

Parliament of Victoria
Law Reform Committee

*Inquiry into Access by
Donor-Conceived People to
Information about Donors*

Victorian Government Response
August 2013

Introduction

There are currently three separate regimes regulating access by donor-conceived people to information about donors. The changes in the legislative regime reflect changing attitudes to donor conception and the rights of donor-conceived people to have information about their genetic origins.

- Donor-conceived people who were conceived using gametes donated prior to 1988 do not have a right to identifying information about donors.
- Donor-conceived people who were conceived using gametes donated between 1988-1997 can obtain non-identifying information about their donors from the Central Register, and can obtain identifying information about their donors if their donor consents.
- Donor-conceived people who were conceived using gametes donated after 1 January 1998 can obtain identifying information about their donor from the Central Register.

The Parliamentary Committee *Inquiry into Access by Donor-Conceived People to Information about Donors* was asked to consider the possible legal, practical and other issues that may arise if donor-conceived people who do not currently have access to information about their donors were provided with that information.

The Committee's Report makes 30 recommendations. The key recommendations include:

- Providing all donor-conceived people access to identifying information about their donor, without the donor's consent.
- Centralising service delivery of donor conception services, including information and education, linking and counselling, and management of donor registers.
- Securing access to records related to donor-conception practices prior to 1988.

The issues addressed by the Inquiry are complex and raise significant legal and practical challenges. The Committee acknowledged that the release of identifying information to donor-conceived people may potentially cause discomfort and distress to donors who donated on the understanding of anonymity. On the other hand, the evidence given to the Committee was that many donor-conceived people are profoundly affected by not having identifying information about their genetic backgrounds.

In making its recommendations, particularly the recommendations regarding access to identifying information, the Committee was required to balance competing rights, interests and expectations. As legislating to enable access to identifying information about donors who donated anonymously, would be a significant step, the Government considered it critical to properly consider and assess the views of the community, in particular the views of donors for whom the recommendation would have significant impact, before it finalised a response.

In seeking to find a balance between the conflicting rights of anonymous donors and donor-conceived people who want to learn about their biological origins, the Government has given extensive consideration to the Committee's principle recommendation to legislate to enable all donor-conceived people access to identifying information about their donors.

Historical context

Prior to 1988 fertility treatment was not regulated in Victoria, and consequently there were no requirements that doctors and clinics keep records on donor treatment procedures. Where records have been kept about donor-treatment procedures carried out before 1988 the information contained therein is likely to be sparse and out of date. The Committee heard evidence that prior to the introduction of legislation, there was some variation in the way that records regarding donor conception procedures were kept. The Committee heard a range of views on the quality and accuracy of records pertaining to donor-conception prior to 1988. Some records from this time period may be in the possession of private doctors who carried out procedures during this time or in the possession of successor clinics of hospitals where the treatment procedures took place. The Committee heard evidence that in some cases records may have been destroyed, particularly where doctors were carrying out insemination in private practice or if these have been retained the quality and completeness of the doctors' records is unknown.

Significantly, persons who donated gametes prior to the commencement of legislation in 1988 likely had no expectation that their details would be retained indefinitely and disclosed to third parties or that they would be sought out in the future to provide further personal information. Donors were either given assurances of anonymity or were told they would be anonymous and could not seek information about the outcome of their donation. This was consistent with prevailing practices at the time wherein anonymity was considered crucial for the protection of the integrity of the family who made use of the donated gametes. Donors from this time received little or no counselling about their donation and were discouraged from following up on the outcomes of their donation. As a consequence clinics and donors may not have kept in contact or exchanged updated contact details or medical information since the time of donation, which in some cases may be more than 30 years ago.

The *Infertility (Medical Procedures) Act 1984* (commenced in 1988) introduced the requirement that clinics and doctors were required to maintain their own registers for donor treatment procedures and to provide the Health Commission with details of gamete donors and children born as a result of donor treatment procedures, every 6 months, for inclusion on a central register. Records from this period onwards are likely to be much more comprehensive as prescribed information was required to be collected and thus likely to be more reliable than records of donor-treatment procedures that occurred prior to 1988. Identifying information that was to be collected about a donor included their name, address, date and place of birth, spouse's name, and their mother's and father's names. Non-identifying information included marital status, religion, occupation, ancestry, physical characteristics (e.g., hair and eye colour, build, complexion, height and weight), highest level of education obtained, personal and professional interests, numbers and sex of existing children (if any) and details of any health problems, family history or genetic disorders, defects and/or major health problems.

Significantly, persons who donated under this legislation were made aware that their information would be retained by doctors/clinics and placed on a Central Register and that non-identifying information about them would be given to the woman undergoing the treatment procedure with their donor gametes. So whilst donors were anonymous, donors gave consent for the retention of their details on a central register and for the disclosure of non-identifying information to the recipient woman.

Following the commencement of the *Infertility Treatment Act 1995* on 1 January 1998, anonymous donations were no longer permitted. Doctors and clinics were required to inform donors that information about the donor (including identifying

information) would be passed on to the Infertility Treatment Authority for inclusion on the Central Register, and that children conceived from their donation could obtain identifying information about the donor when they reached 18, or at a younger age with their parent or guardian's consent. Hence from 1998 persons who donated gametes have been aware of, and agreed, that children born as a result of their donation could access identifying information about them when they turned 18.

Information recorded on the register about the donor included their name, any other name by which the donor has been known; sex; unique donor identifier; date and place of birth; whether the donor has donated gametes other than to the registered ART provider who carried out the treatment; date of the donors consent to use the gametes or embryos in a treatment procedure; number of women who have children conceived using the donor's gametes or from an embryo formed with the donor's gametes including the donor and any current or former partner; number of children born as a result of treatment procedures carried out by a registered ART provider; any genetic abnormality of the donor; Non-identifying information included marital status, occupation, education, ancestry, physical characteristics (e.g. hair and eye colour, build and height), interests, and blood group.

Donor consultation findings

To inform its response to the Committee's recommendations, the Victorian Government commissioned the Victorian Assisted Reproductive Treatment Authority (VARTA) to canvass the views of the broader donor community through consultation. Donor views about the release of identifying information about donors who donated anonymously were sought in interviews with 42 donors who donated gametes in Victoria before 1998. The consultation was successful in encouraging participation by donors who had not previously made their views known - only 7 had made a submission to the Inquiry.

As anticipated, views were mixed, however all participants recognised the profound significance of the decisions to be made about donor anonymity for themselves, their families and donor-conceived people. In summary:

- Whilst there was support by many donors for the Committee's recommendation to provide donor-conceived people with identifying information about their donors, irrespective of assurances of anonymity, a little more than half rejected the recommendation.
- Those that supported the recommendation emphasised the needs of donor-conceived people to understand their genetic heritage.
- Those that disagreed with the recommendation expressed considerable concerns for themselves and their families. Significant concern was expressed that the impact of a retrospective loss of anonymity was equivalent to a breach of contract and would undermine trust in guarantees of privacy and confidentiality as well as government.
- An alternative was suggested that donors could be supported to voluntarily release information, either through promotion of the voluntary register, or by seeking consent directly in response to a request from a donor-conceived individual.
- Diverse opinions were expressed in relation to the other recommendations about contact vetoes, contact preference forms, access to medical information, and the use of DNA matching.
- Different circumstances surrounding donation, including recruitment, collection and record-keeping, influenced donor's attitudes.

The research was undertaken in collaboration with Monash University and the report will be made available at www.varta.org.au.

These findings add to our understanding of donor views and have informed the Victorian Government's response to the Committee's recommendations.

Victorian Government Response

Providing all donor-conceived people access to information

Based on the consultation findings, and further detailed consideration of research into all stakeholder interests and human rights impacts, the Government supports the introduction of legislation to allow all donor-conceived people to obtain identifying information about their donors. However, the Government considers that identifying information should only be released with the consent of donors; seeking consent would increase the likelihood that donor-conceived individuals could gain access to relevant contemporaneous information about their donors. To this end, the Government intends to introduce legislation to extend the 1988-1997 legislative arrangements to all donor-conceived people conceived using gametes donated prior to 1988.

Evidence suggests that most donors will consent to the release of identifying information if given the choice. In cases where donors are opposed to the release of identifying information, the provision of non-identifying information may still be able to offer the narrative information about the donor required to assist the donor-conceived individual in overcoming identity issues. Moreover, for those donors that are opposed to the release of identifying information, this model respects the privacy and choice and acknowledges the context within which the donor originally consented to donation.

Whilst the Government intends to establish a legal right of access to information for persons conceived from gametes donated prior to 1988 there is no guarantee that that information will be available, complete or accurate. Even if the information contained in records from before 1988 is complete there will be no guarantee that the donor could be traced to provide consent to disclose identifying information or provide contemporaneous information, as during the intervening decades donors are likely to have moved or some donors may have died. Under the Government's proposal information will only be given to donor-conceived individuals seeking it, in the case of non-identifying information if this available from the records, and in the case of identifying information where the donor consents to its release.

Centralising service delivery

The underlying objective of the Government's response is to achieve a simplified and enhanced service system for the client. Minimising the level of infrastructure change allows for a timelier and cost effective implementation whilst still offering improved and better integrated service provision to address the shortcomings identified in the report. The Registry of Births, Deaths and Marriages (BDM) will continue to manage the central and voluntary registers, providing a centralised point of access to information from the registers that will enable BDM to respond readily to information requests from clients, regardless of date of conception. VARTA will also be given a key role, in the provision of increased counselling services and offering intermediary support for donor-linking, including a letter box service.

Securing pre 1988 donor records

Legislative measures will be introduced to facilitate access to and preserve pre-88 records related to donor treatment procedures involving the use of gametes donated prior to 1988, specifically as this provides for access to information contained therein by donor-conception stakeholders. Consistent and centralised

access to information held in records will be established for stakeholders seeking information by securing records and facilitating information exchange or access to records between relevant record keepers and BDM.

Summary of responses

Responses to each of the Inquiry recommendations are presented in the following pages. Whilst some details of the responses do not represent direct support for the Inquiry recommendations, they do consider the intent of the recommendations and offer in principle support or partial support with adapted solutions, having regard for the complex operational context.

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

Government response: Support in principle

The Government supports the introduction of legislation to allow all donor-conceived people to obtain identifying information about their donors. However, following further research and consultation with donors, the Government considers that this information should be released with consent of donors. Seeking consent would increase the likelihood that donor-conceived individuals could gain access to relevant contemporaneous information about their donors.

Recommendation 2: That, in implementing Recommendation 1, the Victorian Government require that a child applying for identifying information about his or her donor only be provided with that information if:

- 1) *the child's parents have consented to the application; or*
- 2) *a counsellor has provided counselling to the child and has confirmed in writing that the person is sufficiently mature to understand the consequences of the disclosure.*

Government response: Support

The Government supports this recommendation as it is consistent with current access conditions for children conceived from gametes post 1 January 1998.

Recommendation 3: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government require donor-conceived people to attend counselling prior to obtaining identifying information about donors.

Government response: Support

The Government supports donor-conceived people receiving compulsory counselling prior to obtaining identifying information about donors. This is consistent with the current requirement for applicants (persons conceived using donated gametes post 1 July 1988) seeking information from the Central Register to undergo counselling prior to obtaining identifying information.

Recommendation 4: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for contact vetoes that may be lodged by a donor or a donor-conceived person following counselling, with the following features:

- *that contact vetoes only be available to people conceived from gametes donated prior to 1998, and the donors of those gametes;*
- *that donors may only lodge a contact veto after they have been informed that a donor-conceived person has lodged an application for identifying information about them;*
- *that a veto prohibits contact between the donor and the donor-conceived person;*
- *that suitable penalties be established for breach of a veto;*
- *that a veto lapses within five years if not renewed by the person who lodged it; and*
- *that the person who lodged a veto may withdraw it at any time.*

Government response: Not supported

The implementation of recommendation 1 in line with the Government's position provides a facilitative and relationship-focused model that is more appropriate in the donor-conception context and would remove the necessity of introducing contact vetoes.

Recommendation 5: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for donors to lodge a contact preference form for presentation to a donor-conceived person.

Government response: Support

The Government supports the introduction of contact preference forms. A contact preference form could enable donors and donor-conceived people to indicate their preferences for contact for example: they would like to be contacted; would prefer to be contacted through an intermediary; or would prefer not to be contacted at this time.

Recommendation 6: That the Victorian Government introduce the measures proposed in Recommendation 1 through Recommendation 5 following a period of time sufficient to publicise and inform the Victorian community of retrospective changes to donor-conception arrangements.

Government response: Support

The Government agrees that a period of advance notice is necessary to inform the community of changes to donor-conception arrangements. It is proposed that the legislative amendments commence 12 months after the passage of the proposed legislation. This will provide key agencies with ample time to prepare for and publicise the changes to donor-conception arrangements.

Recommendation 7: That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release, upon request, non-identifying information about a donor to a donor-conceived person, his or her parents, and his or her descendants.

Government response: Support

The Government supports encouraging organisations, agencies and persons holding information on donor-conception to release to a donor-conceived person, his or her parents, and his or her descendants, upon request, non-identifying information about his or her donor.

Recommendation 8 That the Victorian Government encourage organisations, agencies and persons holding information on donor-conception to release to a donor, upon request, non-identifying information about his or her donor-conceived offspring.

Government response: Support

The Government supports encouraging organisations, agencies and persons holding information on donor-conception to release to a donor, upon request, non-identifying information about his or her donor-conceived offspring.

Recommendation 9: That the Victorian Government introduce a mechanism for medical information from a donor to be provided to a donor-conceived person, where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Government response: Support in principle

The Government supports facilitating the provision of medical information from a donor to a donor-conceived person where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person, and notes that registered providers have the requisite expertise, established processes and

experience to respond to these issues routinely with their own patient groups. The Government will work collaboratively with providers to explore legislative options to enable them to extend this service to donor-conception stakeholders irrespective of when gametes were donated or whether a person was a patient with that provider.

Recommendation 10: That the agency managing the donor registers be empowered to release to a donor-conceived person, upon request, non-identifying information about his or her donor-conceived siblings.

Government response: Support

The Government supports the release of non-identifying information to a donor-conceived person, upon request, about his or her donor-conceived siblings. This information will be limited to number of donor-conceived siblings, gender and year of birth to assist with avoiding consanguineous relationships.

Recommendation 11: That the agency managing the donor registers be empowered to release to the parents of a donor-conceived person, upon request, non-identifying information about that person's donor-conceived siblings.

Government response: Support

The Government supports the release of non-identifying information to the parents of a donor-conceived person, upon request, about that person's donor-conceived siblings. This information will be limited to number of donor-conceived siblings, gender and year of birth to assist with avoiding consanguineous relationships.

Recommendation 12: That the voluntary register remain the only means for donor-conceived people to seek identifying information about their donor-conceived siblings.

Government response: Support

The Government supports the recommendation that the voluntary register remain the only means for donor-conceived people to seek identifying information about their donor-conceived siblings.

Recommendation 13: That the Victorian Government introduce a mechanism for medical information from a donor-conceived person to be provided to that person's donor-conceived siblings where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.

Government response: Support in principle

As per recommendation 9, the Government notes that registered providers have the requisite expertise, established processes and experience to respond to these issues routinely with their own patient groups. The Government will work collaboratively with providers to explore legislative options to enable them to extend this service to donor-conception stakeholders irrespective of when gametes were donated or whether a person was a patient with that provider.

Recommendation 14: That the Victorian Government introduce legislation to empower one agency to provide all services relating to the provision of information, linking and counselling services related to donor-conception, including management of the donor registers, a letterbox service, education and public campaigns.

Government response: Partially support

The Government acknowledges the importance of the objectives of this recommendation. However it considers that a more effective and efficient option is to retain the existing service provision infrastructure and to improve and better integrate existing services to address the shortcomings identified in the Report. To this extent the Government will retain the Registry of Births Deaths and Marriages as the manager of the donor registers and will provide for VARTA to have an enhanced role in the provision of counselling and donor-linking intermediary services related to donor-conception.

Recommendation 15: That the agency referred to in Recommendation 14 be granted access to the Victorian register of electors in order to conduct its functions.

Government response: Support in principle

The Government supports in principle access to the Victorian register of electors to find donor-conception stakeholders; for specific information beyond the level access available to all members of the public, it is intended that the Registrar of Births Deaths and Marriages could make a request for such information under section 34 of the *Electoral Act 2002*.

Recommendation 16: That VARTA assume the responsibilities of the agency referred to in Recommendation 14.

Government response: Partially support

Whilst the Government does not support the centralisation of services, it does support the provision of a centralised point of support for stakeholders who require it. As such, VARTA would assume the main counselling role (in place of Family Information and Networks Discovery) to improve the integration of service provision. VARTA would also provide donor-linking and letterbox services as part of an intermediary service to facilitate the exchange of information between parties. VARTA's role in education and public campaigns would continue.

Recommendation 17: That the Victorian Government introduce legislation to transfer ownership of, and responsibility for, the donor register databases currently held by the Victorian Registry of Births, Deaths and Marriages, to the agency referred to in Recommendation 14.

Government response: Not supported

The Government will retain the Registry of Births Deaths and Marriages as the manager of donor registers due to its resources and expertise in the management of data relating to significant life events. The Government however acknowledges the need to improve and better integrate existing service provision. To this extent the Government will amend the legislation to enhance the information exchange between relevant agencies involved in the provision of donor-conception services to provide more effective and streamlined services to clients.

Recommendation 18: That the agency referred to in Recommendation 14 offer comprehensive and ongoing counselling and support services, in association with managing the donor registers, to all donor-conceived people, recipient parents and donors, and their relatives, and that counselling be compulsory for:

- *a donor-conceived person who is seeking identifying information about his or her donor;*
- *a donor who is seeking identifying information about his or her donor-conceived offspring; and*
- *a donor or donor-conceived person who applies to lodge a contact veto.*

Government response: Partially support

It is proposed that VARTA offer comprehensive counselling and support services, to all donor-conceived people, recipient parents and donors, and their relatives, but not in association with managing the donor registers. As per recommendation 3, counselling will be compulsory only for applicants seeking identifying information.

Recommendation 19: That the Victorian Government introduce a mechanism by which identifying information about a donor can be released directly to a donor-conceived person, in appropriate circumstances.

Government response: Support

The implementation of recommendation 1 in line with the Government's position would entail the sensitive handling of information release in appropriate circumstances.

Recommendation 20: That the agency referred to in Recommendation 14 provide a letterbox service for donor-conception stakeholders, based on the service previously provided by the ITA.

Government response: Support

The Government is supportive of VARTA providing donor-linking and letterbox services to provide an important intermediary service and facilitate the confidential exchange of information between parties.

Recommendation 21: That if the Committee's recommendations are implemented, VARTA conduct a public information and awareness campaign advising the public of relevant changes in the provision of information to donor-conception stakeholders, particularly targeting pre-1998 donors.

Government response: Support

The Government supports VARTA undertaking a public education and information campaign to inform donor-conception stakeholders of changes in the provision of information.

Recommendation 22: That VARTA continue its education and public campaigns role, with a particular focus on encouraging and supporting the parents of older donor-conceived children to tell their children about the circumstances of their conception.

Government response: Support

The Government supports VARTA continuing its successful public education and information campaign, encouraging and supporting recipient parents of donor-conceived children to disclose the circumstances of their conception.

Recommendation 23: That the Victorian Government introduce legislation to provide that destruction of, falsifying or tampering with, any records that identify parties to donor-conception, is an offence.

Government response: Support

The Government notes that the *Assisted Reproductive Treatment Act 2008* already provides for the destruction of records being an offence; this protection will be extended to records relating to donor treatment procedures involving the use of gametes donated prior to 1 July 1988. In addition, the Government will legislate to ensure that all health records relating to donor treatment procedures be retained for a period of 99 years, the expected lifetime of a donor-conceived individual.

Recommendation 24: That the Victorian Government introduce legislation to require that persons or organisations that hold records containing information on pre-1988 donor-conception provide copies of the records to a central agency, and in the case of PROV, that pre-1988 donor-conception records be transferred to a central agency.

Government response: Partially supported

This recommendation is partially supported. The Government will improve and centralise access to information held in pre-1988 records by:

- inviting individuals who may have records to provide these to the Registrar of Births Deaths and Marriages so that the Registrar can add relevant information to the Central Register;
- requiring ART providers to compile a register of prescribed information from records held by them and to provide the register to BDM so that this information may be added to the Central Register;
- BDM will have legislative authority to access records held at the Public Records Office Victoria in order to fulfil requests for information from donor-conceived stakeholders.

Recommendation 25: That the legislative changes proposed in Recommendation 24 be advertised in a public campaign targeting the medical profession.

Government response: Support in principle

There is likely to be only a small number of medical professionals who may have retained records relating to donor treatment procedures using gametes donated prior to 1988, hence the Government will undertake a more targeted approach inviting them to provide these records to BDM to enable relevant information to be added to the Central Register.

Recommendation 26: That the agency referred to in Recommendation 24 approach individual doctors who are known to have provided donor insemination services and obtain copies of records held by them, if any, containing information on parties to donor-conception.

Government response: Support in principle

As per recommendations 24 and 25, individual doctors will be approached and invited to provide any records they hold to the Registrar of Births Deaths and Marriages to enable relevant information to be added to the Central Register.

Recommendation 27: That the Victorian Government introduce legislation to transfer responsibility for the central and voluntary registers from the Victorian Registry of Births, Deaths and Marriages to the agency described in Recommendation 14.

Government response: Not supported

The Government supports retaining the Registrar of Births Deaths and Marriages as the manager of donor registers due to their resources and expertise in management of data relating to significant life events.

Recommendation 28: That the Victorian Government provide a facility within the voluntary register for DNA matching.

Government response: Further consideration

The Government recognises that there may be records that are unavailable, incomplete or ambiguous; however the extent of this issue and the consequent demand for DNA matching is not able to be determined. The Government will ask BDM and VARTA to monitor the need for a DNA matching facility on the Voluntary Register.

Recommendation 29: That where records for donors or donor-conceived people are unavailable, incomplete, or ambiguous, the Victorian Government offer a concession for DNA testing if that person wishes to lodge DNA matching data on the voluntary register.

Government response: Further consideration

As above.

Recommendation 30: That the Victorian Government provide regular reports to an appropriate inter-jurisdictional body, such as the Standing Committee of Attorneys-General (now Standing Council on Law and Justice) or the Council of Australian Governments, on progress with the development and implementation of reforms to donor-conception legislation.

Government response: Support in principle

The Government will provide reports as appropriate to inform other jurisdictions of the implementation of the reforms following from this Government Response.