



Western Australian Reproductive Technology Council submission 6/04/2016

The Reproductive Technology Council (Council) has a central role in the regulation of artificially assisted human conception under the *Human Reproductive Technology Act 1991* (HRT Act) in Western Australia (WA). Council has a broad range of expertise and interests from its membership and welcomes the opportunity to comment on the establishment of a 'Donor Register' for South Australia.

Council wish to make comment on four inter-related issues around donor-assisted conception:

- keeping of records;
- information management;
- authorities and agencies; and
- counselling for release of donor information.

Keeping of records

Council endorses and encourages the retention of secure, detailed and accurate records so as to promote access to donor information by resulting children.

Background

Prior to the implementation of the HRT Act, there was no legal requirement in WA for clinics to retain donor or recipient information. Accordingly, record keeping was not of a standard that would be expected today, particularly with the culture of secrecy prevailing at that time. The result is that in WA very limited information is available from clinics or individual doctors for people who were conceived prior to the implementation of the HRT Act.

The introduction of the HRT Act enforced retention of records and provided for uniform standards of record keeping. The Reproductive Technology Registers were established in WA in 1993 under s45 of the HRT Act and require submission of donor and recipient information, including identifying information, to the Department of Health Reproductive Technology Registers.

Access to donor information

Amendments introduced into the HRT Act in 2004 provide that, from 1 December 2004, donated reproductive material can only be used on the understanding that any resulting person may access identifying donor information when they reach 16 years of age. Donors are required to undergo counselling prior to becoming a donor, so they are aware that they must consent to future release of identifying information as part of the donation process.

However, the HRT Act prohibits release of identifying information about a donor prior to 1 December 2004:

- unless the donor gives consent to such release;
- or the Chief Executive Officer, Department of Health, is satisfied that prior to the donation the donor was adequately informed that the law might change to permit release of the donor's identity without the donor's consent.

In other words, this protects the anonymity of donors who donated material at a time when it was understood that their identity was to remain confidential.



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The HRT Act does allow for access to identifying information when there is consent from each donor, recipient and child in question or other person, so far as it does not disclose the identity of any person who was a participant in the procedure and does not give consent. A person who has parental responsibility may give consent on behalf of a child under 16 years of age. In addition to requiring the consent of all participants, identifying information can only be provided where a donor link has been verified and counselling has been undertaken.

Donor-conceived adults (18 years old), parents of donor-conceived children (< 18 years old), and donors may join the WA Voluntary Register so that information may be shared with mutual consent. Voluntary registrations are not limited to pre-2004 donations and this allows an option for the provision of additional information and for donor-conceived adults, parents of donor-conceived children and donors to connect (link) with their biological relatives, including half siblings. However, this does depend on other donor related people joining the Voluntary Register. To raise awareness of the Voluntary Register advertising is undertaken four times a year in the West Australian newspaper, as well as periodic advertisements in university alumni newsletters, national and local medical journals, parenting publications and 'Google' metadata advertisements.

As of 30 June 2015, there were 205 voluntary registrations (30 donor-conceived adults; 76 donors; and 99 parents of donor-conceived children) with a total of 28 donor links (3 donor-conceived adults; 12 parents of donor-conceived children; and 13 half-siblings) and 14 have shared identifying information.

The current layers of complexity regarding access to donor information in WA pose ethical, administrative and operational challenges. Table 1 provides an overview of access and availability of information pre and post the HRT Act.

	Availability of information
HRT Act amendments 1 December 2004	Clinics must retain their records indefinitely. Mandatory submission of identifying and non-identifying information to the Department of Health Reproductive Technology (Donor) Registers. Prospective access for donor-conceived adults (16 years of age) to identifying donor information. Five family limit (not including donor).
HRT Act 1991 1993 – 2004	Clinics must retain their records for at least 25 years Mandatory submission of identifying and non-identifying information to the Department of Health Reproductive Technology (Donor) Registers. Donor identifying information confidential. Five family limit (not including donor).
Before the HRT Act	Very limited information may be available from clinics and individual doctors. Donor anonymity. Multiple recipients (no family limit).
Voluntary Register 2002 onwards	Voluntary registration system for donor-conceived adult (18 years of age), parents of a donor-conceived child (less than 18 years of age), and donors. Registrations not limited to before the HRT Act.

Table 1: Legal epochs and availability of donor information in WA



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Information management

Donor information is often detailed and includes complex relationships. Capturing, storing, and retrieving this information requires a clear understanding of operational objectives and the development of appropriate information management systems. As Donor Registers continue to expand, sophisticated information management systems will be required.

Council submits that there is a clear need for Donor Register information management systems to be developed. The design of such systems is related to the core purpose of the register, for example:

- Information that supports the welfare of the child / parents: Biographical information about the donor that helps build a description of the donor as a person, for example personal statement / pen portrait. This information is usually available as part of the donor profile to help parents to choose a donor. However, the information needs of a donor-conceived person / family will change over time.
- Medical history is increasingly important to donor-conceived persons. Council note there is no consensus regarding what relevant information comprises medical history.
- Provision of health-related information requires careful consideration. The relevance of health-related information may require consultation with clinicians to help people to consider the implications.
- There is a need for mechanisms for prospective updating of registration details.
- Accommodation of single donor record with large numbers of recipients records, as prior to the HRT Act there were no restrictions on the number of families using the same donor and recipient with more than one donor.
- Operational complexities also arise when a person is an egg donor / sperm donor and has also donated embryos as a couple. Information management systems require functional capabilities to identify these types of configurations.
- Council note that the Human Fertilisation and Embryo Authority encountered difficulties in tracking the movement of donor gametes and introduced a unique donor reference, to track donated reproductive material within the United Kingdom and internationally.
- Consideration should be given to a unique donor reference system to support donor-recipient linking nationally and internationally.
- The development of donor registers must include appropriate methods to ensure the validation and verification of source data to establish genetic relatedness and accommodate developments in genetic testing.

Statutory authorities and agencies

In WA, current experience of donor linking and release of information is through the small number of people who have joined the Voluntary Register, which is managed by the Reproductive Technology Unit, Department of Health.

Council considers the management of information related to donor-assisted conception to be a complex process that requires a package of related measures. It embodies deeply private and emotional experiences and is of profound significance to families affected by donor conception. Research suggests that information sharing (non-identifying and identifying) and contact with donors and other families with 'half siblings' is, for the most part, a positive experience. However, there is a lack of research on long-term outcomes.



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Donor Registers are established principally for the benefit of people affected by donation. Integral to the operation of donor registers is support for the parent/s, with reference to resources for open disclosure (consumer factsheets, counselling, support groups), so donor-conceived persons may know of their genetic origins. Council notes that applications for donor information and donor / sibling matching are significant decisions and there can be unexpected consequences, which can impact on the lives of all the people involved.

Council is aware that mandatory and voluntary Donor Registers are just one aspect of a package of interventions, resources, and policy decisions that are required to appropriately manage donor information. The management of Donor Registers is operationally complex because it is inextricably linked with sharing of sensitive and personal information, which must sit within a legal framework that requires translation into policy, operational procedures, service delivery and the role of statutory authorities.

Parents and donor-conceived persons sometimes have concerns about inadvertent consanguinity between donor-related siblings and access to identifying information can ameliorate those concerns. Consequently, it is reasonable to give consideration to linking Donor Registers to Birth, Death and Marriage Registers (BDM). This is an established and enduring agency, which has existing infrastructure for in perpetuity management of personal information related to births involving donor gametes and embryos. This is particularly so for potential generational needs and in dealing with complex biological relationships, such as genetic testing which may be necessary in some cases.

The BDM experience with adoption could inform future policy for donor-linking, including referral to other community services or non-government organisations for on-going support and contact tracing if needed.

Cross border reproductive care is a growth industry, particularly for surrogacy and BDM would be well placed to monitor trends and gather donor information if available. Consideration must also be given to the information needs of children where donor conception has been through private arrangements, or with sperm purchased via the Internet, and the options for registering donor-related information. Midwives may be well placed, through their birth notification system, to record this information and provide support or directions to appropriate resources.

Council notes recent amendments to Victorian legislation, which now enables release of donor identifying information regardless of donor consent, with the option of a contact veto. The Victorian Assisted Reproductive Treatment Authority is the statutory authority that will provide an integrated service.

Counselling for release of donor information

Advanced notification of applications for release of identifying information would also be an important aspect of psycho-social preparation. It is also important for donors to be prepared if there are no requests for information or contact. It is not clear how many donor-conceived people are told of their origins or how many might seek contact. In addition, there may be certain life events that trigger a request for information or contact. Importantly there may be crisis events (for example a death or serious illness) that might precipitate specific intervention and counselling review.

Other types of support might include State support for contact tracing through Social Work Departments or family services agencies that have existing capabilities and infrastructure for



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contact tracing for people who were adopted. Consideration should also be given to the role of the original service provider. Some clinics provide letter drops or facilitate contact.

Council considers that 'donor-linking' is an emerging area of practice. Counselling and support services should be made available. However, individuals ought to be able to choose the services they wish to access. Information provided from a Donor Register has the potential to have both positive and negative outcomes. Consideration should be given to the range of counselling services (information, implications, support, therapeutic) that may be required in the future.

