

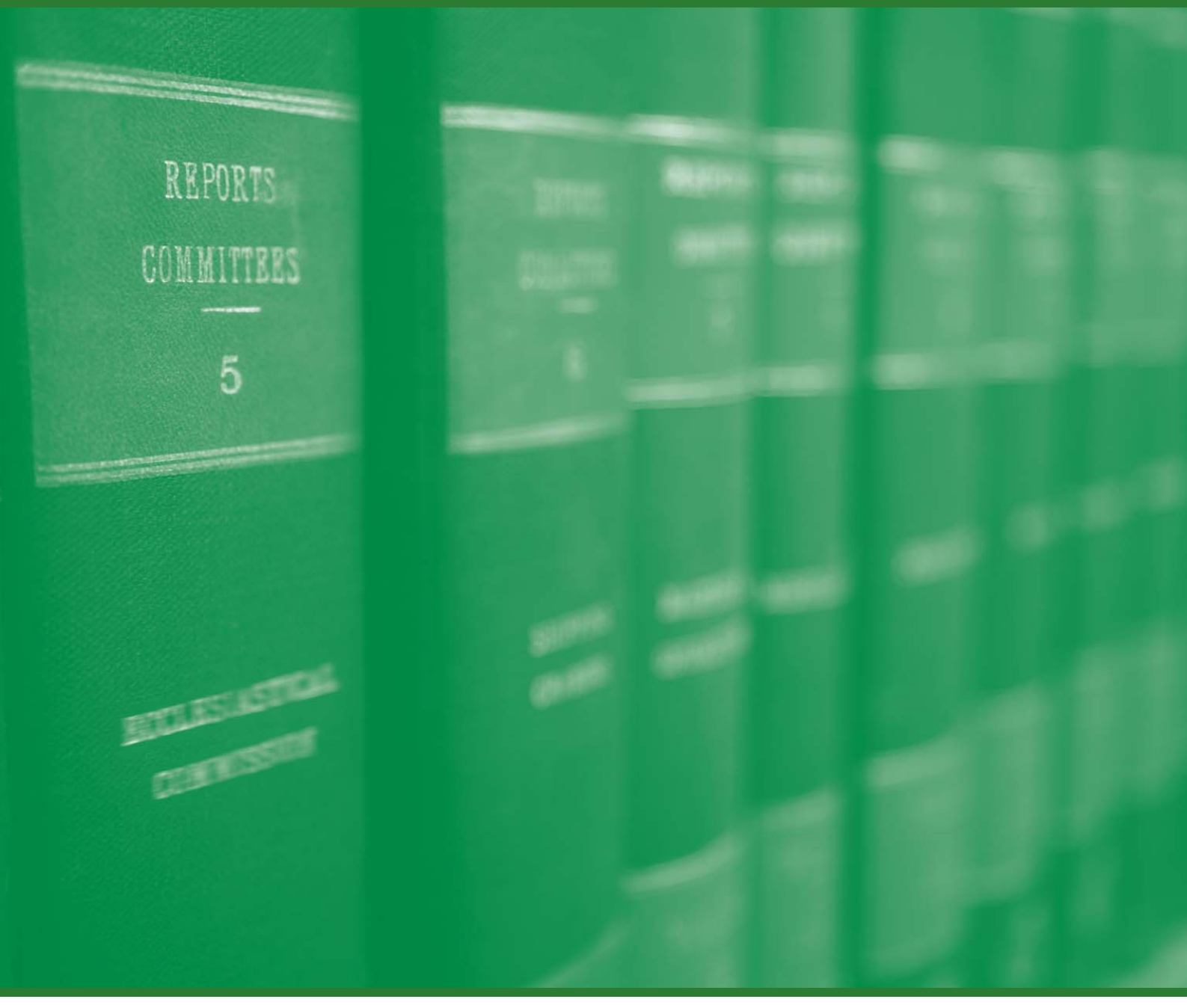


LEGISLATIVE ASSEMBLY OF NEW SOUTH WALES

Committee on Law and Safety

REPORT 2/55 – OCTOBER 2013

MANAGING DONOR CONCEPTION INFORMATION



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The motto of the coat of arms for the state of New South Wales is “Orta recens quam pura nites”. It is written in Latin and means “newly risen, how brightly you shine”.

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Membership

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Terms of Reference

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.

Chair's Foreword

This inquiry into Managing Donor Conception Information follows on from, and makes recommendations about, issues that arose from our first Law and Safety Committee inquiry into the inclusion of donor details on the register of births.

The previous inquiry highlighted a number of issues around the way donor conception information is stored, accessed, and managed, and the fragmented approach that currently exists for donor conceived people in accessing donor conception information in New South Wales. Our terms of reference for this inquiry were deliberately broad in order to allow the committee to explore three key areas: collection of donor information, recording and maintaining of donor information, and access to donor information.

Each of these areas is complex, and this complexity is further compounded by the sensitivity of questions around anonymity, retrospectivity and the impact this may have on both donors and donor conceived individuals. The Committee recognises that this is a very personal and emotional issue for many donor conceived people and their families.

The Committee was mindful of work conducted in this area by other states as well as the Federal Government and believes that this, together with evidence gathered through the submissions and hearings of this Inquiry, highlights the need for national standardisation of donor conception information management practices. The Committee also notes that the recommendations in this report are convergent with those recently released by the Victorian Government in response to the Inquiry into Access by Donor-Conceived People to Information about Donors.

This report is a comprehensive collection of individual, industry and stakeholder views on the key issues facing donors and donor conceived individuals. It acknowledges the changing tide in relation to shining light on an area that has unfortunately been under the veil of secrecy. The report also highlights the importance for a donor conceived child to know as early as possible their 'life story', that is, one which includes their biological makeup.

In relation to the terms of reference around how donor conception information is collected, recorded and maintained, the Committee has recommended the establishment of a new agency to manage a Register of donor conception information. This agency would also be responsible for providing support and public education services.

In relation to maintaining current donor information, the Committee heard alarming evidence that information held by independent organisations may, at times, have been tampered with or destroyed, either deliberately or through a lack of correct process. Therefore, the Committee has recommended that, as a matter of urgency, the *Assisted Reproductive*

Technology Act 2007 be amended to make it an offence to destroy, tamper or falsify donor conception records.

Of course, a key area of this inquiry looked into how donor information is accessed, particularly the contentious discussion around the issue of retrospective access to donor conception information. The Committee was overwhelmed by the personal accounts and stories of individuals who wanted to learn more about their biological makeup, but due to the possible negative effects of making identifying information available retrospectively for any or all parties, the Committee has chosen to make only minor recommendations in this area.

These recommendations deal with identifying and non-identifying information separately, but provide the ability, where all parties are in agreement, to make identifying information available.

The Committee has acknowledged the importance of flexible counselling services being tailored to individual needs and recommends that such services should be offered before access to donor conception information is made available.

I again stress the point that the Committee recognises the need for national uniformity in relation to donor information collection, recording and access. We are keen to see this on the national agenda through the appropriate inter-governmental forums. In the meantime, I believe that this report and its recommendations bring us closer to other states.

I would like to recognise the exceptional work of the Committee Secretariat, especially on such a complex and contentious issue. I would like to acknowledge the meticulous work performed by everyone involved, particularly Clara Hawker. Her contribution to this report has been nothing less than exceptional.

I would again like to acknowledge my Committee colleagues, Jai Rowell MP, Garry Edwards MP, Guy Zangari MP, and Nick Lalich MP for the way they embraced a sensitive, complex and controversial issue. Their individual input, exhaustive research and determination to strike a balance for all parties has been unparalleled.

As it was with the previous inquiry, this has been an emotional rollercoaster ride for all.

John Barilaro MP
Chair

Executive Summary

This inquiry arose as a result of the first Law and Safety Committee inquiry into the inclusion of donor details on the register of births, the report of which was tabled in 2012.

Throughout the first inquiry, the Committee found that a number of issues were raised, such as retrospective access to records relating to donor conception, and the need for support services for people seeking donor conception information. Although these issues were outside the Inquiry's terms of reference, the Committee considered that these issues merited further investigation, and resolved to conduct a broader inquiry to examine them.

The key issues examined by the Committee in this inquiry into managing donor conception information are:

Which agency should collect and maintain donor conception information?

Presently, donor conception records for people conceived prior to 1 January 2010 are held by the clinic or doctor that provided Assisted Reproductive Technology (ART) treatment. Access to donor conception records is made extremely challenging when clinics close down or doctors retire. The Committee was very concerned to hear of donor conception records that had been deliberately damaged or destroyed.

The Committee heard evidence on the value of having an appropriately experienced and resourced agency to maintain donor conception information, and ensure that the information is stored and accessed effectively.

For these reasons, the Committee has made several recommendations in the area of management of donor conception information, including the recommendation to establish a new agency to manage a Register of donor conception information, irrespective of when that information was created. The Committee recommends that the new agency's role be greater than record keeping, and that it should also offer support and public education services. The Committee also recommends that, as a matter of urgency, the *Assisted Reproductive Technology Act 2007* be amended to make it an offence to destroy, tamper or falsify donor conception records.

Retrospective access to donor conception information

The most sensitive and complex issue that the Committee examined in the course of the inquiry was the issue of retrospective access to donor conception information. The Committee received substantial evidence from donor conceived people who wish to know their genetic heritage. The Committee understands that this is a very personal and emotional issue for many donor conceived people and their families.

In considering the issue of retrospective access to information, the Committee sought to consider the perspective of all parties. However, despite the Committee's best efforts to

gather their views, the voice of donors was largely missing from this inquiry. Only one submission was received from a donor and no donors appeared at public hearings. In light of the lack of direct evidence received from donors, the Committee is unwilling to recommend substantive change in relation to access to donor conception information.

The Committee is mindful that community attitudes towards donor conception continue to move away from past attitudes of secrecy and considers that access to identifying donor conception information should always be made possible where all parties to donor conception consent. The Committee has made six recommendations relating to access to donor conception information in this regard.

While some ART providers do facilitate the exchange of information between donors and donor conceived people, the Committee considers the provision of such information is a sensitive area that requires specialist skills and falls outside the main role of ART providers. For this reason the Committee recommends that the agency established to manage the Register of donor conception information should provide an ‘active register’ and engage people with specialist skills to enable the exchange of donor conception information with the consent of all parties.

Such a Register will strike a balance between fulfilling the needs of donor conceived people to know their genetic heritage and respecting the wishes of those donors who donated under a different system to maintain their anonymity if they wish.

Support for people seeking donor conception information

Facilitating access to donor conception information requires the specialist capabilities of counsellors who understand issues particular to donor conception. Donor conceived people, donors and their parents may need different forms of support at different stages in their lives. At present, support is often limited and not always easy to access.

The Committee made three recommendations relating to support for people seeking donor conception information. The Committee recommends that the agency established to manage the Register of donor conception information also provide comprehensive community education, public awareness campaigns, counselling, intermediary support and DNA testing. Having a single agency manage donor conception information and provide associated support services would provide a simple ‘one-stop shop’ for people that would be easy to navigate and able to provide ongoing support.

Report structure

Chapter One gives the background to the establishment of the inquiry, describes the terms of reference and the conduct of the inquiry.

Chapter Two provides an overview of the current way donor conception information is managed in New South Wales.

Chapter Three examines the evidence received regarding which agency should have responsibility for the collection, storage and management of donor conception information.

Chapter Four explores the differing viewpoints of inquiry participants regarding whether there should be retrospective access to donor conception information. The Chapter also looks at retrospective access to information in comparable jurisdictions.

Chapter Five looks at the counselling, public awareness campaigns, education, intermediary support and DNA testing essential for supporting people access donor conception information.

Many donor conceived people shared their personal stories with the Committee. The Committee examined all the evidence received in great detail, and wishes to thank those people who shared their views and experiences. The Committee recognises the important contribution made by informal support networks in supporting donor conceived people, donors and recipient parents.

List of Recommendations

RECOMMENDATION 1 _____ 22

The Committee recommends that the Attorney General establish a new agency to manage a Register of donor conception information and that this agency also assume responsibility for providing support to those involved in donor conception.

RECOMMENDATION 2 _____ 22

The Committee recommends that in the interim, and as a matter of urgency, the Ministry of Health should engage specialists to liaise with donors, donor conceived people and recipient parents, to facilitate access to identifying information with the consent of all parties.

RECOMMENDATION 3 _____ 26

The Committee recommends that the donor conception management agency, once established, collect all donor conception information from assisted reproductive technology clinics and enter it into a secure Register of donor conception information. This Register, once established, should comply with relevant National Health and Medical Council Research guidelines with reference to security and privacy provisions.

RECOMMENDATION 4 _____ 26

The Committee recommends that, as a matter of urgency, the Attorney-General amend the *Assisted Reproductive Technology Act 2007* to make it an offence to destroy, tamper or falsify any donor conception records.

RECOMMENDATION 5 _____ 51

The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access non-identifying information about their donor, regardless of whether or not the donor consents to such information being released.

RECOMMENDATION 6 _____ 51

The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access identifying information about their donor where the donor consents to such information being released.

RECOMMENDATION 7 _____ 51

The Committee recommends that the new donor conception management agency implement procedures that enable the parents of a donor conceived person to access non-identifying information about the donor regardless of the donor's consent on behalf of their child or/and until the child reaches 18.

RECOMMENDATION 8 _____ 51

The Committee recommends that, for those individuals conceived before 1 January 2010, the new donor conception management agency implement procedures that enable the parents of a donor conceived person to access identifying information about the donor, where the donor consents to such information being released, on behalf of their child or/and until the child reaches 18.

RECOMMENDATION 9 _____ **51**

The Committee recommends that the new donor conception management agency implement procedures to ensure that the donor and the donor conceived person's siblings have access to:

- a) any information that the donor conceived person has consented to being placed on the Register of donor conception information and
- b) further information, if the Registrar is of the opinion that the contact is justified in order to promote the welfare and best interests of one or more of the persons concerned.

RECOMMENDATION 10 _____ **52**

The Committee recommends that the new donor conception management agency operate the Register of donor conception information on an active, or consent-release based approach, to best facilitate access to donor conception information.

RECOMMENDATION 11 _____ **62**

The Committee recommends that, as a matter of urgency, the Ministry of Health conduct an advertising campaign to raise awareness of the Voluntary Register.

RECOMMENDATION 12 _____ **67**

The Committee recommends that the services provided by the agency established to manage the Register of donor conception information include public awareness campaigns, community education, intermediary support, counselling, DNA testing, and the facilitation of contact where this is desired by both parties.

RECOMMENDATION 13 _____ **67**

The Committee recommends that the agency established to manage the Register of donor conception information conduct an advertising campaign to raise awareness of the Register and associated services available, such as intermediary support, counselling and DNA testing.

Glossary

ANZICA	Australian and New Zealand Infertility Counsellors Association
ART	Assisted reproductive technology
ART Act	<i>Assisted Reproductive Technology Act 2007</i>
BDM	Births, Deaths and Marriages
FIND	Family Information Networks and Discovery
FIOM/ISS	Dutch national social work agency
ITA	Infertility Treatment Authority
NHMRC	National Health and Medical Research Council
RTAC	Reproductive Technology Accreditation Committee
VARTA	Victorian Assisted Reproductive Technology Authority

Chapter One – Introduction

TERMS OF REFERENCE

1.1 The Committee on Law and Safety adopted an Inquiry into managing donor conception information on 15 November 2012. The Committee adopted the following terms of reference:

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.

BACKGROUND TO THE INQUIRY

1.2 The Inquiry into managing donor conception information arose from a previous inquiry conducted by the Committee, into the inclusion of donor details on the register of births, which was tabled in November 2012.

1.3 The Inquiry into the inclusion of donor details on the register of births arose from a court case challenging how parents are legally recorded on birth certificates in cases where assisted reproductive technology has been used to conceive a child. The Inquiry was conducted to examine whether the donor's details should be recorded on the birth register.

1.4 The key recommendations of the Inquiry were: that when the information is available, the Registrar of Births, Deaths and Marriages should note that a child was donor conceived on the register of births; and that the Registrar of Births, Deaths and Marriages should issue an addendum on a separate page indicating that further information is available when the donor conceived individual aged over 18 applies for a birth certificate.

1.5 The Committee also made recommendations around establishing a nationally consistent framework for managing donor conception information and publicising the current voluntary register to raise public awareness of its existence.

1.6 During the Inquiry into the inclusion of donor details on the register of births, several issues arose that were outside the Inquiry's terms of reference but which

held obvious significance for those affected by donor conception. These issues involved the way donor conception information is registered and stored, and particularly, the way in which information is accessed and who is able to access it. A key finding of this Inquiry was that the Committee should undertake a further Inquiry to examine these issues.

- 1.7 The Inquiry into managing donor conception information examined issues around the management of donor conception including: which agency should collect and maintain the information, whether people conceived at a time when anonymous donation was allowed should now be able to access their donor's information, and what services may be necessary to support those involved in the donor conception process.
- 1.8 Public discussion on the issue of donor conception information management has been increasing in recent years, as evidenced by the Victorian Law Reform Committee's report on the Inquiry into Access by Donor-Conceived People to information about Donors, and the recently released United Kingdom's Nuffield Report on Donor Conception. This Inquiry into managing donor conception information makes a valuable contribution to this discussion.

CONDUCT OF THE INQUIRY

Submissions

- 1.9 The Committee called for submissions by advertising the Inquiry on the Committee website, in the *Sydney Morning Herald* and in *Sydney's Child*. The closing date for submissions was 15 February 2013. A media release was also distributed to media organisations in New South Wales and the Chair of the Committee wrote to key stakeholders inviting them to make a submission to the Inquiry.
- 1.10 In total, the Committee received 40 submissions from a broad cross-section of the community including donor conceived individuals and parents of donor conceived individuals, the NSW Government, academics, legal and medical professionals, consumer advocacy groups and non-government organisations.

Public Hearings

- 1.11 The Committee held two public hearings at Parliament House on 29 April and 6 May 2013. Evidence was taken from 22 witnesses. A list of witnesses who appeared before the Committee can be found at Appendix Two.
- 1.12 The transcripts of evidence from the public hearings can be found on the Committee's website: <http://www.parliament.nsw.gov.au/lawandsafety>

Chapter Two – The current situation

- 2.1 This chapter provides an overview of how information related to donor conception is currently managed in NSW, including the relevant legislation and regulations and the agencies which have responsibility for administering the information. The chapter also details the recommendations made in a number of recent inquiries into management of donor conception information.

HOW INFORMATION IS MANAGED AND ACCESSED

- 2.2 The way in which information relating to donor conception is managed is dependent on when the conception using assisted reproductive technology (ART) occurred. Legislation was introduced at different times, and grants different levels of access for people depending on when they were conceived.

Pre 2010 conceptions

- 2.3 Prior to 1 January 2010, there were no central registration requirements for gamete donors and donors were permitted to remain anonymous.
- 2.4 Those who were conceived prior to 2010 and wish to find out details of their donor must approach the clinic where their mother's fertility procedure was performed to see if non-identifying information is available.
- 2.5 This approach relies on the clinic having maintained the records appropriately and on the individual being aware that they are donor conceived. As such, it is not a reliable method of facilitating access to conception information by a donor conceived person.
- 2.6 Record keeping practices vary among fertility clinics and until recently have not been regulated. As a result, there is little consistency historically between different clinics and the Committee has heard of instances where records have been either destroyed or mislaid by the clinic, making it impossible for the donor conceived person to find out details about their donor.¹
- 2.7 The ability of donor conceived people to access information about themselves is dependent on them being aware of the circumstances of their conception, an issue which has been the subject of much discussion. With the introduction of recent legislation and changes in social mores, parents are being encouraged to be open with children about donor conception and it is believed that the numbers of parents who do disclose this information is increasing.²
- 2.8 As an alternative to granting retrospective access to donor conception information, the *Assisted Reproductive Technology Act 2007* (ART Act) and the *Assisted Reproductive Technology Regulation 2009* (Regulations) established a

¹ Evidence received by the Committee in a confidential submission.

² Blyth E and Frith L, 'Donor-conceived people's access to genetic and biographical history: an analysis of provisions in different jurisdictions permitting disclosure of donor identity', *International Journal of Law, Policy and the Family*, 23 (2009), p 185

Voluntary Donor Register as part of the Central Register, to hold information about donors and donor conceived individuals.

- 2.9 Both those who donated and those who were conceived prior to 2010 are able to place their information on the register voluntarily and this information is disclosed in accordance with the consent of the person who entered it. This system allows the person entering the information to decide what information they will allow to be released and whether they wish contact to occur or not.³
- 2.10 Under this passive type of register, connections are made and information disseminated only when a person requests it, and the other person has already chosen to place their information on the register. There is no active linking of parties or outreach to encourage people to consider placing their information on the register.
- 2.11 The current system in NSW has the effect of providing different levels of access to information for individuals depending on when they were conceived. It is this apparent inequity that many participants to the Inquiry feel is discriminatory and are seeking to have addressed through the granting of equal access rights to information.⁴

Post 2010 conceptions

- 2.12 In 2010 the ART Act and Regulations were introduced, which ended donor anonymity for people born after 2010. This legislation also provided for the establishment of a Central Register as a repository of all donor conception information. This Register is managed by the NSW Department of Health.
- 2.13 Under this legislation, from 1 January 2010, identifying information about both donors and recipients must be provided by the ART clinic to the Central Register and this information may be accessed by donor conceived people when they turn 18.
- 2.14 The Central Register contains information relating to both ART conceptions and surrogacy arrangements.
- 2.15 The Regulations stipulate that the following information must be provided to the Register when donated gametes are used:
- (a) the full name of the donor,
 - (b) the residential address of the donor,
 - (c) the date and place of birth of the donor,
 - (d) the ethnicity and physical characteristics of the donor,

³ NSW Ministry of Health, NSW Health Central Register Information Sheet, viewed 12 February 2013, <http://www0.health.nsw.gov.au/art/egg_embryo_donor.asp#para_2>

⁴ See for example: Submission 2, Confidential, p 3, submission 4, Mr Damian Adams, p 5, and submission 5, Donor Conception Support Group, p 27

(e) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:

(i) a person undergoing ART treatment involving the use of the donated gamete, or

(ii) any offspring born as a result of that treatment, or

(iii) any descendent of any such offspring,

(f) the name of each ART provider who has previously obtained a donated gamete from the donor and the date on which the gamete was obtained,

(g) the sex and year of birth of each offspring of the donor.

2.16 In addition to the donor conceived adults being able to access the identifying information, the non-donor conceived adult offspring of the donor as well as the donor themselves can access information about the sex and year of birth of the donor's other offspring.⁵

2.17 The parents of the donor conceived child can access details about the ethnicity and physical characteristics of the donor, any relevant medical history and year of birth and sex of other offspring of the donor.⁶

2.18 The Central Register records only information from registered ART providers and people who enter private donor conception arrangements outside the registered clinic system cannot presently enter their details on this Register.

REGULATION

2.19 There is no national regulation of ART as it is regulated at a state level. However, there is a framework consisting of ART guidelines issued by the National Health and Medical Research Council (NHMRC), and an accreditation system administered by the Reproductive Technology Accreditation Committee (RTAC).

National Health and Medical Research Council Guidelines

2.20 The NHMRC is an independent statutory agency whose role includes fostering consideration of ethical issues relating to health. NHMRC guidelines are non-mandatory rules or principles developed to achieve best practice in specific fields.⁷ The NHMRC updated its ethical guidelines on the use of assisted reproductive technology in clinical practice and research in 2007. In outlining the ethical dimension and issues relevant to ART that were taken into account in preparing the guidelines, the guidelines state that the Australian Health and

⁵ Committee on Law and Safety, *Inclusion of donor details on the register of births*, report 1/55, Parliament of New South Wales, October 2012, p 11

⁶ Committee on Law and Safety, *Inclusion of donor details on the register of births*, report 1/55, Parliament of New South Wales, October 2012, p 11

⁷ National Health and Medical Research Council, 'How NHMRC develops its guidelines', viewed 14 December 2011, <<http://www.nhmrc.gov.au/guidelines/how-nhmrc-develops-its-guidelines>>

Ethics Committee 'has recognised that the welfare of people who may be born as a result of the use of ART is paramount.'⁸

Donation of gametes

2.21 In terms of the donation of gametes, the guidelines state that ART clinics should uphold the right to knowledge of genetic parents and siblings. Specifically that:

- Donors should understand and accept the biological connection they have with the donor conceived child, and that the child has a right to knowledge about them;
- Recipients should be understand the biological connection they child has with the donor and be encouraged to tell their child of their origins;
- Public forums be used to encourage donors who were previously anonymous to consider registering their details; and
- That clinics should not use genetic material collected prior to the introduction of these guidelines without the consent of the donor.⁹

Entitlement to information

2.22 The NHMRC guidelines state that clinics should provide donor conceived persons with the following information about their donor on request, once the person has reached 18 or is sufficiently mature to understand the significance of the request:

- all medical and family history information
- identifying information about the gamete donor
- the number and sex of persons conceived using gametes provided by the same gamete donor, the number of families involved, and any identifying information that these siblings have consented to being released.¹⁰

2.23 The information should be provided by a medical practitioner, or a health professional with appropriate qualifications.

2.24 The guidelines also state that gamete donors are entitled to some information about the recipients of their gametes and the offspring born (in particular, to prepare them for future approaches by their genetic offspring) which may include

⁸ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 9, view 10 January 2012, <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e78.pdf>

⁹ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, pp 25-26 , viewed 10 January 2012, <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e78.pdf>

¹⁰ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 29, viewed 10 January 2012, <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e78.pdf>

non-identifying information about gamete recipients, including the number and sex of persons born.¹¹

- 2.25 The guidelines state that the principles outlined above should also apply to the use of donated embryos.¹²
- 2.26 In terms of clinics' provision of professional counselling for participants in gamete or embryo donation, the guidelines note that discussion of the issues relating to donation should include 'the right of persons born to have identifying information about their genetic parents and information about the possibility that they will make contact in the future.'¹³
- 2.27 The guidelines also contain requirements for obtaining informed consent from participants, including for the use of identifying information, and recommended record keeping practices to record and facilitate the exchange of information between donors, recipients and donor conceived persons. The following information should be collected from donors:
- name, any previous name, date of birth and most recent address;
 - details of past medical history, family history, and any genetic test results that are relevant to the future health of the person conceived by gamete donation (or any subsequent offspring of that person) or the recipient of the donation; and
 - details of physical characteristics.¹⁴

Reproductive Technology Accreditation Committee Code of Practice

- 2.28 ART clinics and providers in Australia must obtain accreditation by the Fertility Society of Australia's Reproductive Technology Accreditation Committee (RTAC). The RTAC produces a Code of Practice for ART, and compliance with the Code is compulsory for ART providers.¹⁵ As part of the Code, providers are required to demonstrate that they have certain policies and processes in place including:
- support of the offspring's right to know their genetic origins;
 - retaining records about donors and recipients ;

¹¹ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 29, viewed 10 January 2012, <<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e78.pdf>>

¹² Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 33, viewed 10 January 2012, <<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e78.pdf>>

¹³ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 44, viewed 10 January 2012, <<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e78.pdf>>

¹⁴ Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, pp 44-45, 50-51, viewed 10 January 2012, <<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e78.pdf>>

¹⁵ Fertility Society of Australia, Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, October 2010, p 4, viewed 10 January 2012, <<http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf>>

- the organisation explains the provisions, responsibilities and obligations associated with linking between donors, recipients and offspring;
- the legislation defining the legal status of children born as a result of the procedure;
- the information that service providers collect and the extent to which that information may be disclosed to people born as a result of the donation; and
- the process for the disclosure of identifying information.¹⁶

2.29 While both NHMRC and RTAC guidelines stipulate that couples undergoing fertility treatment should receive counselling, this is counselling at the time of the treatment, referred to as implications counselling, rather than counselling after treatment when they or the donor conceived person may seek further information.¹⁷

PREVIOUS INQUIRIES

2.30 The rights and interests of all parties involved in ART and donor conception have been increasingly discussed in recent years. This is evidenced by a number of inquiries both in Australia and overseas, including the Senate Inquiry into donor conception practices in Australia, the Victorian Law Reform Inquiry into Access by Donor-Conceived People to Information about Donors, and in the United Kingdom, the Nuffield Council on Bioethics Report on Donor Conception: Ethical Aspects of Information Sharing (the “Nuffield Report”). An overview of these reports is provided below.

Senate inquiry into donor conception practices

2.31 The Senate's Legal and Constitutional Affairs References Committee conducted an inquiry into donor conception practices in Australia, which reported in February 2011. The relevant recommendations are summarised below.

2.32 The Committee recommended the establishment of nationally consistent legislation regulating the practice of donor conception, and a national register. If a national donor conception register is not established, it recommended that each state and territory should establish their own centralised register in such a way that will ensure a consistent approach to the granting of access to information held on the registers.

2.33 If the states and territories did not consider that there should be retrospective access to donor conception information, the report recommended that a national voluntary register or separate register in each state and territory should be established to allow donors who donated anonymously to agree to have their

¹⁶ Fertility Society of Australia, Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, October 2010, Appendix 2, p 23-24, viewed 10 January 2012, <<http://www.fertileysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf>>

¹⁷ Committee on Law and Safety, *Inclusion of donor details on the register of births*, report 1/55, Parliament of New South Wales, October 2012, p 91

information recorded and disclosed to any individuals conceived as a result of their donation.

- 2.34 The voluntary register should also record donor conception that took place privately and have a DNA databank to enable donors and donor conceived individuals to place their details on the register for possible matching, in circumstances where records relating to their identities have been destroyed.
- 2.35 The report also recommended that the states and territories jointly fund a campaign to publicise the establishment of either a national voluntary register or separate voluntary registers in each state and territory.
- 2.36 States and territories that have not already done so should notate birth certificates of donor conceived children so that when they apply for a birth certificate over the age of 18, they can be provided with additional information about their conception, if they choose.¹⁸

Victorian Law Reform Committee Inquiry into Access by Donor-Conceived People to Information About Donors

- 2.37 The Victorian Law Reform Committee inquiry report was tabled in 2012 and made thirty recommendations that broadly covered: access to donor conception information by all parties to donor conception; centralised management of information and provision of education and support services; and securing access to donor conception records created prior to 1988.
- 2.38 The report recommendations aimed to give all donor conceived people uniform access to donor conception information, irrespective of the date of their conception, recognising ‘that the welfare and interests of persons born as a result of assisted reproductive treatment are paramount,’ and make access to donor conception information consistent with access to adoption information in Victoria.¹⁹
- 2.39 Before it could respond to the recommendations in the report, the Victorian Government determined that further research was needed on the potential impact of the recommendations on donors who donated in the era of anonymous donation. The research, conducted by the Victorian Assisted Reproductive Treatment Authority (VARTA) and Monash University, found there was a wide range of donor perspectives regarding retrospective access to donor conception information.
- 2.40 Most donors supported the release of identifying information, provided that they were asked for their consent. Slightly less than half of donors supported the Law Reform Committee recommendation to provide donor conceived people with identifying information regardless of the consent of the donor and slightly more than half of donors rejected this recommendation. Of the group who rejected the recommendation, approximately half suggested that information could be

¹⁸ Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp xi-xvii

¹⁹ Victorian Law Reform Committee, *Report on the Inquiry into Access by Donor-Conceived People to Information About Donors*, March 2012

released with the donor's consent, either through promotion of the voluntary register or directly in response to a request made from a donor conceived person.²⁰

- 2.41 The final government response to the inquiry was tabled on 20 August 2013. In relation to access to donor conception information by all parties, the Victorian Government expressed support for the introduction of legislation to enable all donor conceived people access identifying information about their donors, with the consent of the donor. In cases where donors opposed the release of identifying information, the Victorian Government supports the release of non-identifying information.
- 2.42 The Victorian Government noted that '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.'²¹
- 2.43 In response to recommendations regarding the centralised management of information and provision of education and support services, the Victorian Government supports maintaining the current arrangement whereby the Registry of Births, Deaths and Marriages manages donor conception information. It also supports an expanded role for VARTA, providing increased counselling and intermediary support, including a letter box service.
- 2.44 In relation to the securing of access to donor conception records created prior to 1988, the Victorian Government intends to introduce legislation to facilitate access to and preserve pre-1988 donor conception records by:
- Inviting individuals who may have records to provide these to the Registrar of Births Deaths and Marriages (BDM) 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.²²

The Nuffield Report

- 2.45 The Nuffield Council on Bioethics Report examined the sharing of donor conception information in the United Kingdom (UK). Donor conception in the UK has not been anonymous since 2005, and the report recommended that the rules relating to anonymity for donors who donated prior to 2005 should not be

²⁰ Victorian Assisted Reproductive Treatment Authority, *Consultation with donors who donated gametes in Victoria, Australia before 1998: Access by donor-conceived people to information about donors*, 2013, p 5

²¹ Victorian Government, *Inquiry into Access by Donor-Conceived People to Information about Donors*, Victorian Government Response, August 2013, p 5

²² Victorian Government, *Inquiry into Access by Donor-Conceived People to Information about Donors*, Victorian Government Response, August 2013, p 12

altered to allow for retrospective access to information. However, the report did recommend that a public information campaign be conducted to ‘increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor conceived adults.’²³ The report also recommended that the public awareness campaign encourage donors to register with the voluntary register.

- 2.46 Other recommendations included that counselling for all parties to donor conception be made routinely available, and the establishment of a dedicated donor conception website with information relating to all aspects of donor conception. The Nuffield Report also recommends that the government provide financial support where necessary, to make specialist advice and resources available to those who need them and would not otherwise be able to afford it.²⁴

ADDITIONAL SUPPORT SERVICES

- 2.47 The Committee heard evidence about the importance of having a range of counselling and support services in place to support individuals when they are seeking donor conception information. Evidence was received on the benefits of having services such as public awareness campaigns, community education, intermediary support, counselling, DNA testing, and informal support networks. These will be examined in detail in Chapter Five.
- 2.48 The ART Act stipulates that ART providers must offer counselling to people wishing to donate gametes or conceive using donor gametes, to assist them in understanding the implications of their decision. Implications counselling is paid for by the person making the donation or accessing the treatment. However, there are no requirements under the Act for ART providers to offer counselling or other support measures to people seeking access to donor conception information.

THE VICTORIAN MODEL

- 2.49 The Victorian experience was referred to consistently by participants during this Inquiry process as a good model.²⁵ The system in place prior to 2010 has been widely acknowledged as best practice both in terms of managing donor conception information and providing support services.
- 2.50 The Fertility Society of Australia submitted that ‘VARTA provides an excellent model of an agency that provides a spectrum of support for donor conceived persons and their families’.²⁶ This system and its subsequent changes are outlined below.

Before 2010

- 2.51 The Infertility Treatment Authority (ITA) was a statutory authority established in 1998 whose responsibilities included maintaining donor registers, managing

²³ Nuffield Council on Bioethics, *Donor Conception: ethical aspects of information sharing*, April 2013, p xxvi

²⁴ Nuffield Council on Bioethics, *Donor Conception: ethical aspects of information sharing*, April 2013, p xxiv

²⁵ See for example: Ms Fiona Hearne, p 5, Dr Sonia Allan, p 11, Ms Caroline Lorbach, p 21, Mr Geraldine Hewitt, p 27, transcript of evidence, 6 May 2013

²⁶ Submission 14, The Fertility Society of Australia, p 7

access to information on the registers and providing support services such as counselling and donor linking.

2.52 The ITA offered counselling to all parties to donor conception, including donor conceived people, donors and recipient parents. Counselling was offered to people contemplating accessing information on the donor registers, to both donors and donor conceived people in the process of donor-linking, and to people whose records were incomplete or had been destroyed.

2.53 Ms Lauren Burns, a private citizen who, along with her donor, received counselling and intermediary support from ITA outlined her experiences:

I went in to the ITA for an interview and listed a short resume of my personality and interests and discussed my short and long term goals for contact..... I found it helpful to be able to speak to a counsellor and have access to an intermediary service. I also found it helpful that my donor had access to a counsellor and was able to talk about any uncertainties or fears in regards to proposed contact. It was also initially useful to have access to a 'mailbox service' whereby we could exchange letters without having to use our full names or addresses.²⁷

2.54 Having responsibility for management of the donor registers and the employment of counsellors allowed ITA to provide a donor-linking service in response to requests for identifying information made by all parties to the donor conception arrangement. ITA was able to act as intermediary between parties and explain the motives of people seeking information and communicate expectations between parties. Professor Jenni Millbank, Faculty of Law, University of Technology, noted in her submission that donors were far more willing to receive contact as a result of this intermediary service, which made the process both personal and comprehensive.²⁸

January 2010 to the present day

2.55 From January 2010, the responsibility for managing donor registers was transferred to the Victorian Registry of Births, Deaths and Marriages (BDM). Education and public awareness campaigns became the responsibility of the Victorian Assisted Reproductive Authority (VARTA), and counselling and support services were transferred to Family Information Networks and Discovery (FIND), operated by the Victorian Department of Human Services.

2.56 People who seek information from the donor registers apply to the Registry of BDM, which maintains the central and voluntary donor treatment registers. The Registry then refers people to FIND for a mandatory session of counselling to explore the implications of receiving identifying information.²⁹

2.57 FIND has counsellors who provide information to individuals who are referred by the Victorian Registry of BDM and only for the purpose of providing information about the potential consequences of disclosure of information. FIND counsellors

²⁷ Submission 6, Ms Lauren Burns, p 8

²⁸ Submission 7, Professor Jenni Millbank, p 10

²⁹ Victorian Registry of Births, Deaths and Marriages, *Application for information from the Central register*, viewed 10 July 2013, <https://assets.justice.vic.gov.au/assets/bdm/resources/b27d0928-fd66-4cd9-b333-4ac2b713ecf0/7778+0781+bdm_central+register+form+proof+v1.pdf>

are experienced in provision of support to people associated with adoption and wards of the state.

2.58 The intermediary and letterbox service for linking parties once provided by ITA is no longer offered by either VARTA, FIND or BDM.

2.59 VARTA was established as a statutory authority in 2010, to provide public education and resources for professionals and the community on fertility and issues related to ART, including donor-conception.³⁰ In the area of donor conception, VARTA provides resources and support for donors, recipient parents and donor conceived people including using personal stories and providing links to counsellors and support groups. The agency also provides support and resources through campaigns such as:

- *Time to Tell*, aimed at helping parents to tell children that they are donor conceived,
- *Time to Consent*, for people considering consent to the release of their personal information held on either the voluntary or central donor registers, and
- *Time to Apply?*, for people considering seeking information on the voluntary or central donor registers.

2.60 The current system of separating the donor registers from the other support mechanisms such as counselling and education has been criticised by many inquiry participants. For example, Ms Lauren Burns submitted that:

This splintering of authority and services is not ideal. It is preferably the agency managing donor conception has both full authority and full responsibility for undertaking services related to application to the donor registers, including information management, counselling, and release of information.³¹

2.61 As outlined earlier in this chapter, the Victorian Government, responding to the *Inquiry into Access by donor-conceived people to information about donors*, supports the provision of counselling and intermediary services by VARTA (in place of FIND). However responsibility for management of donor conception information will remain with the Victorian Registry of Births, Deaths and Marriages. The Victorian Government noted that it will amend the legislation to allow for better information exchange between BDM and VARTA.

³⁰ Victorian Assisted Reproductive Authority, viewed 10 July 2013, <<http://www.varta.org.au>>

³¹ Submission 6, Ms Burns, p 8

Chapter Three – Managing the Information

- 3.1 In this chapter the Committee will outline evidence it received on how the information related to donor conception should be managed. In response to the Inquiry's terms of reference b), this included evidence taken on which agency should have responsibility for collecting, storing and managing the release of information, how the information will be collected, and considerations for storing it safely.

WHO SHOULD KEEP THE INFORMATION?

- 3.2 The Committee heard different views from stakeholders about who is best placed to manage donor conception information. The Committee heard that the existing system should be expanded from the current passive-type register, to a register which takes a more active role in linking donors and donor conceived individuals born prior to 2010, regardless of which agency administers the information. The extra work involved in providing the recommended counselling and support measures needs to be considered when deciding who should manage the information. These additional responsibilities are examined in depth in Chapter Five.
- 3.3 The Committee received evidence in favour of retaining the registers with the Ministry of Health, moving them to the Registry of Births, Deaths and Marriages, and establishing a new agency to manage donor conception information. This evidence is outlined below.

Current situation

- 3.4 As discussed in Chapter Two, all donor conception information about births after 2010 is currently held on a Central Register operated by the Ministry of Health. Information is submitted by the clinic that performed the reproductive treatment and will be available to the donor conceived person when they turn 18.
- 3.5 Information about pre-2010 conceptions may be registered with the Voluntary Register, also operated by the Ministry of Health, which then enables the information to be shared with the donor if they have also registered and agreed to information release.
- 3.6 The Ministry of Health currently operates both the Voluntary and Central Registers but has no responsibility for actively linking the donors and donor conceived individuals, offering counselling or other support services, or conducting public awareness campaigns.

Need for a national register

- 3.7 The Committee heard evidence in favour of establishing a national register to house donor conception information.³²

³² Submission 29, Name suppressed, p 2

- 3.8 The Committee heard from a confidential submission maker that a federal agency should be established to compile and manage a national register and that in addition, the agency should also work with international clinics in order to make sure that the importation of gametes is managed appropriately.³³
- 3.9 The Senate's Inquiry into Donor Conception Practices in Australia recognised the importance of establishing a national donor conception register, or at least, developing a consistent approach among the States and Territories to the granting of access by donor conceived people to donor conception information.³⁴
- 3.10 While different Australian states and territories continue to operate different legislation and regulations regarding donor conception and approach discussions of the issues at different times, it is difficult to implement a comprehensive national system. There are various forms that a state based system could take, however, and these are considered below.

Evidence regarding the Ministry of Health

- 3.11 Some evidence received by the Committee supported the retention of the current system, whereby the Ministry of Health continues to manage the donor conception registers, along with the administration of any additional services that may be required.
- 3.12 If a single agency was charged with managing donor conception information and all its associated services, the Ministry of Health is in a strong position to be able to provide this. This would include the management of an active donor linking, or letterboxing system, as this is integral to the management of donor conception information. Mr Greg McAllan, Associate Director of the Ministry of Health, explained to the Committee that their capacity to do this effectively would depend on the number of inquiries they received and what information was available on the register:

At the moment we have 11 offspring on the voluntary register and 14 donors. At the same period in Victoria from the commencement of its voluntary register in 2001 it had 48 donors and nine offspring and I attribute that to the fact that although the voluntary register only started in 2001, they had been operating since 1988 so there was much greater public awareness, particularly among donors, of the existence of the infertility authority. For us we have just kicked off so we have a lower profile of donors. In terms of offspring we have more than for the same period in Victoria...

Obviously it depends on volume. At the moment voluntary is low. If the offspring or donor wanted to collect information on the file awaiting the other party to consent then we would be able to maintain that information.³⁵

- 3.13 A substantial public awareness campaign would be necessary to ensure both donors and donor conceived people were made aware of the new arrangements and their rights. Mr McAllan told the Committee that the Ministry of Health has

³³ Submission 27, Confidential, p 2, used with permission of the author.

³⁴ Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp xi-xvii

³⁵ Mr Greg McAllan, Associate Director, Ministry of Health, transcript of evidence, 6 May 2013, p 32

extensive experience in running effective public awareness campaigns of this type:

As you may be aware we have had a low-level campaign producing pamphlets and distributing information through GPs across New South Wales. The Ministry itself obviously has vast experience in running high-level more intense campaigns in areas such as immunisation, sexually transmitted diseases and HIV. I think the Ministry is well placed to produce more campaigns in this kind of area.³⁶

3.14 The Committee received evidence that in Western Australia the Department of Health successfully manages both the mandatory (since 2004) and voluntary registers of donor conception information through its Reproductive Technology Unit.³⁷

3.15 Other evidence received by the Committee suggested that the Ministry of Health should not continue to have responsibility for the registers, particularly if the responsibilities are to be expanded. For example, Associate Professor Mark Bowman, President, Fertility Society of Australia, told the Committee that he was not sure that the Ministry of Health has the expertise necessary to deliver the range of services that would be required under a comprehensive information management system:

The Health Department currently is performing a bureaucratic role of collecting a whole lot of names. From what I can see there is no resourcing within that instrument to handle anything like ...connections, the privacy, the counselling—all of those things—which takes a lot of resourcing, but ultimately, if you are going to do that properly you would argue that that is what the elements would be, so it is not just an Excel spreadsheet of names.³⁸

3.16 The Committee also heard evidence that donor conception is not a health issue and as such, should not be managed by the Ministry of Health. Ms Caroline Lorbach, of the Donor Conception Support Group, told the Committee that adoption processes and information management are managed by community services rather than the health sector. She believes that donor conception legislation and practice should not be part of the 'health' model:

I think one of the major problems is that our legislation is within the health model. Children who were relinquished for adoption were born in hospitals. That comes under the health model, but their legislation is not under the health system. People decided that their records and information should be within Community Services... Our group has never been happy with our legislation being firmly entrenched in the health model because it makes it just about the medical side and more about the conception than about what comes afterwards. It is about the infertility treatment. ... we need legislation for this area to be moved sideways, into Community Services if possible.³⁹

³⁶ Mr McAllan, transcript of evidence, 6 May 2013, p 34

³⁷ Submission 38, Reproductive Technology Council of Western Australia, p 4

³⁸ Associate Professor Mark Bowman, President, Fertility Society of Australia, transcript of evidence, 29 April 2013, p 35

³⁹ Ms Caroline Lorbach, transcript of evidence, 6 May 2013, p 22

3.17 Mr Damian Adams, a private citizen, expressed the opinion that the Ministry of Health is not the best agency to manage the information as they 'do not have the expertise in managing registers of this type nor do they understand the complexities required in successful linking programs'.⁴⁰

3.18 International Social Service Australia also agreed with the view that the Ministry of Health is not the most appropriate agency to manage donor conception information:

The primary issues donor conceived people face when accessing their information are to do with identity, relationships, grief and loss and contact – they are not medical issues.⁴¹

Evidence regarding the Register of Births, Deaths and Marriages

3.19 The Registry of Births, Deaths and Marriages is considered by some to be an appropriate place to hold donor conception information as the Registry has considerable experience in recording and managing sensitive personal information.

3.20 Given the sensitive nature of donor conception information, it is important that it be treated in a secure manner and release only when appropriate. In discussion with the Committee about the potential difficulties in making sure that the correct information is provided only to the right people, Mrs Sharon Swinbourne, Assistant Registrar from the Registry of Births, Deaths and Marriages explained:

Our role is to provide the information that the legislation allows us to provide. It is not our role to decide who can receive what. Our role is to give people what the Government wants us to give people.⁴²

3.21 Dr Sonia Allan, Senior Lecturer in Law, Deakin University, told the Committee that when she was working for the Law Reform Commission, the general view was that the Register of Births, Deaths and Marriages was well equipped to deal with this type of information:

... when I was working for the Law Reform Commission in Victoria, we were the body that suggested moving the information to Births Deaths and Marriages, and it seemed like a good idea because that is where everybody's birth information is held and you have all those links and systems which enable that sort of communication across States.⁴³

3.22 This view was supported by the Life, Marriage and Family Centre which opined that the Registry is the natural place for people to seek information relating to births and family information. They believe that if such information were to be

⁴⁰ Submission 4, Mr Damian Adams, p 9

⁴¹ Submission 20, International Social Service Australia, p 3

⁴² Mrs Sharon Swinbourne, Assistant Registrar, Registry of Births, Deaths and Marriages, transcript of evidence, 29 April 2013, p 8

⁴³ Dr Sonia Allan, Senior Lecturer in Law, Deakin University, transcript of evidence, 29 April 2013, p 16

stored separately then it would risk treating donor conceived children differently to all other children.⁴⁴

3.23 The Law Society of NSW, in the public hearing on 6 May 2013, offered the view that it would be preferable to have all information held by one agency and that the Registry has the appropriate privacy and security measures in place to manage the information. Resourcing and staffing the Registry appropriately would ensure that it could also offer additional services.⁴⁵

3.24 The Committee heard that the Registry of Births, Deaths and Marriages does have the technical expertise that would be required to administer a donor conception register. Mrs Swinbourne told the Committee that the process could be managed in a manner similar to the adoption information release process, where the applicant is provided with an authority to obtain information by the Department of Family and Community Services, and they then take this to the Registry. Ms Swinbourne described how the process might work:

Once we had that information we could put a flag in the register against a particular birth. The flag would indicate that the birth was a donor conceived birth and then a separate file containing the donor details would be made and the nature of the provision of the sort of information we keep would be done through legislation, so the legislation would tell us what to keep... Now, when the person applies for their birth certificate, once they turned 18 that flag would come up and say this person is actually entitled to have that information now, because the flag would show us that. Once the person turns 18, they would get the information that was in that separate file.⁴⁶

3.25 The Assistant Registrar noted the importance of having accurate information on the Voluntary Register and that verifying information can be more difficult when dealing with retrospective information:

We believe the key to the successful provision of this service is being able to provide correct information and information that has been verified and the information needs to be of high quality and it needs to be accurate so that person does not receive information that is going to make them distressed, or they find out later it is not right.⁴⁷

3.26 Some witnesses who gave evidence to the Inquiry believed that the Register of Births, Deaths and Marriages is not the most appropriate place to hold the information. For example, Dr Allan drew a comparison with the situation in Victoria where the responsibility for managing the register transferred from the Victorian Assisted Reproductive Treatment Authority (VARTA) to the Registry of Births Deaths and Marriages (BDM) in 2010 and found that this has not been a success:

I have struggled to find someone who has a good word to say about the transfer of those functions to the Registry of Births, Deaths and Marriages. I do not think it has been a success. Having a specialist agency to manage the information, to manage

⁴⁴ Submission 19, Life, Marriage and Family Centre, p 4

⁴⁵ Submission 37, Law Society of NSW, p 5

⁴⁶ Ms Swinbourne, transcript of evidence, 29 April 2013, p 1

⁴⁷ Ms Swinbourne, transcript of evidence, 29 April 2013, p 2

the register is important. I do not think it is a function for the Registry of Births, Deaths and Marriages. It is not a register of births, it is a register of legal parentage. They are a government records office. They do not do counselling or have special expertise in this area.⁴⁸

Evidence in favour of a new agency to manage the information

3.27 Over the course of this Inquiry, the Committee heard considerable support for the idea of establishing an independent agency to manage all aspects of donor conception information from collecting and releasing the information to offering all the services that are associated with managing donor conception information, including donor linking, counselling and DNA testing. These support services are discussed in detail in Chapter 6. The evidence received highlighted the need for a single agency to be independent and specialised, and this evidence is outlined below.

Need for a single agency

3.28 In evidence to the Committee, Dr Allan outlined her belief that it would be simplest and most effective to have one agency that manages all aspects of donor conception information:

I am all for the simplest approach possible when you are dealing with complex matters. It complicates things when you start to have numerous bodies involved. The simplest approach possible for me is to streamline it and then possibly in respect of counselling or support services, depending on funding, outsource but to particularly skilled infertility counsellors or people who have experience in the donor conception realm. When you start to have a number of bodies responsible for various bits of the information or pieces of the puzzle, it can get even more complex to navigate for people who are trying to access the system. So you can create problems that do not need to exist when they are already seeking information in maybe a stressful environment or things that are very personal to them, so it would be better to be able to go to one place and have that all dealt with, rather than having to navigate lots of different bodies. The Committee made the point, too, that if you are looking at cost, it can make things far more costly when you start to share the responsibility amongst many different agencies.⁴⁹

3.29 Support for a single agency that manages all aspects of donor conception information was echoed by Ms Lauren Burns, a private citizen, who stated:

...it would be important to frame the legislation in such a way that services such as counselling and information release were integrated into a 'one stop shop' so that people are not shunted between multiple agencies and relevant information is available to personalise counselling sessions, rather than counselling degenerating into merely providing generic information.⁵⁰

3.30 Dr Allan informed the Committee of research she has conducted into the donor conception information management practices in several different jurisdictions. This work highlighted the importance of gathering all the donor conception information in one place. Dr Allan noted that the best practice programs are

⁴⁸ Dr Allan, transcript of evidence, 6 May 2013, p 41

⁴⁹ Dr Allan, transcript of evidence, 6 May 2013, p 17

⁵⁰ Submission 6, Ms Lauren Burns, p 8

those countries with a central register for storing all information such as Sweden and the Netherlands.⁵¹

3.31 The Committee received evidence about donor conception information management in Victoria. The system in place prior to 2010 had many positive elements. Prior to 2010, the Infertility Treatment Authority (ITA) was responsible for managing donor conception information in Victoria, including maintaining the registers, donor linking and letterboxing, offering counselling, and regulating licences of practitioners. In 2010 the ITA became VARTA and responsibility for the donor registers was transferred to the Registry of BDM, while VARTA retained responsibility for public awareness campaigns and education.⁵²

3.32 Professor Millbank, Professor, Faculty of Law, University of Technology, recommended the establishment of a similar agency in NSW and outlined the benefits and experience that such an organisation could have:

... I think they are a unique agency in Australia and the counsellors that they have working there have 15 or 20 years of experience each. They have thought very hard. They have run things like the Time To Tell campaign, trying to get people to voluntarily come on to the registers, and they have the experience of having counselled people through what they used to have in the ITA—they had a DNA matching service for people whose records had been lost or were inaccessible—as well as their counselling and facilitation of contact and communication with formerly anonymous donors. The range of their experience is really valuable and I think that having an agency that is just there for families, it is not about regulating clinics, it is not about being part of government as such, it is an independent agency to give information and counselling, would be very helpful.⁵³

Need for an independent agency

3.33 The Donor Conception Support Group identified in their submission to the Inquiry that an independent agency would be best placed to manage the register:

There are a number of shortcomings in the current service model for the donor conception registers in NSW including problems with accessing counselling services as the current Register provides no counselling and no proper referrals for counselling nor support services.⁵⁴

3.34 The need for the agency to be independent of the clinics offering reproductive treatment was highlighted by Ms Burns:

It is crucial that the agency managing donor conception information be separate and independent from assisted reproductive treatment clinics and related bodies such as the Fertility Society of Australia. This is to ensure impartiality and minimise the possibility for conflicts of interest, for example where a donor being contacted is part of the medical fraternity, or where a clinic has acted in a manner that might be

⁵¹ Dr Sonia Allan, transcript of evidence, 6 May 2013, p 16

⁵² Parliament of Victoria, Law Reform Committee, *Report on the Inquiry into Access by Donor-Conceived People to Information about Donors*, March 2012, p 120

⁵³ Professor Jenni Millbank, Professor, Faculty of Law, University of Technology, transcript of evidence, 6 May 2013, p 40

⁵⁴ Submission 5, Donor Conception Support Group, p 18

perceived as unethical, for example used a single donor to create dozens, or even hundreds of children.⁵⁵

- 3.35 Ms Miranda Montrone, psychologist at The Counselling Place, and Ms Myfanwy Cummerford, a private citizen, also believed that in order to ensure that the information continues to be stored securely and is appropriately accessible, it should be managed by a government agency not affiliated with the ART clinics.⁵⁶

Need for a specialised agency

- 3.36 Mrs Swinbourne told the Committee that the issues around release of information, and possible contact between parties, are so complicated and sensitive that a specialised agency is needed to manage them:

Access between parties in terms of contacting each other is really out of our scope of operation. I personally would not recommend, or the registry would not recommend any access method that was not controlled by some sort of intermediary body. In adoptions, there is an organisation called PARK which you may or may not have heard of and they act as intermediaries between adopted persons and their adopted parents. They provide the counselling because it does not always end well. It is not always an easy thing to do. There are a lot of issues.⁵⁷

- 3.37 Ms Sharon Hunt, President of Solo Mums by Choice, supported the view that the specialised aspects of donor conception information are best administered by a specialised agency:

We believe the establishment of a national body to manage donor information is preferable. However, given that a State body is more likely, we believe it should manage information, facilitate contact and arrange counselling and support groups. It would also need to run public awareness and information campaigns.⁵⁸

- 3.38 Mr Damon Martin, Manager, Social Services Australia, and Secretary, NSW Committee on Adoption and Permanent Care, discussed the benefits of having an agency such as the earlier model of VARTA, which could manage multiple aspects of donor conception information management, but thought that it did not necessarily need to be a government agency:

Maybe a similar agency to VARTA in New South Wales but even a non-government organisation basically that can setup and be a centralised spot to hold records, provide educational seminars, share information, facilitate contact and become an expert in that area. In saying about a national register, we are very much for something happening nationally.⁵⁹

Adoption model

- 3.39 During this Inquiry evidence was presented that discussed the differences and similarities between donor conception and adoption. When reviewing this

⁵⁵ Submission 6, Ms Lauren Burns, p 7

⁵⁶ Submission 17, Ms Miranda Montrone, Psychologist, p 5, submission 22, Ms Myfanwy Cummerford, p 3

⁵⁷ Ms Swinbourne, transcript of evidence, 29 April 2013, p 5

⁵⁸ Ms Sharon Hunt, President, Solo Mums by Choice, transcript of evidence, 6 May 2013, p 3

⁵⁹ Mr Damon Martin, Manager, Social Services Australia, and Secretary, NSW Committee on Adoption and Permanent Care, transcript of evidence, 6 May 2013, p 55

information the Committee also considered the model of information release that is used in adoption.

- 3.40 Under the *NSW Adoption Act 2000* and *NSW Adoption Regulation 2003* both adult adopted people and birth parents of adoptees are entitled to access identifying details and information about each other. The process currently involves several different organisations and requires an adoptee seeking information to first obtain a supply authority from the Department of Family and Community Service. Following this the Registry of BDM will release information to them.
- 3.41 The person seeking information is offered counselling as part of this process and there are a number of bodies that may be involved. In addition to the Government departments that release the information, there are non-government bodies that work in the adoption area offering advice and counselling and support to those seeking information.

Committee Comment

- 3.42 The Committee considers that there is a need to establish a new agency to manage donor conception information. While existing agencies such as the Ministry of Health and the Registry of Births Deaths and Marriages could provide elements of donor conception management, a dedicated agency would be best placed to provide a comprehensive service.
- 3.43 Giving one organisation responsibility for managing all aspects of donor conception information will have substantial benefits both in terms of resource savings and in satisfactory outcomes for all clients of the service.
- 3.44 There are myriad issues involved in managing donor conception information and these issues have been explored in detail in both the United Kingdom and Victoria recently. It is best practice to have an expert agency administering such sensitive information and that this responsibility should lie with a single agency.

RECOMMENDATION 1

The Committee recommends that the Attorney General establish a new agency to manage a Register of donor conception information and that this agency also assume responsibility for providing support to those involved in donor conception.

RECOMMENDATION 2

The Committee recommends that in the interim, and as a matter of urgency, the Ministry of Health should engage specialists to liaise with donors, donor conceived people and recipient parents, to facilitate access to identifying information with the consent of all parties.

COLLECTING THE INFORMATION

- 3.45 The Committee recognises that in order to establish an effective Register and donor conception management agency, the right information must be collected.

Evidence was received during the Inquiry about the importance of collecting all available information as quickly as possible.

- 3.46 Ms Hunt emphasised the importance of collecting all the donor conception information quickly and efficiently in order to ensure that as little as possible is lost:

The longer we go on, the further we get away from 19-year-olds, 30-year-olds who have used anonymous donors. That information is just not going to be there or it is going to be so old that nothing is chaseable.⁶⁰

- 3.47 The Committee heard that collecting information from various clinics, hospitals and medical practices where it is stored could be an involved process and Professor Millbank reiterated that the first step in obtaining the information is to get agreement from the clinics that currently hold the data.⁶¹

- 3.48 Dr Allan described how the Netherlands went about collecting information from clinics all over the country. She informed the Committee that the clinics were required to contact the donors to ask them to reconsider their request for anonymity, and then the clinics were required to furnish the donor register with the donor conception information:

In relation to donors who donated before 2004, when the mandatory register was implemented, the clinics were required to contact the donors. Rather than searching for the donors and writing them a letter the clinics were required to contact them but the clinics were also mandated to hand over all records to the register. There was no choice. It was not a question of, "Have you contacted the donor and has he said it's okay?" All records went to the register, and that is a way to protect the records and avoid their being lost or destroyed. Then the issue with retrospectivity was addressed. They took a slightly different approach by asking the donors whether they would consent.⁶²

- 3.49 While there are likely to be challenges in collecting historical donor conception information, it is important to do so in order to preserve the integrity of the information and to enable people to access it. Dr Allan told the Committee that some people have not been able to access their personal information because it was not recorded properly and that establishing a central repository would go some way to mitigating this type of problem occurring:

I certainly know firsthand of donor-conceived people who have approached clinics who are given all sorts of inconsistent information and varying records at different points in time, which means somewhere between the request and the provision of information, and even the provision of information over time, things are changing. I think the best we can do is to try and get these records. A lot of the records are not in the hands of the clinics anymore; they are in archive boxes in the bowels of libraries.⁶³

⁶⁰ Ms Hunt, transcript of evidence, 6 May 2013, p 6

⁶¹ Professor Millbank, transcript of evidence, 6 May 2013, p 42

⁶² Dr Allan, transcript of evidence, 6 May 2013, p 12

⁶³ Dr Allan, transcript of evidence, 6 May 2013, p 16

- 3.50 Dr Allan related the personal story of a donor conceived individual who encountered many obstacles before being able to access her donor's information:

...I have an example too. Narelle, a young girl in Victoria who for 15 years was searching for information, everybody knew where it was and who the donor was—that was the clinics and even the authority that looked after the register for some time—but nobody could tell her or took action to tell her the information. Finally one of the politicians stepped in and she was given information. She met with her donor and died two weeks later of a hereditary form of cancer. I think this is the big—it is an awful scenario. She was saying it 15 years ago. I met her 10 years ago as a young teenager and she was asking for information. It is that journey, and what the clinics did in terms of the doctors denying her information. I think the best thing we can do is do what we can to get the information on the register so that that does not happen again.⁶⁴

Records management

- 3.51 The management of medical records is mandated by the *Health Records and Information Privacy Act 2002* and the *Health Practitioner (New South Wales) Regulations 2010*, which state that for adults, health information must be kept for seven years. If the health information relates to a child, the information must be kept until the patient attains the age of 25 years.
- 3.52 The NSW Public Sector Government Recordkeeping Manual stipulates that those public sector agencies with responsibility for assisted reproductive treatment must retain records for at least 75 years from the date of birth of a child born from an ART procedure. Records relating to any other type of ART procedure must be kept for 15 years.⁶⁵
- 3.53 The National Health and Medical Research Council Guidelines recommend that records be kept indefinitely or least for the life of anyone who may be born as a result of the procedure.⁶⁶
- 3.54 While these regulations and guidelines prescribe how long medical records should be kept for, there is no direction in the ART Act to ensure that records are stored appropriately and not tampered with or altered.
- 3.55 Many participants in the Inquiry were concerned with ensuring that information is properly stored and maintained, including Ms Geraldine Hewitt, appearing as a private citizen, who told the Committee she has concerns about the document management practices that have been used with donor conception information:

I think that the information on donors needs to be preserved by an independent body. I do not trust the hospitals. I have worked for 4½ years implementing a project for the faculty of medicine at Sydney University. I have worked in most of the major

⁶⁴ Dr Allan, transcript of evidence, 6 May 2013, p 16

⁶⁵ NSW State Records, viewed 1 August 2013, <<http://www.records.nsw.gov.au/recordkeeping/government-recordkeeping-manual/rules/general-retention-and-disposal-authorities/public-health-services-patient-client-records-gda/part-1-the-general-retention-and-disposal/1.0.0-patient-client-treatment-and-care>>

⁶⁶ National Health and Medical Research Council, *Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research*, viewed 1 August 2013, <http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/e78.pdf>

teaching hospitals across New South Wales. I know the state of the documentation that they keep. I know their interesting methods for document retention. I think that it needs to be an independent body.⁶⁷

- 3.56 The Committee heard evidence that donor conception information may be lost by clinics, or filed incorrectly, or sometimes deliberately destroyed. Professor David Handelsman, Director of the Andrology Department at Concord Hospital, explained to the Committee that some medical practitioners may destroy records out of a misguided sense of protecting the donors, as they fear what will happen to the information if they hand it over to a central register:

We would never destroy information, but I know that where that is done it is done for precisely the reason that the doctor at that clinic had no confidence that his records would not be seized and disclosed compulsorily in the way in which we are discussing it now. That is the reason they do it; it is the only reason they do it. You should bear in mind that it is a vicious circle if you make it clear that you want to seize the records. We would certainly never destroy our records but I would not want to say there would not be a single doctor who would not do that out of a sense of obligation to the privacy that they entered into in all good faith.⁶⁸

- 3.57 Dr Joel Bernstein, Medical Director, Fertility East, also told the Committee that in the past there have been dubious information management practices which could mean that donor conception data from pre-2010 may not be available to be collected. Dr Bernstein told the Committee that the record keeping practices at the clinic he took over and currently runs were not sufficient:

We are all grown up and one does not want to waste time, but the quality of this information that we have of this clinic is atrocious. It would be unacceptable today, so my concern is I do not know how it is being stored, who has got it. Would somebody destroy it? I have no idea.⁶⁹

- 3.58 Dr Bernstein expressed concern to the Committee that information may already be being destroyed:

A lot of information is missing. If the legislation is passed, the information will not be available or it could be conveniently lost. It may be already being lost because this inquiry is being held.⁷⁰

- 3.59 This fear was substantiated by a confidential submission received by the Committee from a donor conceived person who stated that they were aware of a particular doctor who used to deliberately destroy donor information in order to maintain the donor's anonymity.⁷¹

- 3.60 Ms Montrone told the Committee that she was also aware of similar practices occurring which destroyed donor conception information:

⁶⁷ Ms Geraldine Hewitt, transcript of evidence, 6 May 2013, p 21

⁶⁸ Professor David Handelsman, Director, Andrology Department, Concord Hospital, transcript of evidence, 6 May 2013, p 50

⁶⁹ Dr Joel Bernstein, Medical Director, Fertility East, transcript of evidence, 6 May 2013, p 60

⁷⁰ Dr Bernstein, transcript of evidence, 6 May 2013, p 61

⁷¹ Submission 3, Confidential, p 3, used with permission of the author.

I am also aware that there was some information removed—some of the names and identifying information was removed. I think the person who did it probably regretted it but he felt obligated, that he had a moral obligation to the donors in that he had guaranteed them anonymity. I do not know; I was told by someone else—he did not talk about it with me in detail. I did not see him do it or anything but it was, they were cut—the information that I was using was cut off. It was a very, very different world in the 1980s.⁷²

Committee Comment

- 3.61 It is imperative for all donor conception information to be collected as efficiently as possible and stored in a central repository. Having a single database of information will make it easier for people to access the information and maintain information integrity if a clinic closes.
- 3.62 The Committee is concerned by allegations of deliberate destruction of donor conception material and believes that every effort should be made, by conducting education and awareness programs, to prevent any more instances of information being destroyed.

RECOMMENDATION 3

The Committee recommends that the donor conception management agency, once established, collect all donor conception information from assisted reproductive technology clinics and enter it into a secure Register of donor conception information. This Register, once established, should comply with relevant National Health and Medical Council Research guidelines with reference to security and privacy provisions.

RECOMMENDATION 4

The Committee recommends that, as a matter of urgency, the Attorney-General amend the *Assisted Reproductive Technology Act 2007* to make it an offence to destroy, tamper or falsify any donor conception records.

STORING THE INFORMATION

- 3.63 Donor conception information needs to be stored securely, as with any personal information, and appropriate procedures and policies will need to be developed to enable this. As mentioned previously, the National Health and Medical Research Council Guidelines recommend that records be kept indefinitely or least for the life of anyone who may be born as a result of the procedure.
- 3.64 In addition to privacy and security concerns, the Committee heard evidence about the importance of storing the information in such a way that it will be useable in the future, for example to exchange information across states. Dr Allan told the Committee that:

The Federal Government said that it would not set up a national register, but I think what you can do in the long run, if you get agreement between the States, is link the registers, and that would be a way of exchanging information. You need quite good technical assistance to make this happen and the right kind of database and register

⁷² Ms Montrone, transcript of evidence, 29 April 2013, p 25

to work because it can be very complex, because you are dealing with lots of different families and information, but you can do it across States if it was not one Federal register.⁷³

- 3.65 In evidence to the Committee, Dr Bernstein emphasised the importance of respecting the private medical records of patients and making sure that the data was stored securely and still readily accessible to doctors. He believed that this may be done by either a third party or the doctor concerned:

The point is one would need safe and efficient storage and I think if one could do that, then I think it is a possibility that it could be done. I think most people, from a comfort point of view, and from a patient's point of view, may prefer their doctor to store the information. I think that is something for the public to answer.⁷⁴

- 3.66 Dr Allan made the point that the information needs to be stored securely for the long term and that a government agency is best placed to provide this assurance:

...management of donor registers should not be left to non-government organisations as the long-term operations of not-for-profits, or voluntary organisations often depend on funding or the dedication of one or two people. We need to ensure that such records and information release is available for generations to come.⁷⁵

Committee Comment

- 3.67 The Committee acknowledges the importance of storing this information in a secure database to ensure the information maintains its integrity and remains accessible. Both the Ministry of Health and the Registry of Births, Deaths and Marriages use models relevant for storing information which could be drawn on for the purpose of designing a new database.
- 3.68 The Committee believes that any recommendations arising from this Inquiry need to be clear and transferrable to donor registers in other states and territories if sharing of information becomes an option in the future.

⁷³ Dr Allan, transcript of evidence, 6 May 2013, p 16

⁷⁴ Dr Bernstein, transcript of evidence, 6 May 2013, p 61

⁷⁵ Submission 10, Dr Allan, p 17

Chapter Four – Retrospective access

4.1 In this Chapter the Committee addresses the first term of reference for this Inquiry and provides an overview of what information is currently available to donor conceived individuals. This chapter also considers the views held by inquiry participants around retrospective access to donor conception information; from those who believe retrospective information access should be mandated through legislation to those who believe that the current policy of not allowing retrospective access should be maintained. The Committee also reflects on various proposals of how certain schemes could work, and examines the situation in comparable jurisdictions.

CURRENT ACCESS TO INFORMATION

4.2 In any discussion around assisted reproductive technology in general, and donor conception in particular, it is important to acknowledge the changes in social values and mores that have occurred over the past two decades. Prior to the 1990s recipient parents of donor conception were advised by their treating clinics not to disclose information about the treatment and sperm donation to the child. At the time this was considered to be in the best interests of the child, their family and the donor.

4.3 Since the 1990s there has been an increasing awareness in Australia and internationally of the importance of a child having access to their genetic information. Legislation prohibiting anonymous donation was introduced in NSW in 2010, but some clinics had already been requiring donors to donate without anonymity since 1997.⁷⁶

4.4 This shift in attitude resulted in the introduction of the *Assisted Reproductive Technology Act 2010* (ART Act), and since then all children born as a result of assisted reproductive technology (ART) procedures have the right to access their genetic information, including full identifying information about their gamete donors.

4.5 While current best practice dictates that there is no longer anonymous donation, the issue facing this Committee is to consider the extent to which current practice should inform and be incorporated into policy that could affect past practices. Ms Miranda Montrone, a psychologist at The Counselling Place, summarised the situation thus:

It was a very, very different world in the 1980s. It is very hard when you look back with the morals, values and processes and the transparency and stuff of today; it was a very different world.⁷⁷

4.6 For people born prior to 2010 there is no means of ensuring that they can access their donor conception information. However, there is a Voluntary Register where both donors and donor conceived people can enter information about

⁷⁶ Submission 25, Professor David Handelsman, Director, Andrology Department, Concord Hospital, p 4

⁷⁷ Ms Miranda Montrone, Psychologist, The Counselling Place, transcript of evidence, 29 April 20132, p 25

themselves and this may enable them to gain information about, or contact each other at a later stage.

- 4.7 People who entered into private donor conception arrangements, or those outside the formal ART clinic system, are not permitted to lodge their details with the Voluntary Register and have no way of registering their particulars in a formal manner.
- 4.8 Each state and territory in Australia has its own laws governing ART and there is currently no national method of recording information or sharing it among jurisdictions.
- 4.9 The Australian Medical Association (NSW) highlighted the importance of taking a national approach to developing policies around managing donor conception information. They consider that it would not 'serve the best interests of children, donors or parents to create fragmented arrangements that may have different implications for residents of different states'.⁷⁸
- 4.10 The recent research conducted by Victorian Assisted Reproductive Treatment Authority (VARTA) and Monash University detailed the cases of two donors whose sperm had been used interstate without their permission. Poor record keeping practices amongst different states have meant that these donors cannot obtain any further information on the results of their donation.⁷⁹

OTHER JURISDICTIONS

- 4.11 Jurisdictions both within Australian and overseas have spent considerable time in recent years examining issues around donor conception, and a number have enacted relevant legislation. While several countries have introduced legislation banning anonymous donation, Switzerland is the only one to have introduced legislation giving donor conceived individuals the retrospective right to information about their donor.⁸⁰ In Victoria, the Government supports the introduction of legislation to enable donor conceived people access to identifying information about their donors, with the consent of the donor.⁸¹

Switzerland

- 4.12 The Swiss *Federal Act on Medically Assisted Procreation 1998* (Federal Act) came into effect in 2001 and provides for all donor conceived individuals to have access to information about their donor. Since the Act was introduced, all information is held by the Swiss Federal Office.
- 4.13 Although the Federal Act provides that donor conceived people born before 2001 may access the information, they must go to the clinic that performed their mother's treatment to find the information and in practice are still not able to obtain it. Dr Sonia Allan told the Committee that:

⁷⁸ Submission 39, Australian Medical Association (NSW), p 1

⁷⁹ Victorian Assisted Reproductive Treatment Authority, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, p 27

⁸⁰ Submission 10, Dr Sonia Allan, Senior Lecturer in Law, Deakin University, p 9

⁸¹ Victorian Government, *Inquiry into Access by Donor-Conceived People to Information about Donors*, Victorian Government Response, August 2013

...because the retrospective legislation still is clinic-based when you try to trace the information through the clinics they will say that the records have been destroyed”.⁸²

United Kingdom

- 4.14 Whether or not a United Kingdom donor conceived person can access their donor’s information depends on when they were conceived. Rights of information access are divided into three eras:
- i) Prior to 1991: anonymous donation was permitted and the individual can seek access to information and contact with their donor, through the Donor Conceived Register (formally known as UK DonorLink), an agency funded by the Department of Health.⁸³ Both donors and donor conceived individuals can register their details voluntarily on this Register.
 - ii) 1991-2005: the *Human Fertilisation and Embryology Act 2008* established the Human Fertilisation and Embryology Authority (HFEA), which collected non-identifying information from donors. Donor conceived people are able to access this information from the age of 16.
 - iii) Post 1 April 2005: donor conceived individuals can access non-identifying information about their donor from age 16 and identifying information when they turn 18.
- 4.15 The HFEA established a donor sibling registry where donor conceived people can seek non-identifying information about their siblings from the age of 16. From the age of 18, they may request identifying details, provided both parties consent.⁸⁴

The Netherlands

- 4.16 Since 2004 Dutch individuals conceived through sperm donation have had the right of access to identifying information about their donor. Those conceived prior to 2004 have the right to ask for their information but the donors have the right to maintain confidentiality.
- 4.17 The Department of Health maintains a central Register of donor information which donor conceived people are able to access from the age of 16. The Register information is updated by clinics when they perform a treatment and women who have undergone treatment are also required to inform the clinic when they give birth.
- 4.18 For donations prior to 2004 the Netherlands has a contact and consent approach whereby the clinics contact the donor and ask if they are prepared to be contacted. If they are not prepared to do so they are required to sign a confidentiality agreement.

⁸² Dr Sonia Allan, Senior Lecturer in Law, Deakin University, transcript of evidence, 6 May 2013, p 16

⁸³ Donor Conceived Register, viewed 27 June 2013, < <http://www.donorconceivedregister.org.uk/about-the-register.html>>

⁸⁴ Human Fertilisation and Embryology Authority, viewed 27 June 2013, < <http://www.hfea.gov.uk/112.html>>

- 4.19 The Register is managed by a Board of seven members who are represented by a lawyer, ethicist, child psychologist, chairman (gynaecologist) and three members who work in the ART field. The Board meets four times a year to discuss applications.
- 4.20 The Register is staffed by a single lawyer. The role is filled by a lawyer because one of their responsibilities is the 'weighing' of interests in the event of a conflict between a donor conceived person and a donor over the release of information. Although donors after 2004 were informed that they were not able to donate anonymously, they still have the right to say 'no' in the event that their information is sought. If they do say no, it is the job of the Register's lawyer to weigh the interests of all parties, noting that the law says the interests of the child come first unless there are exceptional circumstances.
- 4.21 The Register is supported in its work by the Dutch National social work agency and International Social Services, who together provide counselling and DNA services.⁸⁵

ACCESS TO INFORMATION AND CONTACT

- 4.22 The Committee heard very clearly that there is a significant and vital difference between access to information about a donor and contact with the donor. Providing someone with access to information is very different to seeking a relationship with that person.
- 4.23 A confidential submission to the Inquiry highlights the importance of maintaining balance when considering contact between the parties:
- If one party requests contact, it needs to be mutually agreed upon by both the donor conceived person and their biological (donor) parent(s). The request for contact should be facilitated by an independent, experienced donor linking counselling service who would act as an intermediary.
- In the case where contact is not mutually desired, this should not prohibit the donor conceived person access to information about their familial heritage. The donor conceived person still has a right to know their origins. However, both donor conceived person and donor have the right to decline contact with each other. The wishes for non-contact must be adhered to.⁸⁶
- 4.24 The Committee heard from one confidential witness of a situation in which the recipient parent chose a donor on the basis that he agreed to release his information and then at a later stage revoked this consent. As this agreement was made prior to 2010 there was nothing the recipient parents could do to obtain the donor's details.

⁸⁵ Information on practices and legislation taken from S Allan, *A Cross-Jurisdictional study of regulatory requirements and practice regarding the recording of donor information and its release to donor conceived people*, Churchill Trust, 2012, pp 21-33

⁸⁶ Submission 16, Name suppressed, p 3

Contact vetos

- 4.25 Contact vetos are currently used in the release of adoption information and evidence was received that stated this has been a successful component of the model so far, with few breaches being noted.⁸⁷
- 4.26 The NSW Committee on Adoption and Permanent Care also advocates that while information should be available to donor conceived individuals retrospectively, provisions should be in place to prevent unwanted contact between the parties. This could be achieved through the use of contact vetos.⁸⁸
- 4.27 Contact vetos have been one way of attempting to balance the interests of the donor conceived person and the donor in circumstances where contact between parties is sought. A contact veto offers assurance to the donor whose information is being released that there will be no contact unless they consent to it and at the same time gives them the chance to make such a choice.
- 4.28 The Committee also heard evidence about the plausibility of an 'automatic contact veto' system, whereby all donor records would initially be placed on a register with a contact veto in place. Donors would need to contact the register in order to have the veto removed.⁸⁹
- 4.29 However, a model such as this would require active outreach by the register to contact the donors when a contact request was made in order to ask them to consider their position. If this outreach was not performed then the donors may never be aware of the register or of the implications for them.
- 4.30 The Victorian Government did not support a recommendation made by the Victorian Law Reform Committee *Inquiry into Access by donor-conceived people to information about donors* to implement contact vetoes. Rather, the Government proposed a 'facilitative and relationship-focused model'⁹⁰ of access to identifying information being provided with the consent of the donor, alleviating the need for contact vetoes.

Committee Comment

- 4.31 Bearing in mind the distinction between access to information and contact between parties, the Committee concentrated its deliberations on how the information should be managed and accessed, as prescribed in the terms of reference for this Inquiry. Whether contact is made between parties is a private decision to be made by each of the parties after they have accessed the relevant information.

⁸⁷ See for example: Dr Allan, and Mr Damon Martin, Manager, Social Services Australia, and Secretary, NSW Committee on Adoption and Permanent Care, transcript of evidence, 6 May 2013, p 13 and p 56

⁸⁸ Submission 21, NSW Committee on Adoption and Permanent Care, p 2

⁸⁹ Dr Allan, transcript of evidence, 6 May 2013, p 14

⁹⁰ Victorian Government, *Inquiry into Access by Donor-Conceived People to Information about Donors*, Victorian Government Response, August 2013, p 7

PARALLEL WITH ADOPTION

4.32 Many participants in this Inquiry drew parallels between donor conception and the adoption process and the changes in legislation that granted retrospective access to information about birth parents for adoptees. Some inquiry participants expressed the view that granting retrospective access to information for adoptees has set a precedent for the same access to be introduced for donor conceived people.⁹¹

4.33 Ms Christine Whipp, a private citizen, stated in her submission that retrospective access to information should be permitted as:

The benefits for the donor conceived person will outweigh any perceived negative effects for the gamete donor, as has already been demonstrated by the way in which adopted people have benefited from having access to their full adoption records.⁹²

4.34 International Social Service Australia outlines some similarities with adoption and donor conception and the change in the way these processes are seen in our society:

Both adoption and donor conception practice were historically shrouded in secrecy but adoption practice has now changed significantly and practices in the 'spirit of openness'. "This move within adoption practice to 'openness' attempted to achieve the best of both worlds- providing security for the child and the new family without cutting the child off from knowledge of its roots or totally excluding the birth parents."⁹³

4.35 While there are some differences in the circumstances of people who are adopted and those who are donor conceived, both situations raise similar issues around curiosity about genetic heritage. This was expressed by Mr Damon Martin:

... you cannot underestimate how important knowing that other half must be for adoptees and donor-conceived people. I think it is very similar. They talk about grief and loss in terms of adoptees, and with donor-conceived people I suppose there is still grief and loss. It might not be the same in terms of relinquishing or forced adoptions, or things like that, but there are still issues around how was I conceived and how was it facilitated, or was money used, what was the motivation of my sperm donor and things like that. These are all questions around trying to fill in the pieces of who am I, and it is very similar in that respect.⁹⁴

4.36 Not all submission makers agree that the situation with adoption can be extended to apply to donor conception as well. There are significant differences between the circumstances that warrant a different policy response to the release of information. A commonly cited difference was that donor conception does not have the same level of trauma associated with it and donor conceived

⁹¹ Submission 4, Mr Damian Adams, p 6

⁹² Submission 13, Ms Christine Whipp, p 2

⁹³ Submission 20, International Social Service Australia, p 1

⁹⁴ Mr Martin, transcript of evidence, 6 May 2013, p 56

people do not often have the sense of abandonment that may be felt by adoptees.⁹⁵

- 4.37 The Fertility Society of Australia expressed the view that ‘There is no fit with the role of a donor in the adoption models where birth parent(s) had legal rights prior to consenting to adoption.’⁹⁶
- 4.38 A key argument that is made for treating the two situations differently is how the ramifications may affect not just the donor conceived person, but other family members as well. In adoption, at least one of the parents was present at the child’s birth and had legal parental rights as opposed to donor conception, where the donor never had legal rights or expectations of interaction with the donor conceived child.
- 4.39 Professor Handelsman told the Committee that an accurate parallel cannot be drawn between adoption and donor conception as gamete donation is usually a voluntary act with no adverse consequences for the donor:

This contrasts with adoption where the central tragedy of the relinquishing mother is inescapable. Uniting adoptees with their biological parents provides late relief of this tragic relinquishment. No equivalent drive is present for sperm donation, where the drive to identify genetic paternity is driven solely by genetic curiosity of the offspring.⁹⁷

ARGUMENTS FOR FULL RETROSPECTIVE ACCESS

- 4.40 The Committee heard many reasons in support of the introduction of retrospective access to information. The right of a child to know its genetic parents was considered paramount. Other arguments include doubts about the legality of the anonymity contracts, the psychological implications of people being unable to identify their genetic background and heritage, the health benefits of having access to medical records, and the danger and fear of forming consanguineous relationships.
- 4.41 A common theme among many participants in the Inquiry was the belief that donor conceived people had no choice in the manner of their conception and it is not fair to deny them access to the truth about their personal history.⁹⁸

Rights of the child

- 4.42 The belief that every child has the right to know their genetic parents is widely held. This belief is supported in international law and has been tested in several legal cases overseas, with previously anonymous donors being compelled to make their information available.⁹⁹ Integral to this view is the belief that while

⁹⁵ See for example Ms Lisa Karam, Manager of Amendments, NSW Registry of Births, Deaths and Marriages, transcript of evidence, 29 April 2013, p 7, and Ms Elizabeth Hurrell, Representative, Fertility Society of Australia, transcript of evidence, 29 April 2013, p 38

⁹⁶ Submission 14, Fertility Society of Australia, p 4

⁹⁷ Submission 25, Professor Handelsman, p 8

⁹⁸ See for example submission 8, Mr Tom Ellis, p 1

⁹⁹ See for example, the case of ‘Sarah P’ as ruled by the regional appeals court in the German city of Hamm in 2013, and the case of Johnson v. Superior Court (California Cryobank, Inc) (2000), 80 Cal. App. 4th 1050

the donor was an adult undertaking an action of their own free will, the donor conceived child has an inalienable right to their personal information.

- 4.43 The United Nations *Convention on the Rights of a Child* is often cited as an underlying principle supporting the idea that the rights of the child are paramount. Article 7 of the *Convention* is particularly relevant in this discussion as it states that a child shall have, as far as possible, “the right to know and be cared for by his or her parents”.¹⁰⁰ Some people hold the view that this extends to genetic parents as well as legal ones.¹⁰¹
- 4.44 This right is supported by the current National Health and Medical Research Council (NHMRC) Guidelines which acknowledge the importance of a child knowing their biological origins. This right has also been enshrined in the ART Act, which ensures that all donor conceived children born after 2010 have the right to access information about their genetic history.
- 4.45 The Committee also heard the commonly held sentiment that it is discriminatory to allow one group of people access to information while denying an equivalent group access based on the date of their birth.¹⁰²
- 4.46 The Donor Conception Support Group stated that: ‘We are concerned that denial of such rights purely on the basis of their date of birth will produce a minority group afforded less rights than those of their younger counterparts’.¹⁰³
- 4.47 Ms Lauren Burns echoes this sentiment that some donor conceived people are being discriminated against:

Donor conceived people born prior to 2010 are currently the only group of citizens in NSW who are denied access to information about their biological identity and this anomaly should be rectified in a timely manner in the interests of fairness, equality and natural justice.¹⁰⁴

Doubts around the validity of clinic contracts

- 4.48 The Committee received evidence about the types of contracts or agreements that were signed between donors and clinics, and received evidence questioning how much protection these agreements would afford the donor if they were to be challenged in court.
- 4.49 The Committee viewed examples of contracts that were signed in the 1970s and 1980s from different states in Australia. Typically these were simple forms where the donor ticked a box agreeing to no information being released. The forms usually drew no distinction between information and contact.
- 4.50 The forms the Committee has seen all provide that the donor agreed not to seek information about the recipient and agreed that their own identity not be

¹⁰⁰ UN Convention on the Rights of the Child, < <http://www.unicef.org/crc/>>, viewed 3 June 2013

¹⁰¹ See for example submission 4, Mr Adams, p 5, and submission 5, Donor Conception Support Group, p 27

¹⁰² Submission 2, Confidential, p 3 and submission 4, Mr Adams, p 5

¹⁰³ Submission 5, Donor Conception Support Group, p 2

¹⁰⁴ Submission 6, Ms Lauren Burns, p 6

released to the recipient. Only one form mentions the donor conceived child or prevents them from seeking information.¹⁰⁵

4.51 An analysis of donor contracts/agreements by Professor of Law, Anne Rees, concludes that these agreements would not meet the legal requirements to be deemed contracts. She added that:

- (1) Even if they were contracts, a provision for the anonymity of the donor could be declared contrary to public policy by a court, and
- (2) Using the argument that they are contracts of anonymity may be seen as having a stronger impact than referring to privacy laws around medical information.¹⁰⁶

4.52 In the early days of ART, it was less common for either the donor or the recipient parent to receive counselling, and this gives rise to questions about whether the consent of the person who signed the anonymity form was informed.¹⁰⁷

4.53 The Donor Conception Support Group presented evidence to the Committee that sometimes it was not the donor who requested the anonymity, but the clinic:

It is indeed true that most doctors and fertility clinics did require donors to sign anonymity agreements but our group has been contacted by donors who have stated that signing these documents was not an option; they signed them or they would not be considered suitable to donate. So anonymity was not necessarily requested by donors but by the medical profession.¹⁰⁸

4.54 Further to this, the Committee has also heard the view that a contract signed on behalf of an unborn child cannot be valid, as the person it concerns did not exist at that point:

Ms HEWITT: I never signed an agreement that said I agreed to have no information given to me, and my parents went to Justice Michael Kirby and he said that when parents sign away the rights of the child to seek information—you cannot do that. You cannot sign on behalf of somebody else and you definitely cannot sign on behalf of somebody that has not even been created yet.¹⁰⁹

Psychological issues

4.55 Through this Committee's previous Inquiry into the 'Inclusion of donor details on the register of births' and the current Inquiry, the Committee is aware that there are significant psychological effects that a lack of knowledge of one's donor parents can have on a donor conceived individual. The impact of disclosure of such information, and the manner in which this occurs, can also affect the wider family and relationships.

¹⁰⁵ The forms were supplied to the Committee on a confidential basis and are from a range of clinics throughout Australia from 1970s to the 1990s.

¹⁰⁶ Rees, A, 'Keeping mum about dad: "contracts" to protect gamete donor anonymity', *Journal of Law and Medicine*, (2012), 19, p 767

¹⁰⁷ Submission 5, Donor Conception Support Group, p 8

¹⁰⁸ Submission 5, Donor Conception Support Group, p 7

¹⁰⁹ Ms Geraldine Hewitt, transcript of evidence, 6 May 2013, p 28

- 4.56 Several submissions to the Inquiry asserted that there may be significant psychological disadvantage for donor conceived people who do not have access to information about their genetic heritage. Mr Adams stated that:

The donor conceived can suffer from kinship separation, the deprivation of contact with half of their biological family and the associated deprivation of culture and heritage. Their identity formation can be severely hampered by not having those that they are descended from in their daily lives.¹¹⁰

- 4.57 This psychological disadvantage has been described as ‘genetic bewilderment’ and has been well documented in recent years. It has been described as a sense of loss of one’s biological links, which, when a donor conceived person finds out about their true parentage, can leave them with an incomplete sense of themselves and make it difficult for them to live a fulfilled life.¹¹¹ The Committee received evidence from one donor conceived person who expressed their feelings this way:

To be completely honest, for me, not having knowledge and access to part of my own identity and medical history is confusing, upsetting and distressing. When asked questions about my background or medical history, I don’t have the answers. I look at myself in the mirror and wonder. I look at people in the street and wonder. I worry about unknown genetic medical conditions. This affects not only myself, but my children also. It is so disempowering to have no rights to fully know who I am and where I come from. I have no way of knowing my history, or passing this on to my family.¹¹²

- 4.58 Granting retrospective access to information about a person’s donor is seen to be the major way of alleviating the pain of the donor conceived person and allowing them to come to terms with their genetic parentage.

- 4.59 The Committee received many submissions, including from Solo Mothers by Choice Australia, who believe that the positive psychological benefit to donor conceived people of knowing their background should outweigh any previous offers of anonymity that were made to donors.¹¹³

- 4.60 The Australian Christian Lobby supported the view that past practices have had a substantial negative impact on donor conceived people and that they should be permitted to access their donor’s information:

...pain and trauma caused by donor-conception practices, particularly donor anonymity, is now well-documented. Retrospective access to donors’ identifying details is a necessary rectification of past error.¹¹⁴

- 4.61 The Plunkett Centre for Ethics was also of the opinion that ‘The parliament should now authorize arrangements to address the injustice inflicted on donor-

¹¹⁰ Submission 4, Mr Adams, p 2

¹¹¹ See submission by Mr Adams to previous inquiry, submission 10, Dr Allan to this inquiry, submission 33, Plunkett Centre for Ethics to this Inquiry

¹¹² Submission 16, Name suppressed, p 2

¹¹³ Submission 26, Solo Mothers by Choice Australia, p 3

¹¹⁴ Submission 30, Australian Christian Lobby, p 3

conceived people in the past' and that this could be done by making identifying information available to donor conceived individuals.¹¹⁵

- 4.62 Mr Martin supported the view that legislation should be introduced to enable retrospective access to donor conception information and this would encourage families to be open with their children:

I think then it kind of forces families and donors to be upfront and honest, and to be open. In the long run, as you have heard other people talk about today, it might be devastating and traumatic to hear that you are not related to your father, and we know from adoptees that it is traumatic, but they would rather know than not know. I just think if you can facilitate a way to encourage openness—we already have legislation that encourages that, but even more so, like the Victorian legislation which has the birth certificate extract but also retrospective release. We have done that in adoption and it just ends all secrets and lies.¹¹⁶

- 4.63 While the Committee does not doubt the importance of having access to one's genetic parentage information, it realises that each person will have an individual response to such a situation. As Professor Jenni Millbank, Faculty of Law, University of Technology explained:

When we are talking about the interest in information for some people it will be a crucial piece of information in their identity formation for other people it will be a mere curiosity, it will not be fundamental.¹¹⁷

Health

- 4.64 It is commonly accepted that in order for people to manage their own health effectively, they need to have access to their complete medical history. This allows for screening and genetic tests to ascertain an individual's risk of developing certain diseases.

- 4.65 This knowledge becomes particularly important if a donor finds out some time after they have donated that they are a carrier of a particular disease. Professor Handelsman told the Committee heard of an instance where a donor did indeed discover they had a disease some time after they donated:

...we have had two instances in 30 years: one an offspring was born with a genetic disease that was not present in the mother. We went back to check the donor and his family and it was not present there either. It was just a new mutation that occurred in pregnancy. We had another instance of a donor coming to us and saying he had a disease which had only been picked up 20 years after he had been a donor. We then passed that back to the clinic to take it up.¹¹⁸

- 4.66 The Committee is aware of the potential impact that health information has not only for the donor conceived person but for future generations as well. Dr Allan points out that not knowing about one's genetic heritage may have ramifications

¹¹⁵ Submission 33, Plunkett Centre for Ethics, p 4

¹¹⁶ Mr Damon Martin, transcript of evidence, 6 May 2013, p 58

¹¹⁷ Professor Jenni Millbank, Faculty of Law, University of Technology, transcript of evidence, 6 May 2013, p 38

¹¹⁸ Professor Handelsman, transcript of evidence, 6 May 2013, p 49

‘...not just for the person unaware of such information but for generations to come’.¹¹⁹

Consanguinity

- 4.67 Evidence was received by the Committee that fears of consanguinity also play a role in the need of the donor conceived person to access their donor’s information.
- 4.68 While uncertainty around the number of people born as a result of donor conception makes the likelihood of this occurring very hard to judge, the Committee heard that given the relatively small population in Australia the risk may not be insignificant.¹²⁰
- 4.69 Some donor conceived individuals reported a fear of forming consanguineous relationships with either their siblings or their donor. This has not only legal implications but also genetic implications if any children are born from the relationship.¹²¹
- 4.70 Both Mr Michael Sobb and the Law Society of New South Wales address the issue of consanguinity and note the unease that donor conceived people live with around this possibility. The Law Society of NSW observed:

There is a public interest in allowing easy identification of one’s parents. This may be for a range of reasons, such as to eliminate the risk of consanguinity for such things as marriage or having a sexual relationship.”¹²²

ARGUMENTS AGAINST RETROSPECTIVE ACCESS

- 4.71 It is a broadly accepted principle that retrospective legislation should be avoided unless there are extremely persuasive reasons for introducing it. During the course of this Inquiry the Committee has considered evidence that argues against the introduction of retrospective information access in the case of donor conception.
- 4.72 The NSW Government submission to this Inquiry noted that the discussion around the retrospective release of donor conception details is a sensitive one, balancing the interests of donors and donor conceived people. The submission noted that:
- As a general principle, compelling justification is required in order to affect rights and liberties retrospectively, as fairness requires that the legal rights and obligations governing certain conduct should be known at the time that conduct occurs.¹²³
- 4.73 In addition to the general legal principle against introducing retrospective legislation, the Committee heard other reasons, including the sanctity of the

¹¹⁹ Submission 10, Dr Allan, p 7

¹²⁰ Submission 10, Dr Allan, p 7

¹²¹ Submission 3, Confidential

¹²² Submission 37, Law Society of NSW, p 3

¹²³ Submission 9, Mr Michael Sobb, p3; Submission 18, NSW Government, p 1

doctor-patient relationship, the validity of the original contracts and the circumstances in which the donations were made.

Doctor-Patient relationship

4.74 The strongest argument against allowing retrospective access is that the donors originally donated on condition of anonymity and this undertaking should be honoured. Professor Handelsman told the Committee in evidence that the donors carried out an altruistic act which they are unlikely to have agreed to if they had foreseen that their information would be released at a later date. He told the Committee that disclosure should not be imposed on donors:

We cannot say that on average there should be disclosure and force it on everybody. We do not do that to the families, half of whom have not told their children that they are donor conceived, so why would we force disclosure on donors?¹²⁴

4.75 This view was also expressed by a participant in the Victorian research who felt that if information disclosure is made compulsory it should apply to both recipient parents and donors:

It's all right for them to, you know, the legislators and the do-gooders coming out and flushing out donors and saying, you know, 'We want you to come out of the closet', so to speak, when some of the children don't even know that they're donor conceived. You know, if you're going to make it compulsory for us, it should be compulsory for the parents too.¹²⁵

4.76 Several participants in the Inquiry were concerned that allowing full retrospective access to donor conception information would breach both the doctor-patient relationship and the privacy which the donor was promised at the time of making the donation. Associate Professor Mark Bowman, the President of the Fertility Society of Australia, explained to the Committee that:

...there is a fundamental problem with retrospective divulging of information because that, to us, is untenable because we also, in a sense, managed the donors at the time, or my forebears did, and in good faith those individuals—particularly we are talking here about sperm donors as it leads back— were given information, in good faith, that their details would not be divulged in the future. So, it is our strong view that it would be untenable, against their consent, to go and release that information.¹²⁶

4.77 An important aspect for the Committee to consider was if the relationship between the doctor and the donor is the same as that between a doctor and a patient.

4.78 The Committee heard evidence from Associate Professor Bowman that the same principles that govern a doctor-patient relationship also apply to the doctor-donor relationship. The doctor takes the donor's history and examines them in

¹²⁴ Professor Handelsman, transcript of evidence, 6 May 2013, p 45

¹²⁵ VARTA, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, p 21

¹²⁶ Associate Professor Mark Bowman, President, Fertility Society of Australia, transcript of evidence, 29 April 2013, p 30

the same way that they would a patient and there are the same considerations around the privacy of medical information.¹²⁷

4.79 Some of the clinics that participated in the Inquiry stated that they believe they have a duty of care to protect the privacy of the donors, as they are unlikely to do this for themselves. According to Professor Handelsman, the nature of their donation and the fact that it was made a long time ago under different conditions means it is unlikely that donors will form a lobby group to represent themselves.¹²⁸

4.80 Fertility East submitted that no information should be made available retrospectively, apart from that which is entered into the voluntary register. This opinion is based on the following reasons:

- (1) A foundation of the ethical basis of medicine and the patient doctor relationship is the maintenance of confidential information and privacy even if this was not enshrined in law.
- (2) Retrospective legislation breaking this basic rule of law and medicine would have a devastating prospective effect on every aspect of medicine as patients could no longer trust their confidential medical information to doctors in case the government made this available to all. By the same token this concept could be extrapolated to every branch of human endeavour with untold consequences.
- (3) Should the State Government proceed with this retrospective process, it would contradict current ethical thinking as it would represent an attempt to service one very small section of the community and place their needs, above the common good and would represent an abhorrent abuse of authority and should not be pursued.¹²⁹

4.81 Ms Montrone made the point that the parents of the donor conceived person agreed to the anonymous provisions on behalf of themselves and their unborn child. She considers that to allow retrospective access would place the rights of the donor conceived children above those of the donors, which would not be an equitable situation.¹³⁰

4.82 Professor Handelsman felt strongly that the past anonymity should be maintained and argues that the same provisions that apply to the families of the donor conceived person should apply to the donors themselves. Professor Handelsman explained that there is a considerable proportion of families who use donor sperm and do not tell their children:

Despite any prevailing disapproval of this, it would be intolerably intrusive to force disclosure on such families or even to survey them (risking breach of privacy) to determine if their children had been informed of their donor origins. It is hard therefore to understand why similar protections for sperm donors against

¹²⁷ Associate Professor Mark Bowman, transcript of evidence, 29 April 2013, p 33

¹²⁸ See for example Submission 25, Andrology Department, Concord Hospital, p 6

¹²⁹ Submission 23, Fertility East, p 2

¹³⁰ Submission 17, Ms Montrone, p 3

irrevocable, unauthorised and potentially harmful breach of privacy requires elaborate defence.¹³¹

Guarantees of anonymity

4.83 The Committee sought to understand the types of contracts, or agreements that were entered into between the donors and the clinics, and the legal ramifications of these. The Committee heard opposing views about the validity of these contracts/agreements and below outlines the evidence received in favour of regarding the contracts/agreements as a legal article protecting donor anonymity.

4.84 The Fertility Society of Australia explained that the clinics may have been privately owned or run through a public hospital, but in effect the donor signed a contractual agreement within the context of a medical consultation. The agreements that were signed were usually between the donor and the doctor, signing on behalf of a clinic.¹³²

4.85 The Committee heard differing views on the validity of the contracts that were originally signed between the donors and the clinics. Mr John Dobson, President of the Law Society of NSW, expressed the opinion that these contracts override the rights of the donor conceived child:

My view is that the agreement you entered into at the start, with full knowledge that you were not going to be disclosed as the donor, takes paramount over that of the child. The information that you could seek, which is necessary, can be obtained without the identity of the donor being disclosed.¹³³

4.86 Professor Handelsman told the Committee that the contract between the donor and the clinic should be considered valid in the same way as any legal contract:

We would not simply take a contract and void it because of someone else's wish. We could not run businesses or any other human affairs if every contract was subject to people saying subsequently that they regretted it or that they were not there to comment. It happens and it is not the greatest tragedy. I can certainly understand and appreciate that the offspring would like to know. However, reasonable ends do not justify any means, and in this case the means are forcible retrospective disclosure. That is not the way to do it. Many donors will agree to change their consent agreements, but they have to be asked, not bludgeoned into it.¹³⁴

4.87 There was a view among some participants in the Inquiry that the terms of the contract should be upheld as it was signed by the unborn child's parents who were to become their legal guardians. Dr Joel Bernstein, Medical Director, Fertility East, explained to the Committee:

... my comment would be that parents who were not coerced into using donor sperm make decisions about their children all the time and the children have to bear the brunt of those decisions. You cannot, obviously, have somebody present with that

¹³¹ Submission 25, Andrology Department, Concord Hospital, p 2

¹³² Ms Hurrell, transcript of evidence, 29 April 2013, p 32

¹³³ Mr John Dobson, transcript of evidence, 29 April 2013, p 11

¹³⁴ Professor Handelsman transcript of evidence, 6 May 2013, p 46

kind of decision when they do not exist. I think children, as a result of parents' decisions, will either suffer or do very well and I think the parents do have a right in their decision-making process.¹³⁵

- 4.88 The Committee also heard evidence from Ms Amy Corderoy, a donor conceived person who strongly believes that the law should not allow for retrospective access to information, as this would violate the anonymity under which the men originally donated. She expressed concern that this could lead to negative effects on other aspects of the men's lives:

To think that the very real rights of men who donated anonymously and do not want to be contacted by children could be violated on the basis of a cultural mythology that I believe we should be fighting, rather than endorsing, saddens me greatly ... by changing the laws and allowing men who identified anonymously to have their identities revealed is the wrong approach.¹³⁶

Circumstances of donation

- 4.89 The Committee received evidence that some of the circumstances in which men donated their sperm were less than ideal. This included clinics taking donations without counselling donors on the implications, or taking donations from university students under some type of duress.
- 4.90 The Committee recognises that the social mores of the time were markedly different and there was less emphasis placed on openness, but in addition to this, the counselling available to donors appears to have been inadequate. Ms Montrone told the Committee in evidence that clinics did not routinely offer counselling to donors prior to the 1990s.¹³⁷
- 4.91 In some circumstances there may have been some level of coercion or persuasion involved. According to Ms Montrone there is anecdotal evidence that medical students were expected to donate sperm:
- It is said anecdotally that many of the donors were medical students, so they were of that era—I have heard stories that they were. Some hospitals would say things like—they were told in the third year medicine course: "We need sperm, go over and donate." and they would donate. My sister actually reminded me—I had forgotten—of my telling her about my friends when I was at university who would get \$10 for a donation. They would go and donate. There was no thought or consideration of the implications; it was just the culture of the time. In fact, some writing at the time said it was just like blood—it patently is not just like blood. It is said that they were mainly medical students, so they may have been medical students.¹³⁸
- 4.92 Ms Hewitt informed the Committee that sometimes the decision to donate had been made under considerable pressure and the donors may not have had the opportunity to fully consider the consequences of their actions:

¹³⁵ Dr Joel Bernstein, Medical Director, Fertility East, transcript of evidence, 6 May 2013, p 59

¹³⁶ Submission 12, Ms Amy Corderoy, p 4

¹³⁷ Ms Montrone transcript of evidence, 29 April 2012, p 20

¹³⁸ Ms Montrone, transcript of evidence, 29 April 2013, p 26

Some donors were forced to donate under duress. Medical students at the University of New South Wales were told that all male students were expected to provide a semen sample by the end of the year. If they did not donate they would not pass the course. They might have been failing and they would be told to donate and the fail would be turned into a pass.¹³⁹

- 4.93 In addition to compelling men to donate, the ART donation system in the past did not allow for the donors to leave identifying information even if they wanted to. They were informed that the system was anonymous only and this was the condition upon which donations were accepted.¹⁴⁰

The impact of biology

- 4.94 Not all donor conceived people support making donor conception information available retrospectively. For example, Ms Corderoy told the Committee that she does not advocate retrospectivity. She feels that one's biological identity is not tied to an understanding of one's self and that perhaps people should reconsider the discussion around how biology impacts on relationships. She explained to the Committee that:

I think it is really important that it is dealt with sensitively and that we don't just buy lock, stock and barrel the idea that people have a right to know and their identity is tied up in this biological parent and all that kind of thing.¹⁴¹

ARGUMENTS FOR PARTIAL ACCESS

- 4.95 In addition to strong arguments advocating both for and against retrospective access, the Committee heard from several witnesses who believe there can be a compromise found in a scheme that combines elements of both. Such a compromise would involve either limiting the amount and type of information that would be made available retrospectively, or a system which clearly delineates between information and contact and offers a way of negotiating this between parties.

Consent-release model

- 4.96 The Inquiry received evidence in favour of a model in which information is released with consent of the donor. In such a model, non-identifying information would be released retrospectively to the donor conceived individual, but the donor would need to be contacted and give his consent for any identifying information to be released.
- 4.97 This was commonly considered to be a model that strikes an appropriate balance between the interests of all parties and relies on a significant contribution by a designated agency to facilitate active contact between parties and other support measures.

¹³⁹ Ms Hewitt, transcript of evidence, 6 May 2013, p 20

¹⁴⁰ Ms Lorbach, Donor Conception Support Group, transcript of evidence, 6 May 2013, p 21

¹⁴¹ Ms Corderoy, transcript of evidence, 6 May 2013, p 71

- 4.98 Professor Millbank supported the view that retrospective access to information should be facilitated, but only on a voluntary basis, where it is agreed to by the donor. She envisages that such an approach would:
- ... provide far more flexible and supportive voluntary disclosure services, including active registers and associated counselling. This will better serve offspring in the long run by ensuring that more donors come forward and are more willing to receive contact if that is desired.¹⁴²
- 4.99 This approach was supported by Mr John Mayger, who in his submission stated that the donor and his family should be consulted before any details were disclosed to the donor conceived person.¹⁴³
- 4.100 This approach of releasing information with the consent of all parties was also proposed by the Fertility Society of Australia, provided that voluntary registers are established, a community education campaign about donor conception is undertaken and outreach to donors is conducted by clinics in a sensitive manner.¹⁴⁴ This process of active “donor-linking” could be used to connect parties where all agree to it.
- 4.101 Fertility First explained that while they do not agree with full retrospective access to identifying details by donor conceived adults, they do attempt to facilitate contact between the donor conceived individual and the donor, provided both parties are willing. They explain this ‘mailboxing’ service so:
- Initial contact occurs through the forwarding of letters containing non-identifying information only. The decision to provide identifying information can be made at a later date by the parties involved if they wish to do so.¹⁴⁵
- 4.102 The Information and Privacy Commission proposed a solution which sees donor conceived people able to retrospectively access non-identifying information about their donor at a minimum, and then if the donor chose to make further information available, this would also be released.¹⁴⁶
- 4.103 The Law Society of NSW was also of the opinion that medical information could be released retrospectively without any problems, as long as no identifying information was released.¹⁴⁷ This view was supported by others, including Ms Montrone.¹⁴⁸
- 4.104 The Committee is aware of models such as that currently used in the Netherlands, in which the donor conception register will perform outreach to

¹⁴² Submission 7, Professor Millbank, p 10

¹⁴³ Submission 1, Mr John Mayger, p 2

¹⁴⁴ Submission 14, Fertility Society of Australia, p 1

¹⁴⁵ Submission 35, Fertility First, p 2

¹⁴⁶ Submission 36, Information and Privacy Commission, p 2

¹⁴⁷ Mr Dobson, transcript of evidence, 29 April 2013, p 12

¹⁴⁸ Ms Montrone transcript of evidence, 29 April 2013 p 22

donors who donated anonymously, to see if they would consider allowing their information to be released.¹⁴⁹

- 4.105 This approach, using a consent-release, or active model, would require intermediary services to be implemented successfully. These intermediary and support services are discussed in more detail in Chapter Five.

Release of non-identifying information only

- 4.106 The Committee is aware of some support for a model in which only medical or non-identifying information is released retrospectively.¹⁵⁰ Given the sensitivities around the issue of retrospective access, this approach can be seen as treading a middle ground and giving donor conceived people the essential information they require, without impinging on the privacy rights of donors.
- 4.107 The Information and Privacy Commission noted that this option does not present any problems from a privacy perspective.¹⁵¹ The Law Society of NSW agreed with this view.¹⁵²
- 4.108 Mr Guido Pennings notes, however, in his article entitled 'How to kill gamete donation: retrospective legislation and donor anonymity', that empirical research is necessary to determine exactly what information would be considered useful by donor conceived children.¹⁵³ The Committee heard that there are varying ideas of what type of information could be considered non-identifying and that different jurisdictions collect vastly different types of non-identifying information. In some clinics in America this can include voice recordings, silhouettes, medical history and childhood photographs of the donor.¹⁵⁴
- 4.109 Dr Allan told the Committee that the release of non-identifying information is not sufficient:

For some time I thought non-identifying information would at least be a compromise but I think it does not go far enough. My position is it does not go far enough ... Sometimes you will find that donor-conceived people do not want to meet the donor but they do not want to call their donor "donor". They do not want to call their genetic—I do not want to say "parent"; the person who has contributed half of their genetic material, by a number. It is very depersonalising, so a name is important.¹⁵⁵

¹⁴⁹ For a discussion of these regimes please see Allan, S, *A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor Conceived People*, Churchill Fellowship Trust, 2011

¹⁵⁰ Submission 15, Commission for Children and Young People, p 2

¹⁵¹ Submission 36, Information and Privacy Commission, p 1

¹⁵² Mr Dobson, transcript of evidence, 29 April 2013, p 12

¹⁵³ Pennings, G, 'How to kill gamete donation: retrospective legislation and donor anonymity', in *Human Reproduction*, 2012, Oct, 27 (10), 2881-5

¹⁵⁴ Dr Allan, transcript of evidence, 6 May 2013, p 13

¹⁵⁵ Dr Allan, transcript of evidence, 6 May 2013, p 12

WHAT THE DONORS THINK

- 4.110 The lack of significant input from donors is a key difficulty in assessing the issues around assisted reproductive technology and information disclosure. The Committee acknowledges that this has presented some challenges in understanding all aspects of the issues and how it affects all parties. Professor Handelsman told the Committee that as donors do not form an identifiable group, it is difficult to ascertain what they think.¹⁵⁶
- 4.111 Among the clinics that the Committee heard from, it is a commonly held belief that the donors, if they could be contacted, would wish to preserve their anonymity. For example, Associate Professor Bowman told the Committee:
- The challenge is that the donors by their very desire to maintain their anonymity are the ones who do not have a voice. This comes from a time when donors were young individuals, often university students, some of them legal students some of them medical students, and some of them have probably ended up in fairly high parts of society and are quite interested in maintaining their anonymity.¹⁵⁷
- 4.112 In line with this belief, some evidence received by the Committee stated that as soon as anonymous donation was removed, the numbers of sperm donors dropped dramatically and that this demonstrates the donor's desire for anonymity as it:
- ... clearly highlights that most sperm donors of the pre-mandatory disclosure era would not have become sperm donors had disclosure been required with their donation. This is also verified directly by first-hand comments from sperm donors. Whatever hindsight wisdom that may be applied now, the legal contract entered into voluntarily and in good faith by the donor and institution should not be breached without the donor's freely give consent.¹⁵⁸
- 4.113 Professor Handelsman informed the Committee that the sperm donation program run by his clinic had to close following the end of anonymous disclosure, due to the lack of donors.¹⁵⁹
- 4.114 In contrast to the opinions held by the clinics, the Committee received a substantial amount of evidence from academics and individuals stating that it is not necessarily the case that donors wish to remain anonymous and that if they were contacted then they may change their mind. Anecdotal material from other countries shows it is likely that many donors would indeed change their mind if they were asked to do so.¹⁶⁰
- 4.115 This view was supported by Ms Fiona Hearne who told the Committee:
- A lot of the critics think that that is what they chose, to be anonymous, and no-one has checked back with a lot of the donors. Research anecdotally shows overseas and

¹⁵⁶ Professor Handelsman, transcript of evidence, 6 May 2013, p 47

¹⁵⁷ Associate Professor Bowman, transcript of evidence, 29 April 2013, p 33

¹⁵⁸ Submission 25, Andrology Department, Concord Hospital, p 4

¹⁵⁹ Professor Handelsman, transcript of evidence, 6 May 2013, p 51

¹⁶⁰ See for example Submission 10, Dr Sonia Allan p 8, Submission 29, Confidential, p 1, transcript of evidence, 6 May 2013, p 20

here that people who donated when they were 30 now, maybe 20 years later, think, "Yes, actually I wouldn't mind knowing how many children resulted from that. I don't particularly want to be in touch with them, but I am happy to give updated medical information and let them know a little bit more about me."¹⁶¹

4.116 A confidential submission received by the Committee quoted a study that reviewed the attitudes of sperm donors towards the release of their personal information and found that the majority were willing to consider it.¹⁶² In evidence, Ms Montrone mentioned a study of a small sample of donors that questioned whether they would change their mind about their anonymity and some of them agreed that they would agree to be identified.¹⁶³

4.117 Ms Hewitt told the Committee that donors must be invited to review their decision to remain anonymous as the first step in any process:

Of the hundreds of donors that the Donor Conception Support Group has contacted only five have said that they wanted their anonymity preserved. Those decisions were made 20, 30, 40 or 50 years ago and they were made without really understanding the long-term implications for them and their families and for the person created. I know that many of them were not given counselling at the time that they donated.¹⁶⁴

4.118 This view is supported by Professor Millbank and Professor Handelsman, who told the Committee that it would be logical to approach donors before retrospective disclosure is mandated and assess their willingness to reconsider their original decision to remain anonymous.¹⁶⁵

4.119 The Donor Conception Support Group told the Committee that they have heard from many donors who are willing to have their identity and other personal information disclosed to their genetic offspring. They quote one donor who wanted to pass on medical information but had been unable to do so:

Now, 15 years on and with a new wife and two kids of my own (son 5 and daughter 2). I have a totally different outlook on conception and all its responsibilities, especially the consideration of the child. While the donor's anonymity, where requested, should be respected, I believe all offspring deserve to at least have access to the donor's identity. They should also have the chance to make contact with the donor, as should the donor with the offspring. Again, though, anonymity should be respected where requested.

To reinforce my point I have a congenital heart defect (bicuspid aortic valve). So any child created using my sperm is highly likely to be afflicted with the same problem. He or she, like me, may not become aware of it until later in life. I was unaware of the valve defect when I donated.

¹⁶¹ Ms Fiona Hearne, transcript of evidence, 6 May 2013, p 4

¹⁶² Submission 3, Confidential, p 4

¹⁶³ Ms Montrone transcript of evidence, 29 April 2013, p 27

¹⁶⁴ Ms Geraldine Hewitt, transcript of evidence, 6 May 2013, p 19

¹⁶⁵ Professor Jenni Millbank and Professor Handelsman, transcript of evidence, 6 May 2013, p 38 and p 45

This year I tried to get my records, but the clinic advised me they had been destroyed after the clinic apparently tried to contact me. I didn't move house or change telephone numbers at any time while I lived in Sydney.¹⁶⁶

4.120 The UK Human Fertilisation and Embryology Authority (HFEA) stated that after the legislation was changed in 2005 to allow previously anonymous donors to re-register as identifiable, the HFEA conducted a public campaign encouraging donors to re-register and remove their anonymity. More than 120 donors have re-registered and made their details available.¹⁶⁷

4.121 The research conducted by the Victorian Assisted Reproductive Treatment Authority (VARTA) and Monash University provides significant insight into the thoughts and opinions of donors to the issue of retrospective information access. Following a comprehensive publicity campaign, 42 donors were interviewed. The respondents were found to be diverse in their range of ages, place and year of donation, disclosure patterns, outcome of their donations and whether or not they had been approached by donor offspring or joined the Voluntary Register.¹⁶⁸ While the total number of donors in Victoria is unknown, due to incomplete and missing donor conception records, the diversity of the respondents, and the diversity of their views, suggests that their opinions are representative of more than a 'narrow segment of donors'.¹⁶⁹

4.122 A summary of the donors' opinions on retrospective access to donor information by donor conceived people is as follows:

- Slightly less than half of the donors supported the recommendation for full retrospective access by donor conceived people to identifying information. This group suggested that they should also have access to identifying details of their donor offspring.
- Slightly more than half of the donors rejected the recommendation for full retrospective access to identifying information, expressing concern about the impact on themselves and their families. This group also expressed strong concerns regarding the revocation of their original guarantee of anonymity as a being a violation of the original contracts that they entered into.
- Of those donors who rejected the recommendation for retrospective access, approximately half were satisfied with a compromise of persuading donors for their consent to release information to donor conceived people.
- Donors suggested that their consent to release information could be obtained in two ways – through publicising the existing voluntary register and via an intermediary organisation contacting the donor personally and

¹⁶⁶ Submission 5, Donor Conception Support Group, p 13

¹⁶⁷ Submission 24, Human Fertilisation and Embryology Authority, p 3

¹⁶⁸ VARTA, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, p 6

¹⁶⁹ VARTA, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, p 6

seeking permission. They advocated encouraging parents to tell their children about their donor conception. This group also expressed the view that if it was going to be compulsory for donors to release identifying information it should be compulsory for parents to tell their children of their donor conception.¹⁷⁰

Committee Comment

- 4.123 The Committee received a substantial amount of credible evidence both for and against retrospective access to donor conception information being made available. In considering the information, the Committee felt it was necessary to assess the needs and responsibilities of all parties to the donor conception arrangement on their own merit, rather than comparing them in terms of competing 'rights'.
- 4.124 The Committee heard the personal experiences of donor conceived people and understands the strong emotions that underlie some people's desire to know the truth of their conception and their genetic heritage. The Committee also acknowledges the view that donor conceived people should not be the ones to carry the burden of decisions that were made in a different time, with different attitudes where different attitudes prevailed.
- 4.125 The Committee is grateful to those who contributed to this Inquiry, and shared their personal stories. The Committee is aware of the important and sensitive nature of this Inquiry and considered all the evidence presented in great detail.
- 4.126 While the Committee does not doubt the impact that a lack of information can have on a donor conceived individual's life, it notes that there was a substantial opinion missing from the discussion, and that was the perspective of the donors. Through the course of this Inquiry the Committee heard only from one donor. The Committee tried to address the lack of evidence from the donors by targeting advertising and liaising with others involved in this type of research.
- 4.127 The Committee feels there are many parallels in the experience of donors in Victoria and NSW and gives considerable weight to the results of the Victorian research into donor attitudes. This research clearly shows that a 'consent-release' model is the preferred model amongst donors and implementing such a system will also contribute to the development of a unified system amongst Australian states.
- 4.128 The Committee believes strongly that parents should engender a sense of openness and be encouraged to tell children the truth about their conception and that the State should provide the necessary services to assist with this.
- 4.129 One way of facilitating this process is the 'consent-release' model of information management. In this model, an active register is established which offers a variety of services to all parties to donor conception arrangements, one of which is to actively link donors and donor conceived people who wish to be linked. The

¹⁷⁰ VARTA, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, pp 5-6

Committee considers that active linking registers and programs are likely to have positive outcomes for the individuals involved.

- 4.130 While the Committee did not receive a lot of evidence about the extent to which other parties should have access to donor conception information, this access should follow sensible guidelines and reflect the current legislative provisions.

RECOMMENDATION 5

The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access non-identifying information about their donor, regardless of whether or not the donor consents to such information being released.

RECOMMENDATION 6

The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access identifying information about their donor where the donor consents to such information being released.

RECOMMENDATION 7

The Committee recommends that the new donor conception management agency implement procedures that enable the parents of a donor conceived person to access non-identifying information about the donor regardless of the donor's consent on behalf of their child or/and until the child reaches 18.

RECOMMENDATION 8

The Committee recommends that, for those individuals conceived before 1 January 2010, the new donor conception management agency implement procedures that enable the parents of a donor conceived person to access identifying information about the donor, where the donor consents to such information being released, on behalf of their child or/and until the child reaches 18.

RECOMMENDATION 9

The Committee recommends that the new donor conception management agency implement procedures to ensure that the donor and the donor conceived person's siblings have access to:

a) any information that the donor conceived person has consented to being placed on the Register of donor conception information and

b) further information, if the Registrar is of the opinion that the contact is justified in order to promote the welfare and best interests of one or more of the persons concerned.

RECOMMENDATION 10

The Committee recommends that the new donor conception management agency operate the Register of donor conception information on an active, or consent-release based approach, to best facilitate access to donor conception information.

Chapter Five – Counselling and Support Services

THE NEED FOR SUPPORT

5.1 This chapter responds to the Inquiry's third term of reference by reviewing the evidence that was received about counselling, support services and public education measures that are considered necessary to support people who are seeking access to donor conception information. It surveys how services are currently provided and which organisations or groups are best placed to provide support.

5.2 The Committee found widespread agreement between inquiry participants that support services should be available to all parties to donor conception, including donors, donor conceived people, recipient parents and their families. Services may include campaigns to inform the wider community of voluntary registers and successfully navigate the complexities around seeking information related to donor conception, as well as assisting families to talk to their donor conceived children about donor conception and assisting donor conceived people to come to terms with lost or incomplete donor records.

5.3 The Reproductive Technology Council of Western Australia noted that support services need to be flexible, as the type of support required would vary from person to person:

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.¹⁷¹

5.4 Dr Sonia Allan reiterated this view and submitted that while the full range of support services should be available to people seeking donor conception information, it should not be assumed that all people would require counselling:

...the provision of support services should not be underpinned by a view that donor conception leads to 'unhealthy outcomes' or negative consequences. That is, while donor conceived people may wish to have information about their donor and their conception, they may therefore not need 'counselling' but rather need 'support' or 'intermediary' services.¹⁷²

5.5 The Donor Conception Support Group submitted that the same support given to adopted people should be given to those involved in donor conception:

Donor conception has in the past three decades gradually taken over from adoption in being the most common way for people unable to have their own biological children to achieve a family. So it would seem appropriate that given the long term

¹⁷¹ Submission 38, Reproductive Technology Council of Western Australia, p 8

¹⁷² Submission 10, Dr Sonia Allan, pp 18-19

consequences that are evident in donor conception that we give the same support to donor conception that we have given to adoption practices.¹⁷³

5.6 The Committee heard that existing support for people seeking access to donor conception information is very limited and offered in a haphazard way across different assisted reproductive technology (ART) providers.¹⁷⁴ Historically, donor conception was seen as providing a solution to infertility issues through the use of assisted reproductive technology, and support was provided by the ART provider to the person who experienced infertility at the time they received treatment. Less consideration was given to the potential future support needs of the donors, recipient parents, donor conceived people or their families.

5.7 Donor conceived people or donors wishing to access information on the NSW Health Central Register are encouraged to obtain counselling, and upon supplying information to the register they will be provided with a list of counsellors. However, the counsellors suggested are fertility counsellors, rather than counsellors experienced in donor conception. Mr Greg McAllan, Associate Director of the Ministry of Health told the Committee:

On our website we refer them to the Australian and New Zealand Infertility Counsellors Association [ANZICA]. With their consent we put them on our website and they would refer them to appropriately qualified people.¹⁷⁵

WHO SHOULD PROVIDE SUPPORT SERVICES?

5.8 The Committee received evidence describing different organisations and the models they could use to provide donor conception support services. These included using existing agencies such as NSW Health, the Registry of Births Deaths and Marriages (BDM), non-government organisations, or ART providers, and the establishment of an expert stand-alone body.

Existing Agencies

5.9 The Committee found that there was broad support among inquiry participants for the same body which manages donor registers to manage all support services, however the Committee heard differing views on which body would be best placed to perform such a role. The following paragraphs discuss evidence relating to NSW Health, the Registry of BDM and non-government organisations.

5.10 Ms Miranda Montrone, a psychologist at The Counselling Place, submitted that there are a number of groups that could offer counselling and support services based on the Australian and New Zealand Infertility Counsellors Association (ANZICA) guidelines and that these could include NSW Health, the NSW Benevolent Society and ART providers.¹⁷⁶

¹⁷³ Submission 5, Donor Conception Support Group p 19

¹⁷⁴ Submission 5, Donor Conception Support Group, pp 19-20

¹⁷⁵ Mr Greg McAllan, Associate Director, Ministry of Health, transcript of evidence, 6 May 2013, p 33

¹⁷⁶ Submission 17, Ms Miranda Montrone, p 5

NSW Health

- 5.11 NSW Health currently manages the Central and Voluntary Donor Registers. It does not offer access to counselling or support services. A number of inquiry participants pointed to this as a shortcoming of the management of the existing registers. The submission from the Donor Conception Support Group noted that:

There are a number of shortcomings in the current service model for the donor conception registers in NSW including problems with accessing counselling services as the current Register provides no counselling and no proper referrals for counselling nor support services.

This means that when people make applications to have their details placed on the Voluntary Register no counselling is available. If a person applies for identifying information and is told that this information is not available to them (there may be many reasons for this denial) there is no counselling or support available to them.¹⁷⁷

- 5.12 The Committee notes that while NSW Health does not currently offer counselling or support services, it does have experience in public education and public awareness campaigns, and it could be an administratively straightforward task to expand their function to include provision of counselling, intermediary and other support services.

Registry of Births, Deaths and Marriages

- 5.13 Ms Lauren Burns submitted that were the donor registers to be managed by the Registry of BDM, support services could also be provided by the Registry. Provision of support services, information release and management of the donor registers would provide a 'one stop shop' for people seeking information that would avoid the need for people to make multiple applications for services at multiple agencies and also allow for the tailoring of support such as counselling:

In principle the Donor Register could be managed by the NSW Registry of Births Death and Marriages. This has the advantage that the agency is guaranteed long term funding and continuity and is not likely to disappear in the future. However, as noted, it would be important to frame the legislation in such a way that services such as counselling and information release were integrated into a 'one stop shop' so that people are not shunted between multiple agencies and relevant information is available to personalise counselling sessions, rather than counselling degenerating into merely providing generic information.¹⁷⁸

- 5.14 Mr Michael Sobb submitted that the Registry of BDM would be a natural place for donor registers to reside and recommended that the Registry employ suitably qualified counsellors to support and advise those people making requests for information on the donor registers.¹⁷⁹

- 5.15 Ms Sharon Swinbourne, Assistant Registrar, Registry of BDM, commented that the Registry had some experience in undertaking small scale public awareness campaigns for sensitive issues. However it had not conducted large scale

¹⁷⁷ Submission 5, The Donor Conception Support Group, p 18

¹⁷⁸ Submission 6, Ms Lauren Burns, p 8

¹⁷⁹ Submission 9, Mr Michael Sobb, p 4

campaigns.¹⁸⁰ Ms Lisa Karam, Manager, Amendments, Registry of BDM noted at a public hearing 29 April 2013 that the Registry was not currently well placed to provide counselling and support services.¹⁸¹

Non-Government Organisations

- 5.16 International Social Service Australia noted that an agency experienced in post adoption issues would be well placed to manage the counselling and support services as 'it is the closest equivalent professional field to working with clients facing these issues'.¹⁸²
- 5.17 Post adoption support in New South Wales is currently provided by four NGOs (CatholicCare Adoption Services, Barnados Australia, The Benevolent Society, and Anglicare Adoption Services) which specialise in intermediary and contact services.¹⁸³
- 5.18 Professor Jenni Millbank, Faculty of Law, University of Technology, shared her concerns regarding the provision of counselling and support services by non-government organisations. In giving evidence, she noted that there were potential issues around protecting the security of private, sensitive information, and also issues as to how that information would be accessed. Professor Millbank pointed out the need to consider the impact that organisations with a religious affiliation could have if such groups were opposed to non-traditional families.¹⁸⁴
- 5.19 Dr Allan expressed the view that a system where a service provider contracts to provide support services would be undesirable, as this added to the cost of the system and would lead to the type of fragmentation currently seen in Victoria:

I do not believe that a system in which a service provider (eg a commercial or not-for-profit agency) contracts to provide 'support services' would be desirable. I believe this would add to the costs of a system, and have not in my research come across any one agency that would be best placed to undertake this role. For example, while we do have agencies that deliver post-adoption services, such services may not be best placed to address matters related to donor conception. While there may be similarities in searching for information, there are also many differences between donor-conceived people and adoptees. In addition, engaging external providers may lead to the fragmentation found in the current system that is under review in Victoria.¹⁸⁵

Assisted Reproductive Technology providers

- 5.20 The Committee heard evidence from several participants in the Inquiry that some individual ART providers, such as the Royal Prince Alfred Hospital and the Royal

¹⁸⁰ ¹⁸⁰ Ms Sharon Swinbourne, Assistant Registrar, transcript of evidence, 29 April 2013, p 3

¹⁸¹ Ms Lisa Karam, Manager, Amendments, transcript of evidence, 29 April 2013 p 1

¹⁸² Submission 20, International Social Service Australia, p 4

¹⁸³ Submission 20, International Social Service Australia, p 4

¹⁸⁴ Professor Jenni Millbank, transcript of evidence, 6 May 2013, p 38

¹⁸⁵ Submission 10, Dr Allan, p 24

Hospital for Women do provide highly regarded support to people seeking donor conception information.¹⁸⁶

5.21 Fertility First submitted that as it was mandatory for all ART providers to have an association with a counsellor with ANZICA membership, the ART provider could provide a referral service for people who contacted them seeking donor conception information. In the event that the individual preferred to use a counsellor independent of an ART provider; had little or no knowledge of who provided the ART treatment; or the original ART provider no longer operated, Fertility First suggested that the NSW Ministry of Health could provide a directory of appropriately qualified counsellors.¹⁸⁷

5.22 However, the Committee also heard that the ART clinics should not play a role in offering additional support services. The main reason for this was concerns around the impartiality of clinics. Ms Lauren Burns submitted it was important that the agency that managed donor conception information be independent of ART providers to ensure impartiality:

It is crucial that the agency managing donor conception information be separate and independent from assisted reproductive treatment clinics and related bodies such as the Fertility Society of Australia. This is to ensure impartiality and minimise the possibility for conflicts of interest, for example where a donor being contacted is part of the medical fraternity, or where a clinic has acted in a manner that might be perceived as unethical, for example used a single donor to create dozens, or even hundreds of children.¹⁸⁸

5.23 This view was supported by the Australian Christian Lobby, who submitted that support should be provided privately. They stated that:

ART clinics with a financial interest should not be providing counselling services themselves. People should be pointed to the range of non-government community counselling services available, and funding should be provided for individuals to use on counselling services wherever they choose.¹⁸⁹

5.24 A confidential submission maker noted the deep hurt and pain they felt as the result of 'appalling contact with my clinic' and the knowledge that the clinic had knowingly damaged records in order to prevent donor conceived people from ever knowing who their donor was. The submission maker went on to add that at each interaction with the clinic, they were offered counselling, which they found an affront considering that the counselling was offered by the very people responsible for damaging records. They stated that 'it is incredibly offensive to be offered counselling by the very people responsible for such malpractice'.¹⁹⁰

¹⁸⁶ Ms Miranda Montrone, transcript of evidence, 29 April 2013, p 19; Associate Professor Mark Bowman, transcript of evidence, 29 April 2013, p 33; Ms Geraldine Hewitt, transcript of evidence, 6 May 2013, pp 20-21

¹⁸⁷ Submission 35, Fertility First, p 3

¹⁸⁸ Submission 6, Ms Lauren Burns, p 7

¹⁸⁹ Submission 30, Australian Christian Lobby, p 4

¹⁹⁰ Submission 3, Confidential, p 7, quoted with permission of the author.

A stand-alone body

- 5.25 Many participants to the Inquiry, such as Professor Millbank, supported the establishment of a specialist agency, to provide all counselling and support services, and with the statutory power to access the electoral roll to obtain information about donors. Professor Millbank gave the example of the Victorian Assisted Reproductive Treatment Authority (VARTA) and the former Infertility Treatment Authority (ITA) in Victoria:

I think VARTA has a wealth of experience. Formerly they were the Infertility Treatment Authority [ITA] and I guess previously they straddled a more awkward divide in the sense that they were both a regulator and an agency providing consumer information to individuals. Now that VARTA's primary function is community education and support, I think they are a unique agency in Australia and the counsellors that they have working there have 15 or 20 years of experience each. They have thought very hard.

They have run things like the Time To Tell campaign, trying to get people to voluntarily come on to the registers, and they have the experience of having counselled people through what they used to have in the ITA—they had a DNA matching service for people whose records had been lost or were inaccessible—as well as their counselling and facilitation of contact and communication with formerly anonymous donors. The range of their experience is really valuable and I think that having an agency that is just there for families, it is not about regulating clinics, it is not about being part of government as such, it is an independent agency to give information and counselling, would be very helpful.¹⁹¹

- 5.26 Mr Damian Adams also noted that the former ITA in Victoria successfully managed information sharing and donor linking and suggested that this be used as a model for a stand-alone body in New South Wales.¹⁹²

- 5.27 The Donor Conception Support Group favoured delivery of support services by the same organisation that managed the register. Their submission argued that issues for people seeking donor conception are often ongoing, and a stand-alone body could provide comprehensive access to information and support:

The issues surrounding donor conception are not short lived and for some they may be affected for many years; there is no capacity for ongoing counselling within the current system.¹⁹³

- 5.28 Dr Allan submitted that her research had led her to conclude that counselling and support services would be ideally delivered by the same stand-alone body that manages information:

My preference would be to see a stand-alone body deliver support services to those involved in donor conception (donor-conceived people, donors and recipient parents.)¹⁹⁴

¹⁹¹ Professor Jenni Millbank, transcript of evidence, 6 May 2013, p 40

¹⁹² Submission 4, Mr Damian Adams, p 7

¹⁹³ Submission 5, Donor Conception Support Group, p 19

¹⁹⁴ Submission 10, Dr Allan, p 24

- 5.29 The Fertility Society of Australia pointed to experience in Victoria and suggested that 'there are efficiencies in giving one body ownership of all aspects of the donor conception information management process'.¹⁹⁵

Informal support networks

- 5.30 In the absence of formal support for people seeking access to donor conception information, a number of informal forums have developed that are run by volunteers, including groups such as the Donor Conception Support Group and Solo Mums by Choice Australia. The NSW Committee on Adoption and Permanent Care told the Committee that due to the absence of suitable support services, donor conceived people had begun accessing adoption support services in New South Wales.¹⁹⁶

- 5.31 Informal support networks provide a means by which people can make contact with other people with shared experiences. The Donor Conception Support Group commented on the value of being able to draw on the experiences of others:

One of the most important areas of support is that of being able to access the experiences of people living with the long term consequences of donor conception. The Donor Conception Support has found over many years that people really do want to learn from each other; be they parents, donor conceived people or donors; they want to hear the good stories and the bad.¹⁹⁷

- 5.32 Ms Burns, who discovered that she was donor conceived as a young adult, commented that she found one of the most useful forms of support was provided by others in the same situation:

Actually in my experience the most useful support service was simply meeting other adult donor conceived people. They instinctually understood how I felt because of our similar histories. Therefore it would be an ideal and very effective use of funds to establish peer support groups. In 2012 I helped establish a support group for adult donor conceived people through the post-adoption organisation VANISH...This has been very successful and we regularly have 10 or more people at the bi-monthly meetings.¹⁹⁸

Committee Comment

- 5.33 The Committee shares the concerns expressed by inquiry participants that information and associated support can be very difficult or impossible to access when there are multiple parties involved in donor conception arrangements. This is exacerbated in situations where ART providers close down or infertility doctors retire.
- 5.34 Evidence from Victoria indicates that provision of support services is considered a vital component for effective operation of the donor registers. Having a single agency manage the Register of donor conception information as well as

¹⁹⁵ Submission 14, Fertility Society of Australia, p 5

¹⁹⁶ Submission 21, NSW Committee on Adoption and Permanent Care Inc, p 4

¹⁹⁷ Submission 5, Donor Conception Support Group, p 21

¹⁹⁸ Submission 6, Ms Lauren Burn, p 9

associated support services would bring all these components together and provide a 'one stop shop' experience for those people seeking access to information. This would be less confronting and easier to navigate for people facing significant and emotional decisions.

- 5.35 Combining the Register of donor conception information and support services would minimise administrative cost and complexity. The establishment of one agency would facilitate the development of a breadth of experience in managing information on the Register, providing community education, counselling people and facilitating contact. The Committee refers to its earlier recommendation made in chapter three:

Recommendation 1: The Committee recommends that the Attorney General establish a new agency to manage a Register of donor conception information and that this agency also assume responsibility for providing support to those involved in donor conception.

RECOMMENDED SUPPORT SERVICES AND COMMUNITY EDUCATION MEASURES

- 5.36 While the Committee heard that support currently available to people who seek donor conception information is haphazard or non-existent, it received a number of suggestions for support services and public education measures considered to be essential. These measures are outlined in the following paragraphs and include:

- Public awareness campaigns and community education
- Intermediary support to assist in linking that may occur between donor conceived people, their donor and donor conceived siblings
- Counselling to assist people in managing expectations
- Informal support networks such as the Donor Conception Support Groups and Solo Mums by Choice
- DNA testing

Public awareness campaigns and community education

- 5.37 Public awareness campaigns were considered of vital importance to inform the wider community of the existence of the current Voluntary Donor Register, and to direct people seeking donor conception information to the appropriate body. However, many inquiry participants commented that the existing voluntary register maintained by NSW Health was not widely known about, and that this could be mitigated with well-directed publicity. Dr Joel Bernstein, Medical Director, Fertility East, told the Committee the voluntary register is a 'massive tool that is being totally underutilised.' He noted that:

As a point of some criticism, I do not believe that the State Government has done enough to attract people to opt-in. The fact that it appears on a website is meaningless. For the people you need to target, you need to get a message to them

and regularly. I honestly believe that that would be the best approach to the problem.¹⁹⁹

5.38 Ms Elizabeth Hurrell, of the Fertility Society of Australia, noted that there was a lot of ignorance in the community of the existing voluntary register, which prevented donors coming forward.²⁰⁰ This ignorance could be overcome with a public awareness campaign.

5.39 Professor David Handelsman, Director, Andrology Department, Concord Hospital, informed the Committee that NSW Health recognised the need to publicise the voluntary register to donors, and had gone as far as consulting with all ART providers on the best method to effectively conduct a publicity campaign. However, the campaign had been suspended in the wake of the 2011 election:

Clearly it needs a publicity campaign. The Health department recognised that when before the last election it called all the ART providers in and said, "How are we going to do this?" They had an advertising person there who they were briefing as to running a campaign to go past donors: Please consider registering. We went through all the scenarios. Can we get a past donor to do it? They were going to get an actor to do it and so on. It would not be hard if the will was there. It would need a publicity campaign. A health district has contemplated trying to do it but we really are only a small part of the picture. It should be done on a State basis. I think it can be done that way.²⁰¹

5.40 Ms Amy Corderoy, appearing in a private capacity, told the Committee that donors were a small group, so a broad campaign such as television advertising may not be very effective. However, she added that identifying groups who were known to make sperm donations, and targeting advertising/public awareness in that area could be beneficial:

We have heard anecdotally that a lot of people through the registered sperm donor system were medical students, so maybe trying to identify those types of people and advertising among doctors and in publications for doctors might be a useful way of doing it.²⁰²

5.41 The Committee notes that other jurisdictions have reported an increase in enquiries to voluntary registers after media reports publicising donor conception and donor registers.²⁰³

5.42 The Fertility Society of Australia submitted that New South Wales needs 'provision of public education and resources for professionals and the community on fertility, and issues related to assisted reproductive treatment', and noted that the agency established to manage donor conception information could have responsibility for:

- Promotion of the Register

¹⁹⁹ Dr Joel Bernstein, Medical Director, Fertility East, transcript of evidence, 6 May 2013, p 61

²⁰⁰ Ms Elizabeth Hurrell, Representative, Fertility Society of Australia, transcript of evidence, 29 April 2013, p 37

²⁰¹ Professor David Handelsman, transcript of evidence, 6 May 2013, p 49

²⁰² Ms Amy Corderoy, transcript of evidence, 6 May 2013, p 69

²⁰³ Dr Allan, *A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor Conceived People*, October 2012, p 28

- Provision of public education re fertility, including promotion of the need for recruitment of donors
- Development of resources for donor conceived families eg 'Time to tell' program (VARTA)
- Letterboxing service connecting donors and donor conceived adults
- (Possibly) retention of records if a clinic closes.²⁰⁴

Committee Comment

- 5.43 The Committee has received much evidence that the current Voluntary Register is not well utilised simply because the register is not widely known about. Stakeholders in the inquiry were unanimous in their support for increased efforts to inform the community of the existence of the existing Voluntary Register.
- 5.44 A public awareness campaign is a method of reaching donors without revealing their identities and would at the same time expand community awareness of the Voluntary Register and its purpose.
- 5.45 While a public awareness campaign could encourage donors to come forward to place their details on the Register, a campaign would need to be well designed to effectively reach the target audience. The Committee accepts that no matter how extensive the campaign, there would be no guarantee that all donors would be reached.

RECOMMENDATION 11

The Committee recommends that, as a matter of urgency, the Ministry of Health conduct an advertising campaign to raise awareness of the Voluntary Register.

Intermediary Support

- 5.46 While many inquiry participants did not support full retrospective access to donor conception information for those conceived prior to January 2010, the Committee heard of broad support for outreach to donors where donor conceived people desired identifying information or contact with their donor.
- 5.47 Providing an active register which enables donor conceived people and donors to be linked through an intermediary allows for the informed consent of all parties before release of any identifying information. In line with this Committee's recommendation to promote a 'consent-release' approach to donor conception information, it is essential to establish comprehensive intermediary support including donor-linking and letterboxing services.
- 5.48 Donor linking strikes a balance between fulfilling the needs of donor conceived people for information about their genetic heritage and respecting the wishes of those donors who donated under a different regime maintain their anonymity.
- 5.49 The Fertility Society of Australia strongly supported the facilitation of voluntary and sensitive links between donors and donor conceived people and provided the

²⁰⁴ Submission 14, The Fertility Society of Australia, p 6

Committee with the Australian and New Zealand Infertility Counsellors Association (ANZICA) practice model for donor linking.²⁰⁵

- 5.50 The ANZICA model of donor linking provides for a counsellor to mediate and support both parties throughout the donor linking process. Information may be exchanged by parties via the counsellor in an anonymous fashion, through the use of a letterboxing service. If both parties wish to proceed to direct contact then this also is mediated by the counsellor. At all times throughout each stage, the needs and wishes of both parties are respected.
- 5.51 The Fertility Society of Australia noted that the model had been shown to be successful in clinical practice and recommended that it be adopted as the primary mechanism for exchange of information between donors and donor conceived people.
- 5.52 The idea of donor linking is not new, and Ms Montrone outlined her role in the implementation of the voluntary contact register at Royal Women's Hospital, Paddington. The register contains information about the donor program dating from 1978. Ms Montrone informed the Committee that the Hospital had a policy of attempting to contact donors where they had been approached by donor conceived people:

They were already having people contacting some offspring, some recipient parents who were interested. That was before 2001. I gathered all that information that was available. There was a lot of information that was not available because the approach to record-keeping and the approach to information gathering has changed over the years. I also did some "trying to link", so the hospital had made a decision that they would try to contact some of the donors that the offspring were interested in. It was not that many—less than 10—but I did a lot of trying to find people. Even when there was identifying information on some of the donors, some of them could not be found, which is another aspect I mentioned in my submission. People can have an expectation that if they do get the name that they will find this person.²⁰⁶

- 5.53 Ms Geraldine Hewitt, a donor conceived person, commented on the outreach conducted by the Royal Hospital for Women which protected the privacy of donors:

I think the way that donors were contacted by the Royal Hospital for Women where I was born is a good model. They sent letters by registered mail and used a blank template so it had no letterhead that would in any way imply that this was from the infertility clinic.

All they said was, "Dear so-and-so, we have information to say that you were in contact with our hospital during these years, 1982 to 1984. Please contact this person." They would get a note from the post office saying they had a parcel to collect. They would have to go there and present identification to receive that letter. As I explained, the letter would have no information if they left it lying around their house and their wife picked it up.²⁰⁷

²⁰⁵ Submission 14, The Fertility Society of Australia, pp 9-15

²⁰⁶ Ms Montrone, transcript of evidence, 29 April 2013, p 20

²⁰⁷ Ms Geraldine Hewitt, transcript of evidence, 6 May 2013, p 21

- 5.54 Associate Professor Mark Bowman, President of the Fertility Society of Australia, discussed the donor linking program currently conducted by the Royal Prince Alfred Hospital. Dr Bowman noted that when linkages have occurred they have been positive. However, Dr Bowman commented there were sometimes obstacles from within their own hospital and noted that provision of donor linking services by an independent authority would be preferable:

We have tried to introduce donor linkage in specific cases. It is usually but not always driven primarily by the recipients and the offspring first and then with some kind of link back to the donor. Sometimes it is actually driven the other way. It has been our experience that when those linkages one way or another have occurred, they have been fairly positive. The challenges have been in our own unit.

There has been a lot of intransigence at different levels and from different sides, because different members of different departments have different opinions. Although it is not our own personal experience, when we then go and look at, for example, Victoria, where there is an independent authority, that has taken some of those individual views out of it...the argument for an independent authority is quite good.²⁰⁸

- 5.55 Some private ART clinics also offer donor linking, such as the voluntary Donor Siblincs program run by IVF Australia. Donor Siblincs is available only to patients of IVF Australia and provides patients who have used donor programs the opportunity to access more details about the number of families and children that have been conceived using the same donor, contact between half-siblings and their families if both parties consent, counselling and support, and the opportunity for donors to provide updated non-identifying information.²⁰⁹
- 5.56 Many inquiry participants commended the Victorian model of donor linking, practiced by the former ITA. Professor Millbank commented that the ITA method of donor linking could be developed into a model for an active register in New South Wales.²¹⁰
- 5.57 The VARTA research report showed that there was clear agreement among research participants that approaches from donor conceived people to their donors should be mediated by experts with relevant professional experience.²¹¹

Counselling

- 5.58 The majority of inquiry participants agreed that counselling was an essential component of support for people seeking donor conception information, and that counsellors need to have skills particular to the issues encountered in donor conception. Counselling is necessary for people in a range of situations relating to donor conception, not only when accessing information, but also when first finding out about the manner of their conception. The Committee heard that those who find out later in life that they are donor conceived often require

²⁰⁸ Associate Professor Mark Bowman, transcript of evidence, 29 April 2013, p 33

²⁰⁹ IVF Australia Donor Siblincs, viewed 13 June 2013, <<http://www.ivf.com.au/donor-siblincs>>

²¹⁰ Professor Millbank, transcript of evidence, 6 May 2013, p 39

²¹¹ Victorian Assisted Reproductive Treatment Authority, *Consultation with donors who donated gametes in Victoria, Australia before 1988: Access by donor conceived people to information about donors*, 2013, p 7

counselling support as they grieve the loss of their prior belief about their genetic heritage and come to terms with their new knowledge.²¹²

- 5.59 The Senate Legal and Constitutional Affairs References Committee's report *Donor Conception Practices in Australia* recommended that guidelines or requirements be developed to ensure that counsellors involved in supporting people who seek access to donor conception information understand the issues involved with donor conception. Recommendation 27 of the report states:

The committee recommends that State and Territory governments, in consultation with the Fertility Society of Australia, should develop guidelines or requirements to ensure that counsellors providing counselling to donors, donor recipients or donor conceived individuals have an appropriate understanding of the issues involved with donor conception.²¹³

- 5.60 Ms Lauren Burns submitted that counsellors needed to be trained in the issues particular to donor conception, and cautioned against provision of counselling by fertility counsellors:

Ideally the counsellor should have professional experience in dealing with disenfranchised grief and the losses associated with separation from family of origin through donor conception, adoption or family breakdown. I believe it is a mistake to assume that all fertility counsellors, who have previously counselled infertile people seeking to have a baby will have an understanding of the issues faced by donor conceived people ... Counsellors could be recruited with relevant experience or undergo professional training.²¹⁴

- 5.61 The Donor Conception Support Group emphasised the need for specialised counsellors and noted that ART clinic counsellors were more often trained in fertility issues than donor conception issues.²¹⁵

- 5.62 Ms Burns told the Committee that the knowledge and experience of organisations such as VARTA and the Post Adoption Resource Centre who have expertise in donor linking and post-adoption counselling could be drawn on for counselling donor conceived people.²¹⁶

- 5.63 In other jurisdictions neither the Reproductive Technology Council of Western Australia nor the Human Fertilisation and Embryology Authority (HFEA) in the UK offer counselling services. However, both provide links to professional support on their websites. In contrast to this, the same agency in the Netherlands that maintains the voluntary donor register also provides counselling services.

DNA testing

- 5.64 The Committee received evidence that DNA testing could be a useful additional support measure for those people seeking donor conception information in circumstances where their records were incomplete or had been destroyed. It

²¹² Submission 20, International Social Service Australia, p 5

²¹³ Submission 40, Australian Government, p 14

²¹⁴ Submission 6, Ms Lauren Burns, p 9

²¹⁵ Submission 5, Donor Conception Support Group, p 20

²¹⁶ Submission 6, Ms Burns, p 9

heard that DNA testing has been used successfully in other jurisdictions, including Victoria and the United Kingdom.²¹⁷

- 5.65 In the United Kingdom, a voluntary register known as the *Donor Conceived Register* exists for those people who donated or were conceived through donor conception prior to the introduction of mandatory donor identification in 1991. People who wish to register are strongly advised to have a sample of genomic DNA taken, at their own cost. The Donor Conceived Register will not confirm genetic relationships unless both parties have provided a DNA sample.²¹⁸
- 5.66 The Netherlands also administers a DNA register, held by FIOM/ISS, a national social work agency. The DNA Register is available for donors and donor conceived people who were conceived prior to the end of donor anonymity on 1 June 2004. Donors and donor conceived people pay for the DNA test themselves. In addition to managing the DNA Register, FIOM/ISS provides intermediary and support services for people who wish to access information on either the DNA Register or the register. FIOM have provided intermediary and support services for more than 20 years and this system is considered to be very effective.²¹⁹
- 5.67 NSW Health does not currently offer DNA testing as part of the Voluntary Register. Ms Leanne O’Shannessy, General Counsel and Director, NSW Ministry of Health, cautioned that the introduction of DNA information on databases such as the Central Register would require strong and complex processes, including an appropriate legislative or guidelines regime.²²⁰
- 5.68 The federal Senate Legal and Constitutional Affairs References Committee report, *Donor Conception Practices in Australia*, recommended that voluntary registers incorporate a DNA databank so that in circumstances where records had been destroyed, both donor and donor conceived individuals could have their details recorded. Recommendation 12 stated:
- The committee recommends that any voluntary registers incorporate a DNA databank, to enable donors and donor conceived individuals to have their details placed on the register for possible matching, in circumstances where records relating to their identities have been destroyed.²²¹
- 5.69 In its response to the report, the Australian government supported this recommendation in principle.²²²

²¹⁷ Professor Millbank, transcript of evidence, 6 May 2013, p 43

²¹⁸ The Donor Conception Register, viewed 8 July 2013, <<http://www.donorconceivedregister.org.uk>.

²¹⁹ Dr Sonia Allan, *A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor Conceived People*, 2012, pp 21-33

²²⁰ MS Leanne O’Shannessy, General Counsel and Director, NSW Ministry of Health, transcript of evidence, 6 May 2013, p 13

²²¹ Senate Legal and Constitutional Affairs References Committee report, *Donor Conception Practices in Australia*, 2011, viewed 25 July 2013, <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=legcon_ctte/completed_inquiries/2010-13/donor_conception/report/b02.htm>

²²² Submission 40, Australian Government, p 14

Committee Comment

- 5.70 The Committee is aware that some donor conception records have been destroyed and that it will be impossible for people to obtain their original records from ART clinics. For this reason the Committee recommends that the Register provide DNA testing or a DNA matching service. This, along with a public awareness campaign may increase the likelihood that people whose records were destroyed are able to obtain information on their genetic heritage.
- 5.71 The Committee recognises that the support needs of people seeking access to donor conception information will vary from person to person. For this reason, the Committee recommends that the agency established to manage the Register of donor conception information offer a broad suite of support services.
- 5.72 It is the Committee's opinion that when the agency that manages the Register of donor conception information is established, a public awareness campaign will be vital to inform the community of the agency, the Register and the associated support services available.

RECOMMENDATION 12

The Committee recommends that the services provided by the agency established to manage the Register of donor conception information include public awareness campaigns, community education, intermediary support, counselling, DNA testing, and the facilitation of contact where this is desired by both parties.

RECOMMENDATION 13

The Committee recommends that the agency established to manage the Register of donor conception information conduct an advertising campaign to raise awareness of the Register and associated services available, such as intermediary support, counselling and DNA testing.

Appendix One – List of Submissions

1	Mr John Lindsay Mayger
2	Name suppressed
3	Confidential
4	Mr Damian Adams
5	Donor Conception Support Group of Australia
6	Ms Lauren Burns
7	Professor Jenni Millbank
8	International Donor Offspring Alliance
9	Mr Michael Sobb
10	Dr Sonia Allan
11	Name suppressed
12	Ms Amy Corderoy
13	Mrs Christine Whipp
14	Fertility Society of Australia
15	Commission for Children and Young People
16	Name suppressed
17	Ms Miranda Montrone
18	NSW Government
19	Life, Marriage and Family Centre
20	International Social Service Australia
21	NSW Committee on Adoption and Permanent Care Inc
22	Ms Myfanwy Cummerford
23	Fertility East
24	Human Fertilisation and Embryology Authority, United Kingdom
25	Andrology Department, Concord Hospital
26	Solo Mothers by Choice Australia
27	Confidential
28	Confidential
29	Name Suppressed
30	Australian Christian Lobby
31	Ms Cheryl Fletcher

MANAGING DONOR CONCEPTION INFORMATION
LIST OF SUBMISSIONS

31a	Ms Cheryl Fletcher
32	Ms Del Purcell
33	Plunkett Centre for Ethics
34	The Hon Greg Donnelly MLC
35	Fertility First
36	Information and Privacy Commission
37	The Law Society of New South Wales
38	Reproductive Technology Council, Western Australia
39	Australian Medical Association (NSW) Ltd
40	Australian Government

Appendix Two – List of Witnesses

29 April 2013, Waratah Room, Parliament House

Witness	Position and Organisation
Confidential	<i>Private citizen - closed session</i>
Ms Sharon Swinbourne	Assistant Registrar, Registration Services
Ms Lisa Karam	Manager, Amendments <i>Registry of Births, Deaths and Marriages</i>
Mr John Dobson	President
Mr Jason Goode	Member, Elder Law and Succession Committee
Ms Margaret Linden	Member, Family Issues Committee <i>The Law Society of NSW</i>
Ms Miranda Montrone	Psychologist <i>The Counselling Place</i>
Associate Professor Mark Bowman	President
Ms Elizabeth Hurrell	Representative of Australian and New Zealand Counsellors Association <i>Fertility Society of Australia</i>

6 May 2013, Waratah Room, Parliament House

Witness	Position and Organisation
Ms Fiona Hearne Ms Sharon Hunt Ms Cheryl Fletcher	<i>Solo Mums by Choice Australia</i>
Dr Sonia Allan	Senior Lecturer in Law <i>Deakin University</i>
Ms Geraldine Hewitt Ms Caroline Lorbach	National Consumer Advocate <i>Donor Conception Support Group of Australia</i>

MANAGING DONOR CONCEPTION INFORMATION
LIST OF WITNESSES

Ms Leanne O'Shannessy	General Counsel and Director, Legal and Regulatory Services
Mr Greg McAllan	Associate Director, Private Health Care <i>NSW Health</i>
Professor Jenni Millbank	Professor, Faculty of Law <i>University of Technology, Sydney</i>
Professor David Handelsman	Director <i>Andrology Department, Concord Hospital</i>
Mr Damon Martin	<i>International Social Service Australia</i> <i>NSW Committee on Adoption and Permanent Care Inc</i>
Dr Joel Bernstein	Medical Director <i>Fertility East</i>
Ms Amy Corderoy	<i>Private citizen</i>

Appendix Three – Extracts from Minutes

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 15)

9.37am, Thursday 15 November 2012
Room 1153, Parliament House

Members Present

Mr Barilaro (Chair), Mr Edwards, Mr Rowell, Mr Zangari, Mr Lalich

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravec, Ms Clara Hawker, Ms Jenny Whight

1. Apologies

No apologies have been received.

2. Confirmation of minutes

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the minutes of the deliberative meeting of 20 September 2012 be confirmed.

3. Forward planning

Issues Paper

The Committee discussed the issues paper.

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the issues paper be published and uploaded onto the Committee website.

Terms of Reference

The Committee discussed the draft terms of reference for the inquiry.

Resolved, on the motion of Mr Zangari, seconded by Mr Edwards, that the Committee inquire into and report on the management of information related to donor conception in NSW.

Inquiry Timeline

The Committee noted the indicative timeline for the conduct of the inquiry and the completion of the report.

Call for submissions – advertising and writing to stakeholders

The Committee discussed the media strategy.

Resolved, on the motion of Mr Rowell, that the Committee advertise the call for submissions to the inquiry in *Sydney's Child* and on the Committee website, and write to relevant stakeholders with a closing date of 15 February 2013. The Committee will advertise in the *Sydney Morning Herald* in stage two of the media strategy if this is necessary.

Media Statements

The Committee discussed the media release and the Chair advised that it will be published on the Committee website and sent to media outlets.

4. General Business

The Committee adjourned at 9.43am until a date and time to be determined.

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 16)

1.35pm, Tuesday 12 March 2013

Room 1153, Parliament House

Members Present

Mr Barilaro (Chair), Mr Rowell, Mr Zangari, Mr Lalich

Officers in attendance: Ms Rachel Simpson, Ms Clara Hawker, Ms Jenny Whight

5. Apologies

No apologies have been received.

6. Confirmation of minutes

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari: That the minutes of the deliberative meeting of 15 November 2012 be confirmed.

7. Inquiry into managing information related to donor conception

a) Submissions – consideration of and approval for publication

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari: That submissions:

1, 4, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39 will be published;

That submissions: 2, 11, 16, 29 be published, with names and identifying details suppressed;

That submissions: 3, 27 and 28 remain confidential.

b) Public hearing arrangements

Resolved, on the motion of Mr Zangari, seconded by Mr Rowell: That the following witnesses be invited to give evidence on Monday 29 April or Monday 6 May 2013:

- NSW Government
- Federal Attorney General
- Prof Jenni Millbank

- Dr Sonia Allen
- Fertility Society of Australia
- Fertility East
- Andrology Department, Concord Hospital
- NSW Committee on adoption and permanent care
- Solo Mothers by Choice
- Fiona Hearne
- ***
- ***
- Amy Corderoy
- Law Society of NSW

8. Forward planning

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell: That, given the difficulty experienced by the Committee in this and the previous Inquiry in obtaining information from gamete donors, the Chair seek approval for funding to engage an external consultant to undertake research with donors to assess their views on managing donor information. This will enable the Committee to make recommendations based on all stakeholder views.

9. General Business

The Committee adjourned at 1.52pm until a date and time to be determined.

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 17)

11:02am, Monday 29 April 2013

Waratah Room, Parliament House

Members Present

Mr Barilaro (Chair), Mr Edwards, Mr Lalich, Mr Zangari

Officers in attendance: Abi Groves, Clara Hawker, Jenny Whight, Millie Yeoh

1. Apology

An apology was received from Mr Rowell.

2. Confirmation of minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That the minutes of the deliberative meeting of 12 March 2013 be confirmed

3. Inquiry into managing donor conception information

a) Media orders

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari: That the Committee authorise the audio-visual recording, photography and broadcasting of the public hearing on 29 April 2013 in accordance with the NSW Legislative Assembly's guidelines for coverage of proceedings for parliamentary committees administered by the Legislative Assembly.

b) Publication orders

1) In camera evidence

Resolved, on the motion of Mr Zangari, seconded by Mr Edwards: That the transcript of in-camera evidence given today not be corrected by the witness as described in Standing Order 293, and any portion which is determined to be used as evidence, will be paraphrased and approved by the witness prior to publication.

2) Public evidence

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari: That the corrected transcript of evidence given today be authorised for publication and uploaded on the Committee's website.

3) Answers to questions on notice

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich: That witnesses be asked to return answers to questions taken on notice and supplementary questions within 2 weeks of the date on which the questions are forwarded to the witness.

4) Submissions

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That the Committee authorise publication of submission no. 40.

c) Correspondence

The Committee noted the incoming correspondence from the Hon. David Davis, MP, Victorian Minister of Health, dated 5 March 2013.

d) Forward planning

The Committee deliberated on the need to reach donors in order to hear their views, as the Committee has received only one submission to the inquiry from a donor. The Committee agreed to request the assistance of fertility clinics and the Fertility Society of Australia in contacting donors.

e) In-camera hearing

The Chair opened the in-camera hearing at 11:15am.

A private citizen, affirmed and examined. The Chair welcomed the witness and commenced questioning, followed by other members of the Committee. The witness gave evidence via telephone, pursuant to Standing Order 295.

Evidence concluded. The Chair thanked the witness for their evidence.

f) Public hearing

The press and public were admitted.

The Chair opened the public hearing at 11:54am and after welcoming the witnesses made a brief opening statement.

Ms Sharon Swinbourne, Assistant Registrar, Registration Services, Registry of Births, Deaths and Marriages, and Ms Lisa Karam, Manager, Amendments, Registry of Births, Deaths and Marriages, both sworn and examined. Evidence concluded. The witnesses withdrew.

The Committee took an adjournment at 12:40pm and resumed the public hearing at 1:44pm.

Ms Margaret Linden, Member, Family Issues Committee, The Law Society of NSW, affirmed and examined. Mr John Dobson, President, The Law Society of NSW, and Mr Jason Goode, Member, Elder Law and Succession Committee, The Law Society of NSW, both sworn and examined. Evidence concluded. The witnesses withdrew.

The Committee took an adjournment at 2:25pm and resumed the public hearing at 2:45pm.

Ms Miranda Montrone, Psychologist, sworn and examined. Evidence concluded. The witness withdrew.

Ms Elizabeth Hurrell, Counsellors Association, Fertility Society of Australia, and Associate Professor Mark Bowman, President, Fertility Society of Australia, both affirmed and examined. Evidence concluded. The public and witnesses withdrew.

The public hearing concluded at 4:22pm.

g) Deliberative meeting

The Committee commenced a deliberative meeting at 4:25pm. Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That the Committee write to the Fertility Society of Australia regarding facilitating contact between donors and the Committee.

The Committee adjourned at 4:27pm until Monday 6 May 2013 at 9.30 am.

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 18)

9:33am, Monday 6 May 2013

Waratah Room, Parliament House

Members Present

Mr Barilaro (Chair), Mr Edwards, Mr Lalich, Mr Zangari

Officers in attendance: Abi Groves, Clara Hawker, Jenny Whight, Millie Yeoh

1. Apology

An apology was received from Mr Rowell.

2. Confirmation of minutes

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari: That the minutes of the deliberative meeting of 29 April 2013 be confirmed.

3. Inquiry into managing donor conception information

h) Media orders

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich: That the Committee authorise the audio-visual recording, photography and broadcasting of the public hearing on 6 May 2013 in accordance with the NSW Legislative Assembly's guidelines for coverage of proceedings for parliamentary committees administered by the Legislative Assembly.

i) Publication orders

5) Public evidence

Resolved, on the motion of Mr Lalich: That the corrected transcript of evidence given today be authorised for publication and uploaded on the Committee's website.

6) Answers to questions on notice

Resolved, on the motion of Mr Edwards: That witnesses be asked to return answers to questions taken on notice and supplementary questions within 2 weeks of the date on which the questions are forwarded to the witness.

j) Public hearing

The press and public were admitted.

The Chair opened the public hearing at 9.35am and after welcoming the witnesses made a brief opening statement.

Ms Fiona Hearne, senior member, Solo Mums by Choice Australia, sworn and examined. Ms Sharon Hunt, President, Solo Mums by Choice Australia, and Dr Cheryl Fletcher, senior member, Solo Mums by Choice Australia, both affirmed and examined.

Dr Fletcher tendered her thesis entitled *The Stories of Australian Single Mothers by Choice Through Donor Conception* for the information of the Committee.

Evidence concluded. The witnesses withdrew.

Dr Sonia Allan, Senior Lecturer in Law, Deakin University, sworn and examined.

Evidence concluded, the witness withdrew.

The Committee took an adjournment at 10:53am and resumed the public hearing at 11:15am.

Ms Geraldine Hewitt, private citizen, affirmed and examined, and Ms Caroline Lorbach, National Consumer Advocate, Donor Conception Support Group of Australia, sworn and examined. Evidence concluded, the witnesses withdrew.

Ms Leanne O'Shannessy, General Counsel and Director, Legal and Regulatory Services, NSW Ministry of Health, and Mr Greg McAllan, Associate Director, Private Health Care, NSW Ministry of Health, both affirmed and examined. Evidence concluded, the witnesses withdrew.

The Committee adjourned for lunch at 12:36pm and resumed the public hearing at 1:15pm.

Professor Jenni Millbank, Professor, Faculty of Law, University of Technology Sydney, affirmed and examined. Evidence concluded, the witness withdrew.

Professor David Handelsman, Director, Andrology Department, Concord Hospital, affirmed and examined. Evidence concluded, the witness withdrew.

Mr Damon Martin, International Social Service Australia and NSW Committee on Adoption and Permanent Care, affirmed and examined. Mr Martin tendered a document for the information of the Committee. Evidence concluded, the witness withdrew.

The Committee took an adjournment at 3:07pm and resumed the public hearing at 3:45pm.

Dr Joel Bernstein, Medical Director, Fertility East, affirmed and examined. Evidence concluded, the witness withdrew.

Ms Amy Corderoy, private citizen, affirmed and examined. Evidence concluded, the witness and the public withdrew.

The public hearing concluded at 4:55pm.

k) Post-hearing deliberative meeting

The Committee commenced a deliberative meeting at 4:59pm.

a. ****

b. Consideration of acceptance and publication of tendered documents

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That the Committee accept the thesis entitled *The Stories of Australian Single Mothers by Choice Through Donor Conception* by Dr Cheryl Fletcher, tendered during the public hearing.

Resolved, on the motion of Mr Zangari, seconded Mr Lalich: That the Committee accept the document authored by Mr Damon Martin of International Social Service Australia, tendered during the public hearing.

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari: That the Committee publish the thesis entitled *The Stories of Australian Single Mothers by Choice Through Donor Conception* tendered by Dr Cheryl Fletcher.

The Committee adjourned at 5:02pm until a date and time to be determined.

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 19)

12:07pm, Tuesday 25 June 2013

Room 1153, Parliament House

Members Present

Mr Barilaro (Chair), Mr Edwards and Mr Rowell; and
via teleconference: Mr Lalich and Mr Zangari.

Officers in attendance: Ms Helen Minnican, Dr Abi Groves, Ms Clara Hawker, Ms Jessica Falvey,
Ms Jenny Whight

1. Confirmation of minutes

Resolved, on the motion of Mr Edwards, seconded by Mr Rowell: That the minutes of the deliberative meeting of 6 May 2013 be confirmed.

2. ***

3. Inquiry into managing donor conception information

a) Correspondence

The Committee noted the incoming correspondence from:

- Professor David Handelsman, Andrology Unit, Concord Hospital, dated 20 May 2013
- Ms Caroline Lorbach, Donor Conception Support Group, dated 28 May and 12 June 2013
- Ms Leanne O'Shannessy, Director, Legal and Regulatory Services, NSW Health, dated 3 June 2013
- Dr Sonia Allan, Deakin University, dated 14 May 2013

b) Forward Planning

The Chair opened discussion on the main issues that had arisen during the inquiry, as outlined in a paper prepared by Committee staff.

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell: That Committee staff draft a report on the Inquiry into managing donor information in consultation

with the Chair, to reflect the outcomes of the discussion as agreed by the Committee at the deliberative meeting on 25 June 2013.

The Committee adjourned at 1:03pm until a date and time to be determined.

Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 22)

1.35pm, Tuesday 15 October 2013
Room 1254, Parliament House

Members Present

Mr Barilaro, Mr Edwards, Mr Lalich, Mr Spence and Mr Zangari

Officers in attendance: Ms Helen Minnican, Dr Abigail Groves, Ms Clara Hawker, Ms Jenny Whight

1. ***

2. ***

3. Confirmation of minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That the minutes of the deliberative meeting of 30 August 2013 be confirmed.

4. ***

5. Inquiry into managing donor conception information

5.1 Correspondence received

The Committee noted the following item of correspondence received:

- 7 July 2013 from Registrar, Registry of Births, Deaths and Marriages, regarding the Registry's review of the content of birth certificates

5.2 Consideration of Chair's draft report

The Chair spoke to the draft report, previously circulated. Discussion ensued.

The Committee agreed to consider the report chapter by chapter.

Chapter one, read and agreed to.

Chapter two, read and agreed to.

Chapter three, read and agreed to.

Chapter four, read and agreed to.

Chapter five, read and agreed to.

Appendices one, two and three, read and agreed to.

Executive summary, read and agreed to.

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich: That the draft report be the report of the Committee, signed by the Chair and presented to the House.

Resolved, on the motion of Mr Edwards, seconded by Mr Lalich: That the Chair and secretariat be permitted to correct stylistic, typographical and grammatical errors.

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari: That, once tabled, the report be posted on the Committee's website.

6. Adjournment

The Committee adjourned at 1.45pm *sine die*.