Submission
No 38

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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NSW LEGISLATIVE COMMITTEE
INQUIRY INTO MANAGING INFORMATION RELATED TO DONOR CONCEPTION

The terms of reference are that the Committee inquire into and report on the management of information related to donor conception in NSW, with particular regard to:

a) Whether people conceived by donor conception prior to January 2010 should have access to donor conceived information, including information that identifies their donor and donor conceived siblings.

b) Which agency should manage donor conception information and provide services related to the release of this information.

c) What counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

d) Any other relevant matter.

Introduction

The Reproductive Technology Council (Council) has a central role in the regulation of artificially assisted human conception (*Human Reproductive Technology Act 1991* (HRT Act)) in Western Australia (WA). Council has a broad range of expertise and interests from its own membership, and welcomes the opportunity to comment on the management of information related to donor conception. This submission provides an overview of the current system in WA, the Reproductive Technology Registers (RT Registers) and the Voluntary Register (VR).

A) 1.0 Whether people conceived by donor conception prior to January 2010 should have access to donor conceived information, including information that identifies their donor and donor conceived siblings.

Access to information about one’s genetic identity is a basic human right. It is now recognised that secrecy about donor conception can be detrimental to the well-being of participants and the consequences can last a life-time. People are naturally inquisitive about their genetic relatives. Donors are often interested to know how many families they have helped and about the children. Sometimes people just want to say thank you, or that they are open to contact in the future. Research suggests that making contact with donors and other families with ‘half siblings’ is, for the most part, a positive and emotionally satisfying experience. However, there is a lack of research on longer-term outcomes.

1.1 Retrospective access to donors' identifying details

In common with other States in Australia, the current layers of complexity regarding access to donor identifying information in WA poses ethical, administrative and cognitive challenges. There are three legal epochs that are relevant for access to identifying information, which are summarised in table 1.

	Availability of identifying information
Before the HRT Act	Very limited information may be available from clinics and individual doctors. Donor anonymity.
HRT Act 1991 **1993 – 2004**	Clinics must retain their records indefinitely. Mandatory submission of identifying information to the Department of Health. Donor identifying information confidential.
HRT Act amendments 1 December 2004 onwards	Clinics must retain their records indefinitely. Mandatory submission of identifying information to the Department of Health. Prospective access to identifying donor information.

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

1.1.1 Before the HRT Act 1991

The records prior to the HRT Act are not always of a standard that would be expected today, particularly with the culture of secrecy prevailing at that time. Records were retained by fertility clinics and individual practitioners. In addition, there were no restrictions on the number of families using the same donor.

1.1.2 HRT Act 1993-2004

When the HRT Act was implemented this enforced retention of records and provided for uniform standards of record keeping. The Reproductive Technology Registers were established in 1993 and required submission of identifying information to the Department of Health. Restrictions were also imposed on the number of families that could use the same donor to a total of five (not including the donor’s family).

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.

1.1.3 HRT Amendments 1 December 2004

The legislation was changed in 2004 so that donations could only be used on the understanding that any resulting person could access identifying donor information when they reached 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.

The HRT Act allows 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 such consent on behalf of a child under 16 years of age.

1.2 Conditions for retrospective access

In WA there would be significant implications if changes to the law regarding access to identifying information were made retrospective (prior to 2004). Any retroactive changes to access to identifying information should aim to provide consistent eligibility criteria that are easy to understand. This would help to reduce the considerable confusion that often occurs due to the complexity of current provisions.

Over the years there have been a number of inquiries and recommendations regarding access to donor identifying information. Council acknowledge that people are entitled know their genetic heritage and kinship. However, the consequences of legislative changes and the impact on donors and their families should also be given due consideration. Many anonymous donors were not fully informed or aware of the implication of their actions at the time of donation.

Every effort should be made to engage with donors, so they may inform the debate regarding decisions about them and their families. Council note that the Victorian Government recently tasked the Victorian Assisted Reproductive Treatment Authority to canvas donors about such a major change in legislation. This is a significant step that will help to shape and influence the way forward. It is reasonable to ask past donors if they would consider giving consent for release of identifying information. There are some lessons that may be learned from adoption, where research and public debate informed and drove legislative change to enable open access to identifying information. A similar situation is emerging for donor-assisted conception. Contact vetos have been used in the field of adoption and may be of relevance to retroactive release of donor identifying information. However, consideration would need to be given to how this would be enforced.

A gradual release of information (current profiles, letter drops) might better prepare people. However, in preparation for release of information the United Kingdom Human Embryo Fertility Authority found that some personal donor statements contained inappropriate commentary. This is clearly an issue that would need to be considered in the development of information management policy.

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 identifying 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 require specific intervention.

1.3 Information management

Information management issues that may be raised by retro-activation of the laws will vary according to the time of donation. The following section describes information management and access to identifying information in WA.

1.3.1 Reproductive Technology Registers

The RT Registers are held within the Department of Health and can only be accessed by Authorised Officers. The Chief Executive Officer (CEO) of Health is responsible for the RT Registers. In WA, fertility clinics are required under the HRT Act to make and keep proper records in relation to the use of gametes or embryos including the identity of donors, recipients, and where known any children born. Clinics provide both identifying and non-identifying information to the Department of Health as required under the HRT Act.

Donor information is submitted to the RT Registers (once there is a clinical pregnancy) on a form 4 (electronic, scanned or hard copy versions). This data includes the donor code, gender, appearance, health and family history, and an optional personal statement (100 words).

The RT Registers include data from 1993 onwards. Information about all reproductive technology treatments includes:

- The identity of the participants in a procedure
- Identity of children, including the origin of the donations
- Other relevant demographic and clinical information

Records before 1993 are held by fertility clinics and medical practitioners. Information is either very limited or not available.

1.3.2 Voluntary Register

The legislative changes for access to identifying information do not apply to donations made before 1 December 2004. However, donor-conceived adults (18 years old), parents of donor-conceived children (< 18 years old) and donors may join the VR so that information may be shared with mutual consent.

Registrations are not limited to pre 2004 and this means the option for provision of additional information and mutual exchange of identifying information can be facilitated through the VR. The VR provides a vehicle for donor-conceived adults and for parents of donor-conceived children to connect with genetic relatives including donor-related siblings. Access to identifying information can only be provided with the mutual consent of genetically related people. All the people involved must also undergo mandatory counselling prior to the release of identifying information. The participants pay for counselling. To-date, of the 175 registrations a total of 14 matches between donor-related parties have been established and with seven going on to have counselling for release of identifying information.

1.4. Eligible persons 1 December 2004 onwards

1.4.1 Donor-conceived adult

The 2004 legislative changes to the HRT Act means that a person born through donor assisted conception, who reaches the age of 16 on or after 1 December 2020, has a legal right of access to identifying information about their donor. The donor-conceived person must undertake mandatory counselling prior to the release of identifying information.

1.4.2 Donors

It is a requirement of the HRT Act that fertility clinics must provide donors with both a verbal explanation and written information about the use of their donations and the rights of donors, recipients and children. Donors have no right of access to identifying information about the recipients, or the children they have help to create.

Donors are entitled to know how many families they have helped to create, the number of children and their gender and year of birth.

1.4.3 Parents of a donor-conceived child

Access to identifying information can only be given when participants give their consent. If a person who was involved in the procedure does not consent their identity must be protected. A person who has parental responsibility may give consent on behalf of a child under 16 years of age. Mandatory counselling of all participants is required.

1.4.4 Other relatives

Applications for information from other relatives might be considered in exceptional circumstances, such as an emerging medical issue. This would be considered on a case-by-case basis.

B) 2.0 Which agency should manage donor conception information and provide services related to the release of this information.

2.1 The Reproductive Technology Unit

In WA the RT Registers and the VR are the responsibility of the CEO, Department of Health. The Reproductive Technology Unit (RTU), Office of the Chief Medical Officer, manages requests for access to information (non-identifying and identifying). The RTU also manages request for information through the VR.

The complexity of the current situation, with different legal epochs, rights of access for different people and different definitions of ‘adult’ age causes considerable confusion. However, there are also different donor-relative configurations and, in addition, the practice of ‘on-donation’ has generated a legacy of relational complexity. An example of such a complex situation is a person who has had a donor-conceived child, has also donated her eggs and also donated some embryos. Tracking genetic relationships in these circumstances can be extremely challenging.

Our experience with release of identifying information is through the small number of people who have been linked through the VR. It is anticipated that in WA the release of identifying information will continue to be facilitated by the RTU and with the cooperation of the relevant fertility clinics. This work will inform future operational planning as a greater understanding is achieved and as more experience is gained.

2.2 Information Management Agencies

The unique types of data and systems that are involved pose a number of practical issues. The requirements for data collection and management are set out in the HRT Act. In WA the RT Registers are separate collections of personal information and clinical information. The donor code is critical to linking the relationships between donors, recipients and donor-conceived people.

The Register of Births, Deaths and Marriages may be an appropriate body for in perpetuity management of personal information. This is particularly so for potential generational needs and in dealing with complex relationships (between donor-conceived persons, including donor related sibling, and donors), which will need to be traced and confirmed.

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.

Cross border reproductive care is a growth industry, particularly for surrogacy and the Register of Births, Deaths and Marriages would be well placed to monitor trends and gather donor information if available. On the other hand, Heath Departments are well place to manage clinical data and have a strong public health role, which is of relevance to monitoring health trends.

The scope of any information management service will, to a greater extent, shape the requirements for operational support and capability of the information management agency. For example testing for genetic relatedness or verification of a person's donor-conceived status will require different service provisions. Parents and donor-conceived persons 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. However, there would be legal and operational restrictions that would need to be addressed. Importantly, a system that links donor-related people needs operational planning for long term management.

Access to other sources of information is necessary for the process of validation and verification of genetic relatedness. This is a safety issue that requires much more attention. All Registers are open to errors and there needs to be robust verification procedures for release of information.

C) 3.0 What counselling/ support services/ public education measures are necessary to support people seeking access to donor conception information

The type of support will depend very much on the individual circumstances. People who have been informed about their origins early in life will have different needs from those who have found out later in life, or through unintentional disclosure. Counselling and support services should be made available. However, it should be a matter for individuals to be able to choose the services they wish to access.

3.1 Support Services and Resources

Donor-related people, and those who they are close to, will have different needs and expectations. This implies that the support services will need to be flexible and responsive enough to provide individualised support.

Consideration should be given to the range of counselling services (information, implications, support, therapeutic) that may be required in the future. Other types of support might include greater involvement of the original service provider, State support of contact tracing through Social Work Departments, psychosocial support from non-government organisations, and Internet based peer support groups.

There are a number of examples of support services and resources that have been developed and implemented in Victoria, which provide an excellent model of stakeholder and consumer engagement.

3.1.1 WA Operational Procedures

The current experience of release of identifying information in WA, is with the small number of people who have been ‘matched’ through the VR. The RTU provides information resources, administrative support, and is also responsible for the coordination of services. If a match between genetically related people is found then each person is notified and they must confirm that they wish to exchange identifying information. On receipt of this confirmation the name of an approved counsellor is provided to the participants, who arrange their own appointments. The counsellor notifies the RTU once the required counselling is complete and the counsellor also facilitates the initial contact between participants if they choose to meet.

3.1.2 Professional education and research

The Reproductive Technology Council Counselling Committee provides access to professional education for approved counsellors (counsellors with specific skills in the fertility domain). The Reproductive Technology Council has recently funded an exploratory study on counselling for release of identifying information. This will help to inform operational developments, educational programs, and resources for participants of donor-assisted conception.

Council note that there have been recent legal proceedings in Australia, the United Kingdom, and the United States of America that have involved private arrangements and self-insemination with known donor sperm. It is important that there is public awareness of the health risks and potential legal problems that can emerge if people choose to bypass fertility clinics.