Feedback form

Please provide your contact details below.

Name	Name withheld 9
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)	Retired policy analyst

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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 [x] No [ ]

(b) Do you believe there are cultural implications associated with the proposed removal of the biological link policy?

Yes [x] No [ ]

If so, please describe these implications.

The cultural implications I have in mind are not so much those associated with particular ethnic groups, but in regard to the various views about this issue that can arise in a pluralistic society.

I think this may be the most contentious proposal, given assumptions about the importance of a genetic link to ensure the wellbeing of a child, or that a genetic or gestational link is "natural". The legacy of closed adoption may also be an issue for some, or concern about the risk of commmodification of children (commodification can occur without the exchange of valuable consideration, as pointed out by Fitzgerald and Legge).

If past research (ie by Van den Akker) continues to hold true, intending parents will continue to prefer the maximum biological connection to a resulting child, and cases without any biological connection will be rare.

Please give reasons for your views.

Given the risk of ACART being seen to discrimate against some individuals and groups, I think the removal of the "biological link" policy is justified in light of human rights law.

A part of me is worried about the prospect of people seeking procedures with no biological connection for the sake of convenience. I think the filtering processes in clinics should be adequate to address this risk. In addtion, any case with no biological connection will involve a surrogacy arrangement with the subsequent adoption of a resulting child. Surrogacy/adoption involves legal costs and processes not associated with other procedures.

The best protection available for the wellbeing of resulting children is ECART review – not only that the procedure is justified, but also looking at all aspects of an application. In the much longer term, evidence may emerge in the New Zealand context indicating the extent to which a biological link in assisted reproduction is important for a child's wellbeing.

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 [x] No [ ]

Please give reasons for your views.

I support the recommendation of the Law Commission in its 2005 report. This recognises the right of individuals to access information about their history, while not imposing an intrusive obligation on parents which would exceed the rights we give to parents in a democratic society.

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 [x] No [ ]

Please give reasons for your views.

While the development of individual guidelines made sense in light of the established model, I have long thought that there is potential for some guidelines to be amalgamated into one set of guidelines. However, the feedback from clinics and ECART will be interesting because they actually have to use the guidelines.

But, I still think that combined guidelines are the way to go, even if tweaks are made to the finalised guidelines. There are overlaps between guidelines because of the removal of the "biological link" policy, and some applications to ECART will become increasingly complex.

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 [x] No [ ]

Please give reasons for your views.

Yes. This contributes to protecting resulting children from being seen as a commodity.

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 [x] No [ ]

Please give reasons for your views.

This proposed provision is consistent with the informed consent advice ACART gave to the Minister. While the advice is subject to Ministerial consideration, ACART is free to set out consent provisions in guidelines so long as the provisions are not inconsisent with the regulatory framework. And the guidelines should include clear consent provisions, for transparency and the absence of doubt.

The proposal recognises that gametes and embryos may be used years after gametes and embryos are stored. It may be worth including an additional provision to the effect that though a gamete donor is unable to withdraw consent after the stipulated time, any conditions re the specific use of the gametes continue to prevail. This is implicit in the proposal, but perhaps could be stated.

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 [x] No [ ]

Please give reasons for your views.

I think clinics and ECART are already be sensitive to the risk of coercion. However, this provision signals that this risk should be specifically addressed.

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 [x] No [ ]

Please give reasons for your views.

While this limit is arguably arbitrary with no rigorous evidence to support the limit, I suspect it is generally acceptable given that New Zealand has a relatively small population. More importantly, we know that sibling relationships matter, and this limit acts to manage complexity of family networks.

I would like to similarly see a specified limit to the number of children created by the gametes of one donor. However this is outside ACART's remit given that most gamete donations are established procedures. The Standard does require clinics to have a policy on the matter, and so New Zealand is not in danger of having numerous children created from the gametes of one donor.

This is particularly so given that one fertility servces provider has a dominant position and maintains a national database of donors across all its clinics. New Zealand is therefore not in the position (as in the United States) of having donors who are donating to several clinics.

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 [x] No [ ]

Please give reasons for your views.

Fertility Assciates has a timeline for a surrogacy application to ECART at:

https://www.fertilityassociates.co.nz/media/1053/vii-06surrogacy.pdf

I have copied it on to the next page.

I was interested to note that the legal appointments and advice could potentially come quite late in the process. Ideally, independent legal advice, for the surrogate at least, should come early in the process so the informed consent process is based on early understandings of the legal implications. I am concerned that if the legal advice comes late in the application process, and after counselling, the surrogate may feel that she is committed to the arrangement.

I have recently read two books about Australian surrogates first hand experiences:

Phillips Sue. 2010. Someone Else's Child: A Surrogate's Story. University of Queensland Press: St Lucia.
Garner Shannon. 2016. Labour of Love. Simon & Schuster: London.

What was striking was the early investment the surrogates made in the arrangement and the relationships with the intending parents. They were aware how much the intending parents were hoping for a child. In each case, neither surrogate reported doubts about her decision. And legal advice would not be the only determinant where a surrogate wants to withdraw.

But I suggest that it is worth considering a provision that independent legal advice should be obtained in advance of the counselling, so that the surrogate goes into counselling with a clear understanding of the legal situation in regard to surrogacy and adoption. While counselling will be significant in the informed consent process, legal advice is the only completely independent input required for a potential surrogate.

imeline for an EcaRt application for surrogacy	
Week 12	appointment with doctor – intending parents.
Week 13	appointment with different doctor – intending birth mother.
Week 11	intending parents begin discussion with cyF (child, youth and Family Services) regarding adoption/ guardianship process if not already started.
Week 4–12	Medical reports and any relevant test/additional medical reports completed by Fertility associates doctors and other specialists required.
Week 12	First counselling session – intending parents.
Week 12	First counselling session with a different counsellor – intending birth mother and partner.
Week 8	Second counselling session – intending parents.
Week 8	Second counselling session with a different counsellor – intending birth mother and partner.
Week 4–11	draft reports completed and sent to parties by the counsellor. Joint counselling session for both parties with both counsellors. draft report for joint session completed and sent to parties.
Week 4–7	counselling session for any signi cant others.
Week 4–7	all counselling reports completed.
Week 4–11	lawyer appointment for intending parents.
Week 4–11	different lawyer appointment for birth mother and partner.
Week 2–4	legal reports received at Fertility associates.
Week 1–4	application compiled and completed by Fertility associates.
Week 1	application couriered to EcaRt.

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 [X] No [ ]

Please give reasons for your views.

Regardless of the relationship between the donor and an intending parent, all family donations raise the same ethical issues. There is no logical reason for the current exclusion of some family gamete donations from ECART scrutiny.

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 [x] No [ ]

Please give reasons for your views.

This provides another option for the fate of surplus embryos created from donated gametes, and ensures that the interests of gamete donors are protected because they must have given specific consent to the procedure, either at the time of donation or later when the embryo donation is contemplated.

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 [x] No [ ]

Please give reasons for your views.

On donation would result in additional complexity for all parties. The people for whom the embryos were created in effect have a guardianship role until the embryos are transferred to the uterus of a recipient woman, and should retain that guardianship role if re donation is contemplated.

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 [x] No [ ]

Please give reasons for your views.

I used the HART regulatory framework in my work for 8 years, and are of the view that in some important respects it lacks clarity. The matter of embryo donation is one such area. The HART Order 2005 neither includes embryo donation in the list of established procedures, or excludes embryo donation from being an established procedure. Embryo donation is arguably similar to surrogacy in that it is not a procedure per se like ivf or icsi, but is a social arrangement that involves a clinical procedure.

Sonja Goedeke's research shows clearly the complexity of embryo donation for parents. International research shows that while embryo donation is contemplated by people with surplus embryos, a fuller understanding of the implications often means that donation does not proceed. Frequently donation to research is preferred over donation for assisted reproduction. The complexities of embryo donation justify ethical review.

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 [x] No [ ]

Please give reasons for your views.

All surrogacies are ethically complex and involve risks for the parties and resulting children. There is no logical reason to exclude some clinic assisted surrogacies from ethical review.

Question 14: Any other comments

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

I have a comment about a matter which is outside ACART's jurisdiction, but which I want to note.

When new or amended guidelines are issued, there is an impact on ECART's workload. The most significant (necessary) example was in relation to extended storage. As successive tranches of gametes and embryos come up to 10 years storage, ECART's workload will continue to include several applications for extended storage at every meeting.

ACART's current proposed provisions will potentially have a relatively small impact on ECART's workload – perhaps there will be an increase in particular with embryo donation cases where embryos created from donated gametes are donated.

However, if the Order is amended in accord with ACART's proposed advice that all famliy gamete donation cases should be ethically reviewed, this suggests that there will be a significant increase in the number of cases coming to ECART because many family gamete donations are currently established procedures.

My impression from the ECART website is that ECART and its Secretariat support are already very stretched in some ways. No ECART minutes for 2017 have been published. The most recent annual report published is for 2011/12.

I hasten to add that I know ECART and the Secretariat to be hard working: I suspect any problem lies with the resourcing available.