



Donor Conception Register

ASSISTED REPRODUCTIVE TREATMENT: DONOR CONCEPTION REGISTER

Donor Conception: Access to Information

The donation of gametes (sperm or eggs) and embryos, has been integral to the provision of some assisted reproductive treatment. It has meant that people who may not have otherwise had children, were able to use donated materials from others in order to do so.

From the time that donor-conception was introduced as a means to assist such people, there has been discussion, and increasing recognition, that children born as a result of the use of 'donated' gametes or embryos, may desire further information about the donor and/or genetic relatives.

Over time, as donor-conceived people have grown, the psycho-social and medical impacts, for some, of being denied information have also become apparent. There has thus been growing recognition worldwide, and increasing legislative reforms in some countries, to provide opportunities for people involved in donor-assisted conception, to access information. Notably, this includes recipients, donors, donor-conceived people and their genetically related siblings and half-siblings—recognising that all parties involved may wish to exchange information and may desire varying levels of contact.

South Australia

In 2005, the Social Development Committee (SDC) and the South Australian Council on Reproductive Technology (SACRT) raised concerns about the lack of access to identifying information about gamete or embryo donors in South Australia, and recommended that donor registration be addressed.

In 2007, the SDC again recommended that the legislation be amended to ensure that people conceived through donor conception have access to information about their genetic parentage should they request it.

Around this time and prior to the changes to South Australian legislation and regulations in 2010 (see further Fact Sheet 1), expectations had been raised about a national donor register in Australia, which was being considered by the Standing Committee of Attorney's General (SCAG) in the context of a nationally consistent policy framework. The prior South Australian legislation however, contained confidentiality provisions that restricted the provision of information by clinics to 'third parties' (for example, to a donor conception register or Births, Deaths and Marriages).

The changes to the South Australian legislation in 2010 removed any impediments to the release of such information to a register by allowing South Australia to participate in a donor registration program approved by the Minister for Health. Such a program could include a state register, or participation in a national scheme should one be established.

In regard to a state-based register, it was expected that the details of such a register including how it would work, the information to be kept on the register and who would have access to such information, would be developed in conjunction with the stakeholders and detailed in regulations. It was noted that this would ensure that consideration be given to the model of register to be adopted.

What has happened since?

The *Assisted Reproductive Treatment Act 1988* contains the provision for the Minister to keep a register of donors of human reproductive material, as set out in the text box below.

In 2011, the Commonwealth government stated it did not have the power to establish a National Register, and referred the matter back to the states and territories of Australia recognising that issues concerning access to information by donor conceived people should be addressed as a 'matter of priority'.

In 2013 public consultation was conducted concerning the register in South Australia.

In 2016, a register for information about donors used in, or in relation to, A.R.T. in South Australia has not yet been established.

What does the *Assisted Reproductive Treatment Act 1988* say?

- (1) The Minister may keep a register of donors of human reproductive material used in, or in relation to, assisted reproductive treatment provided in accordance with this Act and resulting in the birth of a child (the donor conception register).
- (2) If the Minister does keep the donor conception register, the register must contain, in relation to each donor on the register:
 - (a) the donor's full name and nominated contact address; and
 - (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor's human reproductive material was provided; and
 - (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and
 - (d) any other information required by the regulations, and may include any other information that the Minister thinks fit.
- (3) The Minister must correct an entry in the donor conception register that is not correct.
- (4) The donor conception register may only be inspected in accordance with the regulations.
- (5) A certificate stating that a donor was, or was not, registered on the donor conception register in relation to the birth of a specified child, and purporting to be signed by the Minister will, in the absence of proof to the contrary, be accepted in legal proceedings as proof of the registration, or of the fact that the person was not so registered.
- (6) The Minister may, by notice in writing, for the purpose of preparing and maintaining the donor conception register, require a person to provide the Minister with such information as the Minister may require.
- (7) A person must not, without reasonable excuse, refuse or fail to comply with a requirement under Subsection (6).

Maximum penalty: \$10,000

Information Release in Other Jurisdictions

In Australia registers operate in New South Wales, Western Australia and Victoria. In some of these states there have been moves to allow access to information for all donor-conceived people, subject to certain conditions when gametes or embryos were donated prior to a certain date. The other jurisdictions rely on the National Health and Medical Research Council *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (revised 2007)* which require non-anonymous donation and support from clinics for information release. However such guidelines have no enforcement mechanisms, and may be subject to change. They also do not address certain issues (for example what to do if a donor withdraws consent regarding release of information).

The following international jurisdictions have various systems requiring information recording and release: Argentina; Austria; Croatia; Finland; New Zealand; Norway; The Netherlands; Sweden; Switzerland; Washington State (U.S.); United Kingdom; Uruguay.

Registers vary across jurisdictions in relation to who operates them, who may access information, when such access may occur, the information available, the date from which people may access information, the conditions under which information will be released, and whether there are any support services provided to people accessing information or about whom information is being released. Different register models and systems for information release around the world will be examined as part of this review.

Questions

We are interested in hearing from people about their experience and views regarding information release about donor-conception in South Australia. The following questions may help you to inform the review:

1. Are you affected by South Australian laws and/or practice regarding information release about donors of reproductive materials and/or genetic relatives of donor-conceived people? How?
2. Should a donor-conception register be established in South Australia?
3. What information should be kept on the register?
4. Who should have access to the register? (For example, donors, donor-conceived people, siblings, recipients?)
5. How should the register work? (For example, what conditions, if any, might support release of information?)
6. Should all donor conceived people have the right to request information? If yes, how should this happen? If no, why not?

Please feel free to comment on anything else that is relevant.

The Review of the Act

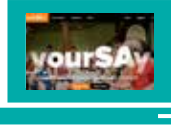
The *Assisted Reproductive Treatment Act 1988* provides that a review must take place of the operation and effectiveness of the Act as soon as possible after the fifth anniversary of the changes that came into effect on or after 1st September 2010. The review will particularly focus upon the operation and effectiveness of the Act in relation to:

- > the requirement that the welfare of any child born as a consequence of A.R.T. is to be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of assisted reproductive treatment;
- > the replacement of the previous licensing scheme with a registration scheme for A.R.T. clinics;
- > the dissolution of the SA Council on Reproductive Technology and its Code of Ethical Clinical Practice;
- > amending eligibility for access to A.R.T. services—noting that such conditions relate to the circumstances in which, and to whom, A.R.T. may be provided;
- > allowing for the establishment of a donor conception register; and
- > provisions for record keeping and confidentiality.

The review will include examination of research and practice, and invite public submissions relevant to the above matters. It will lead to a report, which will include recommendations regarding the regulation of assisted reproductive treatment in South Australia. The report will be tabled in Parliament and made publically available. The recommendations will be considered by the Minister.



We Invite You To Make a Submission



Complete the online submission form on the [YourSA](#) website to provide your views in relation to the issues under review.

Email a submission to Associate Professor Sonia Allan at HealthPolicyLegislation@sa.gov.au with subject heading 'A.R.T. Act Review'



Post a submission to

A/Professor Sonia Allan
A.R.T. Act Review,
C/- Policy and Intergovernment Relations Unit,
SA Health, PO Box 287, Rundle Mall,
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Join the discussion on the [YourSA](#) website.

Please note that all submissions are public unless marked 'confidential'. Public submissions will be posted on the [YourSA](#) website, and the author may be cited in the final report. Authors of 'confidential' submissions will not be referred to by name. We cannot accept anonymous submissions.

Submissions close on Friday 15 April 2016.

Donor Conception Register Fact Sheet 6

Review of the
*Assisted Reproductive
Treatment Act
1988 (SA)*

More Information

For general information on topics relevant to the review of the *Assisted Reproductive Treatment Act 1988 (SA)* see the following Fact Sheets:

[Fact Sheet 1: Introduction to the Review](#)

[Fact Sheet 2: Paramourncy of the Welfare of the Child](#)

[Fact Sheet 3: Registration Scheme for A.R.T. Clinics](#)

[Fact Sheet 4: Dissolution of SA Council on Reproductive Technology, and its Code of Ethical Clinical Practice](#)

[Fact Sheet 5: Access to Assisted Reproductive Treatment](#)

[Fact Sheet 6: Establishment of a Donor Register](#)

[Fact Sheet 7: Record Keeping and Confidentiality](#)

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Prepared by Associate Professor Sonia Allan, for the *Assisted Reproductive Treatment Act 1988 (SA)* review, January 2016.

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