Submission No 36

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Ms Clara Hawker
Committee Manager
Legislative Assembly Committee on Law and Safety
Parliament House, Macquarie Street
SYDNEY NSW 2000

19 FEB 2013

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Dear Ms Hawker

Inquiry into Managing Information Related to Donor Conception

I am pleased to offer the enclosed submission to the above Inquiry on behalf of the Information and Privacy Commission of New South Wales.

The Inquiry deals with many issues of importance concerning information access and privacy, and I welcome the opportunity to contribute to the debate on this challenging area of public policy.

For the sake of clarity, I have confined my comments only to those questions in the Issues Paper that are of direct relevance to the work of the Information and Privacy Commission. However, I am happy to provide more information should you consider it valuable.

[redacted]

Yours sincerely

[redacted]

Dr Elizabeth Coombs
Privacy Commissioner

Legislative Assembly Committee on Law and Safety

Issues Paper: Managing Information Related to Donor Conception

Submission by the NSW Information and Privacy Commission

February 2013

Q1 – Should donor-conceived adults conceived before 2010 have retrospective access to donors' identifying details

In NSW, the only legislative path through which donor-conceived offspring may gain access to information about their biological parentage is the *Assisted Reproduction Technology Act 2007* (NSW) (ART Act). Part 3 of that Act provides for a central register of information about donor conception. Adult children conceived as a result of donor conception have a right under the ART Act to be provided with the identity of the donor and other prescribed information or any other information the donor may have consented to release.

These provisions apply prospectively to donor conception from the date the ART Act came into force, being 1 January 2010. Those conceived prior to this date may ask the relevant clinic for access to non-identifying information, or may obtain information from the voluntary register maintained by the Ministry of Health which contains information about pre-2010 donors who have chosen to have their information included in the register.

Pre-2010 donor-conceived children cannot apply for access to information in the central register under the *Privacy and Personal Information Protection Act 1998* (NSW) (PPIP Act) or the *Health Records and Information Privacy Act 2002* (NSW) (HRIP Act) as those Acts do not provide for access to third party information. Nor can an application be made under the *Government Information (Public Access) Act 2009* (NSW) (GIPA Act), as there is a conclusive presumption against disclosure under the GIPA Act of information contained in the central register the ART Act (see Schedule 1 to the GIPA Act).

This leaves pre-2010 donor conceived children without any legal right of access to information about their donor, unless the law is amended to apply retrospectively.

So far as retrospective access is concerned, there are three possible options:

1. Allow access only to non-identifying information.
2. Allow access to 1 above as well as any information the donor has consented to release.
3. Provide the same right to access information as those conceived after 1 January 2010.

The first two options are not problematic from a privacy perspective. However, option three raises concerns, since donors were not aware at the time of donation that identifying information may be disclosed to children conceived as a result.

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Generally, legislation that has retrospective application should be avoided unless there are strong public policy reasons in favour of its implementation. There are clear and persuasive arguments on both sides of this issue. From the point of view of the donor-conceived person, there is the importance of knowing information about their genealogical heritage, including their medical history and information about any potential siblings. However, this information could be provided without identifying the donor. Should a donor consent to release of identifying information, then this concern would be addressed.

The interests of the donor in protecting his personal information need to be considered, especially in circumstances where confidentiality was guaranteed at the time of donation.

The IPC supports the introduction of a retrospective legislative right for donor-conceived children to have access to non-identifying information about their donor. Enshrining this access right in legislation promotes consistency and clarifies the legal position for all parties concerned. Donor-conceived children should also be able to have access to any other information about the donor that the donor consents to release.

Q2 – If retrospective access were granted what conditions should apply?

If retrospective access is to be granted, it should only be done with the consent of the donor. We understand that this is already occurring with the voluntary register managed by the Ministry of Health. The IPC suggests that a lead-in period should apply before any retrospective provisions come into force, enabling donors to register their consent to the release of particular specified information. This could be accompanied by a publicity campaign inviting donors to contact the Ministry of Health with their consent details.

The idea of a contact veto has merit. This may encourage some donors who do not wish to have contact with donor-conceived offspring to consent to the release of their identifying information. Without the ability to refuse contact with their offspring, the donor may be less inclined to consent to information about them being disclosed.

The 'contact veto' mechanism presents a good balance between the rights of both parties, and affords an additional privacy safeguard.

Q3 – What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed?

The IPC favours information access to be managed centrally by the Ministry of Health, with referrals to other agencies and support services as may be necessary. Having information centrally managed reduces the risk of information security breaches. It also promotes easier and more efficient access for donor-conceived children, and makes it easier for donors to register their consent details.

Q12 - How can we ensure the integrity of records?

The agency responsible for the collection and storage of donor information (presumable the Ministry of Health) should ensure that it complies with the Health Privacy Principles in the HRIP Act. Measures to ensure the security of hard copy files and electronically stored material should be in place, and donors should be advised that their information is being treated securely.

In the event of a data breach, the IPC would strongly encourage the agency to report the breach to the Privacy Commissioner and take all necessary steps to mitigate the effects of the breach.

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