



LEGISLATIVE ASSEMBLY

**LEGISLATIVE ASSEMBLY COMMITTEE ON LAW AND
SAFETY**

**ISSUES PAPER: MANAGING INFORMATION RELATED TO
DONOR CONCEPTION**

NOVEMBER 2012

Contents

DISCUSSION	1
1. INTRODUCTION	1
2. TERMS OF REFERENCE	1
3. BACKGROUND	1
4. ISSUES FOR CONSIDERATION	3
4.1 Access to information	3
4.2 Management of donor registers	5
4.3 Counselling and support services	5
4.4 Record keeping	7
APPENDIX ONE – RECOMMENDATIONS FROM COMMITTEE'S REPORT <i>INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS</i>	8
APPENDIX TWO – RECOMMENDATIONS FROM VICTORIAN LAW REFORM COMMITTEE REPORT	10

Summary and list of questions

The purpose of this paper is to explore some of the issues raised by the Inquiry into managing information related to donor conception.

The Committee is seeking submissions from interested individuals and organisations by **15 February 2013**. The questions below may be used as a guide when preparing a submission, but are not intended to form a complete list of relevant issues.

Question 1: Should donor-conceived adults have retrospective access to donors' identifying details? (p 3)

Question 2: If retrospective access were granted what conditions should apply? (p 4)

Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required? (p 4)

Question 4: Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate? (p 5)

Question 5: Should a standalone body be established to manage the register? What other areas could it have responsibility for? (p 5)

Question 6: Should counselling and support services be offered to those seeking donor conception information from the donor register? (p 5)

Question 7: Are there other types of support that could be offered? (p 5)

Question 8: How would support services be funded? By the government, the individual seeking the service, or by ART clinics? (p 6)

Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)? (p 6)

Question 10: How long should ART clinics be required to retain records? (p 7)

Question 11: What should happen to records if a clinic closes? (p 7)

Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with. (p 7)

Contact Details:	Legislative Assembly Committee on Law and Safety Parliament House, Macquarie Street, Sydney NSW 2000
Telephone:	(02) 9230 2390
Email:	lawsafety@parliament.nsw.gov.au
URL:	http://www.parliament.nsw.gov.au/lawandsafety

Discussion

1. INTRODUCTION

This issues paper has been prepared as part of the Legislative Assembly Committee on Law and Safety's Inquiry into managing information related to donor conception. The paper details the main issues which provide a frame of reference for the inquiry and outlines some questions that the Committee will consider as part of the Inquiry.

The issues paper is released publicly so that stakeholders and other interested parties can be aware of the issues the Committee is looking into and use the paper to assist them in framing their responses to the inquiry.

While the matters described below have been identified as important, they do not form an exhaustive list. The Committee will give consideration to all viewpoints and any other issues raised that are relevant to inquiry's terms of reference.

2. TERMS OF REFERENCE

The Terms of Reference for the Inquiry into managing information related to donor conception 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 conception 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.

3. BACKGROUND

In 2012 the Committee conducted an Inquiry into the inclusion of donor details on the register of births. The Committee heard evidence from a number of stakeholders and received information about practices in other jurisdictions.

The Terms of Reference defined the focus of the earlier inquiry and the main issues examined were: the recording of donor information on birth certificates or the birth register, where the donor register should be held, the age at which donor conceived individuals can access information, and private donor conception arrangements.

The recommendations resulting from the Inquiry can be found at Appendix A of this issues paper.

Several complex issues arose during the Committee's earlier inquiry that were not covered by the Inquiry's Terms of Reference. These matters include: retrospective access to information,

counselling and support mechanisms, how registers of donor information should be managed, and how donor information should be managed by ART clinics.

These issues have become increasingly topical following the 2011 Senate Inquiry into Donor Conception Practices in Australia and the 2012 Victorian Law Reform Committee Inquiry into Access by Donor-Conceived People to Information about Donors.¹ The central recommendation of the Victorian Inquiry was to allow all donor-conceived adults access to identifying information about their donor. This recommendation would implement retrospective access, in that it would apply regardless of undertakings previously given to donors regarding anonymity. Alongside this, the Committee recommended significant changes to the way such information is managed and disseminated, including returning management of the Victorian donor registers to the Victorian Assisted Reproductive Treatment Authority (VARTA), a specialist body which would oversee the registers and provide other associated services.

In October 2012 the Victorian Government released an interim response to the Law Reform Committee report, which stated that the complexity of the issues involved and the significant impact of the proposed recommendations warranted further investigation. The Government has allowed a further six months to examine the relevant issues and formulate a considered response to the report.²

Given the sensitivity and importance of the issues under consideration, and their potential impact on many individual's lives, the Committee on Law and Safety decided to conduct an additional inquiry to examine these matters in full and solicit contributions from all interested stakeholders.

The main issues, as outlined in the Terms of Reference, are discussed below.

¹ A full copy of the Senate report can be found at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Committees?url=legcon_ctte/donor_conception/report/index.htm, and the Victorian Law Reform Committee Inquiry at: <http://www.parliament.vic.gov.au/lawreform/inquiries/inquiry/300>, accessed 25 October 2012.

² The Victorian Government Interim Response can be found at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Interim_Govt_Resp_2012-10-11.pdf, accessed 25 October 2012.

4. ISSUES FOR CONSIDERATION

4.1 Access to information

Question 1: Should donor-conceived adults conceived before 2010 have retrospective access to donors' identifying details?

For those individuals conceived prior to 2010 there is no guaranteed access to information about their donor. They rely first on being informed that they are in fact donor conceived, and second, on the clinic having retained the details of the treatment that resulted in their conception. A voluntary register maintained by the Ministry of Health only holds the details of those donors and individuals conceived as a result of ART treatment prior to 2010 who voluntarily chose to place their information on the register.

Those individuals conceived after 2010, or their parents, are entitled to obtain information about their donor and about other siblings born from the same donor.³ This information is held on a register operated by the Ministry of Health (the ART Central Register).

Arguments for granting donor conceived people who were conceived before 2010 access to information about their donor include: having access to knowledge about their health and medical history; the ability to know their 'place in the world' which leads to a more positive sense of self and psychological benefits; reducing the risk of forming relationships with half siblings; knowing the identity of their donor and having the ability to contact them, if desired; and the right of children to know the truth about their conception and the identity of their genetic parents.

Equally, there are arguments for maintaining the anonymity that donors were frequently promised at the time they made their donation. Many donors' family situations have changed since the time they made their donation, and they may resent the possible intrusion into their lives of something they considered to be in the past.

Parallels are drawn with adoption, where legislation was amended to grant adopted persons retrospective access to their pre-adoption birth certificates. At the time this was considered a radical proposal and as vehemently opposed as it was supported. This policy has now been in place for some time and the Committee is unaware of any significant detrimental effects.

Assisted reproductive treatment clinics in all states and territories in Australia operate within Guidelines set down by the National Health and Medical Research Council and clinics are also regulated by the Reproductive Technology Accreditation Committee Code of Practice. Some states and territories have specific legislation relating to assisted reproduction, which regulates donor conception practices and access to information.⁴ It is notable that no Australian state or territory has legislation that allows retrospective access to donor information.

³ See Division 2 of the *Assisted Reproduction Technology Act 2007* for these provisions.

⁴ For a full discussion of this legislation, see Chapter Two of the Legislative Assembly Committee on Law and Safety report on the Inclusion of donor details on the register of births at: <http://www.parliament.nsw.gov.au/prod/parlment/committee.nsf/0/BFA08A3FF4BB5A03CA257A9A0019C457>, accessed 25 October 2012.

Question 2: If retrospective access were granted what conditions should apply?

The Committee considers that the possible impact of allowing retrospective access, if it were granted, could be mitigated by imposing conditions on such access. For example, in the case of adoption there is a contact veto system in place which applies to those adoptions that took place prior to 26 October 1990. Either the adopted person or the birth parent can place a veto on contact from the other party, but this does not prevent the release of identifying information.

Adoptees, birth parents and adoptive parents can also register for the Advance Notice Register which will allow them to delay the release of identifying information for up to two months, giving them more time to prepare for possible contact.

There are differences in the types of information that donor conceived individuals may wish to seek, and this may be either identifying or non-identifying information about their donor or information about their siblings. Individual needs may be better suited by one class of information than the other and it is important to weigh this up when considering any type of retrospective access.

Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

If retrospective access were granted, consideration needs to be given to what further issues this would raise for the donor conceived person, their family, and the donor and their family.

Currently the ART Central Register is managed by the Ministry of Health in NSW, as is the case in most other jurisdictions. But if other services are needed to help manage the process of access to information, such as counselling and education, would the current system be able to offer this? Does the Ministry of Health have adequate resources and expertise to deliver these specialist services or would they be better placed with another agency?

Victoria has three separate agencies involved in offering services to donor conceived people and their families:

- The Registrar of Births, Deaths and Marriages (BDM) holds the Register of information and must provide a referral for counselling if approached for information.
- The Family Information Networks and Discovery (FIND) (part of the Department of Human Services) offers one counselling session free of charge, but only on referral from the BDM.
- VARTA currently has responsibility for conducting education and awareness campaigns.

Having several agencies involved can result in efficiency losses and higher budget costs, as well as a possibly fragmented approach being taken to support services/systems, which are of critical importance to people seeking to access support.

The Committee is aware of the importance of achieving the right balance of services that should be offered alongside the service of access to information, and seeks feedback on the manner in which they should be administered.

4.2 Management of donor registers

Question 4: Which agency is best placed to manage the donor register? Is the current management of the register adequate?

Question 5: Should a standalone body be established to manage the register? What other areas could it have responsibility for?

In NSW the ART Central Register is operated by the Ministry of Health. Identifying information is held here for all conceptions post 1 January 2010 and for conceptions prior to this date there is a voluntary register where all parties must give consent before any information is released.

The Committee heard a range of views during the Inquiry into the inclusion of donor details on the register of births, for maintaining the Register with the Ministry, or moving it to the Registry of Births, Deaths and Marriages (BDM). Some arguments were made that the BDM is best placed to provide a centralised, streamlined service and that this is where people would naturally look to obtain family and genetic information. It was also noted that the BDM has expertise in records management. In contrast, some argued that ART and related information are health issues and should be managed under the Health portfolio. Privacy and legislative responsibilities may also influence where particular information is stored.

Having considered all the evidence presented to it during the previous inquiry, the Committee concluded that it was premature to change the current system. The Committee is aware however, that the outcome of other issues under consideration, such as retrospective access to donor information and additional support services, is likely to impact on the way in which these records are managed. There is a significant interplay between these issues and the Committee has therefore decided to consider them together.

Looking to the recommendations of the Victorian Inquiry, the Committee can also see the benefits of establishing a standalone body to administer the donor register and perform other functions. Giving one organisation ownership of all aspects of the donor conception information management process may have substantial benefits, both in terms of resource savings and in producing satisfactory outcomes for stakeholders and the community.

4.3 Counselling and support services

Question 6: Should counselling and support services be offered to those seeking donor conception information from the donor register?

Question 7: Are there other types of support that could be offered?

There are no counselling or other support mechanisms currently offered in NSW. Couples undergo counselling when they begin ART treatment but there is no specific support for those seeking information at a later date.

The Committee is of the opinion that some level of counselling may be beneficial for people who are seeking to access donor conception information, and to parents wishing to tell their children about their conception. The nature of any such counselling may be dictated by individual circumstances as well as the type of information that is sought. If retrospective access were allowed, counselling may need to be a mandatory part of the application process.

Western Australian legislation provides for one session of counselling to be paid for by the government and in Victoria there is also one session mandated by legislation, but it is privately paid for. The recent Victorian inquiry recommended that counselling be compulsory for a donor conceived person seeking information about their donor, a donor seeking information about their donor conceived offspring, and a donor or donor conceived person who applies to lodge a contact veto.⁵

In addition to counselling there are other types of support that can be helpful to those individuals seeking information about donor conception. In Victoria VARTA has offered a letterboxing service which connects people with their donor.

Support groups have generally been organised outside the government sphere, such as the Donor Conception Support Group, which operates privately and offers a range of services to donor conceived people and their families. This service is run by volunteers and aims to provide an ongoing support system for families affected by donor conception.

Question 8: How would support services be funded? By the government, the individual seeking the service, or by assisted reproductive technology clinics?

The experience of other jurisdictions shows that most of the counselling and support services associated with ART are privately funded. There are a range of opinions about whether donor conception issues fall outside the scope of public funding.

There are some current government programs such as the Federal Mental Health Care plan, which provide psychological support for people who meet defined criteria. There may be more suitable programs available that could provide support to donor conceived people and their families.

The Committee is interested in stakeholders' views on the most appropriate way of offering support to people seeking assistance.

Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

Support services that are provided to adoptees may provide a suitable system for those seeking donor information. There are also different models already in use throughout Australia which offer a possible alternative.

For adoptees in NSW who wish to access their birth information, the first step is to obtain a 'supply authority' from the Department of Family and Community Services. Once they have this authority they can apply for their original birth certificate. The Department of Family and

⁵Victorian Law Reform Committee, Inquiry into access by donor-conceived people to information about donors, at: <http://www.parliament.vic.gov.au/lawreform/inquiries/inquiry/300>, accessed 25 October 2012, p xxvi.

Community Services has responsibility for arranging support for individuals before they are issued with their pre-adoption birth certificates. Counselling is offered by the non-profit organisation, the Benevolent Society, as well as private organisations, however it is not mandatory.

The current Victorian system offers another possible model. In Victoria counselling is provided by FIND, which also assists people who have experienced wardship or adoption. FIND has counsellors who provide information to individuals referred by the Victorian BDM and only counsels for the purpose of providing information about the potential consequences of disclosure of information. It is important to note that the donor conception stakeholder must have a referral from the BDM to contact FIND and this can only be offered at the initial stage of applying for information.

The recent Victorian inquiry report recommended that counselling services be offered by VARTA as part of the recommended expansion of its role; thus reinvigorating it as a standalone body to offer all services related to the management of donor conception information.

The Committee is interested in feedback from the community about ways in which appropriate support services could be provided, for example which agency or agencies could provide this service.

4.4 Record keeping

Question 10: How long should ART clinics be required to retain records?

Question 11: What should happen to records if a clinic closes?

Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

It is vital to ensure that there are stringent standards in place to guide practices and procedures around collecting and storing information in relation to treatment involving a donor. While these standards need to comply with existing health and privacy regulations, it is important that they also reflect the particular needs of ART and donor conception stakeholders.

The Committee has received evidence that practices differ between clinics in NSW and that 50 years is the minimum time records must be retained for under the ART Act 2007. The NHMRC Guidelines stipulate that records should be kept indefinitely, or at least as long as the expected lifespan of an individual conceived through ART at the clinic. There are also few safeguards around information that could be lost if a clinic holding such information were to close down.

As with all sensitive and personal information, the Committee feels that there may be a need to regulate the manner in which it is collected and stored, and that this be done in a way that retains the information without allowing any details to be tampered with or lost. The Committee notes that the Victorian Inquiry made recommendations on the prohibition of destroying or tampering with records relating to donor conception information and transferring older records to a central repository.⁶

⁶ See Recommendations 23 and 24 of the Victorian Inquiry into access by donor-conceived people to information about donors, at: <http://www.parliament.vic.gov.au/lawreform/inquiries/inquiry/300>, accessed 25 October 2012.

Appendix One – Recommendations from Committee's report *Inclusion of donor details on the register of births*

RECOMMENDATION 1

That the NSW Government work with state and territory governments to develop a nationally consistent system for the registration, management and release of information in relation to donor conception.

RECOMMENDATION 2

That the Attorney-General introduce legislation to provide that, if a birth registration statement specifies that a child was donor conceived, the Registrar of Births, Deaths and Marriages is to note that the child was donor conceived in the entry about that child's birth on the register of births.

RECOMMENDATION 3

That the Registrar of Births, Deaths and Marriages is to issue an addendum on a separate page, indicating that further information is available, when a donor conceived individual aged 18 or over applies for a birth certificate.

RECOMMENDATION 4

That the Registry of Births, Deaths and Marriages and the Ministry of Health inform stakeholders of the changes to birth registration statements and birth certificates, through measures including agency websites and brochures.

RECOMMENDATION 5

That gamete donors' details continue to be held on a separate donor register (the ART Central Register), and not be included on the register of births or birth certificates.

FINDING 1

There was insufficient evidence for the Committee to recommend changes to the management of the ART Central Register. The management of the Register should be examined in the context of the support services that may be required by donor conceived individuals, donors and their families. The Committee will give further consideration to these issues as part of a future inquiry.

In the interim the ART Central Register should continue to be managed by the Ministry of Health.

RECOMMENDATION 6

That the Minister of Health:

- a) Implement processes to enable participants in private donor conception arrangements to voluntarily register their details on the voluntary register;
- b) Publicise information on voluntary registration of details of participants in private arrangements on the Ministry of Health website and through public awareness material such as information brochures.

FINDING 2

The provisions in the Assisted Reproductive Technology Act 2007 for disclosure of information to adult offspring born as a result of treatment using donor gametes and in the case of children, to parents or an appropriate adult, are adequate and should be retained.

FINDING 3

The issue of granting donor conceived individuals retrospective access to information about their donor was not covered by the Terms of Reference for the Inquiry. The Committee is therefore unable to make any recommendation for change.

The Committee will undertake a future inquiry into matters raised during this Inquiry that were not encompassed by the Terms of Reference, including retrospective access to information.

FINDING 4

The provision of counselling and support services and public education in relation to donor conception are important issues that require further examination. These matters should be considered as part of a broader review of the current system for managing donor conception information, and access to this information. The Committee will examine these issues as part of a future inquiry.

Appendix Two – Recommendations from Victorian Law Reform Committee report

Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying 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

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

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

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

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

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

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

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

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

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

Recommendation 12: 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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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