New donor treatment laws provide persons conceived from gametes donated prior to 1988 with access to information about their donors

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In an Australian first, amendments to the Assisted Reproductive Treatment Act 2008 (Vic) passed on 21 August 2014 will enable a person born from a donor treatment procedure from gametes donated prior to regulation of assisted reproductive treatment procedures to request information about their donor, including their medical history. Identifying information about a donor may only be disclosed with that person’s consent.

Introduction

Victoria has a proud history of pioneering technological advances and regulation in relation to assisted reproduction. It was the first jurisdiction to recognise the needs of donor-conceived persons to access information regarding their genetic heritage, with the passage of the Infertility (Medical Procedures) Act 1984. After its commencement in 1988, this Act gave a statutory right to persons born from donor treatment procedures to access information about their donors. Again, Victoria is ahead of the pack with recent amendments to the Assisted Reproductive Treatment Act 2008 (the ART Act), enabling donor-conceived persons born before this first regulation, retrospective access to information about their donors.

The Assisted Reproductive Treatment Amendment Act 2014 (the Amending Act), was passed by the Victorian Parliament on 21 August 2014. The Amending Act amends the principal ART Act, increasing the rights of donor-conceived people to access information about their donors (where that information is available) by extending the rights existing under the current legislation to those donor-conceived people who were conceived prior to 1988. Previously there was no legal right to access such information as these treatment procedures were carried out before State regulation required the centralised storage of information relating to donor treatment procedures.

This significant social policy achievement was implemented in the context of strong public debate, with the support for donor-conceived individuals to have greater access to information having to be balanced against the rights and the interests of donors whose personal information would be disclosed.

Policy background

In Victoria, there are currently three separate regimes regulating access by donor-conceived people to information about their donors:

• People who were conceived using gametes donated prior to 1988 do not have a legal right to identifying information about donors. They may be able to obtain non-identifying or identifying information about their donors if their donors have provided that information to Birth, Deaths and Marriages for the Voluntary Register.

• People who were conceived using gametes donated between 1988 and 1997 can obtain non-identifying information about their donors from the Central Register. They can obtain identifying information about their donors if their donor consents to releasing the information. Donor-conceived people in this cohort may also be able to obtain identifying information about their donors if their donor has provided that information to the Voluntary Register.

• People who were conceived using gametes donated after 1 January 1998 can obtain identifying information about their donor from the Central Register.

The attitude to anonymity of donors has differed widely, ranging from mandatory anonymity to the prohibition of anonymous donors.

• Traditionally the culture surrounding the use of donor gametes was heavily entrenched in secrecy; with children born through donor treatment procedures not being informed of their mode/method of conception and with donor anonymity being demanded.

• However, the culture has moved slowly toward the promotion of disclosure and openness, resulting in more parents disclosing to their children the details surrounding their conception.

The Waller Committee was established in 1982 to consider “whether the process of in vitro fertilisation (IVF) should be conducted in Victoria and, if so, the
procedures and guidelines that should be implemented in respect of such processes in legislative form or otherwise”. The Waller Committee recommended that a register be created and maintained recording information about donors and pregnancies to permit identifying information to be provided to children born through successful IVF procedures.9

Legislative development in Victoria

Donor sperm has been used in medical settings to treat male infertility since the 1940s, however, prior to the introduction of the Infertility (Medical Procedures) Act 1984 (Vic), there was no requirement that doctors record information pertaining to donors.11 This legislation introduced a requirement that information about donors, recipients and children born as a result of donor treatment procedures be recorded in a Central Register,12 and it allowed persons born from donor treatment procedures to access information about their donors once they reached 18 years or older with the donors’ consent.

Subsequent legislation, the Infertility Treatment Act 1995 (Vic), removed donor anonymity. This enabled a donor-conceived person conceived from gametes donated after the commencement of the legislation the ability to access identifying information about their donors, as of right, once they reach 18 years or older.13 This legislation also made provision for a Voluntary Register providing for information exchange between donors and donor-conceived people. The culture of anonymity was still firmly entrenched however as donor-conceived people were only able to access information about their donors if their donor knew about the Voluntary Register and had voluntarily submitted information to it. The subsequent Victorian Parliamentary Committee Inquiry found this to be an unsatisfactory option for persons conceived from gametes donated before 1988, as the numbers of donors who had voluntarily signed up to the Register was very low.14

Following an Inquiry into the laws that governed assisted reproductive technologies, the Victorian Law Reform Commission Report made 130 recommendations reflecting the change in attitudes toward IVF and the advancement in assisted reproductive treatment (ART) technologies.15 The resulting Assisted Reproductive Treatment Act 2008 came into effect on 1 January 2010 and the newest amendments to the Assisted Reproductive Treatment Act 2008 “extends the current law applying to 1988–97 donor-conceived people to donor-conceived people conceived prior to 1988”.16

The Victorian Parliamentary inquiry

The Victorian Parliamentary Law Reform Committee (Parliamentary Committee) was asked to inquire into, consider and report on the rights of donor-conceived people to access identifying information about their donor regardless of when they were born.17 The Parliamentary Committee recommended that all donor-conceived people be provided with access to non-identify information about their donors where gametes were donated prior to 1 July 1988 and identifying information only with the donor’s consent. The recommendation by the Parliamentary Committee to retrospectively release donor information understandably had responses from both ends of the spectrum. Those opposed called the recommendation “unfair”,18 while supporters saw this as a welcoming move “towards openness and honesty”.19 Some donors saw it as their responsibility to assist their donor offspring.20 Regardless of perspective, the amendments to the legislation are limited by the records detailing donor and donor treatment procedures, and the Parliamentary Committee recognised that these records, if they exist, may in fact contain very limited information.

Other jurisdictions

Victoria is not alone in having looked at access to donor information through the lens of a parliamentary inquiry.

- The NSW Legislative Assembly Committee on Law and Safety completed a similar inquiry into access to donor information.21 The Committee recommended that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access non-identifying information about their donor, regardless of whether or not the donor consents to such information being released. The Committee were unwilling to recommend substantive change in relation to access to donor conception information in light of the lack of direct evidence received from donors about the impacts of the release of identifying information without consent.22

- Federally, the Legal and Constitutional Affairs References Committee (the LCAR Committee) was asked to conduct an inquiry into the past and present practices of donor conception in Australia, with specific focus on
  — the regulation and legislation of donor conception across state and federal jurisdictions;
  — the conduct of clinics and medical services;
  — the number of offspring born from each donor with reference to the risk of consanguine relationships and
  — the rights of donor conceived individuals.23
The LCAR Committee recommended that donor-conception legislation in Australia be separate, but consistent in relation to prohibition on donor anonymity, that there be a limit on the number of families that any one donor can assist and that donor-conceived individuals are provided with rights to access identifying and non-identifying information. The Senate Committee Inquiry was reluctant to make any recommendation as to whether to permit retrospective access to identifying and non-identifying information, preferring to leave the consideration of this issue to the states and territories.

**Consultation with donors**

Following the Parliamentary Committee Report, the Victorian Assisted Reproductive Treatment Authority (VARTA) was charged with consulting with donors who donated prior to 1988 regarding the implications of the Committee’s recommendations for the retrospective release of donor information. The consultation process sought to consult with pre-1988 donors in relation to the recommendations to extend the existing legislation to include all donor-conceived persons. The consultation looked at the opinions of donors in relation to retrospective access to donor information; the practical implementation of avenues for donor-conceived people to access information; the notion of a renewal 5-year contact veto; preferred methods of contact; the provision of medical information in instances where there is evidence of heredity diseases; and provisions for DNA matching where records are incomplete or are unreliable.

Further, VARTA sought donors’ opinions in relation to how best to communicate the amendments to the legislation to donors, and how to best support donors if the legislation did not remove anonymity.

Of the 42 donors (36 sperm donors, six egg donors) who participated in the consultation, they were diverse in age (40–73), place and year of donation (1970–97), disclosure patterns, outcome of their donations, and whether or not they had been approached by donor offspring or joined the Voluntary Register.

The consultation revealed:

- A little fewer than half of the donors supported the recommendation. These donors emphasised the needs of donor-conceived people to understand their genetic heritage and the responsibility of donors to do all they can to assist their donor offspring.
- A little more than half of the donors rejected the recommendation. These donors said it would violate the terms of a contract and undermine trust in guarantees of privacy and confidentiality, as well as harming them and their families.

About half of the donors who rejected the recommendation suggested the compromise of persuading donors voluntarily to release information (whether identifying or non-identifying) to donor-conceived people.

**The Assisted Reproductive Treatment Amendment Act 2014**

**Scope of access**

The amendments, once operative, will enable donor-conceived individuals to make a request for access to information from the Registrar of Births Deaths and Marriages (the BDM) on similar terms to persons conceived following the commencement of regulation in this area. The effect of the amendments are that persons born before 1988 from donor treatment procedures, who previously had no legal right to access information, will now, as far as possible, have the same rights to access information from a Central Register maintained by the BDM as persons born from treatment procedures carried out between 1 July 1988 and 31 December 1997. This means that the Registrar may disclose information held on the Central Register to an applicant who was conceived from donated gametes at any time prior to 31 December 1997 and the applicant may receive identifying information about their donor if their donor consents to its release. In addition to persons conceived from donated gametes at any time prior to 31 December 1997, any descendants will also have the same right to seek information from the Central Register.

This new right to seek access to information is not without two significant practical limitations that the new legislation also attempts to address. Records relating to pre-88 treatment procedures were not required to be centrally kept so that records have to be secured and information transferred to the Central Registrar to enable BDM to respond to requests for information. How the legislation responds to this challenge is discussed below. A further challenge is locating the donor, who in most cases would have donated over 30 years ago, in order to obtain consent to the release of identifying information if this is sought by the applicant. This will be the role of the Registry of BDM who will have access to the other registers of significant life events (for example, births and deaths) to cross reference, identify and locate donors where possible.

To assist BDM with obtaining consent from the donor, the role of the Victorian Assisted Reproductive Treatment Authority will be extended to provide counselling and donor-linking services to applicants seeking information from the Central Register. Counselling will be available to not only applicants seeking access to information, but also, recipients of requests, to assist them in understanding the request and to discuss the potential steps involved.
implications of consenting or not to the release of their identifying information. If the release of identifying information is refused, the donor may choose to disclose non-identifying information through the donor-linking services. In addition to counselling services, VARTA will now be able to provide a donor-linking service. This service aims to facilitate an exchange of information or correspondence between donors, donor-conceived persons, descendants of donor-conceived persons, and recipients of donor treatment procedures. This service is not intended to usurp the role that ART providers have in this respect in relation to their patients and their own donor treatment programs. It is intended to be more of a complimentary function.

The donor-linking service will be based on voluntary participation and each party participating in the service will only be involved to the extent that they consent to be involved. For example, a person may only want non-identifying information about their donor but not wish for identifying information or contact with their donor. It is envisaged that if the donor refuses to consent to the disclosure of their identifying information they may choose to use the donor-linking services provided by VARTA to exchange non-identifying information with the person born as a result of the donor treatment procedure.

The amendments also enable a person born from a donor treatment procedure or their parent to access information about their donor-siblings — that is, other persons conceived through donor treatment procedures from gametes of the same donor. The release of a limited amount of information about donor-siblings is intended to ensure that a donor-conceived person does not unknowingly form a romantic relationship with a half-sibling.

**Preserving and securing records of pre-1988 donor treatment procedures**

One of the most significant amendments is the addition of a new obligation for the retention of records identifying participants in donor treatment procedures. Records capable of identifying the participants to donor treatment procedures must be kept for 99 years after the creation of the record. This obligation commenced on the 30th October 2014 and applies not only to registered ART providers but also applies to a natural person. Importantly, this new obligation applies to records created before and after the commencement of the legislation. This means that any former doctors who may be in possession of records relating to pre-1988 donor treatment procedures are required to retain these or surrender the records to the Registrar of BDM.

The new record retention obligation is not dissimilar to the standard set by the National Health and Medical Research Council Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, which requires that records are kept indefinitely (or at least the expected lifetime of any persons born). From the commencement (30 October 2014), it is an offence to destroy or remove or cancel identifying records. The new offence does not operate retrospectively, and as such, it does not create any liability arising from records that have been destroyed, cancelled or removed prior to the commencement of the new retention obligation.

In addition to retaining records, Victorian Registered Assisted Reproductive Treatment (ART) providers who hold records relating to pre-1988 donor treatment procedures will be required to keep a register of prescribed information from those records. ART providers will be required to provide this information to the Registrar of Births Deaths and Marriages to update the Central Register that she maintains. The Assisted Reproductive Treatment Regulations 2014 set out the prescribed information that ART providers need to collect in relation to pre 1 July 1988 donor treatment procedures. This includes information relating to donors, women on whom donor treatment procedures were carried out, the kind of treatment procedure carried out and the outcome of treatment procedures. These requirements closely mirror obligations ART providers already have in relation to post 1 July 1988 donor treatment procedures. The likely reality however is that most of this required information may not be available as it may not have been collected or recorded at the time the gametes were donated; records may be lost or incomplete. In addition, any retired doctors or their relatives who possess records relating to pre-1988 donor treatment procedures will also be required to provide those records or a copy of those records to the Registrar. This ensures that the Central Register includes all relevant information for donor treatment procedures conducted before 1988 regardless of who holds those records.

**Mechanism for sharing relevant genetic and hereditary medical information**

ART providers will be authorised to disclose non-identifying medical information about a donor or adult donor-sibling to a person born as a result of donor treatment where the disclosure is necessary to save a person’s life or to warn the person to whom the information is to be disclosed about the existence of a genetic or hereditary condition that may be harmful to that person or their descendants.

**Conclusion**

The National Health and Medical Research Council’s guidelines on assisted reproductive technologies recognise
the importance of information exchange between donor-conceived persons and the donor. Studies show that knowledge about their donor, their half siblings and their genetic history is essential to identity formation in donor-conceived people. The changes to accessing information about genetic heritage will provide donor-conceived persons with the opportunity to do so if they choose.

Evidence before the Commonwealth Senate Committee Inquiry indicated a high level of dissatisfaction about the differences in legislation and regulation between the states in the management of donor conception data. The Committee considered that there would be significant benefit in having records relating to donor conception, particularly personal information about donors and donor conceived people, stored in a single national register. The Committee chose not to make any specific recommendation about retrospective access to donor information, however, supported, in principle, the rights of donors to retain the anonymity that they were guaranteed when they agreed to donate and donor-conceived individuals having a right to information about their biological heritage.

Following the action in Victoria and proposals in New South Wales, it should be abundantly clear to other jurisdictions that have a history of assisted reproductive technology regulation that further action is required to ensure equality of access to information for persons conceived from gamete donation prior to regulation, irrespective of their state or territory of residence. The approach set down by the Victorian Assisted Reproductive Treatment Amendment Act 2014 offers a sensible balance between the rights of donor-conceived people to information about their genetic heritage and the rights of donors who donated under a promise of anonymity.

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Footnotes
1. Assisted Reproductive Treatment Further Amendment Bill 2013, second reading speech. Legislative Council at p 2449.
2. Assisted Reproductive Treatment Act 2008 — Section 3 defines “identifying information” to mean information that will or may disclose the identity of a person.
3. “Voluntary Register” means the register kept by the Registrar of Births, Deaths and Marriages under the Births, Deaths and Marriages Registration Act 1996. Under s 70 of the Assisted Reproductive Treatment Act 2008, the Registrar must keep a Voluntary Register that contains information about donor treatment procedures. The Voluntary Register must be kept separately to the Central Register and is not part of the Central Register. The voluntary register enables participants to donor treatment procedures to voluntarily register as much or as little information about themselves that they would be willing to disclose to other related participants to donor treatment procedures.
4. “Central Register” means the register kept by the Registrar under s 55 of the Assisted Reproductive Treatment Act 2008. The Central Register contains information pertaining to the number of persons born as a result of a treatment procedure or artificial insemination using that donor’s gametes and the prescribed information.
17. Above, n 11.