

**Submission
No 18**

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation: NSW Government
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Legislative Assembly Committee on Law and Safety: Managing information related to donor conception (Inquiry)

NSW Government Submission

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

Under existing arrangements in NSW, pre-2010 donors may voluntarily register their details on the NSW Health Central Register (the Central Register).

The question of whether pre-2010 donor's identifying details should be provided on a mandatory basis is a complex one that involves a balance between the, at times, competing interests of donors and donor conceived people. 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. Generally, retrospective legislation that derogates from existing rights reduces legal certainty and undermines the rule of law.

The argument in favour of retrospective access is that a donor conceived person's interest in knowing their genetic history remains regardless of when they were conceived. Donor conceived people were not parties to confidentiality agreements that may have applied to their conception, and therefore it could be argued that it is unfair to bind them to such agreements. From a donor conceived person's perspective, it may seem unfair or arbitrary that their right to know their genetic heritage depends on their date of conception.

However, many pre-2010 donors would have donated on the understanding that their identity would not be disclosed. Many pre-2010 donors donated on an altruistic basis and some may feel legitimately aggrieved by the promise of anonymity being retrospectively extinguished. Where a donor wishes to remain anonymous, being contacted by a donor conceived person may infringe on their privacy and have an adverse effect on them and their family.

In its report, 'Donor Conception Practices in Australia' (2011), the Senate Legal and Constitutional Affairs Committee noted its concern "about any contractual or other legal obligations that exist between donors and clinics which, if breached, may potentially leave states and territories or ART clinics open to claims for compensation".¹

There may be significant practical difficulties in allowing retrospective access to donor details. Prior to the establishment of the Central Register in 2010 there was no government controlled register of births resulting from Assisted Reproductive Technology (ART) in NSW. Any attempt to enforce the provision of donor details would rely on those ART clinics remaining in existence and maintaining records of those donations and the births that resulted. If retrospective disclosure requirements were imposed on donations made through 'private' or 'non-medical' arrangements, this problem would be further exacerbated, as it is very unlikely that there would be verifiable records of these births.

¹ Donor Conception Practices in Australia (2011), Senate Legal and Constitutional Affairs Committee, at para 7.25

Analogies have been drawn with changes made to the *Adoption Act 2000* in respect of retrospective disclosure of genetic parent's details. However, there are some differences between the situation of donors and those who provide their children for adoption. A donor has no imperative to donate their genetic material. A donor may not have received any counselling and may not have turned their mind to the long-term implications of donating. It is at least possible that if it were made clear to donors that their donation would not be anonymous some would not have donated in the first place. In contrast, people who present their children for adoption often have no choice but to do so. In such cases the adoption may well have occurred regardless of whether or not there had been a guarantee that they could remain anonymous.

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

Retrospective access to identifying information is already provided in relation to pre-2010 donors on a voluntary basis in NSW, as pre-2010 donors may voluntarily register their details on the Central Register. Donor conceived adults who were donor conceived prior to January 2010 can also register their identifying information voluntarily on the Central Register. With the expressed consent of donors, or donor offspring, this information can be shared with other parties to ART treatment, including donors and siblings of donor offspring.

If further retrospective access were granted, there are various possible conditions that could be imposed to regulate or restrict such access.

One option is that the same access arrangements as apply post-2010 could apply to retrospective access. That is, adult donor offspring could apply to the Central Register for identifying and non-identifying details about their donor. Donors could apply for access to non-identifying details about donor conceived offspring.

Another option is that retrospective access could be limited to non-identifying and medical information about donors. This approach could partially satisfy the interests of donor conceived people without infringing the privacy of donors. However, it would not allow donor conceived children to know the full details of their donor or facilitate contact between donors and donor conceived children.

Alternatively, retrospective access to identifying information about the donor could be limited to where the donor consents to such information being provided. This model currently applies in Victoria in relation to people who were donor conceived between 1988 and 1997.

A final option is that retrospective access to identifying information could be provided subject to a contact veto lodged by the donor. Contact vetos could take several forms. For example, the legislation could provide that a donor could lodge a blanket contact veto, prohibiting contact by any donor conceived children at any stage. Alternatively a contact veto could be permitted only in relation to specific requests for contact. The legislation could permit contact vetos to be indefinite (subject to withdrawal), or only valid for a certain period of time (subject to renewal).

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

A number of options could be considered to manage the provision of information should retrospective access be granted.

Information could be applied for in the same manner as for post-2010 conceptions; that is donors or adult donor conceived offspring apply to the Central Register for access to information. Non identifying details could then be given to donors, while donor conceived offspring would be entitled to identifying and non-identifying information. The *Assisted Reproductive Technology Act 2007* does not currently require parties to undergo counselling, but the Ministry of Health strongly recommends that parties undertake counselling before accessing information on the Central Register.

If retrospective access facilitates contact between donors and donor conceived people, contact could occur either directly between the donor conceived person and the donor, or initially via an intermediary (such as the entity administering the Central Register).

Another option is employing a 'letterbox' service which could facilitate the exchange of non-identifying information, such as that previously employed by the former Infertility Treatment Authority in Victoria. This could allow donor conception stakeholders to develop a connection with one another at a gradual pace and to determine whether they want to have further contact.

A further possibility would be for donors to be given the option to nominate their preferred method of contact through lodgement of a 'contact preference form', as recommended by the Victorian Parliament Law Reform Committee in its 'Inquiry into Access by Donor-Conceived People to Information about Donors'.²

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

At present, the Central Register is managed by the Ministry of Health. The question of whether the register should be retained by the Ministry of Health requires further consideration and may depend on whether additional information about ART births is collected or provided to donor conceived offspring.

It may be possible for the Registry of Births, Deaths and Marriages (BDM) to manage the Central Register. Recommendations 2 and 3 of the Committee on Law and Safety's report *Inclusion of Donor Details on the Register of Births* were that the BDM Registrar note whether a child is donor conceived on the BDM Register, and that the BDM Registrar issue an addendum indicating that further information is available when a donor conceived adult applies for a copy of their birth certificate. If these recommendations are implemented by the NSW Government, it could be argued that transferring the Central Register to BDM would have the advantage of avoiding two separate registers containing similar or related

² Inquiry into Access by Donor-Conceived People (2012), Victorian Parliament Law Reform Committee, recommendation 5

information. This could reduce the administrative burden on government and simplify access to donor information for donor conceived people.

However, the potential disadvantages of this approach are that there are some health related aspects of the Central Register that may be better managed by the Ministry of Health. For example, under the *Assisted Reproductive Technology Act 2007*, the Ministry of Health currently regulates services provided by registered ART providers. If the Central Register were transferred, other aspects of ART, such as the regulation of ART providers, would need to remain with the Ministry of Health. Similarly, if counselling is to be provided to donor conceived people when they are first informed that they are donor conceived, BDM would not be well placed to facilitate this. The Ministry of Health does not currently provide counselling services, but strongly recommends parties obtain their own counselling.

Furthermore, the Central Register maintains medical information relating to donors. In the case of a medical emergency or life-threatening situation, parents may apply to the Director General of Health for identifying donor information. Alternatively, donor conceived people may access such information when they become adults. In contrast, other than limited information occasionally contained on death certificates, BDM does not retain medical information.

In certain circumstances, the Central Register may be accessed by donors, donor conceived people, siblings of donor conceived people, and legal parents of donor offspring. In contrast, access to the BDM Register is generally restricted to the person in respect of whom the entry is made, subject to limited exceptions such as a parent applying for their child's birth certificate and in relation to births that occurred more than 100 years ago.

In Victoria the management of its equivalent donor register was transferred from the Victorian Department of Health to the Victorian Registry of Births, Deaths and Marriages (**Victorian BDM**) in 2008, following the Victorian Law Reform Commission's *Assisted Reproductive Technology & Adoption Report* in 2007.

However, in the 'Inquiry into Access by Donor-Conceived People to Information about Donors' in 2012, the Victorian Parliament Law Reform Committee noted that it had received submissions raising concerns regarding the transfer of the donor register from the Victorian Department of Health to the Victorian BDM. These concerns included that there was:

- Limited counselling and support available to donors, donor conceived people, and other participants
- No facility for the person who is the subject of an application to gain any insight into why the other person is seeking information about them
- Limited information exchange between Victorian BDM and the relevant counselling services
- A disjointed and difficult system to navigate resulting from the splintering of the donor services.

Therefore, the Committee recommended that the Victorian Government introduce legislation to empower one agency to provide all services relating to the provision of information, linking and counselling services related to donor conception, including management of the donor

registers, a letterbox service, education and public campaigns³. The Victorian Government has indicated that it will respond to this report in April 2013.

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

The question of whether a standalone body should be established to manage the Central Register will generally depend on whether additional information, such as retrospective donor information or information from private arrangements, is to be collected, stored and then provided to parties to ART treatment, including donors, donor conceived individuals, and persons undergoing ART treatment. The funding implications of a standalone body would also have to be considered.

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

The Government strongly recommends counselling for donors and their offspring who are contemplating connecting.

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

The NSW Government understands that stakeholders have often called for the provision of counselling services for parties to ART treatment. Regarding other types of support, the NSW Government will be informed by the recommendations and findings of the Committee in this inquiry.

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

How support services are resourced, whether as user-pays, ART provider resourced, or subsidised or paid through public administration, is a matter that the Government will consider in light of the findings of this inquiry. However, it should be noted that existing ART providers did not necessarily provide the ART services in the past that resulted in conception of donor conceived offspring. Many clinics and general practitioners who provided ART services in the past have ceased operation, but their clients and offspring of those clients may still require counselling or other services. There would be no necessary connection between current ART providers and individuals seeking services warranting ART providers resourcing the support services.

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

The NSW Government does not have a recommendation to make to the Committee about how such support services should be provided. Any institution, body or person who provides support services would need to be able to ensure that they or their staff are sufficiently skilled to provide the necessary services.

³ Inquiry into Access by Donor-Conceived People (2012), Victorian Parliament Law Reform Committee, recommendation 14

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

Medical records must be stored according to the *Health Records and Information Privacy Act 2002*. Under this Act medical records must be maintained for 7 years from provision of health service for an adult, and for a person who was under the age of 18 years when the records were created, until that patient reaches the age of 25 years.

Under the Act, a health service provider who deletes or disposes of health information must keep a record of the name of the individual to whom the health information related, the period covered by it and the date on which it was deleted or disposed.

A health service provider who transfers health information to another organisation and does not continue to hold a record of that information must keep a record of the name and address of the organisation to whom or to which it was transferred.

Under the *Assisted Reproductive Technology Act 2007*, clinics must keep prescribed records relevant to the birth of a live child through ART services for 50 years.

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

For those clinics that are licensed under the *Private Health Facilities Act 2007* and the *Private Health Facilities Regulation 2010*, prior to a private health facility ceasing to operate, the licensee of the facility must make arrangements for the safe keeping of clinical records and must provide the Director-General of Health with the details of the arrangements. Not all clinics are licensed under this legislation, as the requirement for licensing is dependent on the services offered.

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

Under the Health Privacy Principles in the *Health Records and Information Privacy Act 2002* at Schedule 1, the holder of health information must ensure that the information is protected, by taking such security safeguards as are reasonable in the circumstances, against loss, unauthorised access, use, modification or disclosure, and against all other misuse.