Queensland Health

Information collection and record keeping fact sheet

Assisted Reproductive Technology Act 2024: Fact sheet

The Assisted Reproductive Technology Act 2024 (ART Act) includes provisions relating to information collection and record keeping.

Part 2, division 6 of the ART Act outlines the requirements relating to:

- information collection;
- transferring information between assisted reproductive technology (ART) providers;
- information retention; and
- a prohibition on destruction of records.

This fact sheet summarises the requirements for ART providers.

It is important that information about ART patients and procedures is collected and retained, in line with good record keeping practices. It is particularly important for information about donor conception procedures to be collected and retained, because it has significant implications for the person born as a result.

Penalties for non-compliance with information collection and record keeping are detailed throughout the Act.

Information collection

The ART Act requires ART providers to collect information about:

- gamete providers, including donors, before obtaining gametes for ART procedures or storage; and
- people who undergo ART procedures.

Information that ART providers must collect is outlined in Table 1.

In relation to information about gamete providers:

- the information must be collected regardless of whether a gamete is obtained directly from an individual, or indirectly, for example through a sperm bank, clinic or another ART provider, in Australia or overseas;
- ART providers must not use a gamete or embryo unless the relevant information has been collected.

Gametes and embryos already in storage

Providers should request any information that they do not have for gametes or embryos already in storage at the time the Act commences before using them in an ART procedure.

An ART provider must not use a gamete or an embryo unless they have collected the information in Table 1.

Table 1: Information to be collected

| Information | All gamete providers^ | Donated gametes providers^ | All people undergoing ART procedures | People undergoing ART procedures using donated gametes or embryos |
|---|--------------------------|----------------------------------|--|--|
| Full name | \checkmark | \checkmark | \checkmark | \checkmark |
| Residential address | \checkmark | \checkmark | \checkmark | \checkmark |
| Phone number | \checkmark | \checkmark | \checkmark | \checkmark |
| Email address | \checkmark | \checkmark | \checkmark | \checkmark |
| Date of birth | \checkmark | \checkmark | \checkmark | \checkmark |
| Place of birth | \checkmark | \checkmark | \checkmark | \checkmark |
| Full name and date of birth of any spouse at the time of the procedure | х | х | \checkmark | \checkmark |
| Ethnicity | Х | \checkmark | Х | Х |
| Physical characteristics | Х | \checkmark | Х | Х |
| Relevant medical history Any medical history or genetic test result of the donor or the donor's family that is relevant to the person undergoing an ART procedure, the donor-conceived person or a descendant of the donor-conceived person. | Х | \checkmark | Х | Х |
| Sex and year of birth of each offspring of the donor Donor-conceived offspring Non-donor conceived offspring* | X | \checkmark | X | X |
| Any other information prescribed by regulation | \checkmark | \checkmark | Х | Х |
| If a person became pregnant as a result of the procedure, within four months after the procedure** | x | Х | x | \checkmark |

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| Information | All gamete providers^ | Donated gametes providers^ | All people undergoing ART procedures | People undergoing ART procedures using donated gametes or embryos |
|--|--------------------------|----------------------------------|--|--|
| If a child was born as a result of the procedure, within 15 months after the procedure*# | x | x | x | \checkmark |
| If a child is born was born as a result of the procedure, the child's full name, sex, date of birth and place of birth*# | x | X | x | \checkmark |

^ Regardless of whether the ART provider obtained the gametes directly from the gamete provider or indirectly, for example through a sperm bank, clinic or another ART provider, in Australia or overseas.

* An ART provider must take reasonable steps to collect this information. At a minimum this should include attempting to contact the person by more than one method of communication, such as via email and phone and following up with a phone call and email if the first attempt at communication is not successful.

Providers are to take reasonable steps to collect information about procedures that occurred before commencement of the ART Act, that resulted in pregnancies and births after commencement:

- In the case of pregnancy the procedure was carried out within four months before commencement of the Act. The information must be collected within six months after the procedure was carried out.
- In the case of the birth of a child the procedure was carried out within 15 months before commencement of the Act. The information must be collected about the birth within 18 months after the procedure is carried out.

Transferring information between ART providers about gametes or embryos

The ART Act requires that when ART providers supply to, or receive, gametes or embryos from another provider, they must exchange relevant information, including a copy of the consents and other information about the gametes or embryos. This transfer of information must occur regardless of the other provider's location.

ART providers must make sure gamete and embryo transfer procedures include an information exchange process that meets the above requirements. Information given to one ART provider by another is considered to have been collected in accordance with the collection requirements in the ART Act. This means that the ART provider does not need to reconfirm the information with the gamete provider, if all the required details are already provided.

Information to be retained

ART providers must keep required records for at least 99 years. ART providers must retain all the information outlined in

Table 2: Information to be retained

Table 1 **and** the information outlined in Table 2. Additional information requirements may be prescribed later in a regulation.

| Information | | |
|--|--|--|
| Gamete or embryo that is or has been in provider's possession | Name of any other ART provider who previously possessed the gamete or embryo (whether in or outside of Queensland). Each relevant consent: Including copies of any consent received by the ART provider or any other ART provider who previously possessed the gamete or embryo. Uses of a gamete or embryo by the ART provider, including supply to another ART provider or person (whether in or outside of Queensland). Period during which the gamete or embryo has been in storage. | |
| ART procedures carried out by ART provider | • For procedures using a donated gamete or embryo, the place where a procedure was carried out. | |
| Each child an ART provider knows was born as a result of its ART procedures | The child's full name, sex, date of birth, place of birth. The full name, residential address, phone number and email address of the person who gave birth to the child. If a donated gamete or embryo was used in the ART procedure, the donor's full name and date and place of birth. | |

Prohibition on destruction of records

The ART Act makes it an offence for an ART provider to destroy records, including records relating to ART procedures undertaken before commencement of the Act. The ART Act outlines that it is an offence to destroy:

- any records outlined in Tables 1 and 2; and
- historical records created before commencement relating to the birth of a donor-conceived person. These records will be required for the donor conception information register.

This reflects the importance of ensuring that ART providers take their role as custodians of information about gametes and embryos used in ART procedures, patients who have used ART services and treatment outcomes, very seriously.

ART providers can apply to Queensland Health to seek approval to destroy records. Queensland Health would only approve destruction in limited circumstances where it is reasonably satisfied the destruction would not adversely affect anyone. As part of applying for this approval, an ART provider would be expected to provide evidence demonstrating all actions taken to ensure that destruction would not adversely affect anyone.

Donor conception information register

The information collected about donors and donated gametes is important for the donor conception information register. The donor conception information register will be established at a later date, following an implementation period.

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: <u>ART@health.qld.gov.au</u>