

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