Fact Sheet

I'm a donor: What should I know?

A donor conception register commenced operation on 7 November 2021. Legislative amendments are now proposed to enable the inclusion of information in the register relating to private arrangements and to also enable access to information contained in the register.

What is a Donor Conception Register?

The Donor Conception Register (DCR) is an electronic register that stores available and verifiable donor conception records/information kept by South Australia's assisted reproductive treatment (ART) clinics. A draft Amendment Bill proposes to allow access to the DCR for people who seek information about their donor (genetic parent) or a person born as a result of donor conception. It is intended that the DCR will also be able to store donor information relating to private arrangements.

Who can access my information on the DCR?

It is proposed that your genetic offspring (donor-conceived people) aged 18 years and over and their recipient parent(s) as well as any direct descendants of your genetic offspring would be able to access varying information held on the DCR about you.

What information about me can be accessed?

Under the proposed amendments, your genetic offspring aged 18 years and over, any direct descendants of your genetic offspring (over the age of 18) and the recipient parent(s) would have immediate access to non-identifying information about you.

It is also proposed that your genetic offspring (aged 18 years and over) and their direct descendants would have access to your identifying information consistent with the below:

- If you donated after September 2004, this information would be disclosed immediately upon application.
- If you donated prior to September 2004, you would be able to choose in the DCR if you wish to disclose your information immediately or prefer to defer disclosure with the support of an intermediary service for three months[1]. For some, this will provide time to adapt to the news that they have genetic offspring and support to advise family members that do not already know.
- If you donated prior to September 2004 but have not expressed your disclosure preference in the DCR, the intermediary service would attempt to contact you and disclosure would be deferred for three months[1].

With your consent, recipient parent(s) would also be able to access your identifying information.

See the ***Fact Sheet – What information is held by the register?*** for details about what is considered identifying and non-identifying information.

[1] The standard timeframe for disclosure is three months, however there may be instances where an extension to this timeframe is permitted due to extenuating circumstances.

Can I add information to the DCR?

It is proposed that you would have the ability in the DCR to lodge contact preferences, specifying if you are open to contact, unsure or do not wish to have contact with your genetic offspring or recipient parent(s). Contact preferences would be applied to each relationship and if you are open to contact, you'll be able to specify your preferred mode of contact.

If you wish to, you could also include a biographical statement, 1-2 photos and/or a legacy video about yourself.

It is also intended that you would be able to include non-identifying information about genetic or heritable medical conditions you or your family members have been diagnosed with that will enable your genetic offspring (or their direct descendants) to seek early medical advice or intervention that they may not know to seek otherwise.

You would also be able to set personal notification preferences specifying if you want the DCR to notify you when your information is accessed or when your genetic offspring's medical information is updated.

What information can I access and about whom?

Under the proposed amendments, you would have immediate access to non-identifying information about any genetic offspring your donation(s) may have resulted in.

You may also have access to identifying information about any genetic offspring aged 18 years and over where they have consented in the DCR to disclose this information to you.

You may also have access to recipient parent(s) contact details if they have consented in the DCR to this disclosure.

What if my donation was anonymous?

Under the proposed amendments, the lifelong guarantee of anonymity provided to donors will be removed without the consent of the donor.

If you donated on the condition of anonymity (prior to September 2004), you would have the ability to select disclosure preferences in the DCR such as opting for immediate disclosure of your identifying information or deferring disclosure for three months[1] with the support of a government funded intermediary service. However, whilst it may be possible to defer the disclosure in some circumstances, it will not be possible to remain anonymous. Identifying information will be made available to genetic offspring.

This approach is not without precedent. Victoria retrospectively removed the anonymity of donors in 2016. For information on the Victorian scheme, you can visit the Victorian Assisted Reproductive Treatment Authority's webpage.

The disclosure of identifying information does not necessarily mean you must have contact with your genetic offspring. Setting your contact preferences in the DCR will let your genetic offspring know if you are open to having contact with them.

Will the DCR contain full and complete records?

It is unlikely that all records used to create the DCR will be full and complete, and it is expected that information gaps will remain, particularly for the older, historical records. The reasons for this include:

- provisions that required fertility clinics to keep identifying information about a donor in a different place to other information about the donor up until 2010
- clinics changing ownership or the place of business moving.

It is anticipated that the information contained in records made since September 2004 when anonymity provisions were removed, will be generally complete. All records made since 2010 are full and complete.

Records prior to September 2004 are held at various locations in South Australia. These must be assessed and verified before being transferred into the DCR. Not all of this information will be verifiable, and it may not be possible to match you with your donor-conceived offspring.

Unfortunately, the DCR may not answer all of the questions that you have, however, it will provide significant amounts of information in one central location with the added benefit of ensuring the preservation of these records.

What if I provided a donation privately?

Private arrangements are those made with a donor that is known to the recipient at the time of the donation. A fertility clinic may or may not be used to assist with the fertilisation procedure.

Where a private arrangement occurred and the donor was recorded on the birth registration statement submitted to the South Australian Births, Deaths and Marriages, it is proposed that your information would be included on the DCR with the same access provisions.

What support is available?

Feedback has previously indicated that people want to choose if they wish to access support, and if they do, the level of support and choice of provider. The DCR will provide links to appropriate support services and offer a library of resources to help support you.

If you donated prior to September 2004, it is proposed for you and your family to have the option of accessing a government funded intermediary service and/or counselling or seeking your own provider that suits your personal circumstances.

If you donated after September 2004, you will be able to choose your own provider that suits your personal circumstances.

Need more information or wish to provide feedback?

The YourSAy webpage contains further information and resources about the DCR.

Written comments and feedback on the draft Amendment Bill can be sent to health.donorconceptionregister@sa.gov.au by 5.00pm Tuesday, 6 December 2022.

For more information

Legal and Legislative Policy
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