European Society of Human Reproduction and Embryology

Registries for Medically Assisted Reproduction: essential tools to secure the protection of the intended parents, third-party donors, and children

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Background

Infertility generates disability and therefore access to healthcare for people with infertility must be provided as per the provisions of the Convention on the Rights of Persons with Disability. Infertility in women was ranked the 5th highest serious global disability.

Risks

The risks of Medically Assisted Reproduction (MAR) treatments for the intended parents, third-party donors, and children born from MAR are limited, although diverse, and there is a known underrecording of incidental complications/adverse events and a lack of awareness of psychosocial consequences.

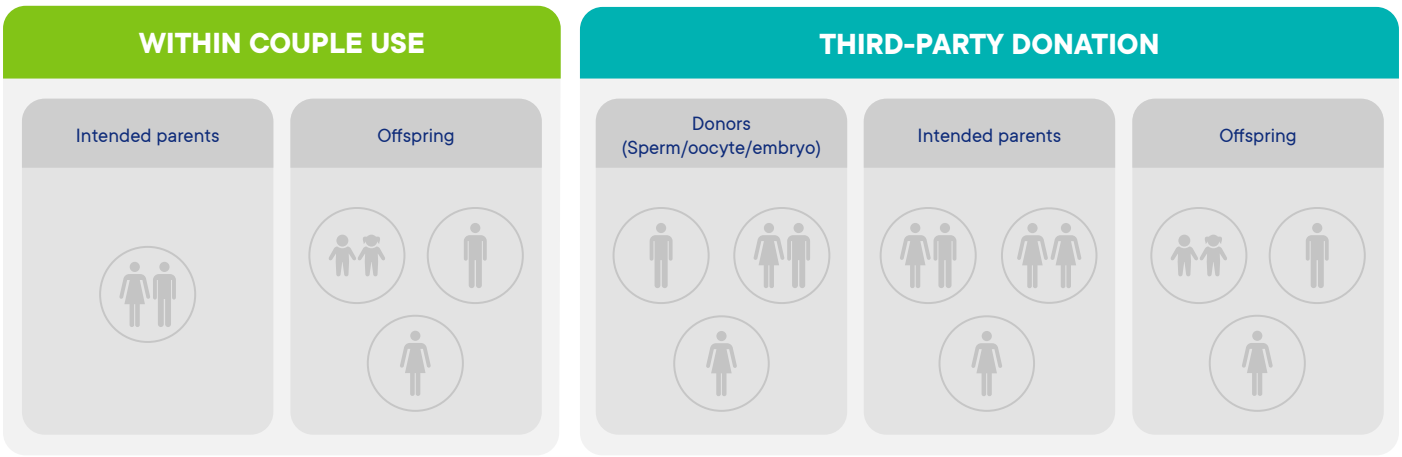
Data

Currently, data in MAR registries are incomplete. The situation is especially problematic in cross-border care both for the transport of gametes or embryos, and when patients travel to receive treatment, including third-party gamete donation. In these cases, there is very little data available.

Registries

Registries must be created and made mandatory to facilitate prospective data collection in order to guarantee traceability and prevent underreporting of serious adverse reactions and events.

Parties involved in Medically Assisted Reproduction



The risks

For women undergoing egg collection:

Serious adverse reactions and events (SARE) are scarce, but probably underreported and include:

- Ovarian Hyperstimulation Syndrome or other complications of ovarian stimulation
- Bleeding, infection or other complications of egg collection
- Anaesthesiologic complications

For children born from MAR:

- Treatments in MAR are known to influence complications during pregnancy and delivery, such as premature birth and low birth weight
- There may also be an effect of MAR treatment strategies on the (long-term) health status of the offspring

Although risks for children born from MAR appear so far modest, they should be carefully considered, adequately monitored and prevented.

How can MAR registries help to protect the intended parents, third-party donors and children?

→ Developing MAR registries further and making them mandatory would allow for prospective data collection and contribute to prevention of underreporting of serious adverse reactions and events, as well as provide direct evidence on the effectiveness of MAR treatments, especially following the introduction of innovations in MAR.

→ The aim of MAR registries is to improve vigilance and to ensure protection of the intended parents, donors and offspring. They provide essential evidence for the identification of risks and for the development of strategies to reduce or prevent risks.

References

1. Amor DJ, et al. Attitudes of sperm, egg and embryo donors and recipients towards genetic information and screening of donors. Reproductive Health. 2018 Feb 9;15(1):26.

2. Berntsen S, et al. The health of children conceived by ART: 'the chicken or the egg? Human Reproduction Update, 2019;25(2):137–58.

3. De Geyter Ch, et al. 20 years of the European IVF-monitoring Consortium registry: what have we learned? A comparison with registries from two other regions. Human Reproduction, 2020;35(12):2832–49.

4. ESHRE working group on information in reproductive donation, et al. Good practice recommendations for information provision for those using and participating in reproductive donation (in preparation for publication in Human Reproduction Open).

5. ESHRE European In-Vitro Fertilisation-monitoring Consortium (EIM) webpage: https://www.eshre.eu/Data-collection-and-research/Consortia/EIM