrective Services Act 2006*: prisoners may not seek examination or treatment for participating in ART
- *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003*, prohibits certain practices and regulates activities that involve the use of human embryos created by ART or other means
- *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Regulation 2015*: prescribing the NHMRC Guidelines for certain provisions of the *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003*
- *Transplantation and Anatomy Act 1979*: provisions relating to the buying of tissue from a person (s 41) and the donation of human eggs and human sperm by individuals, to occur without any form of payment (s 42AC)
- *Surrogacy Act 2010*: regulates surrogacy arrangements in Queensland, including transferring the parentage of a child born as a result of a surrogacy arrangement.

⁴⁵ See, for example, Ian Smith, public hearing transcript, Brisbane, 13 May 2022, p 7; Office of the Information Commissioner, submission 43, p 4.

3 Examination of the issues

This section discusses issues raised during the committee's examination of the inquiry's terms of reference.

3.1 The rights of donors and donor-conceived persons

Stakeholders to the inquiry commented on both the rights of donors to their privacy and the rights of donor-conceived persons to access information about their donor and know their genetic origins.

3.1.1 Donors' right to privacy

As there is no dedicated legislation governing the release of information connected with donor conception in Queensland, ART clinics adhere to the NHMRC Guidelines, which prohibit clinics from using gametes in reproductive procedures unless the donor has consented to the release of their identifying information to any person(s) born as a result of their donation. This has been the position since the NHMRC Guidelines were developed in 2004.⁴⁶ Prior to this, many donations were provided on the condition of donor anonymity.

Donor-conceived persons who have reached the aged of 18 are entitled to know the details of their genetic origins.⁴⁷ When approached by a donor-conceived person, clinics are required to arrange counselling prior to providing the following information:

- medical history, family history and any existing genetic test results that are relevant to the future health of the person who would be born (or any subsequent offspring of that person) or the recipient of the donation
- details of the physical characteristics of the gamete donor
- the number, age and sex of persons already born from the gametes provided by the same gamete donor and the number of families involved
- identifying information about the donor
- any identifying information that any person born from the gametes of the same donor has consented to being released.⁴⁸

The OIC stated:

Privacy issues primarily arise with respect to the release of *identifying* donor information. However, it is important to note that there may be circumstances where release of non-identifying information could lead to identification of the donor and/or their relatives including donor-conceived siblings.⁴⁹ [Emphasis in original.]

The OIC explained the historical context to donor conception and the complex nature of issues relating to disclosure of identifying donor conception information:

⁴⁶ Office of the Information Commissioner, submission 43, p 2.

⁴⁷ NHMRC, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*, section 5.9.

⁴⁸ NHMRC, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*, sections 4.2.4 and 5.9.

⁴⁹ Submission 43, p 3.

Historically, matters related to donor conception were considered inherently private. The stigma of infertility, legal parentage, inheritance disputes and the fear that the lack of donor anonymity would decimate the supply of donors were all contributing factors to the secrecy surrounding donor conception and a guarantee of anonymity for donors. Societal changes have prompted many jurisdictions to adopt an open and transparent approach to donor conception. A number of states and territories now require donors to consent to the release of their identifying information to any persons conceived from their donation.⁵⁰

The OIC noted that ‘the disclosure of identifying donor information to donor-conceived persons can have a significant impact on the donor and the donor family’s right to privacy and reputation’, explaining further:

The *Human Rights Act 2019* protects a person’s right not to have their privacy, family, home or correspondence unlawfully or arbitrarily interfered with and not to have their reputation unlawfully attacked. The disclosure of a person’s status as a gamete donor represents a significant incursion into the privacy of the donor and has the potential to cause fundamental changes to their relationships and the way they are perceived in the community.

Disclosure of identifying information is also likely to lead to identification of persons other than the donor including the donor’s relatives and any donor-conceived siblings.⁵¹

However, the OIC submitted that a donor’s rights to privacy and reputation are ‘not absolute’ and need to be appropriately balanced with the donor-conceived person’s right to seek and receive information about their donor(s).⁵²

Rachael Rangihaeata, the Information Commissioner, also commented on how a change in law in regards to the disclosure of personal information of donors and donor-conceived persons would work in relation to the IP Act:

From a privacy perspective, ... it is important to understand that in Queensland privacy principles in the Information Privacy Act are subject to other laws. Should the parliament legislate to allow the disclosure of personal information of donors and donor-conceived individuals, that would, for the most part, operate outside the Information Privacy Act. To say it another way, the privacy principles are subservient to other laws which permit the collection and dissemination of personal information.⁵³

Given the ‘significant impacts on the privacy of a donor and their family’, the OIC sought consideration of the privacy impacts of disclosing donor information on all persons involved, including:

- requiring consent prior to disclosure as privacy impacts are significantly increased where disclosure is proposed to occur in the absence of consent, particularly where the donor was guaranteed anonymity at the time of donation
- ensuring accuracy of donor information particularly where there are gaps in historical records
- facilitating contact between the donor, the donor-conceived person and their relatives as unwanted contact may constitute an unreasonable interference in privacy of the donor and the donor’s family

⁵⁰ Submission 43, p 3.

⁵¹ Submission 43, p 4. NB: in-text reference removed. Refer to original source.

⁵² Submission 43, p 4.

⁵³ Public hearing transcript, Brisbane, 13 May 2022, p 42.

- managing the identification of persons other than the donor as a result of disclosure of donor conception information
- Notifying affected parties prior to disclosure.⁵⁴

The OIC supported:

the introduction of a legislated right of access for donor-conceived persons to access non-identifying information about their donor upon request. Where hereditary or genetic disease or risks to the health of the donor or donor-conceived person become apparent, OIC also supports the mutual sharing of medical information, including with donor-conceived siblings.⁵⁵

Jigsaw Queensland was of the view that ‘attempting to balance the right of privacy and the right to access information is attempting the impossible’, explaining further:

Firstly, no one has a meter to measure the relative pain and suffering (or happiness) of each party. Secondly, the capacity of one party to unilaterally lodge an enforceable objection prevents any real balance of interests at the personal level—the level that matters most to the individuals concerned. *The policy of achieving a balance would be better served by providing services that assist the parties to understand each other’s point of view and current needs.*⁵⁶ [Emphasis in original.]

Ian Smith, a donor, agreed that considering the interests of donors and the donor conceived was a difficult balancing act:

There is a very difficult balancing act to be undertaken here – meeting the paramount principle of the right of donor conceived people to know their genetic identify while taking into account the significant impact on gamete donors of any change in policy and practice regarding access to information about donors by their genetic offspring. As I’ve argued above, I believe that on balance the scales should tip to the side of donor conceived people having the right, if they wish to, to know of their genetic heritage. However, that brings with it significant impacts for the donors for whom promised anonymity will be removed – in some cases against their will. The more militant in the DC [donor conceived] community say to such men, “Tough, get over it”. I do not think that is it that simple. I support the principle that DC people should be able to discover their genetic identity if they wish to do so. I argue too that this must be achieved while respecting the views of those donors who are hesitant about the removal of their anonymity. In parallel too significant measures should be put in place to engage, support and explain to gamete donors why this change in practice is to be made and how and why it would be implemented.⁵⁷

In this regard, Ian Smith called for a ‘softer and more conciliatory approach’ to releasing donor identity and that change is ‘best achieved through cooperation rather than coercion’. He submitted his proposed approach for managing the conflict as follows:

I argue for consideration of an approach that, while encouraging relinquishment of anonymity, would not force this on donors in the face of opposition. In such cases, I would propose that donors should be actively encouraged to allow themselves to be identified to their DC offspring (if that is the desire of the latter), but that they not be forced to relinquish anonymity. Further, I argue that by force of law, donors who do wish to retain anonymity should be required to provide certain information, (about ancestry and health information for example), to their donor offspring while retaining the right to preserve their anonymity if that is their wish. I believe that this softer and more conciliatory approach has the potential to lead to fuller and further contact between a donor-conceived person and their biological parent at

⁵⁴ Submission 43, p 4.

⁵⁵ Submission 43, p 4.

⁵⁶ Submission 18, p 3.

⁵⁷ Submission 11, p 5.

some future time, when the donor may have had more time to consider and come to terms with the knowledge of their DC offspring's existence and the desire of the latter to know more of and about their donor/bio-parent.⁵⁸

However, Jigsaw Queensland noted the impacts on a donor-conceived person of not knowing their origins and suggested that privacy provisions are becoming redundant:

We do not believe, however, that the right to privacy extends to the right of a person to withhold from another person information vital to that person's own private identity—knowledge of their origins or knowledge of their children. Not having knowledge of one's personal origins is like having the first chapters missing from one's life story. Knowledge of one's personal history is so central to human identity that everyone ought to have a right to knowledge of their personal origins and the circumstances of their birth. Indeed, privacy provisions have been made somewhat redundant by the availability and popularity of commercial DNA kits.⁵⁹

Stephen Page agreed that 'anonymity with genetic donation is dead' due to the following reasons:

- use of DNA databases which hold information enabling individuals to track down their genetic history
- IVF clinics often provide photos of their prospective donors and a Google search can often identify the donor
- social media – photographs can identify lookalike children.⁶⁰

Professor Katharine Gelber, a recipient parent with a donor-conceived child, also commented that 'anonymity is disappearing informally and any promises once made to donors to preserve their anonymity can no longer be upheld', explaining:

DNA testing makes it more than likely that a donor conceived person can discover the identity of their donor. This means anonymity is no longer an option. It is far preferable for disclosure to occur through a government authority, alongside appropriate counselling and support services, and based on accurate records, than for it to happen informally. This is the reality of donor conception today.⁶¹

Donor Conceived Australia also addressed the use of DNA testing:

In regard to privacy and anonymity of donors, some of whom retrospectively signed up as anonymous donors, there is no need to continue to offer them anonymity as the easy to access direct-to-consumer DNA testing market has done away with any level of anonymity. Even if they have not tested themselves, most DCP [donor-conceived people] are able to work at finding their donor with the help of "Search Angels" - professional genealogists - who often volunteer their time to help families connect. Donor Conceived Australia is of the view that this information would be much better to be provided by a government organisation that can provide support and counselling at the same time, rather than a multinational corporation or a volunteer genealogist.⁶²

Sarah Clay provided the committee with her personal perspective on DNA databases:

⁵⁸ Submission 11, p 6.

⁵⁹ Submission 18, p 4.

⁶⁰ Submission 13, p 4.

⁶¹ Submission 1, p 5.

⁶² Submission 59, p 10.

My biological father first found out about his children by ancestry.com. Without going through that pathway, I would not know my status or my child's medical history—not looking at the benefit of relationships. So much has changed from the eighties, when people agreed to anonymous donation. We cannot pretend that 40 years has not passed and science has not improved; human rights have developed and changed.⁶³

Professor Gelber argued that the interests of the donor conceived are paramount, stating:

At the time when anonymity was regarded as standard, donor conception was an emerging and very new industry. We now have decades of research that tells us very clearly that it is not in the best interests of donor conceived people to preserve anonymity at their expense, and that their interests need to be taken into account. Maintaining anonymity is a head-in-the-sand approach to this changing area.⁶⁴

Professor Roos acknowledged that some donors will not want to be identified:

Whilst I think the primary aim or primary focus should be on the right of donor children to discover their genetic origins, there will be a small proportion of donors in the era which included me, when donation was meant to be an anonymous process, who will not wish to be identified. In those circumstances, I think that right also needs to be taken into account.⁶⁵

While Professor Roos noted the importance of sharing medical information, he also commented on the 'right to meet':

I think biological aspects need to be accessible, but the right to meet is something that a few donors will not be comfortable with. To my mind, in terms of the meeting aspect—the identification, the ability to talk, finding out an address—there will be a few donors who will not want to be seen, let alone meet.⁶⁶

Independent Queensland Fertility Counsellors, Social Workers and Psychologists supported a donor-conceived person's right to access identifying information about their donors but sought the introduction of safeguards to 'protect unwanted intrusion in the lives of donors', particularly if donation was made with the assumption of anonymity.⁶⁷

Donor Conceived Aotearoa expressed its view in regards to a donor's right to anonymity:

The choice by a donor to donate, even under supposed 'conditions' of anonymity, or recipient parents' choice to conceive using a donor, should not supersede the rights of donor conceived people to information. Donors and recipient parents have choices (even if it appears limited) whereas donor conceived people are afforded no such choices. The rights of donor conceived people to information must therefore be central to all decisions, to address this lack of choice.⁶⁸

Dr Darren Russell, a donor, also supported the rights of donor-conceived persons to have information about their donors:

Perhaps, most importantly, I am struck by the proposition that the donor-conceived person is the only one who did not sign an agreement regarding confidentiality, and yet they are undoubtedly the ones most affected. It seems profoundly unfair that actions taken by their parents, the clinic involved, and me, 30-40 years ago would be unable to be questioned by the person who was born as a result of those actions

⁶³ Public hearing transcript, Brisbane, 13 May 2022, p 17.

⁶⁴ Submission 1, p 5.

⁶⁵ Public hearing transcript, Brisbane, 13 May 2022, p 5.

⁶⁶ Public hearing transcript, Brisbane, 13 May 2022, p 5.

⁶⁷ Submission 31, p 1.

⁶⁸ Submission 39, p 2.

many years ago and who must live with the donor's DNA. Should a donor-conceived person wish to know information about me I now firmly believe they have the right to that information.⁶⁹

Ian Smith commented on the responsibility of donors to children born of their donations:

One thing is very clear for me. That is that the interests and wellbeing of the children – all of them – are paramount. Regardless of what the legal framework was at the time of my being a sperm donor, I believe that I do have responsibilities to the children born as a result of my sperm donations. At the least, those people have a right to know what my part of their genetic heritage is – more if they want more.⁷⁰

3.1.1.1 Collecting and disclosing identifying information about donors where a donation was made on the condition of anonymity, including matters relating to consent

Disclosing identifying information about donors presents a privacy issue for those donors who donated prior to the introduction of the NHMRC Guidelines in 2004. These donors were not required to consent to the disclosure of their identifying information to any donor-conceived persons and may have donated under the condition of anonymity.⁷¹

In this regard, the committee considered retrospective and prospective models for the disclosure of identifying information about donors. The OIC advised:

Under the prospective model, the identifying information of donors who donated prior to consent being mandated can only be released with the consent of the donor. New South Wales, Western Australia, New Zealand, Sweden, Austria, Norway, the United Kingdom and Finland all have some variation of a prospective model. These models often include a mechanism by which historical donors can consent to the release of their identifying information. Central registers may also be supplemented by a separate voluntary register, which allows the consent-based exchange of donor conception information by those individuals who fall outside the scope of the legislation.

Under the retrospective model, the identifying information of donors who donated prior to consent being required may be released to their donor-conceived offspring without their consent. Victoria, South Australia and Switzerland have all introduced variations of the retrospective model. In these jurisdictions, the intrusion into the privacy of the donor is partially mitigated by the introduction of information release notifications, contact preferences or statements of wishes. Hereby, historical donors may indicate that they do not wish to be contacted by any of their donor-conceived offspring, or that they only wish to be contacted through an intermediary or via their preferred method of communication.⁷²

The OIC advised its support for a prospective model which requires all donors who donated prior to 2004 to give consent to the release of their identifying information as this 'will safeguard the privacy interests of historical donors, particularly where confidentiality was guaranteed at the time of donation'. If a retrospective model is implemented, the OIC suggested consideration be given 'to adopting the approach followed in the Netherlands, where historical donors are given the opportunity to opt-out of their identifying information being released'.⁷³ OIC also noted:

... that either approach will benefit from a long lead-in time and an extensive publicity campaign to ensure donors and all other persons potentially impacted by the disclosure decision are fully aware of the

⁶⁹ Submission 10, p 4.

⁷⁰ Submission 11, p 3.

⁷¹ Office of the Information Commissioner, submission 43, p 4.

⁷² Submission 43, pp 5-6.

⁷³ Submission 43, p 7.

changes and the options available to them in the event the donor does not wish to have their identifying information released.

Under a prospective model, this will also allow historical donors to register their consent to the release of their identifying information, if they wish to do so. Under a retrospective model, it will allow historical donors to register contact preferences, statements of wishes or to opt-out of the disclosure of their information, depending on the approach adopted.⁷⁴

Nigel Page, a donor, explained his experience and view on disclosing identifying information for those donors who donated on the basis of anonymity:

I do recognise that some – probably very few – donors might wish to remain anonymous. Historic donors such as myself were guaranteed anonymity so this should be respected were this to be the donor’s decision. This potential veto of identifying information means the creation of a detailed register is all the more important. I would wholeheartedly support counselling donors of the life changing importance of a donor conceived person learning more about their biological heritage. I was lucky to have seen my wife’s extremely positive experience: not all people might be similarly aware. I also believe the identity of donor conceived children should remain anonymous if that child prefers – as one other person has done so.⁷⁵

A retrospective approach to donor conception is discussed further in section 3.3.

3.1.2 Rights of the donor conceived

Stakeholders argued for the right of donor-conceived people to have access to identifying information about their donors in order to know their genetic origins, establish a sense of identity, enhance wellbeing, have access to medical information, and avoid the risk and fear of establishing consanguineous relationships.

3.1.2.1 Experiences of the donor conceived

Professor Sonia Allan advised the ‘secrecy’ that has surrounded donor conception historically means that ‘for many donor-conceived people both identifying and non-identifying information about their genetic parents (and genetically related siblings) remains unknown’.⁷⁶ Professor Gelber explained that the NHMRC Guidelines do not necessarily guarantee a person’s ability to access information:

In many cases ... access is being denied by the capricious behaviour of individuals who work in clinics. At the moment, a donor-conceived person’s ability to access the information they even have a right to under the guidelines is arbitrarily controlled by the person on the other end of the phone.⁷⁷

Many donor-conceived persons explained the impact of not having information about their donors and genetic origins, particularly the impact on identity and having access to medical information when needed. Patrick Cronin sought the opportunity for donor-conceived persons to receive information, including identifying information, about their donors, stating:

⁷⁴ Submission 43, p 7.

⁷⁵ Submission 5, pp 1-2.

⁷⁶ Submission 69, p 6. NB: in-text reference has been removed. Refer to original source.

⁷⁷ Public hearing transcript, Brisbane, p 2

The positive physical and mental health implications of the release of such information would be immeasurable to donor-conceived people who, like myself, feel as though we are being withheld from a basic human right of self-identity.⁷⁸

Amanda Woodrow, a donor-conceived person, told the committee that she had ‘struggled with identity’ and that ‘not knowing anything about my paternal side has been painful, isolating and produced a feeling that I am different from everyone else’.⁷⁹ She continued:

I have the right to know where I came from, if there are any genetic dispositions (I have also been diagnosed with MS; a possible hereditary disease, no known cases on my mother's side) and identifying factors of my biological father. Secrets are toxic.⁸⁰

Another donor-conceived person, Cate Smith, explained the positive impact of coming to know her donor:

When I started searching for my genetic heritage, my goal was to find medical information, a name and perhaps see a photo or 2 of my donor. I did not expect the process to be so emotionally affecting. Since meeting my bonus family, I have questioned many aspects of my self-identity. I have always been somewhat unsure of myself and struggled with confidence, and now I have come out the other side of this self-discovery process with an almost blinding clarity of who I am and my place in the world. I am confident and centred. I have pieced together the web of influence of my parents who raised me with my new genetic connections.⁸¹

Paul Bellas told his story of finding out who his donor was at 37 and what it meant to him:

For almost all of my life I have not known half of my family medical history. I have not known my Biological Father. I have not known that I have other siblings. I have not known my ethnicity or heritage. ...

I felt lost and helpless, with no way of finding out who I was or who my Biological Father was. I had all but given up. I had been told it was impossible to find out who my Donor was. There were no records. No possible way to answer any of my hundreds of questions.⁸²

After finding his donor via www.ancestry.com, Paul Bellas made contact:

I was ecstatic! Finally, after all these years, I would be able to meet my Biological Father and find out about my family medical history. This is particularly important given my eldest son suffers from a number of conditions, Autism, Sensory Processing Disorder and ADHD, but the investigation into Neurofibromatosis has been impossible without the medical history from both sides of my family.

I have even been able to trace my family tree back to the 1500s. Given my Polish heritage can only be traced back to 1850s due to WW1 and WW2, this is simply amazing.

I am now in the process of building a relationship with my Biological Father. I have also been able to make contact with one of my half-brothers and two half-sisters, who are also donor conceived with the same Biological Father as myself (my children now have 8 cousins on my Biological Father's side that they are yet to meet.⁸³

⁷⁸ Submission 8, p 2.

⁷⁹ Submission 6, p 1.

⁸⁰ Submission 6, p 1.

⁸¹ Submission 22, pp 2-3.

⁸² Submission 17, p 1.

⁸³ Submission 17, p 2.

Ross Hunter explained his experience when his biological father exercised his right to not be contacted:

I am one of the 'unlucky' ones amongst the growing gallery of DC people in my state of Victoria. By this, I mean that my mother's sperm donor exercised his contact veto and does not wish to have contact with me. Like most DC people, I respect and to an extent understand his position. In exercising this veto I was, however, enabled to find out his name. With this, I have been able to research my ethnic origins and get a bit of an idea of the constellation of my paternal line. Furthermore, my biological father was kind enough to give me an A4 page of information that has answered some of my questions about his profession and ethnicity - things that were really important for me to find out.⁸⁴

Several adopted persons also commented about the similarities between their situations and not having access to biological or genetic information about their parentage and the impact of this, including Helen McKenzie, who stated:

I am not a donor conceived person, I am an adopted person and while adoption carries a myriad of other issues with it, I am speaking to you only on the issues raised above in relation to the rights of information. The correlations between the two circumstances of donor conceived and adoption are equal and undeniable in terms of the denial of information and the impact of such.

...

It is a person's innate right to know where they come from. Medical technology has taken that right away from donor conceived people under the guise of a loving family. To refer to a person's information as 'genetic information' demonstrates an objectivity that delineates misunderstanding. Genetic information is not a tangible record for the person missing it, it is the nature of their being, it is 'who I am'.⁸⁵

Several submitters highlighted the difference between donor-conceived people and adoptees in terms of their ability to access information about their biological heritage. Patrick Cronin explained:

In Queensland an adopted person can apply for information about their birth parents. For only a small fee, an adoptee can fill out a simple form and obtain information from the Registry of Births, Deaths and Marriages regarding their biological parents' names and details.⁸⁶

Sarah Dingle stated:

Australians accept the concept of children's rights first when it comes to thinking about adoption. Donor conceived people are no different. We may be raised by one of our biological parents - or by none, in the case of donated embryos. Having only one parent who sold you or otherwise gave you up does not ameliorate any of the problems with donor conception as it exists.

...

Donor conceived children are conceived **by design**. That is: they would not be conceived were it not for the deliberate acts of adults. Donors, arguably, are even **less** entitled to anonymity from their own children than the biological parents of adoptees - and biological parents of adoptees do not have any such entitlement in Australia, because the fundamental human right of the child, as per the UN CRC [United Nations Convention on the Rights of the Child], to family and to identity, trumps any wish of the biological parent.⁸⁷ [Emphasis in original.]

⁸⁴ Submission 49, p 1.

⁸⁵ Submission 3, p 1.

⁸⁶ Submission 8, p 6.

⁸⁷ Submission 7, pp 1, 5.

In this regard, Patrick Cronin proposed:

Consider present QLD and other state legislation regarding adoption and the release of information to adoptees. The Queensland Government should recognise the needs of donor-conceived people to access information of their biological parents just as previously recognised rights of adoptees.⁸⁸

Donor Conceived Australia supported this view stating that ‘the opening up of closed adoption records provides a clear precedent for the removal of anonymity in the donor-conception sphere and a significant body of research relating to the impacts of anonymity on the social, emotional, and physical wellbeing of individuals’.⁸⁹

3.1.2.2 *Identity*

As noted above, having a sense of identity is important for donor-conceived persons as ‘identity development is a key milestone of human development’.⁹⁰ International Social Service Australia (ISS Australia) highlighted the importance of the ‘fundamental human right to have access to information about one’s biological parentage’, stating:

It is critical for all donor conceived people to know they are donor conceived and to have access to information about their donors. Information such as ethnicity, physical characteristics, personality, family history, and so on will assist with possible future identity issues and enable donor conceived people to create a sense of ‘who they are’.⁹¹

Donor Conceived Australia advised that ‘evidence suggests that early disclosure of donor-conceived status is paramount’ as young children will more easily incorporate this information into their identities, which will support donor-conceived people to feel ‘more comfortable about their origins as they reach adolescence’.⁹²

VANISH also supported the view that ‘knowledge about parentage, and genetic and cultural heritage, contributes significantly to a person’s sense of identity’.⁹³ Jigsaw Qld agreed, stating that ‘access to knowledge about one’s origins and to whom one is related is an essential part of a person’s identity’.⁹⁴

ISS Australia confirmed its support that all donor-conceived adults should have retrospective access to their donors’ identifying information as the withholding of donor information from donor-conceived people can manifest long-term identity issues.⁹⁵

Paul Bellas said that ‘many people, like me, are searching for their identity and their place in the world’.⁹⁶ Alison Jones, a donor-conceived person, also explained the importance of knowing her genetic origins:

Donor anonymity harms children. Lack of disclosure harms children. It is not in the best interests of children for them to have their genetic origins erased or hidden. This caused significant distress for myself

⁸⁸ Submission 8, p 6.

⁸⁹ Submission 59, pp 8-9.

⁹⁰ Caitlin Macmillan, submission 36, p 5.

⁹¹ Submission 29, p 2.

⁹² Submission 59, p 7.

⁹³ Submission 71, p 1.

⁹⁴ Submission 18, p 2.

⁹⁵ Submission 29, p 2.

⁹⁶ Submission 17, p 2.

and a crisis of identity when I found out as an adult because no one considered my well-being when I was a child and the negative effect that donor anonymity would have on me.⁹⁷

Emily Noy told her story about finding out she was donor conceived and its impact on her sense of identity:

At the age of 27 I decided to do an Ancestry DNA test for fun. Within three months of receiving my results, I became aware of a half sibling who had matched with me on the website. I then had to confront my parents about why I would have a half sibling that I was unaware of. My mother told me at 10pm at night on Facebook video chat that I was conceived via anonymous sperm donation. I cannot thoroughly express through a simple submission what finding this out so late in life did to me. I had a complete identity crisis, found it impossible to look in the mirror without experiencing emotional turmoil and spent months grieving the loss of a DNA connection between myself and my dad.

To try and solve the puzzle that was now my identity, I needed to seek out my biological father. I came to learn that in Western Australia, we have very little rights to find out anything to do with our own biological identity or family medical history. I had to rely on commercial DNA tests to assist me in finding my biological father. It wasn't particularly difficult but it was tedious work. It took me three long weeks and there he was. All over the internet and exactly like me. I immediately sent him an email, and through those emails and Ancestry DNA, we confirmed our genetic link.⁹⁸

3.1.2.3 Access to medical information

Donor-conceived persons also stated that another significant reason for wanting access to information about their donor related to knowing their medical information and history. Donor Conceived Australia explained why it was important for donor-conceived persons to have their donor's medical history:

Without access to their family medical history, donor-conceived individuals are unable to identify whether they are at a higher risk than the general population to develop particular inheritable conditions and are consequently unable to take preventative measures.

At the time of donation, most donors were in early adulthood, prior to the onset of many diseases. They may also not be aware of their own family medical history at this early stage of adulthood. Were a donor or their biological children (whether donor-conceived or not) to be diagnosed with an inheritable disease, there is currently no mechanism by which donors or donor-conceived individuals can report this to other biological family members.

Whether it is information provided by donors at the time of donation or information that needs to be communicated afterwards, this lack of information sharing is, in the worst-case scenario, life-threatening.

Donor Conceived Australia has members who have been diagnosed too late with genetic diseases that do not run in the half family history they are aware of. If they had known earlier about any medical history and could have had screening tests for such illnesses they may not be as unwell as they are now.

Some of our members don't find this is a problem until they have children of their own, who inherit genetic diseases that are not in the known family history. Again, should this family history be known earlier, more could have been done to help these children from birth, to be aware they may have a predisposition towards certain diseases, rather than wait years for a diagnosis.

Finally, some donor-conceived adults go on to develop life-threatening genetic diseases and wish to communicate this to their siblings/donor. This is vital information for other genetic relatives to have, but

⁹⁷ Submission 26, p 4.

⁹⁸ Submission 28, p 1.

currently, there is no way for the donor-conceived person to find all of their siblings and contact them to let them know they may have a predisposition to a certain disease. This needs to change.⁹⁹

ISS Australia expressed the view that ‘it is a fundamental right and of great importance for donor-conceived people to know their family and medical history’.¹⁰⁰

Professor Roos, a donor, also considered it important that medical information be shared with donor-conceived people and, where possible, mandated.¹⁰¹

Giselle Newton stated early disclosure of donor-conceived status is important to ensure that health issues do not arise from limited or incorrect medical and genetic information.¹⁰²

AMA Queensland was of the view that ‘any reforms to governance and regulatory frameworks relating to donor conception information must ensure that a child conceived using donated gamete/s and his or her family have access to health and genetic information about the donor/s’. In addition, AMA Queensland stated that access to this information must be preserved and be independent of decisions about the retention of donor anonymity.¹⁰³

The Women’s Legal Service Queensland (WLSQ) acknowledged ‘the tension between the donor’s right to privacy, and the donor-conceived person’s need to know their origin and biological history’ and expressed the view that community support has shifted towards the rights of a child/person to know the identity of their donor. In this regard, WLSQ supported legislation and policy guidance that ‘articulates transparency and openness in relation to donor information, especially as it relates to medical conditions’.¹⁰⁴

The OIC supported the mutual sharing of medical information, including with donor-conceived siblings, ‘where hereditary or genetic disease or risks to the health of the donor or donor conceived person become apparent’.¹⁰⁵

A donor-conceived person explained the importance of knowing their donor’s medical history:

I want to know any relevant medical information that may be valuable to me and my own children. My children cannot accurately state if they have a family history of any illnesses or cancer because this information is hidden from me as a donor conceived person.¹⁰⁶

Cath Grassick, a parent of donor-conceived children, explained the importance of better collection of medical information from donors:

My partner and I are extremely grateful for the ability to pursue medical assistance that led to our children being born. We do understand medical and privacy concerns for all those that participate but feel there needs to be greater access to both non identified and identifying information and better regulation of medical clinics that wish to operate (and profit) in this realm. It is important that there is better collection of medical information and for that information to be available at any time from pre

⁹⁹ Submission 59, pp 7, 8.

¹⁰⁰ Submission 29, p 2.

¹⁰¹ Public hearing transcript, Brisbane, 13 May 2022, p 5.

¹⁰² Submission 52, p 2.

¹⁰³ Submission 23, p 1.

¹⁰⁴ Submission 45, pp 1-2.

¹⁰⁵ Submission 43, p 4.

¹⁰⁶ Name withheld, submission 54, p 3.

conception and onwards for DCP and their guardians (if under 18). For example through contact with the donor we have accessed more medical family history which is invaluable for managing and monitoring medical conditions of our children (especially for our children as they progress into adulthood and consider their own relationship connections). This includes cancer diagnosis in grandparents, mental health conditions and scoliosis diagnosis in the donor.¹⁰⁷

Margaret Bellas stated that, as a recipient mother, she would like to know relevant medical history of the sperm donor by consent.¹⁰⁸

3.1.2.4 Risk of consanguineous relationships

Giselle Newton stated late disclosure of donor-conceived status risks the formation of consanguineous relationships.¹⁰⁹

Professor Allan explained the risk of forming consanguineous relationships for donor-conceived persons who do not have identifying donor information:

Some donor-conceived people report the fear of unknowingly forming relationships with siblings or possibly their unknown genetic parent. While the actual probability of such an occurrence is unknown (as the actual number of donor-conceived people is unknown), such a risk may be significant within Australia, given the small population and the significant number of donor conceived people in existence. It is noted that forming such relations may have legal ramifications – see for example, the *Marriage Act 1961* (Cth) which provides that marriages between an individual and their parent, and an individual and their half-sibling are unlawful. Further, such relationships may result in children being born to couples who are related, giving rise to an increased risk of genetic or chromosomal difficulties in those children.¹¹⁰

Professor Allan also explained that there was fear associated with the risk of forming relationships, including consanguineous relationships, for donor-conceived persons:

However, note that it is not just actual risk that need be considered. The fear, angst, and psychological impact of not knowing who one is related to has been described by many donor-conceived people. There have been instances of donor-conceived siblings going to school with each other, living in close vicinity to each other, and even being friends, without knowing they were first-degree relatives. Some have described how this has impacted them when forming relationships, or even just how it impacts them in day-to-day life. The psychological impact in this regard, cannot be discounted.¹¹¹

Patrick Cronin also noted the fear of forming consanguineous relationships and why it was important that donor-conceived persons have information relating to siblings:

Through commercial DNA testing I instantly discovered 3 siblings. One month prior to writing this submission, a fourth sibling appeared. How many are out there? As a donor-conceived person, this question can become absolutely consuming. Every person about your age that you meet for the rest of your life, you will find yourself closely analysing their features and considering if they could be your sibling. An ever-present feeling of uncertainty that donor-conceived people know too well and that regular people would never even consider.

¹⁰⁷ Submission 68, p 2.

¹⁰⁸ Submission 56, p 1.

¹⁰⁹ Submission 52, p 2. NB: A consanguineous relationship is a sexual relationship between second cousins or closer. Refer to submission 39.

¹¹⁰ Submission 69, p 9. NB: in-text references have been removed. Refer to original source.

¹¹¹ Submission 69, p 9.

If I knew the number of offspring created from my donor, how many siblings I have out there, I may have found closure with my newly discovered DNA match that he is the last one. I wouldn't have to look twice or three times at everyone I ever meet.

Another fear among the donor-conceived is the potential for consanguineous relationships to form unknowingly. Although unlikely, it is possible. As a donor-conceived person, I share this fear for my children and their children.¹¹²

Donor Conceived Australia also commented on the risk of consanguineous relationships when information about donors is not accessible:

It stands to reason that being deprived of donor information can lead to inadvertent consanguineous relationships (i.e. a sexual relationship between second cousins or closer) between two unknowingly related donor-conceived individuals. As there are relatively few fertility clinics in Queensland offering donor gametes as a means of conceiving (particularly historically), and the time periods for which donors contribute gametes, it is not unreasonable to argue that most donor-conceived people and their siblings are likely to be born within similar geographical areas and within limited time-spans. This increases the risk of donor-conceived siblings coming unknowingly into contact with one another and possibly forming relationships, including sexual relationships.

The risk of forming inadvertent incestuous relationships is further increased by Genetic Sexual Attraction (GSA), which can be defined as a sexual attraction between biologically related adults who have been separated during infancy and become sexually attracted to one another later in life due to similar attributes. GSA is a phenomenon that has been identified within both the donor-conceived and adoption community.

Discovering that one has accidentally formed a sexual relationship with one's sibling and having possibly even conceived a child together would undoubtedly have significant social and emotional repercussions. Consanguineous relationships not only present social-emotional implications but have been linked to an increased risk of recessive genetic disorders. At each locus (position) of a chromosome, an allele is inherited from each parent. Therefore, if just *one* parent carries a mutant autosomal recessive gene, the offspring will not express the disorder as they have a remaining healthy allele. Offspring of consanguineous relationships have an elevated risk of inheriting autosomal recessive genetic disorders, due to a higher probability of expressing two mutated alleles (Joseph et al., 2014). An example of a severe autosomal recessive condition is cystic fibrosis, which is carried by 1 out of 20 people on average (Kumar et al., 2017). Other examples of autosomal recessive disorders include thalassaemias, haemochromatosis, and Tay-Sachs disease, all of which are capable of causing significant morbidity or mortality (NSW Health, 2020).¹¹³

Donor Conceived Australia noted that limits are in place in regard to the number of families able to conceive using gametes but argued that the 'only method capable of truly removing this risk is the removal of anonymity through both the establishment of a register and through the recording of donor information on birth certificates'.¹¹⁴

Donor Conceived Australia recommended:

... that the committee recognise and maintain the right of donor-conceived individuals to identifying information about their genetic parent/s, regardless of when or where they were born.¹¹⁵

¹¹² Submission 8, p 3.

¹¹³ Submission 59, pp 8-9.

¹¹⁴ Submission 59, p 9.

¹¹⁵ Submission 59, p 9.

Refer to section 3.3.2 for donor conception information on birth certificates.

3.2 Extent to which identifying information about donors should be shared

While noting the matters raised in previous sections in relation to privacy and the impact that disclosing identifying donor information to donor-conceived persons may have on a donor and their family if consent for disclosure is not given, the majority of submitters strongly supported the right of donor-conceived people to access identifying information about their donors in order to know their genetic origins.¹¹⁶

VANISH supported legislation that would give all donor-conceived people the right to identifying information about their natural or biological donor parents and measures to facilitate searching for them.¹¹⁷ FamilyVoice recommended that ‘all donor conceived children from age 18, or earlier with the agreement of their legal parents, should be entitled to access full identifying information about their genetic parents’.¹¹⁸ Jigsaw Qld also supported the right of donor-conceived people over the age of 18 to information about their personal origins and a similar right for donors to have information about their donor children.¹¹⁹ Donor Conceived Aotearoa supported this view, calling for information sharing that would allow donor-conceived people to connect with genetic parents and family members.¹²⁰ The WLSQ supported identifying information about donors being given to donor-conceived persons to the greatest extent possible and the disclosure of this position to donors prior to participation to allow fully informed consent.¹²¹

Professor Fiona Kelly also supported the introduction of prospective and retrospective legislation with the view that identifying information should be provided to donor-conceived persons when they reach a specified age:

While there is some dispute in legal circles as to whether DCPs have a legally enforceable right to know their genetic origins, as well as whether such a right should always trump a donor’s right to privacy, I believe the state has a *moral* obligation to provide identifying information to DCPs. In Australia, the state financially subsidises donor conception via Medicare, playing a role in the creation of children who do not currently have complete access to information about their genetic origins. It is my view that the state of Queensland, in its stewardship role and in accordance with the principle of the best interests of the child, has a duty to ensure that this information is available to DCPs.

If Queensland does not introduce legislation enabling prospective and retrospective access to donor information, DCPs and RPs will locate their donor through other means, including direct-to-consumer DNA testing, internet searches, and social media “stalking”. Research demonstrates that when the state does not support donor linking, parties take matters into their own hands.¹²²

In its support for the rights of donor-conceived people to have access to identifying information about their donor, Donor Conceived Australia addressed the matter of a donor-conceived person having to seek consent from a parent to access medical records:

¹¹⁶ See, for example, submissions 22, 31, 39, 40 and 71.

¹¹⁷ Submission 71, p 1.

¹¹⁸ Submission 9, p 7.

¹¹⁹ Submission 18, p 2.

¹²⁰ Submission 39, p 2

¹²¹ Submission 45, p 2.

¹²² Submission 46, p 2.

Many donor-conceived people conceived in Queensland have reported needing their mother/parents' consent to access medical records which represents a significant problem for several reasons: many donor-conceived people learn of their donor-conceived status from alternative actors such as extended family members, family friends or via direct-to-consumer DNA testing. For these individuals, seeking permission from their parents may not be comfortable/appropriate. In other cases, family members may be estranged or deceased.¹²³

In regard to the extent of information shared, Donor Conceived Australia recommended that donor-conceived individuals be given access to identifying information about their genetic parent/s and siblings regardless of when or where they were conceived and be free to negotiate contact with their genetic family.¹²⁴

Submitters had varying views on whether donor-conceived persons should have access to non-identifying or identifying information about their donor siblings, as well as whether donors should have access to non-identifying or identifying information about their donor children. In this regard, Cate Smith recommended the following:

- All gamete donors who donated to Queensland clinics, irrespective of the time of their donation, should have the right to access identifying information about their biological children
- All donor-conceived persons in Queensland, irrespective of when they were conceived, should have the right to access identifying information about their donor siblings.¹²⁵

Professor Allan stated that the law needs to be changed to provide current and future donor-conceived persons, access to identifying and non-identifying information about their donors and their biological siblings.¹²⁶

While Independent Queensland Fertility Counsellors, Social Workers and Psychologists supported the right of donor-conceived persons to access donor identifying information once they reach adulthood, they also proposed the introduction of safeguards to protect against 'unwanted intrusion' into the lives of donors.¹²⁷

Professor Roos supported non-identifying donor information being made available to donor-conceived persons but did not support mandated release of donor identity for the historical cases where anonymity was 'assured'. In this regard, he called for any related legislation to accommodate an 'identity veto'.¹²⁸ A donor-conceived person was also of the view that mutual consent should be required in regard to providing identifying information: 'meaning the donor consents to information being provided, and the Donor Conceived Person consents to receive that information.'¹²⁹

¹²³ Submission 59, p 10.

¹²⁴ Submission 59, pp 9, 10.

¹²⁵ Cate Smith, submission 22, p 4; see also, Kate Drysdale, submission 33, p 9; Sophie Hicks, submission 21, p 2.

¹²⁶ Submission 69, p 29.

¹²⁷ Submission 31, p 1.

¹²⁸ Submission 4, p 1.

¹²⁹ Name withheld, submission 50, p 2.

The NHMRC noted the importance of voluntary information sharing and consent as set out in its guidelines:

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.¹³⁰

VARTA highlighted that the *right to know* legislative changes in Victoria allows all donor-conceived persons to access identifying information about their donor regardless of the year they were born.¹³¹

Dr Anthony Brown, a donor, supported the rights of donor-conceived persons while also arguing for the right of sperm donors to know how many donor-conceived persons exist from their donations and to what extent, if any, were donations exported by parties involved intrastate, interstate and even internationally.¹³²

3.2.1 Contact between donors and donor-conceived persons

The matter of how contact is managed between donors and donor-conceived persons was also raised, including contact by mutual consent, contact statements indicating contact preferences, and contact vetoes.

Jane Sliwka, a social worker, summarised the contact arrangements in other jurisdictions:

- Victoria: for donations that occurred prior to 1998, donors are no longer able to prevent the release of their identifying information, but can determine how, or if, they have contact with an applicant through a contact statement. The option of a contact statement mirrors current adoption legislation in Queensland. If a 'no contact' statement is breached, penalties may apply. Responsibility for managing a central and voluntary register moved to VARTA on 1 March 2017, which also provides government funded information and support to all parties. This includes assistance with the exchange of information and meetings between all parties.
- Western Australia: clinics must provide donor codes to donor-conceived people, which can be used to facilitate matching via a contact Register. A voluntary contact register is maintained by a non-government organisation with experience in post-adoption support.
- New South Wales: the Department of Health has operated a central register since 2010, and it requires clinics to provide information about people conceived after 1 January 2010 to NSW Ministry of Health for inclusion on the register. For donor-conceived people conceived before 1 January 2010, they can register information about themselves on the central register as can donors. With both parties' consent, information about one another can be exchanged.¹³³

VARTA explained that the *right to know* legislative changes in Victoria allow for the 'the lodging of contact preferences by all parties affected by the changes to decide on the terms of contact and whether they want contact at all'.¹³⁴

¹³⁰ Submission 20, p 2.

¹³¹ Submission 24, p 1.

¹³² Submission 15, p 2.

¹³³ Submission 25, pp 3, 4.

¹³⁴ Submission 24, p 1.

Donor Conceived Australia discussed the different jurisdictional approaches to contact between parties and its view on contact vetoes:

In Victoria, the first state to retrospectively legislate, contact vetoes were introduced as a measure to 'balance' distinct stakeholder perspectives. Many donor-conceived people find this approach paternalistic and inflammatory. There is no evidence of instances of donor-conceived people pursuing unwanted contact, with or without contact vetoes in place. More recently, the proposed changes to the ART Act in South Australia are underpinned by the principle that donor conception be normalised, donor conception story be validated and openness about the practice be encouraged, (South Australian Parliamentary Counsel, 2021). As such, contact vetoes have been avoided. Given these five years of experience from Victoria, and principles outlined in South Australia, Queensland has the opportunity to build on this knowledge, centering the rights of donor-conceived people in line with international human rights principles. Those not wanting contact are able to express their wishes, just as any person has a right to do in other spheres of life.¹³⁵

Some stakeholders expressed the view that any contact between donor-conceived persons and their donor or donor siblings should be by mutual consent.¹³⁶ Professor Gelber expressed this view:

Contact between a donor conceived person and their donor should be subject to the mutual consent of the donor and the donor conceived person. I fully believe that a donor has the right to veto contact, or to express contact preferences (as is the case in Victoria currently). That is how their rights and autonomy can be protected.¹³⁷

Cate Smith, a donor-conceived person, agreed, stating:

Contact between donor conceived persons and their donor or donor siblings should be by mutual consent, with protections available for any person who does not want contact. This ensures that privacy can be protected whilst lifting the veil of anonymity.¹³⁸

While Sophie Hicks, a donor-conceived person, called for the release of identities of donors and siblings to donor-conceived persons, she noted that 'identity and contact are two very different things' and that knowing her genetic origins would support her wellbeing. She indicated that contact was separate to that, adding: 'I'm not out to interrupt anyone's life'.¹³⁹

Jigsaw Queensland agreed, stating that 'while the right to knowledge of one's personal origins ought to be virtually unconditional, contact between parties should be according to the wishes of the persons involved'.¹⁴⁰ Jigsaw Queensland continued:

... parties should have the right to express their preferences if they wish to have no contact or a range of intermediate forms of contact, such as by mail, email, phone, or mediated meeting. Individuals should be able to express their preference for no contact 'at this time', leaving open the possibility to review that preference at a later stage.¹⁴¹

¹³⁵ Submission 59, p 10.

¹³⁶ See, for example, submission 22, p 4; submission 47, p 4; submission 1, p 3.

¹³⁷ Submission 1, p 3.

¹³⁸ Submission 22, p 4.

¹³⁹ Submission 21, p 2.

¹⁴⁰ Submission 18, p 4.

¹⁴¹ Submission 18, p 3.

ISS Australia held similar views:

If retrospective access was granted that a provision similar to the 'contact veto' used in adoption practice be put in place in order to eliminate any unwanted requests for contact. A similar model exists in Victoria and appears to be working well in regards to respecting the privacy of the donor.

However, it is important to stress that such a provision would never prevent the release of identifying information about the donor. ISS Australia strongly believes that a donor conceived person's right to their donor's information should take precedence over the donor's right for their details to remain private or anonymous. However, with regards to contact, donors should still be able to determine if they wish to engage in contact arrangements.¹⁴²

Professor Allan noted that 'it is not necessarily the case that past donors wish to remain anonymous'.¹⁴³ Professor Kelly agreed, stating:

I recommend the introduction of retrospective legislation that gives access to a donor's identity for those people who were conceived prior to the commencement of the legislation. However, I do recommend the inclusion of an option for a donor to file a no-contact preference. Data from Victoria, where retrospective legislation was introduced in March 2017, shows that more than half of the pre-1998 donors approached following a register application have agreed to some form of contact. The contact preference allows the donor to specify the parameters of that contact. For those who do not wish to have contact or wish to limit it, that contact preference can be lodged. Penalties apply if a no contact preference is breached. There have been no instances of breach in Victoria since this was introduced.¹⁴⁴

Dr Anthony Brown, a donor, sought consideration for donors to be able to contact donor-conceived persons resulting from their donations, by mutual consent, and contact with the recipient mothers, by mutual consent.¹⁴⁵

3.2.2 Committee comment

The committee acknowledges the complexity of balancing the rights of donors and the rights of donor-conceived persons in relation to the release of identifying information about donors. The committee notes the historical context that provided anonymity to some donors at the time of their donations and that the release of identifying information about these donors would impact their privacy. The committee also considered the view of the Office of the Information Commissioner, which stated that disclosing identifying information about a donor has the potential to cause fundamental changes to their relationships and the way they are perceived in the community, as well as potentially identifying the donor's relatives and any donor-conceived siblings. However, the committee supports the view of the OIC that a donor's rights to privacy and reputation are 'not absolute' and that these rights need to be balanced with the donor-conceived person's right to information about their donor and to know their genetic origins. In this regard, the committee is clear in its position that any change to legislation regarding the release of identifying donor information should be retrospective as it is the committee's view that the right of donor-conceived people to know their donor's identifying information outweighs a donor's right to anonymity.

The committee understands this will have implications for some historical donors and for this reason agrees that donors need to be supported through any legislative change enacted in relation to the

¹⁴² Submission 29, p 3.

¹⁴³ Submission 69, p 11.

¹⁴⁴ Public hearing transcript, Brisbane, 13 May 2022, p 23.

¹⁴⁵ Submission 15, p 2.

retrospective release of identifying donor information, particularly for those donors who are hesitant about the removal of anonymity. The committee notes that most donor submitters expressed the view that donor-conceived people should be provided with identifying information about their donors.

Further in relation to privacy, a number of submitters argued that the advent of new technology, including DNA testing and the use of social media, now makes it difficult to maintain donor anonymity. The committee notes the experience of some donor-conceived people who advised that there is a risk to the wellbeing of a donor-conceived person if they use these technologies and either discover their previously unknown donor conception status or start the process of making contact with donor relatives without support.

Attitudes towards donor conception and expectations around anonymity have changed over time. Evidence and the experiences of donor-conceived people indicate that a person not knowing their genetic origin may negatively impact on their sense of identity and wellbeing and that early disclosure of donor conception status is important to their formation of identity.

The committee heard evidence that having access to the medical history of donors is important, not only for a donor-conceived person's own health management and awareness of any predisposition to develop genetic diseases, but also for any children they may have. In this regard, the committee recommends all donor-conceived persons have the legislated right to know the identity of their donor from the age of 18, no matter when they were born. The committee also recommends identifying information about donors, including their medical history, should be made available on request to all donor-conceived persons when they reach the age of 18.

Some donors also indicated they would like access to information about any donor-conceived children resulting from their donations. In this regard, the committee recommends information about the gender and year of birth of donor-conceived persons born from their donation be made available on request to all donors.

The committee considers it important that donor-conceived persons have access to information about the gender and year of birth of any donor siblings on request. This would mitigate the risk of forming consanguineous relationships unknowingly and address some of the fear or hesitancy that donor-conceived people may hold about forming relationships in general. In this regard, the committee recommends that information about the gender and year of birth of donor-conceived siblings be made available on request to donor-conceived persons.

While support for releasing identifying information about donors to the donor conceived was strong, submitters called for any contact between parties to be by mutual consent. In this regard, the committee recommends the facilitation of contact between donors, donor-conceived persons and donor siblings be subject to the consent of all parties concerned. The committee notes that facilitating contact by mutual consent between donor siblings will also assist with sharing medical information between siblings. Refer to recommendation 5 in relation to donors being able to lodge contact preferences.

Recommendation 1: Rights of donor-conceived persons, including to know their genetic origins

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, regardless of when they were born.

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

The committee recommends that:

- 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
- information about the gender and year of birth of donor-conceived persons born from their donation be made available on request to all donors
- information about the gender and year of birth of donor-conceived siblings be made available on request to donor-conceived persons
- requests from donors for contact with donor-conceived persons be facilitated subject to the consent of the donor-conceived person
- requests from donor-conceived persons for contact with their donor be facilitated subject to the consent of the donor
- requests from donor-conceived persons for contact with their donor siblings be facilitated subject to the consent of both parties.

3.3 Access to historical clinical records and the implications of retrospectivity

Many stakeholders expressed support for donor-conceived persons to have access to historical clinical records.¹⁴⁶ One of the primary reasons was to create information access equality for all donor-conceived people regardless of when and where a donor-conceived person was born and when the gamete/embryo donation took place.¹⁴⁷

Donor Conceived Australia advised that the current legislation and framework relating to people conceived after 2004 ‘creates different classes of donor-conceived people’ and that ‘retrospective legislation will remove discrimination and afford donor-conceived people equality before the law irrespective of their parents’ timing of treatment and treatment success’. In this regard, Donor Conceived Australia was of the view that ‘donor-conceived people should have access to historical clinical records, regardless of when they were born or any guarantees of anonymity provided to donors at the time of their donation(s)’. Donor Conceived Australia also argued that this access should not be determined by donor consent.¹⁴⁸

Giselle Newton also noted that donor-conceived people’s rights are not uniform across jurisdictions and differ depending on year and location of conception with this resulting in ‘tiers of donor-conceived people, the “haves” and “have nots”’, which is why ‘retrospective legislation is essential to permit access to historical clinical records for all’.¹⁴⁹

¹⁴⁶ See, for example, submissions 38, 58, 59, 61, 62, 65, 66, 69.

¹⁴⁷ See, for example, submission 36, p 1; submission 37, p 2; submission 59, p 11; submission 69, p 10; submission 71, p 1.

¹⁴⁸ Submission 59, p 11.

¹⁴⁹ Submission 52, p 3.

Helen McKenzie agreed that any law reform must be retrospective because ‘if we are to assert that all people are equal before the law we cannot have a class of individuals that merely, by the timing of their birth, are denied the rights attributed to others’.¹⁵⁰ Sarah Dingle agreed, stating:

All children have the fundamental human right to family and identity, as per the UN CRC. It is discriminatory in the extreme to say that only children from a particular point in time onwards, for eg from the passage of any legislation following this inquiry, are entitled to that fundamental human right. It makes no sense, and would be deeply damaging to say, that a child born in 2015 in Queensland is not entitled to a biological father, but a child born in 2022 is.¹⁵¹

The Independent Queensland Fertility Counsellors, Social Workers and Psychologists supported establishing processes which would facilitate access to historical clinical records, and acknowledged that this may require retrospective application of legislation to arrangements which were made in the past under the assumption of anonymity.¹⁵²

The accuracy of historical clinic records was also raised as an issue. Several stakeholders proposed that fertility clinics or medical professionals in Queensland that practice or have practiced donor conception should be required to provide accurate historical records to a government-controlled donor conception authority/register.¹⁵³

A number of stakeholders also noted the importance of protecting and ensuring the accuracy of clinical records. ISS Australia stated:

ISS Australia is aware that there have been previous poor practices in record-keeping, and this is problematic when allowing access to records retrospectively. However, when we look at the adoption sector and past practices, poor record-keeping also occurred, and we have learnt over time that operating in a spirit of transparency and openness is the best approach when it comes to accessing and sharing historical records.

Moreover, moving forward, ISS Australia would support legislation to set minimum standards of record keeping of donor conception practices. This legislation could also prohibit tampering with, or destruction of, any records relating to donor conception information with strong penalties for those breaching such requirements.¹⁵⁴

Professor Gelber stated it was ‘vital that clinics be required to organise their historical records, check them for accuracy, and hand that information over to a government-controlled register’.¹⁵⁵ The OIC also considered it was important to ensure the ‘accuracy of donor information particularly where there are gaps in older historical records’.¹⁵⁶

In addressing potential opposition to retrospectivity, Professor Gelber stated:

I have no doubt that you will receive submissions that oppose retrospectivity. You will be told that donors were guaranteed anonymity for life, and that that was the basis on which they consented to become a

¹⁵⁰ Submission 3, p 3.

¹⁵¹ Submission 7, p 6.

¹⁵² Submission 31, p 1.

¹⁵³ See submissions 22, 30 and 47.

¹⁵⁴ Submission 29, p 3.

¹⁵⁵ Submission 1, p 4.

¹⁵⁶ Submission 43, p 4.

donor. It is true that retrospectivity is usually to be avoided in public policy. However, in this case it is essential for several reasons.

First, without retrospectivity there is an arbitrary date beyond which some donor conceived people have access to vital, life-affirming information, yet others do not (as is the case currently in NSW). This is simply unfair.

Second, norms and expectations around anonymity have changed due to the decades of experience we now have with donor conception.

...

Third, many donors have historically been told they had to be anonymous and there are many who would prefer their identity to be known, but who are prevented from doing so by current practices and the lack of state-based registers in some jurisdictions.

Fourth, the interests of the donor conceived are paramount, and just as views and the law have changed around adoption, so should they change around donor conception. At the time when anonymity was regarded as standard, donor conception was an emerging and very new industry. We now have decades of research that tells us very clearly that it is not in the best interests of donor conceived people to preserve anonymity at their expense, and that their interests need to be taken into account. Maintaining anonymity is a head-in-the-sand approach to this changing area.

Finally, anonymity is disappearing informally and any promises once made to donors to preserve their anonymity can no longer be upheld. DNA testing makes it more than likely that a donor conceived person can discover the identity of their donor. This means anonymity is no longer an option. It is far preferable for disclosure to occur through a government authority, alongside appropriate counselling and support services, and based on accurate records, than for it to happen informally. This is the reality of donor conception today.¹⁵⁷

During the public hearing, Professor Gelber elaborated on the issue:

I realise that the issue of retrospectivity is challenging, partly because donors in the past were guaranteed anonymity. There are multiple responses to that. Times have changed. Our understanding of the harm to donor-conceived people of anonymity is far greater than it used to be. We were brave enough to change the law in adoption. We were brave enough, as the Office of the Information Commissioner has recognised, to limit the right to privacy of, for example, people who gave up children for adoption in order to do the right thing by adopted people. We need to do the same thing here. In fact, there are many donors, some of whom made submissions to this inquiry, who would prefer not to be anonymous but who were told that was their only option. Identifying information should be made available to all people regardless of when they were born and does not require contact. It is central to a person's identity and the donor-conceived have a right to that information.¹⁵⁸

Eleni McIlroy, a donor-conceived person, considered that 'retrospectivity is vital' and agreed that counselling and support for donors should be available:

Historic donors (and clinicians/clinics) have found themselves in one of those difficult places in history whereby had they had better information, they may have made other choices. These times in history are not uncommon and have been experienced in the adoption community, LGBTIQ+ communities, minority communities (etc.) at many turns of history. The world changes, we learn more and in the transition between the old way (excluding rights of the group) and the new way (including rights of the group) uncomfortable situations may occur for some groups who previously had protections for their actions, or

¹⁵⁷ Submission 1, pp 4-5.

¹⁵⁸ Public hearing transcript, Brisbane, 13 May 2022, p 2.

felt their actions were fair and protected. Historic donors who feel strongly about their privacy should be counselled and supported, but the rights of DCPs should not be further aborted to avoid their discomfort.¹⁵⁹

Sarah Dingle also commented on potential implications:

In terms of the 'implications' of opening up the records, all records must be handed over by clinics and practitioners to the Queensland government. This must be accompanied by legislation making it a crime with immediate effect to conceal, destroy, falsify, or tamper with the records of donor conception ...¹⁶⁰

Donor Conceived Australia also addressed potential objections to retrospectivity in regards to accessing historical clinical records:

We recognise that some donors who assumed infinite anonymity may feel uncomfortable about the prospect of their information being made available to offspring. However it is important to note, as discussed in detail within the Victorian 2012 inquiry, that not all Victorians were: under the assumption they were anonymous, supportive of ongoing anonymity, or unsupportive of such legislation, (Victorian Law Reform Committee, 2012).

There are many donors who have actively sought to have their identifying information available to their biological children with no means of doing so or who have, at the very least, wondered about the people that they helped to create. It is highly probable that Queensland donors share a similar attitude. Donors have a right to express their current wishes, rather than it being assumed that they prefer to remain anonymous. Some donors have reported in other state inquiries that they signed (some forcibly) a consent form or 'contract' prohibiting the release of any identifying information from any party to any other. For some it was a non-negotiable condition of donation. Clinics engaging in this practice were misleading.

Furthermore, such restrictions on information release could only apply to consenting adults, namely the donor and recipient parents. Donor-conceived people could not consent to such an arrangement, least of all because they were not born, but that a 'contract' cannot be 'signed' on one's behalf.

Another common argument relating to the retrospective release of information is that in some instances, the records no longer exist or are highly limited and that therefore, it is not possible to share information. However, a lack of information caused by inadequate recordkeeping and the loss or intentional destruction of patient files, should not prevent the release of information to donor-conceived people where it does exist.¹⁶¹

In this regard, Donor Conceived Australia recommended that identifying information relating to donors and donor siblings be released to donor-conceived people retrospectively.¹⁶²

Carolyn Fox, a recipient parent of a donor-conceived child and social worker, stated:

Clinics must be approached to submit their records on the donor, both non-identifying and identifying, as well as information relating to recipients and confirmed births (i.e. siblings). As is evident from past and current practices, guidelines are not sufficient in ensuring clinics responsibly manage this information. Historical records and identifying information must be held in secure perpetuity so no information is lost and there needs to be legitimate consequences for clinics who do not provide this information where it exists.

¹⁵⁹ Submission 42, p 3

¹⁶⁰ Submission 7, p 6.

¹⁶¹ Submission 59, p 11.

¹⁶² Submission 59, p 11.

Retrospectivity must be handled with sensitivity, with all parties being aware of the issues/implications that may arise.¹⁶³

However, several submitters expressed reluctance for implementing a retrospective approach to access to historical records and release of identifying donor information for those donors who were assured anonymity. The WLSQ, for example, stated that ‘assurances of anonymity may have formed the basis of agreements to participate in donor arrangements’.¹⁶⁴ While supporting retrospective access to historical records, Ian Smith, a donor, called for caution:

... retrospective change such as this is a very significant step. Such action sits uneasily with the principle that law should be able to be known to all, so that people can rely on the law as it is at the time that they act.

...

Conversely, advocates of retrospectivity asserted that the right of DC people to know their genetic identity was paramount, and that this justified retrospective action ...

The key argument for retrospective action in this case is that it is necessary in order to make access by donor conceived people equable – regardless of the date of the sperm or egg donation that led to their conception.

The counter argument is that retrospectively changing the rules around access to donor identity is unfair to the donors who donated with the promise of perpetual anonymity. Once again the contest between two sets of rights arises.

On balance I believe that the argument for retrospective action to open donor records is strong. I support that course of action, with the proviso that there should be a nuanced and mediated approach to the release of identifying information about donors...¹⁶⁵

The OIC noted that ‘the retrospective application of legislation is generally only warranted by strong public policy reasons justifying its implementation’ and reiterated its support for the ‘administrative release of retrospective non-identifying donor conception information upon request’. The OIC urged consideration of the implications of releasing retrospective identifying donor information on the privacy rights of donors and their families who have not consented to disclosure. The OIC noted that ‘providing access to historical clinical records raises a number of additional privacy issues including accuracy of donor information and whether historical records represent a full and complete record’.¹⁶⁶ The OIC explained further:

As noted by South Australia, due to the passage of time, some donor conception records may be incomplete or unable to be located. Disclosure of inaccurate historical donor conception information poses a significant risk of harm to the donor, donor-conceived child and relatives of the donor’s family.¹⁶⁷

For these reasons, the OIC recommended:

... legislating a range of mechanisms to mitigate privacy risks associated with inaccurate or incomplete historical clinical records including the right to amend or correct information in any central register and

¹⁶³ Submission 34, p 4.

¹⁶⁴ Submission 45, p 2.

¹⁶⁵ Submission 11, pp 8, 9.

¹⁶⁶ Submission 43, p 5.

¹⁶⁷ Submission 43, p 5; NB: in-text reference removed. Refer to original source.

verification of historical records in circumstances where there is insufficient information to determinate accuracy of donor information prior to disclosure of this information.

OIC notes that the Victorian Assisted Reproductive Treatment Authority has a range of additional powers to assist identifying the potential donor in response to an application for identifying information. This includes the ability to make inquiries of potential donors or other people who may have relevant information or request the potential donor (or their relative in limited circumstances) to undergo a genetic test. OIC does not support genetic testing of historical donors in the absence of consent.¹⁶⁸

Rachael Rangihaeata, the Information Commissioner, stated:

Should a retrospective model be proposed to support the right to know identity and medical information, safeguards will be important to protect the privacy of individuals, even if their personal information is communicated to another without their consent.¹⁶⁹

Associate Professor Anusch Yazdani, medical director for the Queensland Fertility Group (QFG), explained their view on why a legislated requirement for releasing identifying donor information is not supported and the difficulties with providing identifying information of donors who donated decades ago:

We do not support a blanket legislative release of identifying information for donors prior to 2004 as those arrangements occurred within a medical consultation, understanding that those identities would remain confidential. This is a problem for all of us, including for QFG.

QFG does not participate in any private donor arrangements, and we cannot provide any information on this, but I do highlight the risks that are inherent in terms of donor arrangements in this situation. Medicine, like any other profession, has evolved over time. While by current standards some of those practices may not be okay, such actions have to be seen within their historical context, particularly that those actions would have been taken by those individuals in an effort to assist the conception of those people they helped.

We absolutely recognise the importance of the information that donors want. If you asked me now today if you wanted to know who a donor is, I can give you that information in two minutes—on non-identifying information I can tell you who the person is and what their family history is—and within a day I can give you all of the identifying information, but for historical records that is a completely different situation. That has nothing to do with the unit or its structure; it has something to do with the way that medicine was practised 40 years ago, and that is all it is.¹⁷⁰

QFG stated that ‘fertility clinics are optimally positioned to facilitate linkage between donors and donor-conceived persons through voluntary linkage programs and support networks’. However, QFG also noted ‘not all donor-conceived persons will be able to be linked’ and acknowledged ‘the challenges and difficulties experienced by some donor-conceived persons in such circumstance’. QFG added:

QFG recognises that the changes implemented almost two decades ago will protect the current generation of donor-conceived individuals. Fertility clinics have and will continue to support affected donor-conceived individuals, donors and recipients through linkage programs, counselling and support networks.¹⁷¹

¹⁶⁸ Submission 43, p 5; NB: in-text reference removed. Refer to original source.

¹⁶⁹ Public hearing transcript, Brisbane, 13 May 2022, p 42.

¹⁷⁰ Public hearing transcript, Brisbane, 13 May 2022, p 39.

¹⁷¹ Submission 44, p 4.

However, Donor Conception Australia stated:

The current NHMRC guidelines, (Australian Government: National Health and Medical Research Council, 2017), do not work in practice to protect the rights of donor-conceived people since they are not enforceable as they are only guidelines. The ART industry is for-profit and largely unregulated. Additionally, the interests of clinics may be at odds with the interests of the people that they are creating. Given this lack of oversight and/or accountability, clear legislation is crucial to protecting the best interests of donor-conceived people.¹⁷²

3.3.1 Options to manage collection, storage and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives

Independent Queensland Fertility Counsellors, Social Workers and Psychologists stated that *The Privacy Act 1988* (Qld) provides for the storage of medical records and recommended that any records relating to donor conception be held on a central register and kept 'indefinitely to safeguard the right of DC people to access their DC records at any future time'.¹⁷³

The OIC suggested that the Adoption Act could provide a legislative framework for managing the collection, storage and disclosure of information and may serve as a useful model. The OIC also noted that the introduction of a legislative right of access to identifying and non-identifying information for donor-conceived people could result in an increase in external review matters under the *Right to Information Act 2009* (Qld) (RTI Act).¹⁷⁴ In this regard, the OIC stated:

Learnings from the adoption information access experience have shown that access to donor conception information must be released administratively through a single scheme or point of access. This is consistent with the 'push' model under the RTI Act, with formal applications for government-held information under the RTI or IP Act made as a last resort, and use of existing administrative release schemes for access to identifying information such as the Forde Redress Files, Time In Care Information Access and access to adoption information.

OIC recommends any legislative framework for disclosure of donor conception information be subject to appropriate statutory confidentiality and secrecy provisions. We note such confidentiality provisions are sometimes considered for inclusion in schedule 3, section 12 of the RTI Act. The RTI Act generally overrides the provisions of other Acts that prevent the disclosure of information.

However, if the Act is listed in schedule 3, section 12, the information will be exempt from release, unless it is the applicant's personal information. This is consistent with the existing confidentiality provisions contained in section 314 of the Adoption Act. This approach provides clarity and certainty when accessing adoption information for all parties.

Restricting the use and disclosure of donor conception information except as authorised by the legislative framework or as may be necessary to perform functions under the Act through a penalty provision, will also assist to prevent the unauthorised use and disclosure of donor conception information.

OIC further suggests including a provision which makes it an offence for any person to unlawfully destroy, tamper with or falsify donor conception records.¹⁷⁵

¹⁷² Submission 59, p 15.

¹⁷³ Submission 31, p 2.

¹⁷⁴ Submission 43, p 8.

¹⁷⁵ Submission 43, pp 8-9.

QFG explained its processes for collecting, storing and disclosing information:

The medical information of each donor is collated, reviewed and actioned by medical specialists, including subspecialists in reproductive endocrinology and genetics. Donor counselling is performed by appropriately qualified, experienced counsellors under RTAC guidelines, including specific emphasis on identity disclosure, continuity of care and the release of identifying information to donor conceived individuals on request. There is no anonymous donation at QFG.

Document security and medical record management are integral components of modern fertility management. At QFG, donor and recipient data are maintained in a secure, encrypted database with national backup and file recovery, compliant with Australian Standard (2828.1:2019) for digitised and paper health records. Record retention is governed by the Department of Health Standard (QH-IMP- 280-1:2014) for the retention and disposal of clinical records, as mandated by Queensland Health. There has been no loss, alteration, or destruction of donor records in possession of QFG.

Health information is managed in the framework outlined in the *Privacy Act 1988* (the Privacy Act), which outlines the privacy responsibilities of healthcare providers, encapsulated in the Australian Privacy Principles (APPs). Access to the donor database is by authorised staff through dedicated access points, protected by a secure physical entrance requiring identity verification and logged, password protected network access in a fully compliant health informatics infrastructure. Given the regulation in place that already governs the management of Health information by healthcare providers, QFG questions the rationale for the collection, retention and administration of health care records by a non-clinical government agency or registry.¹⁷⁶

In this regard, QFG advocated for donor services to remain with fertility clinics:

In summary, QFG supports the release of identifying donor information to donor-conceived individuals in line with NHMRC and RTAC requirements. Importantly, health care administration cannot be separated from service delivery and therefore, donor services need to continue to rest with fertility clinics who have an established infrastructure and track record of delivering services and managing sensitive health care information. QFG has managed donor services in Queensland in a responsible, safe, transparent and publicly accountable framework without the imposition of state-based legislation or registration. On the contrary, state-based legislation and registration are likely to limit the acceptability of the process to donors, increase complexity and cost for recipients and increase health risks to donor-conceived individuals by imposing a bureaucratic third party.¹⁷⁷

Donor Conceived Aotearoa stated that whatever mechanism is implemented to manage the collection, storage and disclosure of identifying and non-identifying information about donors, the focus should be on providing donor-conceived people with the right to know their genetic origins.¹⁷⁸

3.3.2 Identifying donor conception status on birth certificates

Several stakeholders raised the importance of identifying a person's donor conception status on birth certificates. Jane Sliwka explained:

Another important consideration is that of birth certificates. Unlike adopted people who have two birth certificates (an original birth certificate with their birth mother and sometimes father's name recorded) and a legal amended birth certificate that lists the names of their adopted parents, donor conceived people are currently only issued with one birth certificate. This lists their legal parents' names (not their genetic parent). Based on the Queensland 'Status of Children Act' 1978, the recipient parents are

¹⁷⁶ Submission 44, p 2.

¹⁷⁷ Submission 44, pp 4-5.

¹⁷⁸ Submission 39, p 5.

automatically assumed to be and are recorded as the child's legal parents. This places donor conceived people in a difficult position when seeking information about their donor.

They are at the mercy of a clinic that may or may not be supportive of their request or have appropriate systems in place. Additionally, there are inequalities as different clinics respond differently to such requests. These experiences often cause great distress. Whilst the establishment of a central register would address the issue of information release, there are still other considerations regarding birth certificates.

In regards to adoption, two states of Australia (New South Wales and South Australia) currently have legislation that allows for 'integrated birth certificates'. These documents allow adopted people to have a legal birth certificate that lists their original parents (no longer legal) and their adoptive parents (legal parents) as well as their pre and post adoption names. Adopted people report that the ability to obtain such a document has greatly aided their sense of identity and psychological wellbeing. A similar document should be considered in Queensland for both adopted and donor conceived people.¹⁷⁹

A sperm donor recipient described their experience in relation to this:

My son's official and commemorative birth certificates both have large blank areas under the 'Father' section. I personally found this an affront, based on archaic notions that can give the impression that the 'Father' is unknown, or their identity is being hidden. I would have been happy for the words 'sperm donor conceived' to be written in lieu of 'Father' and the heading modified to 'Father/Donor/Parent.' I am unsure whether this has yet to be rectified and whether a more contemporary layout and progressive language have been considered, demonstrating greater awareness that families are now created in many ways. I am aware that there is still an issue with donor conceived siblings within the same family unit being included on their other sibling's Queensland birth certificates, which has been a source of distress for many families.

Therefore, the lack of inclusivity shown within these official government birth documents, (especially documents of great significance to individuals), may have negative implications upon an individual's self-identity and can be a cause of distress for many.¹⁸⁰ [Emphasis in original.]

Caroline Lorbach, a recipient parent, stated:

All records wherever they are currently held must be given permanent protection; in donor conception these records are the equivalent of true birth certificates. Many donor conceived people have very strong views about their birth certificates, some have called them sanctioned untruths. Some people, in particular donor-conceived people, and people involved in adoption, told me they believe that birth certificates should always display the names of a child's genetic parents, to reflect the biological truth about his or her parentage, and to guard against the secrecy that has historically accompanied donor conception and adoption.¹⁸¹

Professor Allan stated that 'at a minimum an annotation to the birth certificate should exist because in order to make a choice about accessing information about their donors, donor conceived individuals must know about the method of their conception in the first place'.¹⁸²

Professor Gelber explained why an annotation on birth certificates relating to a person's donor conception was important:

¹⁷⁹ Submission 25, p 6.

¹⁸⁰ Name withheld, submission 37, pp 4-5.

¹⁸¹ Submission 48, p 4.

¹⁸² Submission 69, p 25.

Unfortunately, due to the historical encouragement of secrecy, not all donor conceived people know that they are donor conceived. Many discover it accidentally when they are an adult, which can be very harmful to their wellbeing and identity.

In order to avoid this, all donor conceived people should have an annotation on their birth certificate stating that they are donor conceived. This empowers them as an adult to choose whether or not to pursue identification of their donor, or contact with a donor or siblings.

Knowledge of the fact of donor conception is also essential to protect against consanguinity.¹⁸³

In this regard, both Donor Conceived Australian and Professor Gelber recommended all donor-conceived people should have an annotation on their birth certificate stating that they are donor conceived.¹⁸⁴

3.3.3 Committee comment

Currently, the NHMRC Guidelines allow for donor-conceived persons to be provided identifying information about their donor upon reaching the age of 18, or if they are younger than 18 and determined to be sufficiently mature. The NHMRC Guidelines also set the minimum conditions of use of gametes collected before 2004, before which time many donations across Australia were provided on the condition of donor anonymity.

The committee considered the views of submitters in relation to donor-conceived persons having access to historical clinical records, including that the historical context of anonymous donations has created a situation where identifying donor information is available to some donor-conceived people but not others depending on when they were born. Some submitters contended this was discriminatory and that retrospective legislation should be introduced to afford all donor-conceived people equality regardless of when and where they were conceived.

The NHMRC Guidelines stipulate that clinics must ensure all existing information about parties involved in donor conception programs prior to the introduction of the 2004 edition of the NHMRC Guidelines is maintained appropriately. However, the committee heard evidence from submitters that this information was not always available from clinics upon request. Some submitters considered it important that clinics be required by law to protect their historical records, check them for accuracy and submit them to a central register, with some submitters stating that a register should be established and managed by a government agency, rather than fertility clinics. The committee supports legislation to prohibit the deliberate destruction of historical donor records and 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.

The committee also considered the matter of noting donor conception status on birth certificates. The committee heard evidence that early knowledge of being donor conceived is important to the formation of identity for donor-conceived persons and contributes to their wellbeing. Without a requirement to note donor conception on a birth certificate, a person may not be aware of their donor conception status and therefore also unaware of their genetic origins. However, with this information, a donor-conceived person is able to request identifying information about their donor and non-identifying information about any donor siblings once they reach the age of 18. In addition, a donor-conceived person would also be able to pursue contact with consent. In this regard, the committee supports the introduction of legislation to provide that birth certificates of donor-conceived persons

¹⁸³ Submission 1, p 4.

¹⁸⁴ Submission 1, p 4; submission 59, p 9.

be annotated to note the fact of donor conception and that the birth certificates of donor-conceived persons already born be amended to note the fact of donor conception.

Recommendation 3: Access to historical clinical records and implications of retrospectivity

The committee recommends that the Queensland Government introduces legislation to:

- prohibit the deliberate destruction of historical donor records
- 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
- provide that birth certificates of donor-conceived persons be annotated to note the fact of donor conception
- provide that birth certificates of donor-conceived persons already born be amended to note the fact of donor conception.

3.4 Access to support and counselling for donor-conceived persons and donors

Submitters attested to some of the issues people who are donor conceived experience.¹⁸⁵ According to ISS Australia, some of the traumas typically experienced by donor-conceived people include issues about identity and forming relationships, and feelings of grief, loss and anger.¹⁸⁶

Submitters were in general agreement that donor-conceived people, recipient parents and donors 'should have access to low cost support and counselling at a variety of stages during the donor conception and donor-linking processes'.¹⁸⁷ Professor Gelber submitted it 'vital' that appropriate support and counselling services be provided to support both donors and donor-conceived people.¹⁸⁸

Submitters considered who should deliver the support and counselling, as well as who should pay for it. There was general support from submitters for independent counselling and support services to be provided.¹⁸⁹ Sarah Dingle explained what independent counselling meant:

Donor conceived people should be entitled to **independent** support and counselling. What that means is counselling provided by individuals **who are not in the pay of any fertility clinic, nor have come from the fertility industry**. The conflict of interest is insurmountable.¹⁹⁰ [Emphasis in original.]

Cate Smith agreed, expressing the view that independent counselling services should be freely available to donor-conceived persons.¹⁹¹ Eleni McIlroy called for purpose-designed, independent and financially and geographically accessible support to all parties involved in donor conception.¹⁹² Kathryn Leishman observed that:

¹⁸⁵ See, for example, submission 35, p 1; submission 47, pp 2-3.

¹⁸⁶ Submission 29, p 4.

¹⁸⁷ Independent Queensland Fertility Counsellors, Social Workers and Psychologists, submission 31, p 2.

¹⁸⁸ Submission 1, p 5.

¹⁸⁹ See, for example, submissions 1, 3, 5, 7, 8, 11, 22, 26, 30, 31, 45, 69, 71.

¹⁹⁰ Submission 7, p 6.

¹⁹¹ Submission 22, p 4.

¹⁹² Submission 42, p 3.

VARTA and Jigsaw (SA) support and counselling seem to be a good model ... [for] managing information relating to donor conception. Support for unexpected revelations and counselling on expectations of connection are important. The third party intermediary making the connection is beneficial. The experience of those who attempt contact on their own is fraught with anxiety about both the reception they will get and also whether it is the right thing to do.¹⁹³

Professor Gelber recommended that support be funded by the government and provided by independent specialists.¹⁹⁴ A number of submitters supported state provided or subsidised counselling.¹⁹⁵ Donor Conceived Australia stated its preference for a government organisation to provide support and counselling, rather than a multinational corporation or a volunteer genealogist.¹⁹⁶ ISS Australia also supported government funded specialist counselling and support and that this should 'not be provided by a health service or fertility organization, but rather an organization experienced in social issues related to identity, relationships, grief, and loss'.¹⁹⁷

Cate Smith was of the view that the Queensland Government should cover costs relating to this, 'with the potential for also collecting a special levy from IVF clinics'.¹⁹⁸ VANISH submitted that the state had a duty of care to provide support and counselling, and that having people with lived experience provide these services was also important:

Information, counselling and support services should be available at no cost to all parties affected by donor conception across the life-time. These services should be delivered by organisations that are governed and staffed by people with a lived experience and are independent of assisted reproduction treatment service providers.¹⁹⁹

The key for providing counselling services for some submitters was that it should be at no cost to donor-conceived people, donors, and recipient parents.²⁰⁰ Alison Jones expressed this view:

A systematic disclosure of information that provides both donors and offspring with access to free counselling resources and information on how to communicate with the other party would be beneficial.²⁰¹

Some submitters commented on whether counselling should be a compulsory element at certain stages of the donor conception process with Caroline Lorbach submitting that counselling should be mandatory for entering a donor conception program.²⁰²

In contrast, Sarah Dingle argued that donor-conceived people should not be forced to undertake counselling.²⁰³ Donor Conceived Australia also submitted that 'opt-in counselling for donor-conceived persons, donors, and their families is an essential aspect of managing information relating to donor

¹⁹³ Submission 62, pp 1-2.

¹⁹⁴ Submission 1, p 6.

¹⁹⁵ See, for example, submissions 2, 4, 12, 29, 30, 31.

¹⁹⁶ Submission 59, p 10.

¹⁹⁷ Submission 29, p 3.

¹⁹⁸ Submission 22, p 5.

¹⁹⁹ Submission 71, p 3.

²⁰⁰ See, for example, submission 11, p 10; submission 22, p 4.

²⁰¹ Submission 26, p 8.

²⁰² Submission 48, p 5.

²⁰³ Submission 7, p 6.

conception'.²⁰⁴ A number of submitters advocated for optional counselling to be available to all donor-conceived people with the release of donor information.²⁰⁵

Donor Conceived Australia summarised its position:

Donor Conceived Australia advocates for appropriate optional support services, including counselling and linking services, to be provided on a voluntary basis to donor-conceived individuals, donors, and any other relevant family members who feel that they would benefit from this support. This support needs to be independent of fertility clinics or actors representing the fertility industry. Additionally, donors and donor-conceived individuals require the provision of any support independent of each other. Such support services require this independence and separation to ensure that they practise in an ethical manner, avoid conflicts of interest, and facilitate a trusting and respectful therapeutic relationship with their clients.²⁰⁶

In this regard, Donor Conceived Australia recommended that support and counselling for donor-conceived people, donors and other relevant family members be provided independent of the fertility industry, including donor linking services. This support must be offered in a manner that prevents any conflicts of interest.²⁰⁷

3.4.1 Committee comment

The committee considers it vital that measures, such as counselling and support, be in place to support the experience and wellbeing of donor-conceived persons, recipient parents and donors. In this regard, the committee recommends access to support and counselling be provided to these parties and that government considers funding the costs of these services. In addition, the committee considers that support and counselling should be provided independently of the fertility industry.

Recommendation 4: Access to support and counselling for donor-conceived persons, recipient parents and donors

The committee recommends that:

- 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
- such counselling and support services should be independent of the fertility industry.

3.5 Donor conception register

There was general support from submitters for establishing a donor conception register to provide access to information about donor conception and aid donor linking.²⁰⁸ For example, Patrick Cronin stated:

²⁰⁴ Submission 59, p 13.

²⁰⁵ See for example, submissions 8, 34, 39 and 52.

²⁰⁶ Submission 59, p 14.

²⁰⁷ Submission 59, p 14.

²⁰⁸ See, for example, submissions 1, 5, 6, 7, 8, 21, 22, 26, 28, 30, 31, 32, 33, 34, 36, 39, 40, 41, 42, 43, 46, 54, 57, 59, 62, 66, 70, 71.

I believe that the Queensland Government must establish a register, maintained by an independent and experienced authority. Reporting requirements should be audited with transparency and enforced to give all donor-conceived people equal rights and access to the benefits of the register.²⁰⁹

In supporting the establishment of a register, many submitters called for the register to be independent of ART service providers and maintained by a statutory authority or pre-existing government entity.²¹⁰ Professor Gelber explained that a government-controlled donor conception register was essential because having access to accurate historical information is ‘life-changing’ for a donor conceived person. She stated further that information provided by private clinics, which are bought and sold regularly and have a poor history of record keeping, is often incomplete.²¹¹ Donor Conception Australia supported this view:

... fertility clinics change hands over time and may close. Historically, members of Donor Conceived Australia report this has resulted in the loss of records. In these situations, there needs to be an independent body able to manage and retain records in perpetuity.²¹²

Nigel Page supported the creation of a register ‘to allow for faster, cheaper and more accurate location of donors’ and that it be government funded.²¹³ Jane Sliwka urged that, in considering the pros and cons of a central register being managed by government versus a non-government organisation, the needs of those most affected must be of highest priority.²¹⁴

Several submitters advocated for free access for donor-conceived people to the register.²¹⁵

In terms of the scope of the register, Dr Darren Russell submitted:

All information relating to donor conception should be placed on this register. Both donors and those conceived as a result of donations should have access to this information in a controlled manner, regardless of confidentiality agreements signed years or even decades past.²¹⁶

Rainbow Families Queensland stated that mandatory information recorded on the register should include:

... the date and place of birth of any children conceived through donor-conception, the name and date of birth of the donor, the ethnicity and physical characteristics of the donor, medical/genetic information of the donor, de-identified information about donor siblings, the name of ART provider and date of donation.²¹⁷

Donor Conception Australia stated:

Any register should not only include the information of Queensland donors but the information of any donors whose gametes are used to conceive a child in Queensland. This is necessary due to the use of international donors and the buying and trading of gametes across other states and territories. It should

²⁰⁹ Submission 8, p 5.

²¹⁰ See, for example, submissions 48, 58, 59, 65, 68, 69.

²¹¹ Submission 1, pp 1, 2.

²¹² Submission 59, p 15.

²¹³ Submission 5, p 1.

²¹⁴ Submission 25, p 6.

²¹⁵ See, for example, submissions 5, 37, 40, 59.

²¹⁶ Submission 10, p 4.

²¹⁷ Submission 40, p 8.

be noted that Donor Conceived Australia is strongly against the use of international donors and donor trading.²¹⁸

In regards to the type of information that may be recorded on registers, the following is noted from other jurisdictions:

- Victoria: VARTA’s central donor conception register records details of donors, recipient parents and their children, including both identifying (name, date of birth, donor code, contact details) and non-identifying information (medical history, interests, hobbies, physical features, month and year of birth). Donors, donor-conceived adults, parents of donor-conceived children and descendants of donor-conceived people may apply for information about a subject.²¹⁹
- New South Wales: mandatory information includes the full name, sex and date of birth of every child born as a result of ART treatment by the ART provider and the name of the woman who gave birth to the child. In addition, the ART provider must provide identifying information about the gamete donors, including:
 - full name, residential address, date and place of birth
 - ethnicity and physical characteristics
 - any medical history or genetic test results of the donor or the donor’s family that are relevant to the future health of:
 - a person undergoing ART treatment involving the use of the donated sperm, eggs or embryo, or
 - any offspring born as a result of that treatment, or
 - any descendent of any such offspring,
 - sex and year of birth of other offspring arising from the donation
 - name of each ART provider who has previously obtained donated sperm, eggs or embryo from the donor and the date on which the sperm, eggs or embryos were obtained.²²⁰

Submitters discussed their views on whether a government body or independent statutory authority should hold the register. Several submitters supported that the donor conception register be maintained by the Registry of Births, Deaths and Marriages.²²¹ Professor Gelber contended that ‘having information on a register that is controlled by government is just as appropriate for the donor conceived as it is for all other births’.²²² Stephen Page suggested that having the register held by the Registry of Births, Deaths and Marriages would be also beneficial from a cost perspective.²²³

²¹⁸ Submission 59, p 15.

²¹⁹ VARTA, *Donor Conception Register Services*, <https://www.varta.org.au/donor-conception-register-services>.

²²⁰ NSW Health, *The Central Register*, <https://www.health.nsw.gov.au/art/Pages/the-central-register.aspx>.

²²¹ Katharine Gelber, submission 1, p 6; Independent Queensland Fertility Counsellors, Social Workers and Psychologists, submission 31, p 2; Sonia Allan, submission 69, p 29. Also see submission 37.

²²² Submission 1, p 6.

²²³ Submission 13, p 53.

Some submitters expressed a preference for a national register to be established but if that was not possible that each state and territory establish 'independent, digitalised, centralised registers to oversee records on donor conception'.²²⁴ Giselle Newton stated that it was essential that the register function in cooperation with interstate and international bodies.²²⁵ VANISH stated:

It has long been argued by members of the donor conception community and their allies that a national register should be established. This was also recommended in the 2011 Senate Committee Report. A national register is required because although legislation and regulation of third party reproduction may be the remit of the states and territories, donor conception practices have not been retained within state boundaries. The transfer of sperm from state to state, together with the mobility of donor parents, families with donor conceived children and donor conceived adults, mean that there are multiple scenarios where a person in one jurisdiction is seeking to identify a relative in another.

VANISH therefore recommends pursuing a national register with other states, concurrently to establishing a register in Queensland.²²⁶

Independent Queensland Fertility Counsellors, Social Workers and Psychologists agreed:

It is appropriate that a DC register be established, and ideally this should be linked to a national register. A mandatory donor conception register for donations from 2004 and a voluntary register for donations prior to 2004 should be mandated within a specific new piece of ART legislation in Qld.²²⁷

Several submitters also called for ART clinics to be obliged to cooperate with a register.²²⁸ Patrick Cronin stated that 'a central Queensland register should be established, maintained and enforced under legislative requirements'.²²⁹ Natalie Parker stated that 'the new Queensland register must have safeguards in place to ensure that recipients do not bypass the system that is supposed to protect the rights of donor conceived children'.²³⁰ Giselle Newton stated that 'reform in legislation is necessary so that those practicing donor conception in a private setting be obliged to record the conception on the register to ensure sibling limits and access to information be upheld'.²³¹

Several submitters also called for nationally consistent legislation in relation to donor conception.²³²

Donor Conceived Australia recommended that a register be established with records held by a government agency, and that the register be retrospective and linked to other state and national registers.

The OIC contended that the 'establishment of a register to record the details of donors and donor-conceived children, including historical data, raises a number of privacy and data security risks and

²²⁴ Giselle Newton, submission 52, p 4. Also refer to Donor Conception Australia, submission 59, p 15; Emily Noy, submission 28, p 2.

²²⁵ Submission 52, p 4.

²²⁶ Submission 71, p 8.

²²⁷ Submission 31, p 2.

²²⁸ Nigel Page, submission 5, p 1; Jane Sliwka, submission 25, p 2; Patrick Cronin, submission 8, p 5.

²²⁹ Submission 8, p 5.

²³⁰ Submission 53, p 2.

²³¹ Submission 52, p 4.

²³² See submissions 30, 53, 59.

issues'. In this regard, the OIC recommended the Queensland Government create and manage a central register:

... creation of a central register managed by a designated Queensland government agency to reduce privacy and data security risks, promote efficiency and simplify the process of requesting access to information and registering any consents or contact preferences. A central register will also assist in mitigating risks associated with loss of information that may occur if a clinic closes down, doctors retire or if its records are compromised by an information security incident.²³³

The WLSQ supported the establishment of a government register 'with the appropriate safeguards as they relate to safety and privacy'.²³⁴

3.5.1 Consideration of private donor arrangements

Several submitters advocated for donors, recipient parents and donor-conceived people from private donor arrangements to be able to register their information on a donor conception register.²³⁵ Donor Conception Australia stated:

This register should also enable those who have used private donor conception arrangements to register the birth of their child or, for these donor-conceived people to register their own births. While Donor Conceived Australia does not condone the use of unregulated donor conception practices, there needs to be a mechanism for recording births and information and tracking these donors given the growing use of social media by recipient parents seeking donors and the growing number of donors providing gametes to multiple families outside of the fertility industry. This would also assist with maintaining the NHMRC's family limit recommendations, (Australian Government: National Health and Medical Research Council, 2017).²³⁶

Professor Kelly recommended that any central register be open to recipient parents and private donors to self-register for those situations where Australia women are conceiving with sperm donors outside of the clinical environment in order to 'avoid a shadow generation of children who do not have the same rights as those conceived in fertility clinics'.²³⁷

While the OIC noted that 'the inclusion of private donor arrangements on a register would afford persons conceived from private donor arrangements with equal information access rights as those conceived by ART clinical treatments', it was concerned about the integrity and accuracy of information that was not verified by an accredited ART clinic. For this reason, the OIC considered 'that donor information from private arrangements should only be included in a register with the consent of the donor'.²³⁸ The OIC continued:

To provide a clear indication that the accuracy of this information has not been verified by an ART clinic, an appropriate disclaimer should be attached to the entry in the register and be provided with any release of the information.

²³³ Submission 43, p 7. NB: in-text reference has been removed. Refer to original source.

²³⁴ Submission 45, p 2.

²³⁵ See, for example, Independent Queensland Fertility Counsellors, Social Workers and Psychologists, submission 31; Office of the Information Commissioner, submission 43; Donor Conception Australia, submission 59.

²³⁶ Submission 59, p 15.

²³⁷ Submission 46, p 3.

²³⁸ Submission 43, p 9.

Alternatively, the information from private donor arrangements could be recorded in a separate voluntary register. OIC does not support mandating the reporting of private donor arrangements, as this would be difficult to enforce.²³⁹

3.5.2 Committee comment

A central donor conception register in Queensland would provide access to donor conception information and a donor linking service for donor-conceived persons, donors, parents of donor-conceived children, and descendants of donor-conceived people. The committee considers that accurate donor conception information is vital for this. For this reason, the committee recommends establishing a donor conception register to apply retrospectively and prospectively, and that such a register be maintained by the Registry of Births, Deaths and Marriages to ensure its integrity through accurate data verification and the capturing of all available donor conception information.

Many submitters supported this approach, calling for the register to be independent of ART service providers and maintained by a statutory authority or pre-existing government entity. This would ensure users have access to accurate historical information regardless of whether fertility clinics change hands or close down, which may result in the loss of donor conception information.

The committee considers that a mandate for fertility clinics to provide accurate and timely donor conception information would address issues with record keeping. To ensure the register fulfils its purpose, the committee therefore recommends it be mandatory that fertility clinics provide donor conception information to the register. However, while the committee supports all donor-conceived persons having access to identifying information about their donors, the committee notes the potential problems associated with mandating a similar reporting requirement for those involved in private donor arrangements, including the difficulty in enforcing such a requirement. In this regard, the committee recommends that the register be available voluntarily to those who have pursued donor conception in private arrangements. The committee is of the view that further investigation should be undertaken 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.

As noted in section 3.2, the committee is recommending that contact between parties involved in donor conception be by mutual consent. Other jurisdictions allow for donors to submit contact preferences, which allows them to decide on the terms of contact, and the committee supports this approach. In addition, the committee recommends further measures to support donors, particularly historically anonymous donors, including being provided information on relevant changes in law in relation to their circumstance and on the support services available to them. Allowing donors to submit contact preferences would also mitigate any potential impact on a donor's privacy. In this regard, the committee recommends that staff who operate the donor conception register actively contact historically anonymous donors about relevant changes to the law and available support services, and permit them to lodge contact preferences.

Finally, the committee heard evidence that state and territory donor conception registers should be linked as donor conception practices are often not retained within state boundaries. This may lead to various scenarios where a person in one jurisdiction is seeking to identify a relative in another. Linking registers would assist people with accessing donor conception information across jurisdictions. The committee recommends that the Queensland Government work with other states and territories to

²³⁹ Submission 43, p 9.

investigate the linking of donor conception registers across jurisdictions, and any potential implications relating to this, for the purpose of people being able to access information relevant to them regardless of where they were born and live.

Recommendations about what to include on the register are contained in recommendation 2.

Recommendation 5: Whether a register should be established

The committee recommends, as a matter of urgency, that:

- a central donor conception register be established within the Registry of Births, Deaths and Marriages
- this register be mandatory in relation to donor conception achieved within a fertility clinic
- this register be available voluntarily to those who have pursued donor conception in private arrangements
- 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
- 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 preferences
- the Queensland Government works with states and territories to investigate the linking of donor conception registers across jurisdictions and any potential implications.

3.6 Benefits, risks and implications on donor conception practices arising from reforms and recommendations

In regards to establishing a centralised, digital register with retrospective information, submitters advised the following benefits:

- help donor-conceived people and recipient parents and future generations with accessing information decades after their authorship²⁴⁰
- provide an increased sense of identity for donor-conceived people with access to their full medical and genetic records from birth²⁴¹
- a legally mandated system and process will be in place, ensuring proper record keeping practices as is the case with other medical records.²⁴²
- Queensland would be on par with other Australian states and has the opportunity to learn from the changes made in other states to establish a system that operates in line with evidence-based best practice.²⁴³

²⁴⁰ Donor Conception Australia, submission 59, p 16; VANISH, submission 71, p 9.

²⁴¹ Donor Conception Australia, submission 59, p 16; Carolyn Fox, submission 34, p 6; Kathryn A Leishman, submission 62, p 2.

²⁴² Carolyn Fox, submission 34, p 6.

²⁴³ Carolyn Fox, submission 34, p 6.

VANISH also stated that a donor conception register providing retrospective access to donor conception information would have the following benefits:

- donor conceived people subject to anonymous donation will realise their human right to information about their genetic parents and siblings and be supported in the process
- donor parents will get answers to their questions regarding the children they assisted to create
- recipient parents will get support to tell their child(ren) and to navigate the new family dynamics
- media attention to the issue as it becomes public will encourage parents to advise their donor conceived children of their donor conceived status
- media attention will encourage individuals who suspect they might be donor conceived or adopted to connect with services and peer support groups for information and support
- people considering donating their gamete will consider the needs and rights of the children when making this decision
- people considering third party reproduction will consider the needs and rights of the children which is not always in front of mind when going through infertility and fertility treatment.²⁴⁴

Submitters identified the following potential risks with enacting legislation and establishing a donor conception register:

- the release of identifying information about donors may reduce the supply of gametes to the fertility industry and consequently recipient parents.²⁴⁵ However, some submitters argued that it was in the best interest of the child to know their genetic origins and that the wellbeing of donor-conceived people should be the first priority, with Donor Conception Australia noting that there had been no impact on donor numbers with the legislation to release identifying information in Victoria.²⁴⁶
- donor conception laws need to apply both to gametes donated within Queensland and to gametes used in Queensland but imported from elsewhere.²⁴⁷ Professor Gelber explained:

There is a current problem in Victoria; a loophole which allows Victorian residents to access donor gametes from international donors. Where this occurs, the resultant donor conceived people do not have the same protections in terms of access to identifying information as those conceived with gametes donated within Victoria. This loophole should not exist. Queensland should ensure the provisions ensuring donor conceived people have access to identifying information apply to all donated gametes used to achieve conception in reproductive treatment in Queensland, not only those gametes donated in Queensland.²⁴⁸

Independent Queensland Fertility Counsellors, Social Workers and Psychologists stated risks can be mitigated:

²⁴⁴ Submission 71, p 9.

²⁴⁵ See, for example, submissions 1, 59.

²⁴⁶ Submission 59, p 16. See also VANISH, submission 71, p 9; Ian Smith, submission 11, p 10; Carolyn Fox, submission 34, p 6.

²⁴⁷ Submission 1.

²⁴⁸ Submission 1, p 6.

Although risks exist in the establishment of a DC register, the benefits and positive implications outweigh any potential concerns, and risks can be mitigated by careful processes and provision of counselling by properly trained and experienced fertility counsellors.²⁴⁹

Another submitter also contended that risks could be managed in several ways, including through the provision of a 'public awareness campaign leading up to the legislation to inform the public about the forthcoming changes (e.g., access to information, registry) and support services that will be provided'.²⁵⁰ In addition, submitters recommended that resources and workshops be available to prospective recipient parents and donors, as well as trained staff working with the register to ensure it functions efficiently and to assist people with understanding the changes.²⁵¹

Another implication with establishing a donor conception register is the cost. As noted in section 3.5, many submitters called for access to the register for donor-conceived people, donors and the parents of the donor conceived to be free, thereby suggesting the government pay for this.

Other submitters also called for donor-conceived persons and donors to have access to low-cost or no-cost counselling and support, which also has implications for the organisation or agency funding this support.

3.6.1 Committee comment

As noted in previous sections, the committee supports the establishment of a donor conception register in Queensland to provide access to donor conception information to relevant parties and facilitate donor linking by mutual consent. To support all donors through the implementation of changes recommended in this report, the committee also recommends that all past, current and future donors be fully informed of any relevant changes to the law and that they will be identifiable to those born from their donation.

Recommendation 6: Benefits, risks and implications on donor conception practices arising from any recommendations

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.

²⁴⁹ Submission 31, p 2.

²⁵⁰ Name withheld, submission 58, p 3.

²⁵¹ Name withheld, submission 58, p 3; Eleni McIlory, submission 42, p 4.

Appendix A – Submitters

Sub #	Submitter
001	Katharine Gelber
002	Helen J Riley PhD
003	Helen McKenzie
004	Daniel Roos
005	Nigel Page
006	Amanda Woodrow
007	Sarah Dingle
008	Patrick Cronin
009	FamilyVoice Australia
010	Dr Darren Russell
011	Ian Smith
012	Katherine
013	Stephen Page
014	Mari Eleanor
015	Dr Anthony Stephen Brown
016	Toni Sanfilippo
017	Paul Bellas
018	Jigsaw Queensland Inc
019	Name withheld
020	National Medical Health and Research Council
021	Sophie Hicks
022	Cate Smith
023	Australian Medical Association Queensland Limited
024	VARTA
025	Jane Sliwka
026	Alison Jones
027	Trevor L Jordan
028	Emily Noy

029	International Social Service Australia
030	Kerri Favarato
031	Independent Queensland Fertility Counsellors Social Workers and Psychologists
032	Jessica Addley-Cook
033	Kate Drysdale
034	Carolyn Fox
035	Sarah Clay
036	Caitlin Macmillan
037	Name withheld
038	Name withheld
039	Donor Conceived Aotearoa
040	Rainbow Families Queensland
041	Elizabeth Baker
042	Eleni McIlroy
043	Office of the Information Commissioner
044	Queensland Fertility Group
045	Women's Legal Service Queensland
046	Professor Fiona Kelly
047	Name withheld
048	Caroline Lorbach
049	Ross Hunter
050	Name withheld
051	Confidential
052	Giselle Newton
053	Natalie Parker
054	Name withheld
055	Confidential
056	Margaret Bellas
057	Andrew Haines
058	Name withheld
059	Donor Conceived Australia

060 Confidential
061 Krystal Irene Kyriakou
062 Kathryn A Leishman
063 Name withheld
064 Sophie Turner
065 Aimee Shackleton
066 Hayley Smith-Williams
067 Robyn
068 Cath Grassick
069 Sonia Allan
070 Lyndal Dell
071 VANISH

Appendix B – Witnesses at public hearing

Individuals

- Professor Katharine Gelber
- Professor Daniel Roos
- Mr Ian Smith
- Professor Fiona Kelly
- Mx Sarah Clay
- Ms Caitlin Macmillan
- Ms Giselle Newton
- Professor Sonia Allan
- Ms Anne Leishman
- Mx Quill Leishman

Page Provan

- Mr Stephen Page

Rainbow Families

- Ms Heather Corkhill
- Ms Matilda Alexander

Donor Conceived Australia

- Ms Kerry Favarato, Qld Lead Representative
- Ms Aimee Shackelton, Founder and director
- Ms Courtney Du Toit, Member

Donor Conceived Aotearoa

- Ms Sophie Turner

Queensland Fertility Group

- Associate Professor Anusch Yazdani, Medical Director

Office of the Information Commissioner

- Ms Rachael Rangiheata, Information Commissioner
- Mr Paxton Booth, Privacy Commissioner

Independent Queensland Fertility Counsellors, Social Workers and Psychologists

- Ms Narelle Dickinson, Clinical Psychologist and Fertility Counsellor

