

Disclosure of health information fact sheet

Assisted Reproductive Technology Act 2024

The Assisted Reproductive Technology Act 2024 (ART Act) includes provisions relating to the disclosure of health information.

Part 2, division 7 of the ART Act outlines the ability to disclose health information to impacted people.

The ART Act gives assisted reproductive technology (ART) providers clear authority and confidence to disclose health information about a donor, donor-conceived person, or their relative, with impacted people.

This fact sheet summarises the disclosure provisions.

ART provider disclosure of health information

ART providers have an important role in ensuring the appropriate disclosure of health information to people involved in donor conception. This includes health information that may become known many years after the original gamete donation or ART procedure occurred, while a person is pregnant, or while gametes or embryos are in storage.

ART providers are a crucial source of information about gametes and embryos, patients using gametes and embryos, and outcomes of treatments. Providers are therefore best placed to make this disclosure to potentially impacted parties.

The ability to disclose health information to certain people is separate to the donor conception information register.

Test for disclosure

For disclosure to occur, a medical practitioner must certify that the disclosure of health information is necessary to:

- prevent or reduce a serious risk to a person's life or health; or
- warn a person about the existence of a health condition that may be harmful to the person or their descendants.

Clinical understanding of genetic origins of conditions may evolve over time, which is why a list of conditions that meet this test has not been provided. This should be a clinical decision made by an appropriately qualified medical practitioner on a case-by-case basis.

Impacted people

ART providers may disclose information to any of the impacted people, per Table 1.

Table 1: Who health information can be disclosed to

Who information can be disclosed to	Information about a donor or about a relative of a donor	Information about a donor conceived person, or a relative of a donor-conceived person
Donor-conceived person and/or any donor-conceived siblings born as a result of an ART procedure using a gamete donated by the donor	✓	✓
Descendant of a donor-conceived person born as a result of an ART procedure using a gamete donated by the donor	✓	N/A
Parent, or other person with parental responsibility for, a donor-conceived person born as a result of an ART procedure using a gamete donated by the donor	✓	✓
A person who is pregnant as a result of an ART procedure using a gamete donated by the donor	✓	✓
A spouse of a person who is pregnant as a result of an ART procedure using a gamete donated by the donor	✓	✓
A person who has a gamete donated by the donor in storage with an ART provider	✓	✓
The donor	N/A	✓
Medical practitioner treating the person to whom the disclosure may be made	✓	✓
Any other person prescribed by regulation	✓	✓

Disclosure by medical practitioner

Any disclosure by an ART provider must be made by a medical practitioner.

ART providers should determine who could be affected by the health condition based on its clinical records. ART providers may also reach out to other providers who have either supplied or received potentially impacted gametes and embryos previously.

Donor conception status

The medical practitioner disclosing the information must take reasonable steps to ensure a donor-conceived person does

not become aware they are donor-conceived as a result of the disclosure.

The purpose of this requirement is to ensure that disclosures are managed sensitively on a case-by-case basis to prevent unnecessary trauma being experienced by donor-conceived people as a result of health information disclosures. This does not mean that the important health information should be withheld from the donor-conceived person, but rather that they are appropriately informed and supported regarding their donor-conceived status.

Timeliness

ART providers should consider timeliness throughout the disclosure process to facilitate early screening, interventions and improved health outcomes.

Queensland Health disclosure process

There is a safeguard in the ART Act that allows Queensland Health to disclose the health information if providers don't disclose it. ART providers are expected to make health disclosures in the first instance. Queensland Health will only consider the disclosure of health information in limited instances where an ART provider has not done so and the person seeking the information has exhausted all available avenues with the ART provider.

If Queensland Health needs to become involved in the disclosure of health information, there will be an expectation for ART providers to assist with this, through the provision of requested information.

Additional information

The information in this document should not be relied on as a substitute for other professional or legal advice.

This guidance is designed to be read alongside, and is not a substitute for, the:

- *Assisted Reproductive Technology Act 2024*
- Supporting explanatory notes

Key contacts

For more information, contact the Assisted Reproductive Technology Unit:
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