

Frequently asked questions

ART Regulations and the DCR

The South Australian Donor Conception Register (DCR) commenced operation in November 2021 with access restricted to authorised SA Health and assisted reproductive treatment (ART) clinic staff.

In March 2024, the South Australian Parliament passed the Assisted Reproductive Treatment (Posthumous Use of Material and Donor Conception Register) Amendment Act 2024 (the ART Amendment Act).

Once proclaimed, the ART Amendment Act will make the DCR accessible to donor-conceived people aged 18 years and above, donors and parents of donor-conceived children where the donor conception treatment was undertaken in South Australia.

New ART Regulations are now required to support the ART Amendment Act and ensure people accessing the DCR can do so safely.

This document provides basic information about the DCR. The separate Explanatory Guide provides more detail about the ART Regulations.

What is the South Australian DCR?

The DCR holds and links information about people who are connected to a donor conception treatment in South Australia that resulted in the birth of a child.

South Australia's DCR is the first of its kind in Australia to be publicly accessible online. It will allow the donor conception community to access and share information with their connections in real-time through an automated solution. Further, SA Health is one of only a few health authorities worldwide and the second in Australia to establish a DCR with retrospective effect (i.e. providing access to information dating back to the 1980s that may not have previously been available).

SA Health is responsible for the DCR with its operation supported by authorised staff in the Department for Health and Wellbeing (DHW).

Authorised ART clinic staff input information into the DCR about donor conception treatments in their clinic/s and the people connected to each treatment – donors, the people born as a result of the donor conception treatment and the parent/s of the donor-conceived person.

The DCR does not offer DNA or genetic testing.

Why is a DCR needed?

Prior to September 2004, donors, whether they wanted it or not, were guaranteed lifelong anonymity and parents were often advised to keep the truth of their child's conception a secret from their child. Record keeping practices reflected this culture of secrecy, resulting in many records and information being lost, damaged or even destroyed.



Why is a DCR needed? (continued)

It is now widely accepted that knowledge of a person's heritage and biological links plays a significant role in the development of their identity and self-esteem.

The DCR will help people to access verified information, where it is available, about their biological heritage and facilitate the sharing of important medical information between people who are biologically connected.

The DCR will also help donor-conceived people avoid unknowingly forming relationships with people they are related to (consanguinity).

The availability of commercial DNA testing sites (genealogy companies) has also removed donor anonymity, with many donor-conceived people finding their parent's donor/s without any of the privacy safeguards and wellbeing supports the DCR will provide.

How and why are the ART Regulations changing?

New ART Regulations are required to support the administration of the ART Act and to facilitate the operation of the publicly accessible DCR in South Australia.

Proposed changes to the existing ART Regulations include:

- > who may have access to the DCR i.e. donors, donor-conceived people aged 18 years and over, and parents of donor-conceived children
- > the types of information that a person using the DCR may have access to including their own information and information about other people in the DCR where a connection between the two parties has been verified
- > other information that a person may provide for inclusion in the DCR such as information about private donor arrangements
- > new record keeping requirements for ART clinics and any person in possession of ART records.

The ART Regulations also provide for requirements relating to ART clinic registration which are also open to review as part of this consultation.

You can find all the information you need to know about the changes in the *Explanatory Guide to the ART Regulations* provided on the YourSAy website.

Who can access the DCR and what information will they get?

Donor-conceived people aged 18 and over, donors of sperm, eggs and embryos, and the parent/s of donor-conceived children will be able to access the DCR where the donor conception treatment took place in South Australia.

This includes people who provide donations to an overseas sperm or egg bank, and the donation/s is used in a South Australian donor conception treatment.

You can find out who can access what information in the DCR by reading the Information Access Matrices for donor-conceived people, donors, and parents, provided on the YourSAy website.

Can anyone else access information held in the DCR?

People connected to a donor conception treatment (a donor-conceived person, the donor/s and the parent/s of the donor conceived person) can access information held in the DCR.

Can anyone else access information held in the DCR? (continued)

In some instances, access to information held in the DCR will be supported by a manual process outside of the electronic DCR. This includes access to information by guardians of a donor-conceived child aged under 18 years and direct descendants of a donor-conceived person after the death of that donor-conceived person.

I was conceived interstate – can I access the DCR?

The DCR holds information about donor conception treatments conducted in South Australia.

Where donated sperm, eggs or embryos are transferred out of South Australia for use in donor conception treatments in other Australian states or territories South Australia cannot access or verify this information for inclusion in the DCR.

You can contact the clinic which conducted the donor conception treatment for help in finding information.

If you need support, you can contact [Donor Conceived Australia](#), the leading support group in Australia.

How do I access the DCR?

Access to the DCR will be via an online SA Health DCR Resource Library. This Resource Library will contain all the information you will need to know about the DCR, including how to verify your identity for access.

As the DCR contains highly personal and sensitive information, each person's identity will be verified using an approved identity verification service before access to the DCR is provided.

The DCR will become publicly available after the ART Amendment Act and the new ART Regulations are formally proclaimed by the Government of South Australia to commence operation.

Where does the information in the DCR come from?

Since November 2021, South Australian ART clinics have been adding verified donor conception treatment information into the existing DCR via a secure clinic portal.

The publicly accessible DCR will also include information about private donor conception arrangements from the South Australian Births, Deaths and Marriages (BDM) Register where this information is included on the child's birth registration statement and verified by BDM.

Former South Australian ART clinics and other entities that retain historic donor conception treatment records have provided information directly to DHW for inclusion in the DCR when the information has been verified. The majority of these records date back to the 1980's and it is possible information will be missing in the DCR due to the historic culture of secrecy and poor record keeping practices during that time (explained in "Why is a DCR needed?").

Unfortunately, while the DCR may not answer all of the questions that donor-conceived people have about their biological heritage, it will provide significant amounts of information in one central location with the added benefit of ensuring the preservation of these records.

Is information in the DCR verified?

Where needed, the DCR uses a data linkage with the BDM Register to verify information. Where historical information is available and can be verified, it is included in the DCR.

Is information in the DCR verified? (continued)

Information that cannot be verified due to the quality of the records is retained by DHW to ensure the information is securely stored and available if new information becomes available in the future.

If missing ART records or information is found in the future and can be verified by DHW, the new information will be included in the DCR helping fill the gaps.

The DCR allows participants to voluntarily add personal information such as biographical statements, up to two photos and a short video to the DCR which can be accessed by the people they are connected to in the DCR (connections). This information is not verifiable.

Participants may also voluntarily self-report personal and family medical information to the DCR for access by their connections. Medical information is not verified by DHW and people accessing this information are encouraged to seek their own clinical advice about any medical conditions they are made aware of.

Can a donor be recognised as a legal parent of a donor-conceived child?

No. Donors are not legal parents under the law. Part 2A of the *Family Relationships Act 1975* outlines:

- > donors have no parental rights
- > donors are not liable to pay child support
- > donor-conceived people are not eligible to contest the Will of their parent's donor.

Do I have to have contact with the people I am connected to in the DCR?

No. The DCR includes contact preference options where you can specify if you are open to contact with your connections or not.

Contact preferences are set to 'nil contact' as the default setting. Contact details nominated by you (email or phone) are only disclosed if you change this setting in the DCR to 'open to contact'.

Address details are not disclosed to anyone in the DCR.

You can set different contact preferences for your different DCR connection types.

For example, a donor-conceived person may be open to contact with their donor-conceived siblings but not want contact with their parent's donor. In this case, donor-conceived siblings in the DCR would have access to the donor-conceived person's preferred contact details but the donor would not.

Will support services be provided for people accessing the DCR?

We have listened to previous consultation feedback on the ART Amendment Act which told us that donor-conceived people and donors want choice about whether to engage with support services and the ability to choose their own provider.

An appropriately qualified and experienced intermediary support and counselling service (the Donor Conception Register Support Service (DCRSS)) will provide services to support participants of the publicly accessible DCR, including search and find, and counselling upon request.

Will support services be provided for people accessing the DCR? (continued)

Where it relates to donations provided on or before 30 September 2004, donors, their families and donor-conceived people are eligible for free services provided by the DCRSS or can use their preferred provider at their own cost.

Other members of the donor conception community can also access the DCRSS at their own cost, and/or seek support from their ART clinic.

The online DCR Resource Library will also be available on the SA Health website providing resources and links to information for everyone to access.

Need more information or wish to provide feedback?

The YourSAy webpage contains further information and resources about the planned operation of the publicly accessible DCR.

Written comments and feedback on the draft ART Regulations can be emailed to health.donorconceptionregister@sa.gov.au by 5.00pm Sunday, 8 September 2024.

For more information

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