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Level 7
133 Mary Street
Brisbane Q 4000

PO Box 10143
Adelaide Street
Brisbane Q 4000

Phone (07) 3234 7373
www.oic.qld.gov.au

ABN: 70 810 284 665

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

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

Inquiry into Matters Relating to Donor Conception Information

The Queensland Office of the Information Commissioner (**OIC**) appreciates the opportunity to provide a submission in response to the Legal Affairs and Safety Committee's (**the Committee**) inquiry into matters relating to access to donor conception information.

Providing access to donor conception information represents a significant incursion into the privacy of the donor and their relatives where this is done without consent. While the right to privacy is not absolute, an appropriate balance must be struck with other legitimate rights and interests such as the rights of donor conceived persons to access information about their genetic origins. Issues relating to access to donor conception information are complex and invoke a number of considerations apart from privacy, including human rights considerations under the *Human Rights Act 2019* and managing requests for access to information from donors, donor-conceived persons and their relatives.

Issues concerning access to donor conception information mirror a number of the issues raised by access to adoption information. The learnings from the adoption experience, including the current legislative framework provided by the *Adoption Act 2009* (**Adoption Act**) for managing access to adoption information, provide useful learnings and a model to draw upon to inform the Committee's considerations.

About the OIC

The OIC is an independent statutory body that reports to the Queensland Parliament. We have a statutory role under the *Right to Information Act 2009* (**RTI Act**) and the *Information Privacy Act 2009* (**IP Act**) to facilitate greater and easier access to information held by government agencies. We also assist agencies to understand their obligations under the IP Act to safeguard personal information they hold.

OIC's statutory functions include mediating privacy complaints against Queensland government agencies, issuing guidelines on privacy best practice, initiating privacy education and training, and conducting audits and reviews to monitor agency performance and compliance with the RTI Act and the IP Act. Our office also reviews agency decisions about access and amendment to information.

OIC's submission

OIC's comments focus on some of the issues relating to access to donor conception information being considered by the Committee. These issues include:

- a) Extent to which identifying information about donor should be given to donor-conceived persons, taking into consideration the right to privacy of donors
- b) Access to historical clinical records and implications of retrospectivity
- c) 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
- d) Whether a register should be established
- e) Options to manage collection, storage, and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives; and
- f) Whether any model should include information from private donor arrangements.

Background

OIC notes that the Australian Government has not enacted legislation to regulate donor conception practices. Such practices are regulated by the states and territories. Only four states – Victoria,¹ South Australia,² Western Australia³ and New South Wales⁴ have legislation specifically governing donor conception information.

In states and territories where there is no legislation regulating donor conception practices, the National Health and Medical Research Council's (NHMRC) *2017 Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (ART Guidelines)* apply. As a result, Australian states and territories have varying approaches to the practices of donor conception.

Current Position in Queensland

Due to the lack of dedicated legislation governing the release of information connected with donor conception in Queensland, accredited assisted reproductive technology (ART) clinics adhere to the ART Guidelines.

Clinics are prohibited 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.⁵ This has been the position since these ethical guidelines were first developed in 2004. Gametes collected before 2004 without the consent of the donor to the release of their identifying information may only be used in limited circumstances.⁶

Donor-conceived individuals are currently entitled to receive non-identifying information about their donor once they have reached the age of 18.⁷ Similarly,

¹ *Assisted Reproductive Treatment Act 2008* (Vic).

² *Assisted Reproductive Treatment Act 1988* (SA).

³ *Human Reproductive Technology Act 1991* (WA).

⁴ *Assisted Reproductive Technology Act 2007* (NSW).

⁵ ART Guidelines, paragraph 5.6.1.

⁶ ART Guidelines, paragraph 5.13.

⁷ ART Guidelines, paragraph 5.9.1.

donors are entitled to receive non-identifying information about the number, age and gender of any persons born as a result of their donation.⁸

a) Extent to which identifying information about donor should be given to donor-conceived persons, taking into consideration the right to privacy of donors

The 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*'.⁹

The 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.¹⁰

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.

The issues relating to disclosure of identifying donor conception information are complex. 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.¹¹

OIC notes that Victoria passed legislation in 2016¹² enabling donor-conceived persons to be given access to identifying information, regardless of when a donor donated or when the donor-conceived person was born. To balance the privacy interests of persons impacted by the disclosure including donors and any other children of the donor, the legislation provides for these individuals to lodge a contact preference statement detailing the type of contact (if any) they would be willing to engage in.¹³ The applicant for information must give an undertaking to comply with the contact preference before any information is released. Penalty provisions apply if this undertaking is breached.

OIC further notes that South Australia recently passed amendments to establish the donor-conception register¹⁴ and is proposing to ensure that all donor-conceived people have access to identifying information about their donors, regardless of when they were conceived. Under this proposal, adult donor-

⁸ ART Guidelines, paragraph 5.7.1.

⁹ Section 12, IP Act.

¹⁰ Section 248 of the Adoption Act.

¹¹ New South Wales, South Australia, and Western Australia.

¹² *Assisted Reproductive Treatment Amendment Act 2015 (ART Act)* (Vic.)

¹³ Section 63G ART Act.

¹⁴ An amendment to the Assisted Reproductive Treatment Act 1988 commenced operation on 7 November 2021 to mandate the establishment of the donor-conception register.

conceived people will be able to seek identifying information about their donor without the donor's consent.¹⁵

As noted earlier, 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. 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.¹⁶ 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. The privacy impacts of disclosure of donor information on all persons require careful consideration when balancing privacy and the right to access donor conception information. Privacy considerations include:

- Requirements for consent prior to disclosure. OIC notes that the 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 older historical records
- Contact between the donor, the donor conceived child and their relatives. Unwanted contact may constitute an unreasonable interference in privacy of the donor and the donor's family
- Identification of persons other than the donor as a result of disclosure of donor conception information; and
- Requirements for notification to affected parties prior to disclosure.

The 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).

OIC supports 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.

However, given the significant impacts on the privacy of a donor and their family, it is OIC's view that identifying information about a donor should be carefully considered. Some of these competing issues are discussed further below.

OIC notes the current model provided by the Adoption Act which 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.¹⁷ This applies to adoptions which occurred before and after 1 June 1991.

¹⁵ [Fact Sheet - The State of Donor Conception Records in SA.](#)

¹⁶ Section 25, *Human Rights Act 2019*.

¹⁷ Note: The address of the birth parent can only be provided with consent.

b) Access to historical clinical records and implications of retrospectivity

The retrospective application of legislation is generally only warranted by strong public policy reasons justifying its implementation. As outlined previously, OIC supports administrative release of retrospective non-identifying donor conception information upon request. Release of retrospective identifying donor information would have a significant impact on the privacy rights of donors and their families who have not consented to disclosure and these implications should be carefully considered.

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. As noted by South Australia, due to the passage of time, some donor conception records may be incomplete or unable to be located.¹⁸ 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.

OIC recommends 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 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.¹⁹ OIC does not support genetic testing of historical donors in the absence of consent.

c) 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

In Queensland, access to the identifying information of donors primarily presents a privacy issue for those donors who donated prior to the introduction of the first NHMRC ethical guidelines in 2004. These donors were not required to consent to the disclosure of their identifying information to any donor-conceived offspring and may have donated under the condition of anonymity.

Other jurisdictions have addressed this issue by the introduction of either a prospective model or a retrospective model in conjunction with various mitigation strategies.

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,

¹⁸ [Fact Sheet - The State of Donor Conception Records in SA.](#)

¹⁹ Section 56 ART Act.

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.

Before releasing identifying information about a pre-1998 donor in Victoria, the Victorian Assisted Reproduction Treatment Authority must make all reasonable efforts to inform the donor of certain prescribed information, including that the donor may lodge a contact preference.²⁰ A pre-1998 donor may also include a written statement setting out their wishes about the donor's child being contacted by the applicant in their contact preference.²¹ Contact preferences must be extended every 5 years to remain valid.²² The Authority is exempted from giving a pre-1998 donor notice if they are unable to locate the donor within 4 months of receiving the application, or if the donor is deceased.²³ If the Authority has given a pre-1998 donor notice, they must disclose identifying information about the donor as soon as reasonable practicable after the donor consents, or 4 months have expired, whichever occurs earlier.²⁴ The release of information may be delayed for a further 4 months in exceptional circumstances.²⁵ The Authority will not disclose identifying information about a pre-1998 donor unless the applicant provides an undertaking not to contact the donor.²⁶ A donor who knowingly contacts the pre-1998 donor in contravention of such undertaking is liable to a penalty, unless such contact is a continuation of communications which was initiated prior the lodgement of the application.²⁷

While the 'contact veto' mechanism aims to achieve a balance between the interests of historical donors and donor-conceived individuals, OIC notes that it does not mitigate against all potential privacy risks.

Nothing prevents a donor-conceived individual from disclosing the identity of their donor to third parties, including the media. This may disadvantage historical donors who hold prominent positions in society, such as celebrities. Extending undertakings not to contact to also include those that seek to prevent the public disclosure of the identifying information of historical donors may mitigate against this risk.

While contact preferences and undertakings not to contact may extend to a historical donor's child in certain instances, it does not extend to the donor's partner or other family members. The obligation to renew the contact preference may also put unnecessary strain on historical donors who feel strongly that they do not wish to be contacted. If contact preferences are to be utilised, OIC

²⁰ Section 32(2) of the ART Act.

²¹ Section 63C(1)(b) of the ART Act.

²² Section 63D(1) of the ART Act.

²³ Section 63(1) of the ART Act.

²⁴ Section 63B(1) of the ART Act.

²⁵ Section 63B(3) of the ART Act.

²⁶ Section 63(2) of the ART Act.

²⁷ Section 63(3) of the ART Act.

suggests including non-expiring contact preferences which offer the donor the option to provide their preference as to contact with their extended family members as well. Donors who decide to reconsider their original decision to remain anonymous can continue to amend their contact preference at a later stage.

Another approach to the retrospective model has been adopted in the Netherlands, where the access rights of donor-conceived persons depend on their date of conception. Donors who donated after the entering into force of the governing legislation²⁸ in 2004 were only permitted to donate if they had no objection to their identifying information being recorded and released to any potential offspring. Those who donated prior to 2004, were asked to consent to the release of their information, but were given the option to opt-out of any disclosure and remain anonymous.²⁹ During the two years before the law became operational, clinics were asked to contact all historical donors to request that they complete a statement about whether they would agree to the release of their identifying information. If they wished to remain anonymous, they were required to sign a confidentiality statement which would ensure that their identifying information was not released.³⁰ This approach has been described as introducing an 'information-veto'.

OIC supports a prospective model which requires all donors who donated prior to 2004 to give consent to the release of their identifying information. This approach will safeguard the privacy interests of historical donors, particularly where confidentiality was guaranteed at the time of donation.

Should a retrospective model be preferred, OIC suggests 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.

OIC notes 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 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.

d) Whether a register should be established

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 issues.

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 will be bound under the *Privacy Act 1988* (Cth) as an Australian

²⁸ Wet donorgegevens kunstmatige bevruchting, 2002.

²⁹ Article 3:4 of the Wet donorgegevens kunstmatige bevruchting, 2002.

³⁰ Article 12:2 of the Wet donorgegevens kunstmatige bevruchting, 2002.

Privacy Principle entity, whereas ART clinics that operate as a public health service provider in Queensland must comply with the IP Act.³¹

In the absence of a central statutory register, individual ART clinics are solely responsible for collecting, maintaining, securing and disclosing information relating to the ART treatments administered in that clinic.

Individuals seeking access to information about their donor, donor-conceived children or donor siblings are required to approach the fertility clinic who administered the ART treatment. This may present a barrier to access information if the responsible clinic is unknown or in instances where it has ceased to exist or where the treating physician has retired.

Due to the sensitive nature of donor conception information, the sharing of donor conception information between donors and donor-conceived individuals should be facilitated by counsellors with specialist skills, which may not necessarily coincide with the skillset of ART service providers.

OIC recommends creation of a central register³² 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.

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

The current legislative framework provided by the Adoption Act for managing the collection, storage and disclosure of adoption information may serve as a useful model to draw upon to inform the Committee's considerations.

OIC notes that the introduction of a legislative right of access to identifying and non-identifying information for donor-conceived persons could result in an increase in external review matters under the RTI Act. 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.

³¹ ART Guidelines, paragraph 3.9.

³² Victoria, New South Wales and Western Australia all have central registers administered by the Victorian Assisted Reproductive Treatment Authority, the NSW Ministry of Health and the Western Australian Department of Health, respectively. The South Australian Parliament has also recently passed amendments to the *Assisted Reproductive Treatment Act 1988* (SA) to mandate the establishment of a central donor conception register.

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.

f) Whether any model should include information from private donor arrangements

While the use of donated oocytes and embryos generally require the assistance of ART clinics, women are able to conceive a child as a result of self-insemination from a private donor arrangement.

OIC notes 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. Women who self-inseminate using sperm from a known donor should therefore be encouraged to register the donor's name on donor registers.

However, there are concerns regarding the integrity and accuracy of information that has not been verified by an accredited ART clinic. For this reason, OIC considers that donor information from private arrangements should only be included in a register with the consent of the donor.

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.

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.

OIC remains available to assist the Committee with its Inquiry.

Yours sincerely



Paxton Booth
Privacy Commissioner



Rachael Rangihaeata
Information Commissioner