Submission No 10

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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The Chair,
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Dear Mr Barilaro and members of the Committee,

I thank you for your invitation to make a submission to your current inquiry into managing information related to donor conception. As a legal academic and researcher who has, for over a decade, worked on these particular issues I am grateful for the opportunity to contribute to your inquiry.

I note, for your information, that I am not donor conceived, I am not a donor, and I am not a recipient parent. I was, however, first struck by the issues faced by donor-conceived people and their call for access to information when asked to work on a reference for the Victorian Law Reform Commission on access to assisted reproductive technologies in 2003. I have examined the issues related to information release ever since. I have over the past decade of working in the area come to know donor conceived people, donors, and recipient parents, and have significant knowledge of all parties seeking the ability to exchange information.

My submission will address the questions raised in the issues paper you provided to me 'Issues Paper: Managing Information Related to Donor Conception' (November 2012), and provide you with information and views based upon my research in the area. In summary it is my submission that:

1) All donor-conceived people should be able to access information about their donors, , if they wish to do so, regardless of when they were conceived;
2) A system should be put into place that allows people to lodge contact vetoes, contact preferences and advance notice requests, to balance the 'privacy interests' of the respective parties involved. This would allow for information release, while protecting the intimate sphere of a person's daily life should they not wish for contact to occur;
3) Management of releasing information to donor-conceived people about their donors should be done sensitively.

    a. It should involve significant lead times to allow all records concerning donor conception (held at clinics, hospitals or doctors surgeries) to be moved to the register; and to allow donors to lodge pre-emptive contact vetos or preference statements if they wish.
    b. Once records are at the register, and people can lodge information applications, the process should involve contact with the donor (where possible), when a request has been made for information, to discuss that a request for information has been made, and the options of contact vetoes, preferences and advance notices.

4) It would be prudent to explore the option of having a stand-alone body that would be responsible for maintaining the donor register; liaising with donors, donor-conceived people, siblings, recipient parents, (and clinics, infertility counsellors, etc); providing public education about assisted reproductive technologies; and whose functions might relate to other areas of assisted reproduction also (eg. policy and practice). Such a body may have a designated staff member who provides support/intermediary services, or it could refer people to 'approved counsellors/intermediary services' in relation to information release and contact vetos. In either case, support/intermediary services should be provided by people who have specialist knowledge and experience working in the field of assisted reproduction. While there are similarities regarding searching for information to adoptees, the experience of donor conception is significantly different enough to require specialist knowledge of this area. The best practice model for this was that of the former Victorian Infertility Treatment Authority's donor-linking program.
5) Nevertheless, while having a stand-alone body may be the preferred model (due to effectiveness and efficiency), the provision of information to donor-conceived people, and the implementation of a contact veto system is not reliant upon such a body existing.
6) Regardless of the decision made by the committee/government regarding retrospective release of information, all records related to donor conception should be transferred to the register – to ensure that they are not lost or destroyed. A prohibition should also be enacted to prevent intentional destruction of donor conception records.

I hope my submission is helpful to your inquiry.

Kind regards,

Sonia Allan

SUBMISSION TO THE NSW LEGISLATIVE ASSEMBLY'S COMMITTEE ON LAW AND SAFETY INQUIRY INTO

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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i. INTRODUCTION

The use of donor sperm to achieve pregnancy has reportedly existed for centuries. However, since the early 1950s its existence became better known and from the 1970s its use greatly increased. Technological advances further increased the occurrence of donor conception in Australia with the first in-vitro fertilisation ('IVF') procedure in Australia occurring in 1979, and the first IVF baby born in June 1980. Since then numerous assisted reproductive technologies (ART) and practices have been developed (including gamete intra-fallopian transfer ('GIFT'), zygote intra-fallopian transfer ('ZIFT'), intracytoplasmic single sperm injection ('ICSI'), and surrogacy). All of these may involve the use of donor oocytes, embryos or sperm, and take place within the clinic system with ART specialists, counsellors and other professional staff involved in the process using ART to attempt to conceive a child.

The use of ART in Australia continues to increase—for example, the Australian Institute of Health and Welfare ('AIHW') Perinatal Statistics Unit 2008 report states '[t]here were 10,522 babies born to women who had fertility treatment in 2006. This was a 5% increase on 2005.'[1] While the majority of treatments involve the use of fresh or frozen non-donor gametes (eggs and sperm), there were 354 live births following embryo transfers which involved oocytes/embryo donation and 278 live deliveries of children who were conceived using donor insemination in 2006. These figures do not include DI cycles undertaken in hospitals or private clinics that are not fertility clinics. They also do not include the situation in which 'known donors' are used. Given the recorded figures, if at an estimate there has been an average of 600 births per year since the early 70s in which donor gametes were used to conceive, this would amount to approximately 20,000 donor-conceived people living in Australia. However, donor support groups estimate the figure to be closer to 60,000[2] if one includes those individuals that were conceived with the assistance of a GP or outside of the clinic system.

In most jurisdictions in Australia, both identifying and non-identifying information about donors remains unknown to both the recipient parents and the donor-conceived individual in particular due to the secrecy that surrounded donor conception in the past. Such secrecy was often closely linked to family angst about infertility, and doctors trying to assist such families to have children. Recipient parents were told they should not seek information about the donor, and donors were told they should not seek information about the recipient parents or the resultant child. Where heterosexual couples were involved, it has been reported that it was often easier for parents simply not to tell the resultant child they were donor conceived either because of their shame about their own battles with infertility, their fears of being rejected by the resultant child, or because despite their desire to tell their child, they were frustrated by having no way of imparting further information about the donor.

The secrecy does not appear at all to have been ill intended—that is, all involved may have believed that what they were doing was best for the donor-conceived person. However, we are learning, as some of the donor-conceived people born to these families are now reaching adulthood, and having families of their own, that the effects of such secrecy, and being denied access to information about their genetic heritage, have had significant negative impacts for some

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[1] YA Wang, JH Dean, T Badgery-Parker & EA Sullivan, *Assisted reproduction technology in Australia and New Zealand 2006,* (2008). Assisted reproduction technology series no. 12. AIHW cat. no. PER 43. Sydney: AIHW National Perinatal Statistics Unit.

[2] See for example the Donor Conception Support Group, http://www.dcsg.org.au/legislation/inquiry.html at 24 July 2010.

donor-conceived people. There has therefore been a move towards encouraging disclosure and away from secrecy amongst all families that access ART.

In New South Wales, From 1 January 2010 identifying information has been held on a register maintained by the NSW Department of Health. Donor-conceived people may access this information when they turn 18. A voluntary register is also maintained by the NSW Department of Health, upon which information will only be disclosed in accordance with the consent of the person who has entered information upon the register.

The issue for this submission is whether New South Wales should review its laws to allow for access to information by donor-conceived people about their donors regardless of when they were conceived. The submission also addresses how such information should be managed and released, and issues regarding the provision of support services. It further examines whether a standalone body should be established to oversee assisted reproductive technology practices in New South Wales.

ii. RETROSPECTIVE RELEASE OF INFORMATION:

a) The importance of exchanging information for donor-conceived people, recipient parents, and donors

There are numerous arguments that support the call for access to information by donor-conceived people about their donors.[3] These arguments are being voiced more often as the number of affected individuals who are demanding information increases as donor-conceived people enter adulthood, and some have families of their own. We should also anticipate that there are potentially thousands (if not tens of thousands) of individuals who are yet to reach adulthood who may in the future call for information about their donors. The following reiterates arguments drawn from the papers I refer you to in Appendix 1.

Development of Identity and Sense of Self

While academic literature has increasingly emphasised that relations based on blood are less important in shaping a child's development than previously thought, some donor-conceived people

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[3] For detailed discussion of the issues and arguments, I refer the committee to the reports and articles listed in Appendix 1.

report that on discovering they are not biologically related to their parent(s), that they feel a sense of "lost identity" and a corresponding desire to know more about their donor.[4] This has been referred to as "genealogical bewilderment".[5] We can no longer therefore accept arguments that assume that because donor-conceived people were 'wanted' by their parent(s), and the donor was only acting to 'help' those parent(s) conceive, that a donor-conceived person has no interest or rights to access information about their biological heritage. This is particularly so as a person's development of identity is viewed as fundamental to a sense of self.[6]

Further, the curiosity about their donor and the propensity for donor-conceived people to search for information is not related to the desire to escape negative family issues; rather, most donor-conceived people report positive relationships with their parents.[7] On the other hand, such feelings coexist with a strong desire to know about one's donor and frustration at being denied information;[8]

Medical History

There is great importance for having access to information concerning a biological parent's medical history (eg whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases).[9] Donor-conceived people who are denied access to familial medical histories are placed at increased risk as a result of not having access to information about their genetic heritage. This becomes very significant as people age. For example, a donor who donated in the 1970s or 1980s, when donor-conception was shrouded in secrecy, may

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[4] A. Turner and A. Coyle, "What Does it Mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Human Reproduction* 2041; Jadva V, Freeman T, Kramer W and Golombok S, "Experiences of Offspring Searching for and Contacting their Donor Siblings and Donor" (2010) 20 *Reproductive BioMedicine Online* 523 at 524.

[5] Turner and Coyle, n 4; E. Wellisch, "Children without Genealogy: A Problem with Adoption" (1952) 13(1) *Mental Health* 41; H. Sants, "Genealogical Bewilderment in Children with Substitute Parents" (1964) 37(2) *British Journal of Medical Psychology* 133. Such bewilderment may be particularly acute for people who discover later in life that they were donor-conceived.

[6] Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013); Richard Chisholm, 'Information rights and donor conception: Lessons from adoption?' (2012) 19(4) *Journal of Law and Medicine* 722; Eric Blyth, Marily Crawshaw, Lucy Frith and Caroline Jones, 'Donor-conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence' (2012) 19(4) *Journal of Law and Medicine* 769; Naomi Cahn, 'Legal parent versus biological parent: The impact of disclosure' (2012) 19(4) *Journal of Law and Medicine* 790.

[7] Mahlstedt PP, LaBounty K and Kennedy WT, "The Views of Adult Offspring of Sperm Donation. Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States" (2010) 93(7) *Fertility and Sterility* 2236.

[8] Turner and Coyle, n 4; Dennison M, "Revealing Your Sources: The Case for Non-anonymous Gamete Donation" (2008) 21(1) *Journal of Law and Health* 1 at 13.

[9] Centers for Disease Control and Prevention (CDC), "Awareness of Family Health History as a Risk Factor for Disease" (2004) 53(44) Morb Mortal Wkly Rep 1044.

not until more recently have become aware that they are a carrier of certain diseases. Similarly, a donor-conceived individual may become aware of a heritable condition, but has no way presently to notify their donor(s) or half-siblings conceived using the same donor gametes. This may have ramifications not just for the person unaware of such information but for generations to come. (On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected in Australia – clear legislation permitting the release of information about the donor is therefore needed);

Risk and Fear of forming Consanguineous Relationships

Some donor-conceived people report the fear of unknowingly forming relationships with siblings or possibly their unknown donor.[10] While the actual probability of such an occurrence is unknown (as the actual number of donor-conceived people is unknown), such a risk

- may be significant within Australia, given the small population and the significant number of donor-conceived people in existence;
- may have legal ramifications – see for example, the *Marriage Act 1961* (Cth) which makes unlawful marriages between an individual and their parent, and an individual and their half-sibling; [11]
- may result in children being born to couples who are related, and therefore an increased risk of genetic or chromosomal difficulties in those children;[12]

Equality

The law, across Australia, and within jurisdictions (including New South Wales), treats donor-conceived people differently depending upon *where* a donor-conceived person was born and *when* their donor's gamete donation took place.

For example, in New South Wales, only those donor-conceived people born after 2010 will be able to access identifying information about their donor when they turn 18 (provided the donor also donated after 2010). Other donor-conceived people must rely on the voluntary register, and hope that their donor also places his/her name upon it, in a hope to find information. That donor-

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[10] Senate Legal and Constitutional Affairs References Committee, Submission 156 (M Crawshaw) p 7.

[11] *Marriages Act 1961* (Cth), s 23(1)(b), makes marriages involving "prohibited relationships" void. Section 23(2)(a)-(b) states that "marriages between an individual and their parent and an individual and their sibling, including half siblings" are "prohibited relationships".

[12] Bennett RL, Motulsky AG, Bittles A et al, "Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors" (2002) 11(2) *Journal of Genetic Counseling* 97. The authors, in recognising the risk associated with forming consanguineous relationships, recommend genetic counselling and screening for consanguineous couples and their offspring. Donor conceived people who are unaware of their relatedness to others would not have the opportunity to undergo such counselling/screening.

conceived people are not granted automatic entitlement to information has led to some stating that they are being discriminated against. Such claims often also look to the law long since having recognised the need for information about biological heritage in for other people:

a) adoptees (which has involved the laws being enacted to permit retrospective release of information to adoptees about their birth parents),[13]

b) people whose paternity is at issue (where the law allows for orders to be made for DNA testing to establish paternity),

c) indigenous people, including—but not limited to--the stolen generation, and their interests and rights to know their cultural and biological heritage.

The Impact on Families

Denying access to information about donors also impacts upon recipient parents. Parents of donor-conceived people are prevented from being able to provide their children with information that many actually desire to impart. Some report wanting to be able to be open and honest with their children, but at a complete loss when they cannot tell their child anything other than that they were donor-conceived. It is natural in response to such disclosure for a child to then ask questions about who the donor was.

For some families, the lack of information may lead them to decide to keep the method of conception a secret. This in turn can also add to the stigma parents feel about having had to access assisted reproductive treatment in the first place. For other families, it may be that secrecy about donor conception is not an issue. They tell their children about how they were conceived, but are again at a loss when asked for information. Being able to tell the children that they may access identifying and non-identifying information (at whatever age the law deems suitable) may assist all of these families in having open conversations with their child(ren).

Donors

It is not necessarily the case that past donors wish to remain anonymous.[14] The Donor Conception Support Group quoted in their submission to the Senate Committee Inquiry into the issue a former sperm donor:

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[13] Note the analogy between adoptees and donor conceived people relates to the search for information, and not necessarily the personal experience of being adopted or donor conceived. While there are similarities, there are also significant differences. This is particularly important in recognizing that ‘after-adoption’ services may not be best placed to ‘counsel’ donor conceived people, because the issues faced by them may be significantly different to those faced by other clientele.

[14] Senate Legal and Constitutional Affairs References Committee, Submission 73 (Rainbow Families Council) p 2; Submission 122 (Donor Conception Support Group) p 139.

> I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.[15]

Similarly, the Victorian Assisted Reproductive Treatment Authority (VARTA) stated that the belief that secrecy was paramount to protect all parties to the arrangement was based on myths:

> [T]hat donors would not want to be contacted, that parents would not want to know more about their donor, and that donor-conceived people would not want information about their donor if they really loved their parents.[16]

VARTA stated that "donors do not forget they have donated and often wonder about the people they helped to create. Who are they? Are they healthy? Are they happy? Are they loved?"[17]

Lifting the veil of secrecy and shame that has surrounded donor conception

As access to assisted reproduction has expanded, and our country celebrates and recognises many different family formations, so too should it facilitate the access of those families to information. This is vital, as such information is at risk of being lost or destroyed, eg as clinics or doctors' surgeries close.

Precedent

I note that the idea of releasing information to donor-conceived people about their donors, regardless of when they were conceived, is not new. A number of jurisdictions have recognised it as a human right to know one's genetic heritage. Many have enacted laws that prospectively give donor-conceived people rights of access to information about their donor(s).

The call for retrospective release has gained force as donor-conceived people have reached adulthood and have started to have families of their own.

One country addressed appears to have addressed this call by amending its legislation in 2001. That is, in 1992, Switzerland incorporated into its constitution a guarantee for children born because of donor conception to access to data concerning lineage. The Swiss *Federal Act on Medically Assisted Procreation 1998*, which came into effect in 2001, further provides for access to information by *all* donor-conceived people at age 18 (or earlier where there is a legitimate purpose in obtaining it) about their donor. The access is provided for those conceived with sperm donated

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[15] Senate Legal and Constitutional Affairs References Committee, Submission 122 (Donor Conception Support Group) p 74.

[16] Victorian Assisted Reproductive Treatment Authority.

[17] Victorian Assisted Reproductive Treatment Authority.

both *before*[18] and *after*[19] the Act. The system implemented there requires that those conceived with sperm donated before the legislation must contact clinics, while those conceived with sperm donated after the Act may request information from the Federal Office register. While I have been unable to establish how such laws are operating in practice, it does appear therefore that there is a precedent for following through on the recognition that donor-conceived people have a right to access data concerning their biological heritage.

b) Conditions that should apply to retrospective release of information

In considering the retrospective release of information about donors to donor-conceived people, it is however necessary to consider issues that also arise in relation to those donors whose information will be released. That is, while there is no impediment to the legislature passing retrospective legislation allowing the release of identifying and non-identifying information about donors to donor-conceived people,[20] the legal interests and 'rights' to privacy of donors should also be considered. This is particularly so, as some donors may have been 'promised' anonymity at the time of their donation and have acted on that basis. A 'balancing' exercise therefore is warranted in considering how to best serve both donor-conceived people and donors.[21]

To address balance the interests of the parties involved, I therefore submit that there is a need to differentiate between the legal consideration of providing *information* about donors to donor-conceived people, and the issue of whether these parties would like to pursue *contact* with each other. That is, while in some instances people may desire contact with each other, and may form positive relationships (pursuant to the level of support that they personally require), accepting that donor-conceived people should be given access to information does not in itself imply that all people wish to have such contact. It should also not necessitate or obligate contact

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[18] *Federal Act on Medically Assisted Procreation 1998* (Switzerland), Art. 41provides that if sperm cells were donated before, but used after, the commencement of the Act, the information release provisions still apply. In addition, in all other cases, if a donor conceived person makes a direct inquiry to the clinic physicians who used assisted reproductive techniques using donated reproductive cells must provide information, with the provisions of the Act applying mutatis mutandis regardless of when such cells were donated.

[19] *Federal Act on Medically Assisted Procreation 1998* (Switzerland), Art. 27.

[20] Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived people in Australia' (2011) 19(1) *Journal of Law and Medicine* 354.

[21] Ibid. See also Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013).

between the parties – which may be seen as an unwarranted intrusion upon a person's privacy. The law should therefore provide for situations where the parties do not wish to have contact or to form a relationship.

I submit therefore that a balancing may be achieved by protecting the donor's privacy by way of a **CONTACT VETO.**[22] The contact veto system is enforceable at law and protects the lodging person's privacy by preventing interference with their intimate sphere of daily life. It still however allows for information release. In this way, the donor-conceived person's needs are met regarding identity formation, knowledge about their heritage, medical history and so on however a relationship with the donor may not follow unless all parties agreed.

I note that the idea of a contact veto is not new. It has existed in relation to the release of information about birth parents in the adoption context since the 1980s in Australia. In Appendix 2 I provide a summary of how information release and the veto system operates in each state/territory of Australia in relation to adoption. (I do not advocate information vetos such as those that exist in South Australia and the Northern Territory – as this defeats the purpose of recognising legal interests and rights to information.)

I also note a study by Wayne E. Carp on whether opening adoption records had an adverse social impact, in which he considered the retroactive application of laws in the U.S., Great Britain and Australia between 1953-2007 and the implementation of a contact veto or preference system.[23] The study concluded that a vast gap exists between the *fear* that was initially raised by birth parents and adopted adults that their privacy would be invaded and their family disrupted and the reality that few or no offenses are committed where a contact veto system has been operated. It is striking to me to compare that trajectory of arguments that were raised about retrospective release of information in relation to adoptees to the arguments which has occurred in relation to donor conception over the past years. I emplore the committee to recognise the effectiveness that a contact veto system would have in balancing the rights of donor-conceived people and donors while allowing for information release.

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[22] See for further discussion of the contact veto system: Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013); Sonia Allan, 'Donor Identification 'Kills Gamete Donation'? A Response to Professor Pennings' *Human Reproduction* (advanced access October, 2012); Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived people in Australia' (2011) 19(1) *Journal of Law and Medicine;* Sonia Allan, 'Donor Conception, Secrecy, and the Search for Information' 19(4) *Journal of Law and Medicine*. 631;

[23] E. Wayne Carp, 'Does Opening Adoption Records Have an Adverse Social Impact? Some Lessons from the U.S., Great Britain, and Australia, 1953–2007' *30 ADOPTION QUARTERLY.*

Notably, in 2012, the Victorian Law Reform Committee accepted the suggestion that contact vetos would balance the interests of donor-conceived people and donors, and included it as one of its recommendations in its support for retrospective release of information to donor-conceived people.

<u>Alternatives to the Contact Veto system</u>

There are of course alternatives to the contact veto system. These include:

1. Releasing information retrospectively and not providing any form of veto (this is the approach taken in Victoria regarding retrospective release of information about birth parents in the adoption context). This may take the form of simply releasing information, or may entail contacting the donor first. For example, the last mentioned approach is found in Switzerland. There, before personal data is disclosed, the donor is informed of the inquiry (if possible). If the donor does not wish to have personal contact, then the donor-conceived person must be informed and made aware of the donor's rights of privacy and his family's entitlement to protection. If the child insists on the right to obtain information, the information is provided.[24]

   In addition, here (or with other options) an 'advanced notice' system may be implemented in which donors may elect to be given advanced notice that information release will occur. In these instances the advanced notice gives the donor a time period (eg. Two weeks) to inform his or her family or otherwise prepare for information release – but they may or may not elect to lodge a contact veto.

2. Allowing for 'contact preference' statements – these are different to contact vetos as they allow a person to express a contact preference (eg. No contact; contact via an intermediary; contact via letters; etc) but are based on good faith and are not enforceable at law;[25]

3. Contacting the donor first and asking if he/she is willing to have their information release. (I do not agree with this approach as it negates the donor-conceived person's rights or legal interests in having information, leaving the determination for information release in the donor's hands

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[24] *Federal Act on Medically Assisted Procreation 1998* (Switzerland), Art. 27.

[25] Naomi Cahn, Legal parent versus biological parent: The impact of disclosure 19(4) Journal of Law and Medicine 790.

alone and therefore not balancing the donor-conceived person's interests with those of the donors).[26]

iii. MANAGING INFORMATION RELEASE

a) Process

There is a clear need for managing the process of retrospective release of information, including where it is subject to contact vetos or contact preferences. I therefore include suggestions for the steps that this may entail.

First, I suggest that prior to the option of retrospective release of information about donors being opened to donor conceived people that the following should occur:

- Public notification that records will be transferred to register, and explanation of contact vetos and advance notice options;
- All records should then be transferred to the donor conception register – regardless of when the donation or ART took place.
- Public notification of the date from which all donor conceived people over the age of 18 (*or younger) may make an application to the register for information. This should include explanation of how the process will work; (I suggest that the date should be set at some point in the future (probably no more than twelve months away – with option to begin placing contact vetos earlier (eg. within six months)).
- The option for people to place a contact veto on the register opened. Here it might also be possible for people to record contact preferences eg. No contact; contact with an intermediary; open to contact. (Note people do not have to immediately place a contact veto. It should be made clear to the public that they can do so at any time and will be notified in advance when an inquiry is made and given the option to do so then.)

a) Option for people to register an 'advance notice' opened. (See as an example NSW Human Services Adoption Information Unit – this would mean people can delay the release of

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[26] See for further discussion : Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013).

information for 2 months while they prepare themselves for the information release and contact (if desired)).

Once all of the above is in place, then I suggest that in relation to information release the following steps would occur – noting that I have

1) allowed for choice as to whether the party wishes to lodge a contact veto or something lessor (eg. a contact preference).
2) taken the view that when there is an inquiry, the donor should be contacted (where possible) and given the option of lodging a contact preference or veto *prior* to any information being released.
3) taken the view that where a contact veto is lodged a person must be counselled prior to receiving information about the implications of breaching such a veto.

The process I suggest that would occur is:

1. <u>Lodgement of an inquiry</u>

a. Donor conceived person lodges an enquiry to the register for information about their donor.
b. Donor conceived person told that the donor will be notified and informed of the request and given option to lodge contact veto/preferences.
c. Timeframe for release of information explained to DC person.
d. Information release to DC person within 4 weeks (unless an 'advanced notice' option has been placed – then 8 weeks).

2. <u>Once an inquiry has been lodged</u>

A. **Contact with donor is made** (if possible)

  a. Donor is contacted (if possible) by intermediary and notified that there has been a request for information and told about the timeframe for information release.
  b. Donor provided information about what this means, and options regarding lodging a contact veto/preference (if they have not already done so).

- c. It should be explained to donor that a request for information will not necessarily be followed by a request for contact, and that all parties would have to be willing to engage in contact.
- d. Other options/services also explained. Eg. Mailbox service – See W.A. practice; prior ITA service.

B. Liaising with the donor conceived person

- a. If a contact veto is lodged, donor conceived person must engage in counselling and undertake not to breach the veto before information is supplied. The veto and what it means would be discussed at length.
- b. If no contact veto is lodged then information released and donor preferences are explained by an intermediary to DC person regarding future contact.
  - i. Where the donor has requested that future contact occur via an intermediary the DC person must also agree to this.
  - ii. Where the donor has said direct contact would be OK, the DC person can decide whether or not to use the services of the intermediary.

I note that the above is not meant to be prescriptive, but rather an illustration, based upon my research of how such a system could work.

b) Agency best placed to manage the process

The decision about which agency might be best placed to manage the donor register is an important, but very difficult, one. Possible options are to

1) continue the register as it currently operates at the NSW Health Department however expanding the information held on it, and look to related staffing/service options;
2) create a stand-alone regulatory authority (with a similar role to Victoria's former ITA, the Western Australian Reproductive Technology Council, or the registers operated in the United Kindgom, the Netherlands, Finland, or New Zealand);

3) move the register to the Department for Births, Deaths and Marriages which would place information where all birth records are housed and consider again how information release will be managed and support systems provided.

There is also the need to consider whether the Department of Family and Community Services may play a role in offering support services in relation to contact vetos (this is further discussed below).

I do not profess to be able to make the decision about the best place to manage this process. In respect of models for how other places manage information release (and the bodies doing it) I can however contribute by referring you to a report I wrote following research conducted as a recipient of a Churchill Fellowship in 2012. The Fellowship was awarded to specifically consider these issues for Australia by conducting interviews with service providers in the United Kingdom, the Netherlands, Sweden, Finland, and Austria – all countries that require information release. The research entailed examination of

a) what the law in each jurisdiction provides;

b) the practice of recording information about the donor and releasing such information to donor conceived people or the recipient parent(s); and

c) information regarding what underlies the law; how well it had been received; and any aspects of the law or practice that might be improved according to those who were implementing it.

The report may be found at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2160627
and I have emailed a copy to the Committee.

In light of the research I conducted on my Churchill Fellowship, I have drawn the conclusion that

a) the best systems are those in which the government operates a register (as opposed to clinic-based release of information, or systems set up by support groups or not-for-profits). For example, in the United Kingdom, the Netherlands, Finland, New South Wales, Victoria, Western Australia and New Zealand, the government registers all operate as the 'gate-keepers' to information release.

b) that this is important to keep records related to donor conception in highly *secure* and long term storage and management. (this will also be relevant should Australia move to a system in the future in which there is exchange of information across state/territory borders (eg. In instances where donor gametes have been used interstate, or where the offspring was conceived inter-state).

c) 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.

d) knowledge about the particular issues faced by people involved in donor conception is also crucial. Obviously, we do not treat the registration of births, deaths, or marriages lightly – information related to donor conception falls in the same category.

As such, I do think it worth exploring whether New South Wales needs to establish a stand-alone body that ‘regulates’ donor conception. This is because, as pointed out by the committee in their issues paper, ‘having several agencies involved [like the current situation in Victoria] can result in efficiency losses and higher budget costs, as well as a possibly fragmented approach being taken to support services/systems, which are of critical importance to people seeking to access support.’ In addition, there are significant issues surrounding donor conception that arise beyond the recording and release of information to donor-conceived people. While it is beyond the scope of this submission to discuss these, I note the issues relate to

a. non-discrimination in relation to access to services,
b. legal parentage,
c. surrogacy arrangements,
d. record storage,
e. fertility treatment generally,
f. donor recruitment and support,
g. recipient parents
h. offspring
i. assisted reproductive treatment clinics
j. research related to ART

k. public health issues related to the use of assisted reproductive technologies
l. maternal and child health
m. public education and
n. policy.

As the use of assisted reproductive technologies increases the creation of a stand-alone body that is dedicated to such issues may be warranted. (Q6) (I note that I do not advocate setting up such things as a 'Patient Review Panel' or similar 'screening' processes in relation to parents as those that exist in Victoria).

iv. SUPPORT SERVICES

a) Should Support Services Be Provided?

The recording and release of information relating to donor conception is not a simple matter. A donor's sperm may be used by a number of families, and siblings may also wish to share and exchange information. It is my submission that simply recording a donor's information on a register and releasing it on request may not be adequate in all situations. That is, support in relation to the collection and release of information may be seen as essential for donor-conceived people, recipient parents, and donors. In addition, the linking that may need to occur should donors and donor-conceived people and/or donor-conceived siblings wish to move to contacting each other is complex and may, at times, call for the provision of intermediary services.

Regarding retrospective release of information support services may include

a) mandatory 'counselling' (for example in relation to contact vetos)
b) 'intermediary services' as required (for example where donors and donor-conceived people wish to move to contacting each other, but require support)
c) A combination of both (a) and (b).

NOTE: 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. Similarly, donors may need support in understanding how the information release system works, and how any contact veto system would operate. Expectation management may also be important. Any such ‘support’ or ‘intermediary’ services must therefore cater to the individual needs of the parties involved.

b) Who should provide support services; should they be mandatory; who should fund them?

Different jurisdictions have taken different approaches in answering the questions of

a) who should provide such support services
b) whether accessing support should be compulsory
c) who should fund the support provided.

I outline these briefly below (and again refer you to my Churchill Report for more detailed discussion of the various systems in place).

Victoria:

The former ITA provided donor-linking and support services for those donor conceived people who were seeking contact with their donors (and vice versa). The system was established in approximately 2004 by Helen Kane who had experience working in both post-adoption services AND infertility treatment counselling.

The current Victorian Assisted Reproduction Authority (VARTA) provides education and awareness services. The Victorian Births Deaths and Marriages Registry currently maintains the Victorian central and voluntary registers. People searching for information must deal with BDM and are referred to FIND (an after adoption service) for counselling.[27] The current system (regarding ‘donor linking’) has been criticised and may be reviewed subsequent to the VLRC recommendations, which include suggesting a return to the provision of support services by

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[27] For further information concerning the services provided by the former ITA and VARTA please refer to *Louise Johnson, Kate Bourne and Karin Hammarberg.* ‘Donor conception legislation in Victoria, Australia: The “Time to Tell” campaign, donor-linking and implications for clinical practice’ (2012) 19(4) *Journal of Law and Medicine* 803.

VARTA. As a statutory body, the former ITA and now VARTA, receive government funding for the provision of services.

Western Australia:

The law in Western Australia has since 2004 allowed children 16 years or older to access information about their donors subject to compulsory counselling by an 'approved counsellor'. A donor conception register is maintained by a stand-alone body (the Reproductive Technology Council). The Council does not provide the counselling to people who make inquiries. Rather, it publishes as list of Approved Counsellors who have been recognised by the Council as having suitable qualifications and experience as well as at least 'basic knowledge of issues related to infertility'. The Counsellors work in a variety of public and private settings. It appears that people seeking information must fund the compulsory counselling session themselves, unless it is free of charge.

In addition, the WA legislation permits parents who have used donated gametes to consent on their own and their child(ren)'s behalf to the sharing of information about the donor, the recipients and the child (subject to consent). Counselling is again required and must be approved by the Director General of Health on advice from the Council, to address the best interests of the child.[28]

United Kingdom

The Human Fertilisation and Embryoloygy Authority (U.K) (a stand-alone government body) has maintained a register of donor conceptions since 1991. Since 2005, there is no longer anonymous donation of gametes in the United Kingdom. People may seek access to information via the register. While guidelines make reference to 'implications counselling' in relation to fertility treatment, the HFEA does not see it as part of its remit to provide such counselling to people seeking access to information. Nor does it take the view that such counselling can or should be mandated. Rather, it suggests to people who make an inquiry that they may wish to seek counselling and can provide contact numbers for possible services.

UKDonorLink was responsible for running a voluntary DNA register between the years 2004 and 2012 for people conceived prior to 1991. It saw the provision of intermediary and support services

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[28] See Government of Western Australia, Department of Health, *Questions and Answers About the Donation of Human Reproductive Material* (2011), available at http://www.rtc.org.au/publications/docs/Q&A.pdf, accessed 3 February 2013.

to people searching for information via the voluntary register as an integral part of its functions. The staff that provided these services had post-adoption services experience and developed extensive experience working with donor conceived people, donors and recipient parents. This service has recently ceased, and the voluntary register has been transferred to the National Gamete Donation Trust. How the NGDT will manage information release of information for those conceived prior to 1990, and whether any support services will be offered, is not known at this early stage. Government funding was provided to UKDonorLink, and will be provided to the NGDT. UKDonorLink also charged fees for DNA services.

The Netherlands

The Foundation for Donor Information is part of the Ministry of Health, Welfare and Sport. It records all information regarding donor conception in the Netherlands, and manages the data in terms of information release. Since 1 June 2004 donors may only donate if they have no objection to the registration of their data or to the possibility that this information will be released to any offspring. Children over 16 years of age may make an inquiry to the register. The register then writes to the donor letting them know that the register has received an application from the child, and that from the register it shows that s/he is the donor. The register asks permission about whether they can release information. NB. This is done for all people regardless of when they were conceived. There are then two paths taken:

a) If donor donated before 2004, and there is no ‘confidentiality’ agreement that has been lodged then the donor is contacted and asked permission concerning release of information. If the donor says ‘No’ to the request for information then no further steps are taken, and information is not released (if the donor says yes, then the register moves to information release process;
b) If the donor donated post 2004, and the donor says ‘No’ then the law says that the interests of the donor and donor conceived must be weighed. The law also says that best interests of child come first and that generally the weight of decision making will lie with the child unless the donor has some extreme reason to say no. Information will be released except in extreme circumstances.

Once it is established that information may be released the support services of another government funded agency (FIOM) are engaged. FIOM provides support services that relate to a variety of parenting related matters including unintended pregnancy, abortion and processing, adoption, biological family searches, infertility, loss of a baby (eg. miscarriage, still birth) and young parenthood. FIOM uses social workers trained in relation to infertility matters to liaise with the donor and donor-conceived person (and donor-conceived siblings). They have modeled their approach upon the donor linking service provided by UKDonorLink, which is also similar to the former ITA donor-linking program that existed in Victoria. FIOM also manages a voluntary DNA register for people conceived pre 2004 (and operates the same intermediary services in relation to matching on the DNA register).[29]

Government funding to date has recognized the need for counselling and intermediary services.

Finland

The regulatory system in Finland comprises a regulatory authority—the National Supervisory Authority for Welfare and Health (Valvira)—that maintains the donation register 'Louteri' for donated gametes and embryos. A child born as a result of gamete or embryo donation may consult the register at age 18 to learn the donor's identity. At present the information release is not occurring because people have not yet reached the age at which they can make an inquiry. In the meantime, the register and clinics have tried to encourage the Ministry of Health and Social Affairs to establish support services. The general view to date however is that psychological support is best arranged by the fertility clinic referring the person to necessary support systems and counselling providers when the person arrives at the clinic to collect the donor code (necessary for making a request to Valvira).

Austria and Sweden

Information release is clinic and hospital based respectively. Support services (counseling/discussion with clinicians) are provided by the respective clinics or hospitals where the records are held.

SUBMISSION:

It is my view based on visiting the above countries and the research I have conducted regarding contact vetos that should retrospective release of information be adopted then the following support services would be necessary:

Information release

Information would be provided by the body that administers the register. Such information would relate to the *process* for information release and no significant 'support services' are necessary at this stage. However, once an application is lodged an intermediary may be required to contact the donor (if possible) and support services may be offered to him/her;

If a contact veto system is implemented, mandatory counseling should take place to explain to the person requesting information the implications of a contact veto having been lodged, and the consequences of breaching a contact veto;

Contact

Intermediary services should be available to people seeking to make contact with each other. (Noting this is a separate issue to the provision of information). Such intermediary services may be provided by:

i). a designated staff person within the health department / stand-alone body responsible for the registers (as per the former ITA model) – this may require funding of a part-time position for a suitably qualified person;

ii). referral to 'approved Counsellors' (as per the WA model; or like the HFEA) – this may not require any funding, but rather places the costs in the hands of the person seeking information; this may or may not be compulsory;

iii). referral to a designated service that provides intermediary services (as per the Netherlands).

Other support services

Support may also be offered on an ongoing basis not via conventional 'counseling' but rather through education and awareness seminars similar to those currently operated by VARTA in Victoria. Overall, issues related to the provision of support services will be influenced by the decision on whether information will be released and whether a contact veto system will be implemented. It will also be determined by whether future desire for contact is facilitated or supported.

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). As the Committee points out in its issues paper there are ‘benefits of establishing a standalone body to administer the donor register and perform other functions. Giving one organization ownership of all aspects of donor conception information management process may have substantial benefits, both in terms of resource savings and in producing satisfactory outcomes for stakeholders and the community.’

I believe that providing a list of ‘approved counsellors’ may be the second best alternative. However, I do note that such an approach and has been criticized by some ‘stakeholders’ (including donor-conceived people, donors and recipient parents) in the United Kindgom. That said, where people have ongoing needs for ‘counseling’ rather than support in relation to seeking information (which may be much shorter lived), they may in Australia seek help via their GP and referral to an appropriate psychologist under a Mental Health Care Plan—costs then being covered significantly by Medicare for a certain number of sessions.

I do not believe that a system in which a service provider (eg. a commercial or not-for-profit agency) contracts to provide ‘supprort 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.

viii. RECORD KEEPING

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

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

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

I believe that all records should be (electronically) transferred to the central register and that there should be a prohibition on destroying or tampering with records currently in existence. (See model for this occurring with the government agency that maintains the register in the Netherlands).

If all records were transferred to the register, then it would be of no consequence if a clinic closed. (I note that in the Netherlands the transfer of information to the register was compulsory and was the responsibility of the clinics).

Law should be enacted to prohibit destruction of, or tampering with, such records.

viii. CONCLUSION

The issues faced by donor-conceived people concerning information about their genetic heritage and any siblings they may have, are of great importance. This submission calls for New South Wales to address the issues faced by donor-conceived people in their state. **This submission calls for compulsory registration of both identifying and non-identifying information for all donor conceptions regardless of when the donation took place. That is, registration of all identifying and non-identifying information held by clinics, hospitals and doctors surgeries about past donations.** It is noted that opponents of disclosing identifying donor information argue that donor privacy should be respected. However the right to privacy does not and should not trump a person’s ability to know important information about their genetic heritage. Whilst retrospective release of information is controversial, it is not impossible. There is already a precedent set by the release of identifying information in Switzerland, and also in the adoption context across Australia. In addition there is the possibility of ‘contact vetoes’ as per this model. (See Appendix 2).

I have expressed my opinion on how such information should be managed, and the process by which information should be released. This includes suggestions on how support services might operate, and who should provide them.

I hope my submission is of help, and thank you for the opportunity to express my views.

Kind regards,

Dr Sonia Allan

APPENDIX 1: Reports and Articles that discuss arguments concerning release of information to donor conceived people about their donors

Articles:

- Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013) (Advanced draft copy provided – this paper is an alternative analysis to that provided in the Tobin paper cited below).

- Sonia Allan, 'Donor Identification 'Kills Gamete Donation'? A Response to Professor Pennings' *Human Reproduction* (Hum Reprod. 2012 Dec;27(12):3380-4).

- Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived people in Australia' (2011) 19(1) *Journal of Law and Medicine* 354.

The special edition of the Journal of Law and Medicine (June 2012), in particular:

- Sonia Allan, 'Donor Conception, Secrecy, and the Search for Information' (2012) 19(4) *Journal of Law and Medicine*. 631.

- Damian Adams and Caroline Lorbach, 'Accessing donor conception information in Australia: A call for retrospective access' (2012) 19(4) *Journal of Law and Medicine* 707.

- Richard Chisholm, 'Information rights and donor conception: Lessons from adoption?' (2012) 19(4) *Journal of Law and Medicine* 722.

- John Tobin, 'Donor-conceived people and access to information about their genetic origins: The relevance and role of rights' (2012) 19(4) *Journal of Law and Medicine* 742.

- Anne Reese, 'Keeping mum about dad: "Contracts" to protect gamete donor anonymity' (2012) 19(4) *Journal of Law and Medicine* 758.

- Eric Blyth, Marily Crawshaw, Lucy Frith and Caroline Jones, 'Donor-conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence' (2012) 19(4) *Journal of Law and Medicine* 769.

- Naomi Cahn, 'Legal parent versus biological parent: The impact of disclosure' (2012) 19(4) *Journal of Law and Medicine* 790.

Government Reports:

- Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011)

- Victorian Law Reform Committee, *Inquiry into Access by Donor-conceived People to Information about the Donors* (March 2012).

APPENDIX 2: Summary of access to information and contact veto systems in relation to adoption across Australia

State/ Territory Legislation	Access to Information	Vetos/Contact Preferences/Advance Notice; Support Services and/or Counselling
New South Wales *Adoption Act 2000*	Post 2010 - adoptees, adoptive parents, birth parents and siblings of an adoptee can gain identifying information about each other and search from the day the Adoption Order is made. (Birth parents/non-adopted siblings must apply to Director – General of Family and Community Services for authority). Pre – 2010 - adopted person aged 18 or over is entitled to have access to his or her original birth certificate and to information about his or her origins. birth parents to have access to details of their child's adopted identity when that child reaches 18. Birth parents can access information about their child's life after adoption, such as their health and welfare, while the child is under 18. With the permission of the adoptive parents, identifying information may be released. Adoptive parents receive non-identifying information about their child's family of origin when the child is under 18. With the permission of the birth parent, identifying information may be released.	**Contact veto** system for pre- 26 October1990 adoption. Where an order of adoption was made before that date, birth parents and adult adopted persons are able to lodge a contact veto. On the lodgment of a contact veto, it becomes an offence for the information recipient to try to make contact with the person who imposed the contact veto. Information about that person can be released if the applicant for the information gives a written undertaking not to use the information to seek contact. Contact vetos remain in force unless retracted. **Advance Notice:** All adult adopted persons, birth parents and adoptive parents are able to lodge a request for advanced notice of an application for identifying information about themselves. This will delay the release of the information for a period of 2 months to allow everyone time to prepare for its release.
Victoria *Adoption Act 1984*	An adopted person aged 18 or older may apply for a copy of his or her original birth certificate and adoption records. An adopted person under 18 requires his or her adoptive parents' written agreement before information can be given, and the written consent of the birth parent(s) is required before identifying information can be given. Birth parents and birth relatives may obtain non-identifying information from records about the adopted person. Identifying information can be given with the written consent of the adopted person if he or she is aged 18 or older, or of the adoptive parents if the adopted person is under 18. Adult children of adopted persons have the same rights to information as the adopted person, providing the adopted person is first informed in writing and	**Contact Veto**: There is no veto system in Victoria. **Contact Preferences:** A register operates on which people can record their wishes in relation to giving or receiving information and making contact. **Intermediary Services:** Although adopted persons can make contact with birth relatives themselves, an authorised agency makes contact with adopted persons on behalf of birth parents and relatives, or with birth parents on behalf of adoptive parents. The agency will ask the parties what their wishes are and mediate between them.

	has not objected to the release of their adoption information or, where the adopted person is dead, a copy of the death certificate is provided. Adoptive parents may apply for information about the birth family's background. The written permission of the birth parent is required before identifying information may be released. Also, where the adopted person is aged 18 or over, the adopted person must be notified in writing of the intention to release identifying information about the birth family.	
Queensland *Adoption Act 2009*	Adopted people and birth parents are entitled to receive identifying information once the adopted person has reached 18.Where the adopted child is under 18, identifying information can be provided if consent is provided by both the adoptive and birth parents. In certain circumstances, eligible relatives of an adopted person or birth parent who signed an adoption consent can obtain identifying information. This includes siblings of the adopted person who were not adopted. The release of identifying information can be restricted only if the Children's Court has made an order preventing the release of identifying information where the release would pose an unacceptable risk of harm.	**'Contact Statements':** The adopted person and the birth parent(s) who signed the adoption consent can lodge a contact statement to express their wishes regarding the manner in which they would prefer to be contacted or to express their wish not to be contacted. A contact statement remains in place unless it is revoked by the person who lodged the statement or the person dies. Offence provisions apply if an adopted person or birth parent affected by an adoption order made before 1 June 1991 contacts another party who has requested no contact. If a request for no contact is in place, identifying information can be provided only if the person seeking information has signed an acknowledgment indicating that they are aware the contact statement requesting no contact is in place and that it would be an offence to contact the other person. **Contact Vetoes:** The (repealed) *Adoption of Children Act 1964* made provision for objections to contact, and objections to contact and the disclosure of identifying information to be lodged by adopted people or birth parents affected by an adoption order made before 1 June 1991. As of 1 February 2010, all objections in force were transferred to have the effect of a contact statement specifying a request for no contact. **Support Services:** To support people accessing information and considering contact statements, the Queensland Government funds Post Adoption Support Queensland to provide counselling and support to people affected by adoption. This service offers: • telephone counselling and support • face-to-face counselling

		• support and information during the search process • mediation and assistance for people wishing to make contact with relatives. **Mailbox Service:** Parties to an adoption, including adult adopted people, may exchange non-identifying information via the mailbox service which is operated by Adoption Services Queensland. In some circumstances, people who have received identifying information about each other may also exchange other information via the mailbox service. People who lodge a contact statement stating they do not want to be contacted by another party to the adoption sometimes state that although they want no direct contact, they would be agreeable to exchanging information with the other party via the mailbox service.
Western Australia *Adoption Act 1994*	**Pre-1 January 1995 adoption:** if the adopted person is aged 18 or over, all parties can apply for access to birth records and adoption court records (that is, identifying information). Where the adopted person is aged under 18, all parties can apply for access to identifying information however, the release of identifying information to any party is subject to the consent of other parties to the adoption. **Post - 1 January 1995 adoption:** all parties to an adoption may apply for access to identifying information. (NB. Under the *Adoption Act 1994,* birth parents, adoptive parents and adopted persons may also apply for access to identifying and non-identifying information about the adoption from departmental records at the discretionary authority of the departmental Chief Executive Officer. For adoption orders made under the *Adoption of Children Act 1896*, there are additional requirements where the adoptee is aged under 18 years. The *Adoption of Children Act 1896* was repealed in January 1995 when the *Adoption Act 1994* came into operation.)	**Information Vetos –** were once able to be lodged. However, since changes to the legislation in 2003 (*Adoption Amendment Act 2003)*, no new information vetoes are permitted to be lodged. All existing information vetoes became ineffective in June 2005. **Contact Vetos -** As a result of amendments to the law (see *Adoption Amendment Act 2003*) contact vetoes can no longer be lodged. The adoption plan agreed to by parties to the adoption can, however, include provisions for no contact between parties. (Adoption plans are registered with the Family Court of Western Australia and can be varied by the Family Court.) **Message Box System:** In Western Australia, a 'message box system' operates, which allows anonymous contact between the parties. The person for whom the message is intended is always given the opportunity to decide whether or not to accept the message. All messages are confidential. **Negotiated and Supported Information Exchange and Contact:** Currently, before placing a child with prospective adoptive parents, an adoption plan must be negotiated between birth parents and prospective adoptive parents. This is done to facilitate contact and exchange of information between parties to the adoption. This requirement may be dispensed with by application to the Family Court of Western Australia.

South Australia *Adoption Act 1988*	In South Australia, adopted people aged 18 or over can have access to information in their original birth certificate, as well as details about their natural parents (if known) such as occupation, date of birth, physical attributes and personal interests. Adopted people are also entitled to know the names of any biological siblings who were adopted. Once the adopted person reaches 18. Birth parents can have access to the adoptive name of their relinquished child and the names of the adoptive parents. Adoptive parents can apply for certain information under certain circumstances. Descendants of an adopted person and certain birth relatives of the adopted person can apply for information under certain circumstances.	**<u>Information Veto system:</u>** Both adopted persons and birth parents can veto the release of identifying information, thus making contact more difficult, although a specific contact veto is not available. The veto provision is available only for adoptions that occurred before the state's *Adoption Act 1988* came into force. They are lodged for 5 years and are renewable. Adoptive parents are able to lodge a veto to restrict identifying information about themselves being released to the birth parents, with a provision that this does not prevent the adopted person and the birth parent from making contact with each other. Certain information is also available to adoptive parents.
Tasmania *Adoption Act 1988*	In Tasmania, an adopted person aged 18 or over may apply for access to his or her pre-adoption birth record and information from the adoption record. An adopted person aged under 18 may apply for this information with the written consent of his or her adoptive parents. Birth parents, birth relatives and lineal descendants of an adopted person may apply for non-identifying information at any time or for identifying information when the adopted person is aged 18 or over. Adoptive parents may apply for non-identifying information at any time, but may receive information that includes the name of a birth parent only with the written permission of the birth parent concerned.	**<u>Contact Veto:</u>** Any adopted person, birth parent, birth relative, lineal descendant of an adopted person or adoptive parent may register a contact veto. Where a veto has been registered, identifying information is released only after an undertaking not to attempt any form of contact has been signed. An attempt to make contact where a veto is in force is an offence. A contact veto may be lifted at any time by the person who lodged it. **<u>Compulsory Consultation:</u>** All applicants for information who reside in Tasmania must attend an interview with an approved counsellor before receiving information.
Australian Capital Territory *Adoption Act*	An adopted person aged 18 or over, birth parents, adoptive parents and birth relatives may apply for identifying information in relation to the adoption. Identifying information consists of a copy of, or extract from, an entry in a register of births relating to the adopted child, or information from which a birth parent, birth relative or adopted child may be identified (excluding the address of	**<u>Contact Vetos:</u>** The Act provides for an unqualified right to information, but also gives the adopted person aged over 17 years 6 months, an adoptive parent, birth parent, adult birth relatives, adoptive relatives and adult children or other descendants of the adopted person the right to lodge a contact veto. The veto has to refer to a specified person or a specified class of persons. On the

1993	a place of residence). Before the *Adoption Act 1993*, no provision for adoption information existed. However, because **the Act is retrospective**, information is now available for adoptions that occurred under the old Act.	lodgment of such a veto, it becomes an offence for the information recipient to try to make contact with the person who imposed the contact veto. **Compulsory Counselling:** Where information is requested and a contact veto is in force, no information is given unless the person requesting information has attended a counselling service and has signed a declaration that he or she will not attempt contact in any form.
Northern Territory *Adoption of Children Act 1994*	Post – 1994 – unqualified right of access to identifying information by adopted persons and birth parents; Pre – 1994 – right of access to identifying information subject to veto system. NB. In both circumstances – if under the age of 18 years consent may be given by adoptive parents to access information.	**Information Veto:** Prior to 1994 there is provision for adopted persons and birth parents to lodge a veto to prohibit the release of their identifying information. The vetos are lodged for 3 years and are renewable. Post 1994 it is not possible to place a veto to prohibit the giving of information. **Mandatory Counselling**: Applicants will not be supplied with identifying information until they receive mandatory counselling.