

Feedback form

Please provide your contact details below.

Name	Sue Claridge
If this feedback is on behalf of an organisation, please name the organisation	Auckland Women's Health Council
Please provide a brief description of the organisation (if applicable)	The AWHC is a voluntary organisation of individual women and women's groups who have an interest in and commitment to women's health issues.
Address/email	awhc@womenshealthcouncil.org.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	The Council has a special interest in patient rights, informed consent and decision-making in health care, health consumer advocacy, the Code of Health Consumers' Rights, and medical ethics.

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☐ Do not publish this submission.

Your submission will be subject to requests made under the Official Information Act. If you want your personal details removed from your submission, please tick this box:

☐ Remove my personal details from responses to Official Information Act requests.

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.

The loss of links with an individual's genetic history, the issue of cultural loss (e.g. Maori whakapapa is important). NZ adoptive history and inter-country/intercultural adoption has shown that cultural knowledge is important for the child's health and wellbeing. However, these issues remain even if there is a genetic link with the intending parents on only one side. Cultural knowledge and a link with or understanding of the cultural heritage of both biological contributors can be important to an individual.

Please give reasons for your views.

It is important that children be able to follow-up on their own genetic and cultural history. Also genetic background may become important for medical reasons.

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.

The child needs access to their genetic history and the birth certificate would be an easy means by which the child could access the information. The birth certificate should name biological and adoptive parents and their dates of birth.

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

☒

No

☐

Please give reasons for your views.

The same principles from the HART Act underpins all these processes, so it makes sense to have all the guidelines in one place in one document. This especially makes sense where intending parents wish to make use of more than one procedure to have a child, e.g. donor egg and/or sperm and/or surrogacy.

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

☒

No

☐

Please give reasons for your views.

The best interests of the child should be foremost, and the procedure should not be used in any way by any person for social or financial convenience or gain, including any donors or surrogates, or the intending parents.

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 ☒ No ☐

Please give reasons for your views.

This respects any emotional ties that the donor may retain towards the child. In addition, given that we feel it is important that the child born of such procedures be able to find out about their cultural and genetic heritage, this necessarily means that they must be able to acquire at least some knowledge of the biological contributors to their existence. Thus, those donors must be able to provide consent to their gametes/eggs/sperm being used and how they are used, as at least some information about them will be available to the child. Donors must understand the implications of their role in creating a child for all parties involved and be able to provide informed consent to the procedures and the way in which their sperm or eggs are used.

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 ☒ No ☐

Please give reasons for your views.

The decision to donate gametes or enter into a surrogacy arrangement must be made voluntarily, and without coercion or undue influence. The implications of being biologically involved in the creation of a child are considerable. As in question 5 above, there may be ramifications for a donor as the child grows up, and as that child seeks to understand more about his or her genetic and cultural heritage, and donors/surrogates must be able to make a decision to participate on an entirely voluntary basis. In addition, in particular for the provision of eggs and or surrogacy, the procedures are not without risk to mental and physical health, and donors/surrogates must make informed decisions about their participation. For these reasons ECART needs to ensure that there is no economic, social/relational or emotional coercion involved.

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

☒

No

☐

Please give reasons for your views.

There are a number of issues regarding full genetic siblings, especially if they are unknown to each other:

- Siblings wishing to search for each other and have a relationship with siblings from another family, and the emotional harm if some siblings do not wish to enter into any form of relationship or even meet.
- Emotional harm caused if a sibling has a disability, life threatening disease, need for tissue transplant, or dies.
- If the siblings are unknown to each other and as adults meet and enter into a relationship without knowing that they are genetically related. Entering into an unknowing intimate relationship with a close genetic relative has the potential to cause considerable emotional and physical harm to both the siblings and their families.

Thus, we support the limiting of full genetic siblings to no more than two families. We agree with the reasons given by ACART regarding the complexity of having siblings in multiple families and the issue of consanguinity.

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

☒

No

☐

Please give reasons for your views.

If participation has actual known or potential future legal ramifications, e.g. surrogates being the legal mother of a child she carries, or there is any possible future claim or attempt at a claim against the donor of eggs or sperm then those participants should be fully aware of such ramifications through the provision of legal advice to them by an independent party. This should be considered a crucial part of the participant's ability to make an informed decision to be a donor and/or surrogate.

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 ☐

Please give reasons for your views.

All gamete donations and surrogacies have the potential to cause physical and mental harm, whether such procedures are within or between families. In order to be sure that all participants – donors, surrogates and intending parents – are fully aware of, and have considered the implications and ramifications of the procedures that they wish to use, a formal process of approval should be entered into. This is particularly important for ensuring the best interests and wellbeing of the resulting child.

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 ☒ No ☐

Please give reasons for your views.

Our reasons for agreeing with this are effectively encompassed in our answers to previous questions. Of greatest concern is the best interests of any child born as a result of gamete/egg/sperm donation and /or surrogacy, followed by the need for all parties to make truly informed decisions about their involvement in such procedures.

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 ☒ No ☐

Please give reasons for your views.

The need for strict regulation of embryos and the processes that create them and how and by whom they are used should not be lost just because the original recipients do not wish to or cannot use them. As the embryos are the creation of the donating couple, their embryos are “theirs” and they should be responsible for the future of their embryos. Donors may feel a sense of ownership, and this process honours that. It also reduces the complexity of the situation that could result with recipients being able to ‘pass on’ embryos – which may be detrimental to the identity and wellbeing of the future child. This is where counselling from the outset when embarking on ART is critical for women and their partners. Counselling may help raise people’s awareness as to the likelihood of having multiple embryos remaining and the issue of what to do with them if such a situation occurs.

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.

As above, embryo donation is still relatively new and the long-term ramifications for children and their families is unknown. We are familiar with Goedeke’s PhD research and her findings regarding the views of the donors towards their child. ECART’s required processes that parties undergo and review ensures that known ramifications are considered as much as possible. It also ensures that time is taken in the process. However, we are aware that this can be costly and time consuming for the couples.

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.

The need for strict regulation of clinic-assisted surrogacy should apply as it does to all other regulation of donation and surrogacy. The end result of a successful pregnancy is a child, and the same regulations safeguarding the ongoing physical and mental health and well-being of that child should be of utmost importance. In addition, there needs to be clarity around the intentions, rights and legal status of both the surrogate mother and intending parents.

Question 14: Any other comments

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

The AWHC believes that the rights, interests and well-being of any child born as a result of gamete, embryo, sperm/egg donation and surrogacy or any combination of these, should be the foremost consideration in any changes to guidelines on such assisted reproduction.

In addition, we believe it is essential that all parties – donors, surrogates and intending parents – are enabled to make the most informed decisions possible, voluntarily and without any coercion or undue influence and that the guidelines should facilitate such parties having the best information – medical, legal and ethical – made available to them so that can make the most informed decisions firstly in the best interests of the intended child, and also for themselves and their families.

Finally, we believe that it is important for the mental and physical well-being of any child born as a result of gamete, embryo, sperm/egg donation and surrogacy or any combination of these, that such a child is able to retain or forge links to their cultural heritage and learn of their genetic heritage in particular where such knowledge might be important for their future health (e.g. with regard to heritable conditions, genetic predispositions including but not limited to such information as knowing about a family history of cancer, or genetic mutations or variants that may predispose them to certain diseases or conditions.)