Fact Sheet

What information will the register hold?

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.

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 genetic parent(s).

The DCR will however, provide significant amounts of information in one central location with the added benefit of ensuring the preservation of these records.

Where a private arrangement occurred and the donor was recorded on the birth registration statement submitted to the South Australian Births, Deaths and Marriages (BDM), this information will be placed on the DCR via data linkages with BDM.

What information will be held by the register?

The inclusion of information on the DCR is subject to the availability and completeness of the records. Historical records may not contain all of the below information.

Identifying information

Refer to the ***Quick Guide – Who can access the DCR?*** for details about when identifying information may be disclosed.

- Full name, date of birth and place of birth of donors and donor-conceived people.
- Last known address and other contact details such as email, phone number, address etc.

- Name and contact details of recipient parent(s).

Non-identifying information (where known)

- Information provided at the time of donation about the donor concerning medical history, family history and any existing genetic test results that are relevant to the future health of the person born as a result of a donation (or their direct descendants) or the recipient of the donation.
- Details of the physical characteristics of the gamete/embryo donor.
- Information concerning the number of people born as a result of a donation, their sex, month, and year of birth.
- Any current genetic/heritable medical information a donor or donor-conceived person may choose to share on the DCR.

Contact preferences

Donors, recipient parent(s) and donor-conceived people would have the ability to lodge contact preferences in the DCR. If open to contact, they may specify the preferred mode of contact.

Optional information

Donors and donor-conceived people aged 18 and over would have the choice to include a biographical statement, 1-2 photos and/or a legacy video for their genetic relatives to access.

Medical information

Donors and donor-conceived people would also have the choice to include information about genetic or heritable medical conditions they have been diagnosed with, and their age of diagnosis to enable their genetic relatives to seek early medical advice or intervention they otherwise may not know to seek. They would also be able to choose their own notification preferences to receive medical information updates.

Serious medical issue of concern

It is proposed that where a participant of the DCR believes that there is a serious risk to the health of a genetic relative and they should be informed, the participant should seek written advice from a geneticist which may be uploaded to the DCR for genetic relatives to view.

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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