



Consultation with donors who donated gametes in Victoria, Australia before 1998:

Access by donor-conceived people to information about donors.

SUMMARY REPORT

Victorian Assisted Reproductive Treatment Authority
in collaboration with Monash University

Report to the Victorian Government

May 2013



VARTA

Victorian Assisted Reproductive
Treatment Authority



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This is a summary of the May 2013 report *Consultation with donors who donated gametes in Victoria, Australia, before 1998: Access by donor-conceived people to information about donors*. The consultation was conducted by the Victorian Assisted Reproductive Treatment Authority (VARTA) in collaboration with Monash University. The full report is available at www.varta.org.au.



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Monash University, School of Public Health and Preventative Medicine, Jean Hailes Research Unit



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In March 2012 the Victorian Parliament's Law Reform Committee (LRC) delivered its report, *Inquiry into Access by Donor-Conceived People to Information about Donors*. The report is available for download at: <http://www.parliament.vic.gov.au/lawreform/article/1468>

The Victorian Government announced in October 2012 that it wanted to better understand the views of donors who would be directly affected by the legislative changes recommended by the LRC, i.e. those who donated before 1998. It commissioned VARTA to consult those donors about their opinions of some of the LRC's key recommendations, particularly Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

Donor sperm has been used to treat couples with male infertility since at least the 1960s whereas egg and embryo donation became possible some 25 years ago. Until the 1980s, a culture of secrecy about using donor sperm prevailed and gamete donation was anonymous.

Legislation governing donor conception in Victoria

When the 1980s saw a shift in attitudes towards more openness, the Victorian Government, in 1988, became the first jurisdiction in the world to enact a law mandating that identifying information about donors, recipients and children born as a result of gamete donation be recorded in a Central Register. This was to allow donor-conceived people, upon reaching adulthood, the opportunity to apply for access to information about their donor. As a condition of donating, donors between 1988 and 1998 agreed to have their identifying information recorded on the Central Register. However, the release of the information to recipient parents or donor-conceived people could only occur with the donor's consent. This first law was the *Infertility (Medical Procedures) Act 1984* (Vic).

Subsequent legislation, the *Infertility Treatment Act 1995* (Vic), enacted in 1998, removed the necessity for the donor to give consent prior to the release of information to the donor-conceived person. Hence, those who have donated gametes since 1998 have consented to identifying information about them being available to people born as a result of their donation (after the donor-conceived person has turned 18). Therefore, some donor-conceived people can access information about their donor while others cannot.

Although retrospective release of identifying information has occurred in the context of adoption (*Adoption Act 1984* (Vic)), retrospective release of identifying information about gamete donors is without precedent.

Voluntary Register

The 1995 legislation also stipulated that two voluntary registers be established for information exchange between the parties involved in donor conception: one for those involved before the introduction of laws regulating donor treatment and one for those involved after the 1984 legislation was passed.

The two voluntary registers became operational in 2001 and are currently managed as one. The Voluntary Register allows donors, donor-conceived people and their relatives and descendants to lodge information about themselves and apply for information about a related party. If two or more related parties lodge information, they can be matched and information exchange between them facilitated.

The Voluntary Register was managed by the Infertility Treatment Authority (now the Victorian Assisted Reproductive Treatment Authority or VARTA) until 2010 when responsibility for the Central and Voluntary Registers was transferred to the Victorian Registry of Births, Deaths and Marriages (BDM).

Why the LRC was asked to consider legislative change

Many donor-conceived adults who have not been able to trace their donor through the Central or Voluntary Registers express significant distress and frustration about their lack of access to information about their biological origins because of donor anonymity. Research from other jurisdictions also indicates that access to information about the donor and the donor's family can be important to donor-conceived people.

There is increasing societal support for the right of donor-conceived people to be able to access information about their donor. There has also been a shift towards greater public acceptance of the use of assisted reproductive technology and recognition of the need for parents to disclose their donor origins to donor-conceived children.

Evidence suggesting attitudinal changes towards openness in relation to donor conception include studies that have found that: increasingly parents disclose the use of a donor to their donor-conceived children; parents of donor-conceived offspring want to be able to connect with 'donor siblings'; some anonymous donors welcome removal of anonymity; and change in donor anonymity legislation has not resulted in a decline in the number of men willing to donate sperm. Donor-conceived people have asserted the importance of access to medical and genetic information about their donor. The internet is seen as a powerful tool in improving donor-conceived people's access to information about their donor.

Nine donors provided their opinions to the LRC inquiry and expressed a range of views about whether identifying information should be accessible to donor-conceived people and under what circumstances. While acknowledging the value of the views stated by the nine donors who made submissions to the LRC or attended its public hearings, the Victorian Government wished to canvass views from a broader donor community before deciding whether or not to implement the LRC's recommendations.

In the absence of complete records of donations prior to 1998, it is not possible to quantify how many people donated sperm or eggs before that time. Therefore, the most appropriate approach for enabling in-depth discussion of the recommendations was a qualitative research model in which donors were sought as volunteers to participate in semi-structured interviews. It was considered unethical to contact donors directly using information on the donor registers or clinic records because this would have constituted an invasion of their privacy; it was also inappropriate to do so because it would have excluded donors not identified on these data bases.

The consultation was granted ethics approval by the Department of Health Human Research Ethics Committee.

In early 2013, VARTA conducted a public relations and advertising campaign about the consultation, which resulted in 42 donors – 36 sperm donors and six egg donors – volunteering to be interviewed.

VARTA contracted Monash University researchers, Dr Karin Hammarberg and Dr Maggie Kirkman, known for their research expertise in the assisted reproductive treatment field, to conduct the consultation. Researchers were careful to not initiate any discussion about organisations associated with assisted reproductive treatment policy and services, such as VARTA or the Victorian Registry of Births, Deaths and Marriages.

Donor views sought

The interviews sought donors' views about the following:

1. whether donor-conceived people should have a legal right to have access to information about their donor
2. the Law Reform Committee's recommendations and the potential for the Victorian Government to introduce legislation that:
 - allows all donor-conceived people access to identifying information about their donor, including donors who expected to remain anonymous
 - enables the donor to sign a contact veto, which would mean that their offspring would not be allowed to contact them
 - enables the donor to lodge a contact preference form, where he or she could state how they would prefer to be contacted; for example, via e-mail, letter, or telephone
 - enables a donor-conceived person who is at risk of hereditary

- disease to be given medical information about their donor
 - facilitates the use of DNA matching for people on the voluntary register where medical records are unreliable or incomplete.
- 3. donors' suggested alternatives to the recommendations
- 4. how the needs of donors can best be met if legislation changes to enable all donor-conceived people access to information about their donor, and
 - if a donor-conceived person wanted more information about their donor, how the donor would like to see this managed
 - what information or services the donor and those close to the donor might need
- 5. how the Law Reform Committee's recommendations would affect the donor personally
- 6. the best way to communicate any legislative changes to donors and the public
- 7. willingness to join the Voluntary Register if the donor is not already registered.

Participants

Of the 42 donors who were interviewed, only seven had made a submission to the LRC inquiry. The donors consulted were diverse in age (40-73) and in the place and year (1970-1997) they donated. They also varied in disclosure patterns, outcome of their donations, and whether or not they had been approached by donor offspring or joined the Voluntary Register. Because records of donations are incomplete, the total number of donors is unknown and it is impossible to assess whether these 42 donors constitute a representative sample. However, the diversity of characteristics, the range of opinions, and the inclusion of donors who have not previously made their views known suggest that the results represent more than a narrow segment of donors. The number of participants exceeded expectations. Participant characteristics are provided in Table 1 on page 12.

Views about LRC's recommendations

Donors' opinions of the LRC's recommendations covered in the consultation ranged from strong agreement with all recommendations to strong disagreement with all recommendations.

LRC Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

- 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. It was suggested that donors should also have access to identifying details of 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. Some said they would seek redress through the courts. Current legislation against (for example) financial claims on donors was not seen as protective if a precedent were to be set of retrospective change.
- 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.

These donors were themselves willing to supply information to their donor offspring and advocated encouraging parents to tell their children about their donor conception. A stronger view was that, if donors are compelled to release identifying information, parents should be compelled to tell their children they were donor-conceived. The model of voluntary engagement derived from donors' suggestions encompassed:

- publicity about the Voluntary Register to urge donors (and donor-conceived people) to join it;
- an intermediary organisation contacting a donor personally to seek permission for release of identifying or non-identifying information to a donor-conceived person who had made an enquiry.

Concern was expressed that the prospect of retrospective release of identifying information may dissuade donors from making

non-identifying information available through the Voluntary Register because of fears that this would leave a trail of identifying information.

Other LRC recommendations

On other LRC recommendations donors' opinions were diverse and not consistently aligned with their attitudes to Recommendation 1.

- **Contact vetoes**

The LRC had recommended that if legislation were changed to enable all donor-conceived people access to their donor's identifying details, donors who did not want to be contacted by their donor offspring could institute a renewable contact veto lasting five years.

The contact veto recommendation was accepted by some donors as a reasonable compromise. Others rejected it on the grounds that it was unfair to donor-conceived people (on the one hand) and not only put donors in a difficult position but was unenforceable and therefore inadequate protection for donors (on the other hand). Some said that a veto could not prevent the comprehensive gathering and sharing of information about donors and their families, friends, and occupations through the internet and social media.

- **Contact preference form**

A contact preference form was accepted by some as a basic courtesy to donors, while others who did not support Recommendation 1 rejected the preference form as part of an unwelcome package that undermined donors' privacy.

- **Information about medical conditions**

Allowing donor-conceived people access to information about donors' potentially heritable medical conditions was endorsed by some as providing essential information. Others rejected this as beyond the terms of the original agreement.

- **DNA matching**

Some welcomed the potential use of DNA matching for donors and their donor offspring, particularly if it applied only to those on the Voluntary Register; others doubted the accuracy of DNA testing or feared compulsory testing.

Suggestions for managing legislative change

Donors made suggestions for managing the legislative changes proposed by the LRC.

Suggested strategies for notifying donors and the community of any legislative changes ranged from personal communication to advertisements, and included publicising personal stories about donors and donor-conceived people.

There was near consensus that approaches from donor-conceived people to their donors should be mediated by an organisation with expert staff who can provide professional counselling and are experienced in managing the complexities of these new relationships. Donors often spontaneously mentioned the Infertility Treatment Authority (now VARTA) as the model of an appropriate intermediary organisation and the place where information about donors and donor-conceived people should be stored.

Donors identified that the intermediary organisation's role could include the provision of accurate information to donors, and the education of donors and the community about donor-assisted conception, including the rights and responsibilities of all parties.

Donors with a range of attitudes to Recommendation 1 advocated the provision of counselling and support as an essential accompaniment to any contact between donors and donor-conceived people. It was also seen as important to the families of both parties. However, some donors who rejected Recommendation 1 also rejected counselling and support services.

Donors' attitudes and circumstances

Although different circumstances surrounding donation, such as recruitment, collection of gametes and record-keeping influenced donors' views and experiences, attitudes towards the LRC's recommendations did not vary strictly according to the era of donation.

While some donors described being well informed and supported, others reported less than ideal donation practices. There was evidence of absent or inadequate record-keeping and identity-checking for sperm donations. Male donors told of being almost expected to donate as young, often teenage, university students, with assurances of perpetual anonymity. Donations were solicited from men who were having their semen tested or stored for personal reasons. Not all donors thought they had given fully informed consent.

Donors conceptualised their role across a wide range, from being akin to a blood donor to being a parent to their donor offspring.

All donors acknowledged the profound significance of the decisions to be made about the release of information about donors – for themselves, their families, and donor-conceived people.

APPENDIX 1

Table 1: Participant characteristics

TYPE OF DONOR	
Sperm	36
Oocytes	6
Embryos	0
AGE AT INTERVIEW (RANGE)	
40-73	
DONATION YEAR (RANGE)	
1970-1997	
Donated before 1988	28
Donated between 1988 and 1999	13
Declined to answer	1
PLACE OF DONATION	
Royal Women's Hospital	11
Prince Henry's Hospital	9
Queen Victoria Hospital	9
Epworth Hospital	6
Monash IVF	5
Melbourne IVF	1
Declined to answer	1
PRESENT FAMILY AWARE OF DONATION	
Yes	26
No	9
Partner but not children	6
Declined to answer	1
DID BIRTHS RESULT FROM DONATION?	
Yes	32
No	1
Unsure	9
NUMBER OF BIRTHS (RANGE)	
0-36	
JOINED THE VOLUNTARY REGISTER	
Yes	25
No	11
No but considering	6
CONTACTED BY DONOR OFFSPRING	
No	32
Yes	10
MADE SUBMISSION TO LRC	
No	34
Yes	7
Declined to answer	1
TYPE OF INTERVIEW	
Telephone	30
In person	6
Written (email, post)	6



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