Feedback form

Please provide your contact details below.

Name	Ethics Committee on Assisted Reproductive Technology
If this feedback is on behalf of an organisation, please name the organisation	
Please provide a brief description of the organisation (if applicable)	
Address/email	ecart@moh.govt.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Decision-making committee on assisted reproductive procedures

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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.

1. ECART agrees with rescinding the biological link policy with the restriction that the proposed procedure is the best or only opportunity to have a child.
2. ECART notes that rescinding of the biological link policy could increase the complexity of relationships and therefore the considerations for ECART as a decision-making committee.
3. ECART notes that there is a difference in cost for ART procedures and that it is cheaper to receive an embryo than to create embryos from donated gametes.

Please give reasons for your views.

ECART considers that it is appropriate to remove the requirement for a biological link, as this requirement can lead to discrimination in certain situations.

With respect to point 2. listed above, ECART notes that the provisions that apply to all procedures covered in these proposed guidelines includes the requirement that ECART is satisfied that *the procedure is the best or only opportunity for intending parents to have a child,* and that this restriction is appropriate.

With respect to point 3. listed above ECART notes that ACART's assumption that people want to use their own genes may not be reflective of what ECART sees in applications it considers.

For example, ECART has considered applications where people describe that they do not want to use gametes of one partner only with donor gametes as this would feel unequal and they opt for embryo donation instead. This appears to be more common in situations where eggs are viable but sperm is not, and raises the question of whether the reverse would be true and whether this might be a gender issue.

ECART notes that the reasons for choosing embryo donation over donated gametes may be driven by beliefs and/or cost (i.e. embryo donation is cheaper).

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.

ECART notes its support for enabling access to information by donors' off-spring, but suggests that careful thought be given to how this happens in practice.

ECART agrees that access to information should be held on birth certificates and refers to the Law Commission's recommendation on page 20, paragraph 70 that all birth certificates be amended to include a statement indicating that the Births, Deaths and Marriages register may contain other information that may be accessed by the certificate's owner.

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.

ECART agrees with the format of the proposed guidelines.

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.

ECART notes its obligation to consider the principles of the HART Act when considering applications before it.

ECART also notes that, under the proposed guidelines, ECART must be satisfied that the procedure is the "best or only" opportunity to have a child. ECART considers that this provides ECART with the appropriate degree of discretion.

ECART asks whether the definition of social gain includes cultural considerations or potential benefits? ECART notes that cultural considerations may determine embryo donation without a biological link is in the potential child's best interests.

ECART suggests amending its own application forms to include the question "Is this the best or only way of having a family?" in the event the proposed guidelines are adopted.

With reference to the heading 4.3 'Consent by Gamete Donors' on page 28, ECART suggests that consideration be given to whether these guidelines could be extended to address posthumous use, obviating the need for separate posthumous use guidelines.

With reference to page 29, paragraph 109: *"We also propose that donated embryos must not be used in any procedure unless the persons for whom the embryos were originally created gives consent to that specific procedure at the time of donation or before donated embryos are used in the procedure."* ECART suggests ACART carefully consider the use of the terms "specific procedure" (paragraph 109) and "use". The HART order uses the phrase "specific use". ECART suggests that there needs to be more thought given and detail provided around the nature and extent of the consent to be obtained.

ECART also suggests that this might be an opportunity to deal with the use of gametes and embryos from gametes of deceased persons. The HART Order talks about the use of sperm from a deceased man not being an established procedure when no consent for the specific use was given before death.

ECART also considers that oncologists should be aware of these guidelines, as they are consenting patients at the time of collection of gametes, and at this time, there is the opportunity to ensure that the views and nature of consent are appropriately recorded.

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.

ECART had initial concerns around the timing of consent and whether clinics would need to go back to donors in certain situations, such as for the re-donation of embryos. ECART initially thought it would suggest that specific guidance be provided around the implementation of conditions by the gamete donor in situations of on-donation but acknowledges that the requirement of consent from gamete donors "*when a procedure using such an embryo is contemplated*" preserves flexibility as it would introduce the need for the fertility provider to go back to the gamete donors to seek consent for any subsequent use.

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.

ECART agrees that it is appropriate that it is required to take into account any factors in a relationship that might give rise to coercion or unduly influence the consent of a donor or surrogate to a procedure.

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.

ECART agrees with the proposal to continue the two-family limit for full genetic siblings.

ECART suggests that ACART may wish to consider the parameters of this requirement in further detail. For example, if the parents of two children divorce, does this mean that the full genetic siblings are now members of two families and any remaining embryos could therefore not be donated? ECART notes that there are a range of scenarios that may test the meaning of this limit. Further explanation of the intent of the restriction would be useful in guiding ECART's decision-making.

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.

This condition remains the same for surrogacy, which ECART supports, and imposes an additional/lesser requirement that people consider independent legal advice with respect to all other procedures.

ECART notes that what is important is that people know about the legal situation but suggests that a requirement that ECART needs to be satisfied that applicants have considered legal advice is not necessary to achieve what is intended.

ECART suggests the wording be changed (see "legal advice requirements of the draft guidelines, page 4 of the consultation document) as follows:

a. for provision 17, so that it states that "where an application does not include a surrogacy arrangement, parties have considered the legal aspects related to the procedure," and

b. for provision 19, so that it states "any legal reports show that the legal implications of the procedures have been explained to the parties"

ECART thinks it is important not to impose further unnecessary costs on parties, and that a suggestion that each party consider the option of seeking independent legal advice could mean that parties felt that they were required to seek legal advice.

ECART also feels that such a requirement would not add anything to its consideration of the matter – for example, it is unlikely to make any difference to ECART's consideration of the application if legal advice hadn't been sought.

As ECART is aware of not wanting to create additional barriers to accessing fertility treatment without adequate justification it suggests that a standard information sheet summarising key legal points could be provided to applicants.

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 [ ] No [X]

Please give reasons for your views.

In relation to the proposals relating to the provisions applying to family gamete donation ECART strongly disagrees with the proposal that all family gamete donations be referred to ECART.

ECART is of the view that the risks are not all the same for all family gamete donation cases and ECART would end up being deluged with applications where review is not necessary.

ECART also notes that it could potentially reduce timeliness of treatment for applicants. The HART Order seeks to cover certain procedures as established procedures to facilitate access. This proposed change would work against the intent of The Order.

ECART suggests that ACART consider carving out the factors that might cause concern and would require further ethical consideration by ECART.

By way of example, ECART considers that ECART approval should be sought for cases involving:

a) intergenerational donations/outcomes;

b) cases in which there could be concerns about coercion; and

c) concerns about the wellbeing of any potential children.

ECART feels that the above would most appropriately be dealt with by amending the relevant provisions of the HART Order.

Additionally, ECART notes that it can also provide non-binding ethical advice on established procedures and clinics do on occasion request this.

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.

ECART notes that the donation of embryos from donated gametes involves numerous parties.

ECART suggests that ACART give more thought to the complexities of the resulting relationships between the parties. In particular, ECART considers that further thought should be given to the rights and interests of gamete donors and how they would be upheld; the rights and interests of intending parents; the complexity of consequent relationships; the well-being of the potential child(ren); and ongoing contact and access to information.

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.

The on-donation of embryos created from donated gametes potentially increases the complexities around which parties have an interest in the outcome of embryo donation over and above what they are now as relationships could be created that are even more complex than those that can be currently created. ECART suggests that ACART give further careful consideration to such implications.

In addition, ECART notes that the assumption at the moment is that the intending parents (IPs for whom the embryos are created), would retain an element of control over the re-donation of excess embryos. In the case where the IPs are raising a child that is the full genetic sibling of the embryos in question then it seems reasonable to allow the IPs to effectively decide on where the potential full genetic siblings of their child end up. However, what happens in the case where the IPs do not have any children but decide to donate the embryos to another recipient? If this results in the on-donation IPs raising a child who is the full genetic sibling of the embryos in question then it would also seem that the on-donation IPs also have an interest in where the potential full genetic siblings of their child end up. If the embryos in question are created entirely from donor gametes then it would seem that the on-donation IPs in fact have a stronger interest in their fate than the original IPs for whom the embryos were created. Under these circumstances it would seem strange if any excess embryos were required to be returned to the original IPs for re-donation.

Alternatively, if the embryo(s) were created with one of the IPs gametes then one (or perhaps both) of the IPs will retain some interest in the fate of the embryo(s). ECART raises the question of what rights the original gamete donor would have in this situation.

There is also the issue of how “family” is defined and what would happen in cases where couples separated. Would the embryos be able to be used again by one of the parents, or would that parent’s new situation be categorised as a new family?

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.

ECART agrees with the proposal to clarify the status of embryo donation in the regulatory framework. ECART agrees that all embryo donation cases require approval by ECART.

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.

ECART agrees that all clinic-assisted cases should be regulated by guidelines and require ECART approval.

Question 14: Any other comments

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

1. ECART suggests that “and any existing children” be added to provision 2 of the section on clinic assisted surrogacy.
2. ECART does not agree with provision 3 of the section on clinic assisted surrogacy that requires a surrogate to have completed her family before becoming a surrogate. ECART suggests that this be amended so that it reads “there has been discussion between the affected parties as to whether or not the surrogate has completed her family before becoming a surrogate for others”. ECART is of the view that provided that the surrogate has talked to medical practitioners, received counselling and talked to the other parties about what the risks are, the completion of the surrogate’s family should not be a requirement.
3. With respect to the requirement that recipients have been vetted by police, ECART notes this requirement has time and cost implications. Further, there is no guidance on the types of records ECART is required to take into account when considering applications.

   At the same time ECART considers that it is important that donors are fully informed, and refers to the test set out in the Code of Health and Disability Services Consumers’ Rights – that is, what information would a reasonable consumer in his or her circumstances expect to receive when making a decision about whether or not to donate.

   ECART also notes the importance of the health and well-being of future children as a key consideration.

   ECART suggests that if the police vetting requirement is left in the guidelines, ACART may wish to consider whether it wishes to give any further guidance as to what sort of criminal history, and how far back, might impact negatively on an application.
4. ECART asks that certain text be cut from provisions 5 and 6 of the section on clinic assisted surrogacy as follows, on the basis that ECART considers that it is its role to determine that the wellbeing and welfare of the intending surrogate and any resulting child/ren is safeguarded, not that of the counsellor:

   > 5. ~~in the opinion of the counsellor~~ the wellbeing and welfare of the intending surrogate and any resulting offspring is safeguarded
   >
   > 6. all affected parties have considered~~, and in the opinion of the counsellor, have understood~~: (bullet points follow)
5. ECART notes that Oranga Tamariki approval in principle of an adoption order is not mentioned as a requirement.
6. On provision 19 of the proposed new guideline, ECART suggests the wording be amended to say “any legal reports show that the legal implications of the procedure(s) have been explained to the parties.” Fertility services providers cannot be expected to ascertain whether participants have *understood* the implications of the procedures.

7. On provision 21 of the proposed new guideline, ECART asks whether the plan is that all health information will be shared with all parties. ECART has had applications lacking in clarity about whether substantive relevant health information has been shared between applicants. ECART is of the view that the information should be shared if it is significant, while acknowledging that there are privacy and consent implications associated with people's health information.