Good practice recommendations for information provision for those involved in reproductive donation

Medically Assisted Reproduction centres and gamete banks should have in place resources and training to ensure the relevant staff groups are available and can provide informed support

Who needs information and support?

DONORS
Sperm donor, Oocyte donor and Couple/single woman donating

RECIPIENTS
Intended parent(s)

OFFSPRING
Donor conceived children, adolescents, or adults

Direct-to-consumer genetic testing
People submit DNA to find information about their origin. Testing can:

- Reveal the lack of a genetic link between the social parent and the offspring
- Reveal that a family member has donated gametes/embryos
- Identify genetic relatives (donor, siblings, family members)

Key information and support to be offered, in general and in consideration of the availability of direct-to-consumer genetic testing and matching services

- CHECKLISTS on information provision to donors, recipients and offspring

Checklist on information and support to be offered to donors

BEFORE DONATION OF GAMETES OR EMBRYOS

INFORMATION PROVISION

LEGISLATION	Relevant national legislation governing the donation; explain that: – Legislation may change prospectively and retrospectively – Legislation may vary between countries	☐
	Donation is voluntary, but a reimbursement/compensation may be allowed	☐
	Information on recorded personal/medical data; explain: – Who can access the data and when (GDPR) – How medical information can be updated/clarified	☐
	Different options for donation (anonymous, Identity release, known) and what is allowed	☐
	Donor quota (or the lack thereof); explain possible consequences	☐
	Duration of storage; explain possible consequences (with regards to age differences)	☐
	The option for the donor to include his/her own restrictions with regards to the donation (number of families, type of recipients, post-mortem use) or withdraw his/her consent	☐
	Voluntary/mandatory donor registries and direct-to-consumer genetic testing; explain the implications	☐
HEALTH AND RISKS	Medical (genetic) screening and follow-up	☐
	Risks of donating (mainly for oocyte donors)	☐
	The possibility of being contacted by the MAR centre/gamete bank for additional medical information, such as unexpected diseases in the offspring	☐

COUNSELLING

Counselling should be available before, during and after donation	☐

PRIOR TO CONTACT WITH OFFSPRING

Counselling should be available before, during and after contact with offspring	☐

Checklist on information and support to be offered to recipients

BEFORE USING DONATED GAMETES

INFORMATION PROVISION

LEGISLATION	Relevant national legislation governing the donation; explain that: – Legislation may change prospectively and retrospectively – Legislation may vary between countries	☐
	Information on recorded personal/medical data; explain: – Who can access the data and when (GDPR) – How medical information can be updated/clarified	☐
	Different options for donation (anonymous, Identity release, known) and what is allowed	☐
	Donor quota (or the lack thereof); explain possible consequences	☐
	Duration of storage; explain possible consequences (with regards to age differences)	☐
	The option for the donor to include his/her own restrictions with regards to the donation (number of families, type of recipients, post-mortem use) or withdraw his/her consent. Also include the impact on possibility of genetic (half-) siblings	☐
	Voluntary/mandatory donor registries and direct-to-consumer genetic testing; explain the implications	☐
HEALTH & RISKS	Benefits and (medical/obstetric) risks	☐
SIGNPOSTING to resources, including literature (books), websites, peer support groups, dedicated counsellors and/or organisations		☐

COUNSELLING

Counselling should be available before, during and after using donated gametes. It should include: – Implications of using donor gametes – How to handle questions from family/friends – Disclosure, why and how	☐

Checklist on information and support to be offered to offspring

CONTACT WITH THE CENTRE FOR INFORMATION/SUPPORT

INFORMATION PROVISION AND SUPPORT

Type and content of information they can access from the authorities / MAR centre:
– This information may not match their expectations
– The information may have changed since the donation
– Requesting information does not imply that one should contact the donor ☐

Donor registries and how they function ☐

Relevant national legislation governing the donation. Explain that this:
– May change prospectively and retrospectively
– May vary between countries ☐

Donor quota (or the lack thereof) + possible consequences ☐

SIGNPOSTING to resources, including literature (books), websites, peer support groups, dedicated counsellors and/or organisations ☐

COUNSELLING

Counselling should be available, and include:
– Implications of revealing to others their donor conception
– How to deal with unwanted questioning/ judgements
– Revealing donor conception is irreversible ☐

SEARCHING FOR THE DONOR (or same-donor offspring)

INFORMATION PROVISION

The donor may not expect to be contacted and may not be prepared (through counselling) ☐

The donor may not be open to contact or may not have the same expectations ☐

Contacting the donor is not always a positive experience ☐

Same-donor offspring could be found, or not ☐

Revealing your identity is irreversible ☐

Similarities between you and the donor/same-donor offspring may exist, or not ☐

Meeting the donor/same-donor offspring does not guarantee a good relationship ☐

COUNSELLING

Counselling should be available, and include:
– Expectations with regards to contact with the donor or same-donor offspring and how to include them in one's personal life
– Consequences of (not) telling parents and relatives ☐