

Feedback form

Please provide your contact details below.

Name	Name withheld 3
If this feedback is on behalf of an organisation, please name the organisation	N/A
Please provide a brief description of the organisation (if applicable)	N/A
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Donor-Conceived

Privacy

We may publish all submissions, or a summary of submissions on the Ministry's website. If you are submitting as an individual, we will automatically remove your personal details and any identifiable information.

If you do not want your submission published on the Ministry's website, please tick this box:

☐ Do not publish this submission.

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If your submission contains commercially sensitive information, please tick this box:

☐ This submission contains commercially sensitive information.

Question 1: Rescinding the biological link policy

Refer to section 3.

ACART is proposing that:

- the guidelines should no longer require intending parents to have a genetic or gestational link to a resulting child
- instead the guidelines should require ECART to be satisfied that where intending parents will have neither a genetic nor a gestational link to a resulting child, the lack of such links is justified.

(a) Do you agree? Yes ☐ No ☒

(b) Do you believe there are cultural implications associated with the proposed removal of the biological link policy? Yes ☒ No ☐

If so, please describe these implications.

Yes, removing the biological link would threaten the ties to the child's whakapapa.

Please give reasons for your views.

I worry that these changes are not in the best interests of children, but are being driven by the fertility industry and consumer demand.

Unless, policy is being written first and foremost in the best interests of children, I cannot support a deliberate severing of biological ties.

This world is over populated enough. And there are plenty of children in New Zealand needing foster parents, big brothers/big sisters etc. to care for them.

Question 2: Access to information held on birth certificates

Refer to section 3.

ACART is interested in hearing views about potential strategies to strengthen a donor offspring's access to information about their origins, which is held on their birth certificate.

Do you have suggestions? Yes ☒ No ☐

Please give reasons for your views.

I believe that although it's complicated, there is more that could be done to record and reflect the biological as well as legal parents of a donor-conceived person.

One suggestion would be looking at what has been done with Adoptees and their birth certificates over the years, and seeing what, if anything, can be useful in terms of reflecting Donor-Conceived people's legal and biological parentage.

Perhaps one suggestion could be having a private document that can be accessed once the child turns 18. This document could be similar to an Adoptees original birth certificate, or it could simply have basic information about the donor that the Donor-Conceived offspring would receive an official notification informing them of.

This could also help encourage parents to be open and honest with their children from the beginning.

Question 3: Format of the proposed guidelines

Refer to section 4.1.

ACART is proposing to issue one set of guidelines to ECART that encompass family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic-assisted surrogacy.

Do you agree with the format of the proposed guidelines?

Yes

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No

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Please give reasons for your views.

Question 4: Justification to use a procedure

Refer to section 4.2.

ACART is proposing that ECART should be satisfied the proposed procedure is the best or only opportunity for intending parents to have a child and the intending parents are not using the procedures for social or financial convenience or gain.

Do you agree?

Yes

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No

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Please give reasons for your views.

Yes, I agree, but would also suggest that ECART consider, alongside the intending parents, that the child, likewise be considered in this too. We are of course talking about not just the creation of a family, but a person who will be, for better or worse, impacted by these decisions for the rest of their lives.

Prospective parents should be just as thoroughly checked and counselled as foster parents or adoptive parents are.

The best outcome will come from legislation that is centred around the child and their best interests.

Question 5: Consent by gamete and embryo donors

Refer to section 4.3.

ACART is proposing that, where a procedure will involve the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes:

- at the time of donation; or
- when a procedure using such an embryo is contemplated.

In either case, the affected parties should receive counselling on the implications of using gametes before the gamete donor gives specific consent.

If consent is given, the gamete donor can vary or withdraw their consent only up until an embryo is created (in cases where consent is given before the embryo is created).

In addition, where a procedure will involve the use of a donated embryo, the person(s) for whom the embryo was created must give consent to the specific use of the donated embryo:

- at the time of donation; or
- when a procedure using such a donated embryo is contemplated.

Once an embryo is created, the decision to vary or withdraw consent up to the time the embryo is transferred to the womb should remain with the people for whom the embryos were created.

Do you agree?

Yes

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No

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Please give reasons for your views.

Yes, the gamete donor(s) should be able to have a say in who they donate to, and also, be consulted thoroughly and given a choice to withdraw their consent up until the point of transfer.

Question 6: Taking account of potential coercion

Refer to section 4.4.

ACART is proposing that ECART should take account of any factors in a relationship that might give rise to coercion or unduly influence a donor's or surrogate's consent to take part in a procedure.

Do you agree?

Yes

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No

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Please give reasons for your views.

Yes, it's important to insure against any form of exploitation, coercion etc.

This type of behaviour should be picked up especially if all parties are thoroughly counselled through the process.

Question 7: Limit to number of families with full genetic siblings

Refer to section 4.5.

ACART is proposing that full genetic siblings should continue to be limited to no more than two families.

Do you agree?

Yes

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No

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Please give reasons for your views.

Yes, it makes sense to limit numbers.

I would however query the difference between limits for embryo donations, double sperm and egg donations, and the limits for single egg or sperm donations.

What is the rationale for that difference?

As a donor-conceived person, I can say with certainty, that no one in my situation wants tons of siblings. There is a bit of a yuck factor if the number is anything beyond about 4.

Question 8: Legal advice

Refer to section 4.6.

ACART is proposing that ECART must be satisfied that:

- where an application includes a surrogacy arrangement, each affected party has received independent legal advice
- where an application does not include a surrogacy arrangement, each affected party has considered seeking independent legal advice
- any legal reports show that all affected parties understand the legal implications of the procedure(s).

Do you agree?

Yes

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No

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Please give reasons for your views.

Question 9: Regulation of all family gamete donations

Refer to section 5..

ACART is of the view that all family gamete donations through a fertility services provider should be regulated by guidelines and thus require ECART approval.

Do you agree?

Yes

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No

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Please give reasons for your views.

Yes, I agree.

Question 10: Donation of embryos created from donated gametes

Refer to section 6.1.

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships and the gamete donors have given specific consent to the procedure.

Do you agree?

Yes

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No

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Please give reasons for your views.

No, from my perspective, and as a donor-conceived person, this is not something that sits at all well with me. This is something I see happening in the US, where there are no rules or regulations around third party reproduction, and everything is driven by making money for the fertility industry. It's unethical. Donor-conception using one donor is complicated enough. Before this is even considered ACART and ECART should be investing in extensive research into the long-term health and well-being of children conceived through third party reproduction. It's not good enough to take a gamble on our behalf, we, the donor-conceived, deserve better.

Question 11: Embryo on-donation and re-donation

Refer to section 6.2.

ACART is proposing that surplus donated embryos:

- should not be able to be on-donated by the recipients
- but can be returned to the donors, in accordance with any agreement between the parties, for re-donation to another party, subject to a new approval by ECART.

Do you agree?

Yes

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No

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Please give reasons for your views.

Question 12: Clarification of the status of embryo donation in the regulatory framework

Refer to section 6.3.

ACART is of the view that the regulatory framework should clarify that:

- all embryo donation cases are regulated by guidelines and thus require approval by ECART
- embryo donation does not include cases where an embryo created for a couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

Do you agree?

Yes ☒ No ☐

Please give reasons for your views.

Question 13: Regulation of all clinic-assisted surrogacies by guidelines

Refer to section 8.

ACART proposes to recommend that all clinic-assisted surrogacy cases be regulated by guidelines and thus require ECART approval.

Do you agree?

Yes ☒ No ☐

Please give reasons for your views.

Question 14: Any other comments

Do you have any other comments about the proposals in this document?

I'd like to see future documents from ACART have a more child focused point of view. This includes, as a first step, including the option of ticking a box saying *donor-conceived* (or something similar) in forms such as this.

While I can appreciate that third-party-reproduction is helping create families, I think that it's important to note that we're talking about people, not just babies, and that these lives that are created through these practices such as sperm, egg and embryo donation will be intrinsically impacted by these decisions, such as this feedback form and potential changes to the ACART and ECART guidelines.

Can the board please remember for future reference that donor-conceived are key stakeholders in these sorts of discussions.