Fact Sheet – DCR Resource Library

Adding personal biographical information

South Australia's Donor Conception Register (DCR) includes options for DCR users to add personal information about themselves to the DCR. This helps people connected in the DCR to learn more about each other without the need for contact.

Section 10(2) of the *Assisted Reproductive Treatment Regulations 2024* (the Regulations), requires all personal biographical information to comply with the form and content required by the Minister for Health and Wellbeing. This fact sheet details the requirements and should be read in conjunction with the DCR 'Dos and Don'ts: your guide to personal biographical information'.

The legal meaning of personal biographical information

The Regulations define personal biographical information in relation to a person, as including the following information:

- a biographical statement about the person, including information about the person's family
- photographs and video recordings of the person
- personal characteristics (such as height, weight, eye colour, skin colour)
- medical information about the person.

Donors and adult donor-conceived people can choose to add their personal biographical information to the DCR for their DCR connections to view.

A parent(s) of a donor-conceived child aged under 18 years cannot add personal information about themselves or their child to the DCR; but can add medical information about their child to the DCR via the Medical information screen in the DCR.

Who can see your personal biographical information in the DCR?

Be aware that if you add your personal biographical information to the DCR, **all** your connections will be able to see this – even if you have selected different contact preferences for each of your DCR connection types. For example, you can't limit access to this information to just one donor-conceived sibling, or only to donor-conceived sibling(s) and not the donor(s).

Benefits of sharing information

Adding your personal biographical information can help your connections learn more about you, especially if you are not comfortable or ready for (i.e. open to) direct contact with them.

Sharing your relevant medical history via the Medical information screen helps your connections by providing an opportunity for them to seek their own medical advice about conditions they may otherwise not have known about. This knowledge could make a real difference to the lives of your connections.

Your privacy

When adding personal information to the DCR, it's important to (a) protect your own privacy and (b) not to breach the privacy of other people including your DCR connections.

The content you add to the DCR must comply with the:

- information contained in this fact sheet about the form and content approved by the Minister for Health and Wellbeing,
- terms and conditions for access and use of the DCR, which you must read and accept when you register to use the DCR (i.e. this is also viewable in the DCR at any time).

To help support DCR users comply with the above, any information added is moderated (reviewed) by authorised SA Health staff before it is made available for your connections to view in the DCR.

Moderation of personal biographical information

All personal biographical information is moderated by a DCR administrator before it can be made available in the DCR to ensure the form and content is compliant with the requirements of the Minister for Health and Wellbeing.

Moderation protects DCR users from inadvertently disclosing identifying information about themselves or another person and prevents the publishing of offensive or abusive content.

SA Health does not verify the accuracy or truthfulness of personal biographical information added to the DCR unless it is obviously untrue.

If the information you add complies with the form and content described in this fact sheet and the DCR terms and conditions, it is made available in the DCR, and you will be notified of this via your preferred method of either mobile phone or email.

If the content does not comply, it will not be made available in the DCR. You will be notified of this and can add revised information to the DCR for moderation.

Form and content of personal biographical information

Once you have successfully completed your DCR registration, you will have access to the DCR Personal and Medical information screens where you can add the information you want to share with your connections.

Do not disclose more information than you are comfortable with and remember:

- you choose the information (if any) you wish to add to the DCR – there is no requirement to add information to the DCR if you are not comfortable doing this
- while you can update or delete the information you add to the DCR at any time, your contacts may have already viewed the original information you previously added
- not to add information that your connections could use to identify or locate you – apply the same considerations you use in your day-to-day life when sharing your information and review your online and social media privacy settings
- where you are genetically linked to your connections, this does not mean that you share the same culture, social values, likes and dislikes as them.

Adding personal information

There are four different ways donors and adult donor-conceived people may add personal information to the DCR:

1. enter biographical information directly into the DCR (max. 1000 characters)
2. upload a written personal statement (PDF, max. size 3MB)
3. upload 1-2 photos of yourself (JPEG, JPG, PNG, max. size 3MB)
4. upload a video of yourself (MP4, max. size 150MB, max. length 3 minutes).

The following language and content does not comply and will not be accepted for inclusion in the DCR:

- personal attacks or inflammatory remarks, defamatory or libelous language
- any form of hate speech or harassment including on the basis of religion or political views
- obscene, foul, provocative, offensive, insulting, explicit language or images
- discriminatory language on the basis of any personal characteristic, including on the basis of ethnicity, gender, marital or domestic status, disability, sexuality or age
- identifying other people or sharing personal information about them such as their personal biographical or contact information
- content that is misleading, false, or promotes illegal activities
- impersonating or falsely representing any other person
- accusations against individuals or organisations
- defaming anyone or any organisation (i.e. a comment is defamatory if it lowers or harms the reputation of a person or organisation).

Special note: medical information must be added via the Medical information screen in the DCR and not included in biographical information or your written statement as some connections may only wish to view one or the other. To learn more refer ‘Adding medical information’ below.

Any type of content that does not comply will not be accepted for inclusion in the DCR.

Photographs and video

Be mindful of what personal information a photograph or video may contain:

- do not include images of other people, or yourself with other people such as your family or friends
- do not wear clothing that may be used to identify you, for example, the area you live in, your local sports team or club, place of work or study
- do not wear clothing that includes political statements or language that may be considered offensive – this extends to the background of a photo or video
- no identifying features should be visible in the background – examples include any person’s house and letterbox, car and licence plate, your residential street sign, a local community landmark that could be used to find out information about you, graduation certificates and/or sports trophies, etc
- do not include music tracks as these may be subject to copyright or be offensive to your connections.

Tips for writing biographical information and/or a personal statement

- It’s best to keep your information simple and short.
- Always consider how the content might impact your connections. Remember that where you are genetically linked to your connections, this does not mean that you share the same culture, social values, likes and dislikes as them.
- If you feel comfortable, ask someone you trust to review your written information before you add it to the DCR.

Biographical information can include your:

- physical characteristics such as your eye and hair colour, height and build
- personality traits e.g. it can help to think about how your friends would describe you
- interests and hobbies e.g. what you like to do in your spare time
- favourite sport, music, books, food, animals etc

- cultural background, ethnicity or things that are of cultural importance to you
- motivation for sharing this information
- a goodwill message
- any outcomes you might be hoping for.

If you want to share information with your connections that is beyond what is permitted in this fact sheet, this can be done outside of the DCR if you are both open to contact.

The DCR fact sheet 'Contact preferences and notifications' provides more information about letting your connections know if you are open to direct contact or not.

Adding medical information

The DCR offers two different ways to add medical information to the DCR, and you can use one or both options:

1. Select from a list of medical conditions known or suspected of having a genetic link and answer four questions about the diagnosis of each condition selected, and/or
2. Type information about any other medical condition(s) directly into the DCR (maximum 1000 characters). Include the following helpful details (if known):
    - the name of the medical condition
    - whether you or a family member were diagnosed by a medical practitioner with either (a) the condition, or (b) as a carrier of the gene that causes the condition
    - the age of diagnosis.

Remember, you must not include any details which could be used to identify or contact you or a family member.

Parent(s) of a donor-conceived child aged under 18 years

As the parent(s) of a donor-conceived child aged under 18, you can register to use the DCR and can add medical information about your child to the DCR.

When your child turns 18, your settings (including any medical information you have added about your child) and your access to information about your child's connections (including their medical information) in the DCR is removed.

As an adult, your child can register to use the DCR themselves and must consent for their medical information to be included in the DCR.

Can't access the DCR?

If you are unable to access the DCR directly and want to add your personal biographical information, email us at health.donorconceptionregister@sa.gov.au and we'll help make sure your personal biographical information is included in the DCR.

Notifications

As a DCR user you can choose to be notified by the DCR via your preferred method of either mobile phone or email, when your (or your child's) medical information is accessed by a connection or when your connection(s) update their medical information.

To learn more read the DCR fact sheet 'Contact preferences and notifications'.

For more information

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E: health.donorconceptionregister@sa.gov.au
W: www.sahealth.sa.gov.au/donorconception

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