Feedback form

Please provide your contact details below.

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If this feedback is on behalf of an organisation, please name the organisation	Women's Health Action Trust
Please provide a brief description of the organisation (if applicable)	Women's Health Consumer Organisation, specialists in gender-impact analysis and health equities
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Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Consumer Gender Impact Health Equities

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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.

We strongly advise a special consultation with Māori is undertaken to ascertain any cultural implications on the removal of the biological link policy consistent with the principles of the HART Act. This will possibly require an active engagement that does not just rely on response to this consultation document.

Please give reasons for your views.

In principle WHA supports the removal of the biological link policy subject to special consultation with Māori. We agree that the current policy is potentially discriminatory to LGBTIQ people and encourages the use of off-shore assisted reproduction services creating legal issues and unnecessary stress and isolation in the process of family formation through the use of assisted reproductive technologies, along with the perpetuation of potentially exploitative practices of unregulated assisted reproduction for women in developing countries. We agree that ethical assessment on the basis of need, rather than strict adherence to biological link is a fairer and more justifiable approach. We also agree that despite the removal of biological link policy, most intending parents will have a preference for a biological link so the removal of this requirement will impact positively on a small number of intending parents who have genuine need.

We do note, however, that the removal of the biological link policy will increase the responsibility of ECART to ensure an application that does not include a genetic or gestational link is justified and to ensure the interests of any resulting off-spring. ECART will need to be appropriately resourced and supported with this expanded responsibility.

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.

We are of the view that registering information related to the use of assisted reproduction on donor offspring's' birth certificates, while well intended in terms of access to information about genetic origins, is highly complex from the perspective of privacy. It also doesn't take account informal use of assisted reproduction so would be applied adhoc and discriminate against those intending parents who access fertility clinics. We strongly recommended that any such proposals are subject to much greater legal and ethical consideration, including the right to privacy, and are presented for public consultation. This could be part of a wider project on how to strengthen donor offspring's' access to information about their origins without undermining access to assisted reproduction services and off-spring privacy.

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.

We accept the rationale for this change and support improving ECARTs ability to assess applications that include several procedures.

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.

As we have note above in our response to Q.1. we are of the view that responsiveness to a diversity of circumstances and the assessment of need should replace the requirement for biological link and the medical criteria. We believe this will help improve equity of access to assisted reproductive technologies for LGBTIQ people. We strongly support the proposal that ECART be able to assess the merits and ethical basis of the use of a procedure/s on an individual case by case basis taking into consideration the particular circumstances of the applicants.

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.

We strongly agree with the principle of gamete donors' rights to informed consent about the use of their gametes. We also strongly agree that the person/s for whom an embryo was created be assured their right to informed consent regarding the use of the donated embryo. We do, however, suggest two possible considerations:

1. We wonder whether there might be the option for gamete and embryo donors to waive their right to informed consent at the time of donation in the case where the gamete or embryo donor does not wish to be contacted to consent to specific procedures using their gametes/embryos? This would help protect the interests of donors who do not wish to engage in further considerations arising from their donation potentially helping to increase the pool of available donated gametes and embryos. Obviously, the donor would require a very clear understanding of what the waiver meant in terms of the potential future use of their gametes/embryos without their consent.
2. We believe more consideration needs to be given to extent of gamete and embryo donors rights to informed consent, for example should gamete and embryo donors just have the right to consent to the types of procedures to be used or should they be able to choose the types of individuals and/or families who will be the recipient of their gametes/embryo? For example, what are the ethical and human rights issues raised by the current situation in which gamete and embryo donors are effectively invited to discriminate against the use of their donation by same-sex couples? We believe the balancing of rights to informed consent and equity of access to assisted reproduction require further discussion and debate.

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.

We support this proposal in principle but do question by what means ECART will be able to assess situations of coercion or undue influence and how ECART will respond to these? For example, if ECART identifies factors in a relationship that might give rise to coercion will an application automatically be declined? Will counsellor assessment be required? What weight will be given to counsellor feedback versus other sources of information? We would like to see much greater detail behind this proposal including the guidance and criteria that will inform ECART decisions in situations of possible coercion.

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.

We strongly agree with the intention of this proposal in terms of continuing to limit the number of full genetic siblings born from donated gametes. We are interested, however, about the evidence in support of setting the limit at two full genetic siblings? Is this based on international best practice or research evidence? There was no such information provided in the consultation document. The setting of the limit at two should be supported by evidence and a New Zealand specific impact analysis given the current shortage of donated gametes available for use in assisted reproductive procedures.

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.

We strongly agree that in all circumstances relating to surrogacy that all parties should be required to access independent legal advice. We also agree that where an application does not involve surrogacy it is adequate that all parties consider seeking legal advice as a minimum requirement.

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.

We can see the benefit of this proposal given the potential complications arising from family gamete donation however we are concerned that a blanket requirement for ECART approval will unfairly discriminate against family-based gamete donations providing a disincentive to donate within families, potentially adding to a shortage of gametes and/or driving people seeking to use family donated gametes away from fertility services providers. We can see a number of circumstances in which family-based gamete donation can be relatively straightforward, for example a brother's gamete donation to the same-sex partner of his sister. We are concerned that this proposal will unnecessarily clog ECART systems with cases in which gamete donation between family members does not represent particularly complex issues. We recommend that this proposal be subject to further analysis including determining the rationale for the original HART order that exempted some family relationships. We are not satisfied that ACART simply 'does not know why the HART order makes the distinction between the family relationship involved in the gamete donation'.

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.

We support this proposal. We believe this proposal centres the informed decision making of the donor consistent with the principles of the HART Act.

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.

We agree with this proposal in principle however we refer to our response to question 5 above. This proposal asserts the rights of the embryo donors to select 'recipients who they believe are suitable potential parents of children who would be full genetic siblings of their own children'. While we don't disagree with this principle we do recommend that further consideration is given to the potentially discriminatory implications of this for same-sex and single intending parents, and other non-normative families and how the needs and rights of donors and intending parents should be balanced. This will be necessary if New Zealand is to meaningfully address the appeal of off-shore assisted reproductive procedures for non-normative intending parents with all of the attending complications and risks.

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.

We agree with the focus on need and the ability of ECART to decide this on a case-by-case basis. We believe this will help reduce the discrimination of current assisted reproduction regulations towards LGBTIQ.

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.

We strongly agree that all clinic-assisted surrogacy arrangements should be treated consistently and that given the complex issues raised by surrogacy including women's reproductive autonomy that ECART approval should be a requirement.

Question 14: Any other comments

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

As we noted above, many of these proposals increase the responsibility and workload of ECART. We strongly recommend that this be accompanied by additional resources and support and that an impact analysis be undertaken in terms of the costs and time burden this may place on consumers.

We appreciate the opportunity to provide feedback on this consultation and would appreciate being notified directly of any future consultations.