Quick Guide

Response to the 2021 feedback

Public consultation on a draft Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021 closed on 21 June 2021. This Quick Guide provides an overview of how we've responded to the feedback we received in developing a revised draft Assisted Reproductive Treatment (Posthumous Use of Material and Donor Conception Register) Amendment Bill 2022 and the related policy positions.

What's happened since the 2021 consultation?

In mid-2021, the Department for Health and Wellbeing (the Department) consulted on a draft Amendment Bill which was intended to ensure the effective operation of the Donor Conception Register (DCR), provide all donor-conceived people with the right to access identifying information about their genetic parent(s) (donor) with retrospective effect, and provide donor-conceived people with the option to have genetic parent information included on their birth certificate.

Feedback received through consultation was overwhelmingly supportive of the establishment of the DCR. It also identified many differing and complex legal, social, operational and ethical issues for resolution before a Bill enabling access could proceed.

In response, the Department engaged Prof Sonia Allan to develop proposed safe access principles and a support service model informed by extensive consultation and research of existing DCR models across Australia. As a result of Prof Allan's work, key policy positions regarding the provision of safe access and appropriate intermediary and counselling support for participants of the DCR were developed and have informed preparation of a revised draft Amendment Bill which is the subject of this YourSAy engagement.

On the following pages are details of the key feedback received in 2021 and our response. You can find further information about the changes to the Amendment Bill on the ***Quick Guide – Changes to the 2021 Amendment Bill and related policy positions***.

For further information about who can access what information in the DCR refer to the ***Quick Guide – Who can access the DCR?***

What's next?

YourSAy is open and inviting written submissions on the draft Amendment Bill until 5.00pm Tuesday, 6 December 2022. Soon after, we will publish a summary report with the feedback received about the draft Bill and in due course, the Bill will be introduced to the South Australian Parliament.

Quick Guide

Response to the 2021 feedback

The feedback	How we've responded
Ensuring respectful and ethical access to the DCR	
Intermediary support service and counselling > The appropriate model for the intermediary support service > Should counselling be mandatory; and if so, for whom and to what extent > Expertise and qualifications required by the support service	> An appropriately qualified and experienced intermediary support and counselling service would be engaged by the Government to undertake 'search', 'find' and 'outreach' with counselling available (upon request) for donors, their families and donor-conceived people where it relates to donations provided prior to September 2004. > The DCR intends to provide online resources which every DCR participant would be required to engage with before being able to access information. This is to ensure participants are informed of the implications for seeking information and where to seek support should they need it. > All participants would have the right to choose if they wish to undertake counselling enabling them to select the level and type of service, and a provider based on their personal circumstances and preferences. > A dedicated online 'donor conception resource library' would be accessible outside of the DCR to enable access to information and advice regardless of whether a person engages with the DCR. All resources would be developed in conjunction with an appropriately qualified support service provider experienced in providing donor-conception support or similar.
Access and notifications > Who may have access to information within the DCR, and under what conditions? > Whether donors should be advised, and/or donor consent should be sought, before their information is accessed via the DCR	> Refer to the ***Quick Guide – Who can access the DCR?*** for details about when identifying and non-identifying information may be disclosed. > In acknowledgement of historical anonymity provisions, donors from the pre-September 2004 period would have the option to defer disclosure of their identifying information for three months[1] with optional support of an intermediary. This would provide the time and support needed for the donor to adapt to the news that they have genetic offspring, to inform family members and establish contact preferences in the DCR. When access to the DCR commences > Donors and donor-conceived people aged 18 and over would be able to set notification preferences specifying if they want the DCR to notify them when their information is accessed, when access to their information has previously been sought (where consent provisions exist) or when a genetic relative's medical information is updated.

[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.

Quick Guide

Response to the 2021 feedback

> Interaction between the role of Assisted Reproductive Treatment (ART) clinics and the DCR.	> Roles and responsibilities of ART clinics and the Department would be defined in accordance with legislative requirements and any requirements under the clinic's conditions of registration.
Consent and disclosure of identifying donor information (particularly where a donor was promised anonymity)	
> Whether consent should be sought from the donor before their information is released > Whether the donor is able to issue a non-legally binding 'statement of wishes' about contact preferences; or should the donor-conceived person be subject to a 'consent veto' by law > Whether the donor should be told about release of their information > The level of support available for donors when their information is released	> When access to the DCR commences, a media campaign targeting pre-September 2004 donors and donor-conceived people as a priority is intended to inform them of the new provisions and encourage them to establish their contact preferences in the DCR. It is also intended for a transitional period to apply when access to the DCR commences to provide all participants with time to establish contact preferences in the DCR before their information is disclosed. > The Statement of Wishes provision has been removed in favour of a contact preference system which provides the donor with the ability to inform their genetic offspring in advance if they are open to being contacted. Previous feedback indicates donor-conceived people are respectful of the donor's preferences and acknowledge that making contact against their wishes would likely jeopardise any future contact. > All DCR participants would be able to set personal notification preferences specifying if they want to be notified by the DCR when their information is accessed. > An appropriately qualified and experienced intermediary support and counselling service engaged by the Government would be available for donors and their families where it relates to donations provided prior to September 2004. All donors would also have the option of choosing their own service provider that suits their personal circumstances.
Provision of counselling and support services	
> The expertise and qualifications required to provide a service > Whether counselling should be mandatory or voluntary, or required at all > If counselling were made available and/or mandatory, to what extent should it be provided/required, and to whom	> The intermediary support service would be delivered by a service provider experienced with genetic family tracing with additional experience and understanding relevant to donor conception (or capacity to build experience and skills). Staff would be a registered social worker or psychologist or equivalent and would not be connected with the provision of fertility services to ensure impartiality. > There was strong emphasis by donors, donor-conceived people and recipient parents that any support model should be person centred and respect the right of the individual to choose if they wish to engage with an intermediary service and/or counselling. > The DCR intends to provide online resources which every DCR participant would be required to engage with before being able to access information. This is to ensure participants are informed of the implications for seeking information and where to seek support should they need it.

Quick Guide

Response to the 2021 feedback

> Interaction between ART clinics' existing donor linking and counselling services and the DCR support services > Should support services be available for persons involved in privately arranged donor fertilisation procedures	> Intermediary and counselling services would be provided (upon request) to support donors, their families and donor-conceived people where it relates to pre-September 2004 donations. An online resource library outside of the DCR would be accessible to all people regardless of whether they engage with the DCR. > ART clinics still have a role to play in supporting donors, recipient parents and people born as a result of ART provided by their clinic. All participants will still have the option to return to the ART clinic where the treatment took place to access the clinic's support services, regardless of when the donation took place. > Those involved in a private donor conception arrangement would seek their own support and counselling, enabling them to select the level and type of service, and a provider based on their personal circumstances.

Inclusion of donor information on birth certificates

- Many opposing views were received on the inclusion of donor information on birth certificates. Feedback indicated that choice and options for their birth certificate were very important to donor-conceived people.
- Consequential amendments to the *South Australian Births, Deaths and Marriages Registration Act 1996* (BDMR Act) are proposed as detailed below:
  - The birth certificate issued for donor-conceived children aged under 18 (born on or after the commencement of amendments to the BDMR Act) would have a notation of their donor-conceived status (excluding the donor's name) on the back of the certificate. This ensures that the birth certificate of future donor-conceived people accurately reflects their genetic heritage from birth and provide them with choice about accessing more information when they are ready.
  - Where the donor and legal parents' consent, a donor-conceived person under 18 (born before or after the commencement of amendments) may request a birth certificate that includes the names of their genetic parent(s) and their legal parents.
  - A donor-conceived person aged 18 and over (born before or after the commencement of amendments) would have birth certificate options including an 'integrated birth certificate' which includes the names of their genetic parent(s) and their legal parents; a birth certificate notated with a person's donor conceived status (excluding the donor's name); and a standard birth certificate.