

Feedback form

Please provide your contact details below.

Name	Name withheld 7
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)	
Address/email	
Interest in this topic (e.g., user of fertility services, health professional, researcher, member of public)	Researcher/academic

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☐ Do not publish this submission.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.

Biological links are highly valued by many in the New Zealand context – this may be due to a number of factors, including the cultural significance of whakapapa, and an awareness of the significance of genes in terms of later characteristics and issues, and social ties (Glover & Rousseau, 2007; Grace & Daniels, 2007; Hargreaves & Daniels, 2007; Michelle, 2006). The removal of the link may not be as important however, as ensuring that there are appropriate measures in place to support individuals' access to information regarding their genetic heritage. Currently, disclosure depends on parents' willingness to disclose, and offspring are thus not guaranteed the right to access information. Research supports that outcomes of offspring are better when there is early disclosure, and honesty and transparency (Appleby et al., 2012; Blyth, 2002; Daniels et al., 2011; Jadv, Freeman, Kramer, & Golombok, 2009). See below for further detail.

Please give reasons for your views.

Where there are genetic links between the various parties involved in ART's, these are important to recognise, as research suggests that these may be regarded as significant, and as bestowing potentially immutable social ties (see Goedeke, 2014). Access to genetic knowledge is important psychosocially and culturally (e.g. healthy identity development) as well as medically (e.g. Daniels & Douglass, 2008; Goedeke, 2014; Michelle, 2006).

It does not necessarily follow however, that genetic or gestational ties are necessary for the development of close and secure attachments, or in terms of longer-term developmental outcomes. However, what is important to consider in the proposed changes to a biological link policy, may be a number of issues:

1. The complexity of relationships that may ensue – through changing the biological link policy, a child may have links to an increasingly complex network of people, including their parents, different donors (egg, sperm, embryo), and a surrogate. The various adult parties and offspring, as well as their siblings, should have the opportunity to access support to manage the immediate as well as longer-term implications and complexity of relationships that may ensue. Constructs of family and kinship are changing, but there is a significant body of research that suggests that offspring (and frequently donors, as well as recipients) have an interest in knowing about or even forming relationships with each other (e.g. Crawshaw Gunter, Tidy & Atherton, 2013; Daniels et al., 2012; Jadv, Freeman, Kramer & Golombok, 2011; Goedeke, 2014; Goedeke et al., 2015; Kirkman, 2004; Riggs & Scholz, 2011; Speirs, 2012). As cited in the proposal document, research suggests that early age and disclosure are likely to be important factors in children coming to terms with their histories – however, support may be needed to promote such disclosure. Support will be needed in terms of preparing the various parties for ART, and consideration will need to be given to ways of ensuring that this support is available. Further, relationships may not only be complex, with new kinship structures to navigate, but also dynamic. It may be difficult to predict how relationships may develop and change over time. As Kirkman (2004) observes, meanings may change over time and circumstance, particularly as children mature, as disclosure becomes an issue, and as relationships develop. Johnson, et al. (2012) comment that identity disclosure and access by those involved in donor conception should be accompanied by services to facilitate those that seek contact, suggesting that “it becomes essential that adequate support to negotiate these new and complex relationships is available for those involved” (p. 816). Likewise, Allan (2010) has recommended that counselling be available on an ongoing basis for parents, donors and children. This is further reinforced in recent research in New Zealand (Goedeke, 2014; Goedeke et al., 2016)
2. Thus support e.g. counselling should be available on an ongoing basis to promote the welfare of all the parties affected by ART, including the offspring (see HART Act principles). Note also that while circumstances and culture may play a role in the meaning and significance of biological relationships – much current research supports the importance of transparency and disclosure (in terms of family dynamics) as well as, as mentioned above, donor and offspring interest in information and contact. It is important to note that the participants in the UK study cited in the proposal donated under previous conditions of anonymity, and most parents had not or were not planning to disclose to their children – since they had little access to knowledge about the donors, recipients may well have underplayed their significance. New Zealand research (Goedeke, 2014; Goedeke, Daniels, Thorpe & Du Preez, 2016; Goedeke & Daniels, 2017) suggests that recipients do regard the donors as important, albeit framing their role as extended family members. Kirkman's studies may suggest that recipients emphasise biological ties (either gestational or genetic) to reinforce their position as mothers.
3. Facilitating access to offspring's knowledge about their biological history is important. There is supported by research on donor conception as well as in adoption (Appleby, Blake & Freeman, 2012; Blyth, 2012; Daniels, 2004; Daniels et al., 2011; Karnein, 2012, Palacios & Brodinsky, 2010; Richards et al., 2012), and is also a principle of the HART Act. If the biological link is rescinded, such access will include a wider network of people, and policies and practice will need to support access.
4. The benefits of rescinding the biological link include facilitating access to treatment for a wider range of individuals who wish to become parents, and who are currently unable to make use of various third party reproductive technologies. However, these needs must be balanced against the needs and rights of offspring. Research on longer-term outcomes for

offspring of third party reproductive procedures, especially as regards embryo donation which is arguably one of the more complex ART's, is in its infancy – it is difficult to draw conclusions from these studies because in many of these studies, the offspring are still very young (and various psychosocial issues, including around identity, typically emerge later) and/or are based on studies in which donation was conducted under a range of circumstances e.g. anonymity (Blyth et al., 2011; Frith et al., 2011; Kirkman, Bourne, Fisher, Johnson & Hammarberg, 2014; MacCallum et al., 2007, 2012; Paul et al., 2010). This underscores the need for access to support, and for further measures to promote and protect the rights of offspring – see Q2 below.

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.

Birth certificate annotation, possibly similar to what has been adopted in Victoria, Australia

Given the research that suggests the psychosocial, cultural and medical importance of donor offspring access to information about their origins, having a system which encourages access (HART Act principles) but does not guarantee access, leaves open the possibility that offspring are not made aware of their origins. The proposal states that children born from cases where there is no genetic link with the intending parents (3.67) will have access to their genetic history, which is held on the HART register. However, this is currently the case only when recipients elect to disclose – In 3.68, the proposal states that intending parents generally appreciate the importance of knowing about their history, and that it is not possible to enforce the principle of the HART Act without infringing on the rights of parents to make decisions about their children. However, research suggests that secrecy, or not finding out about origins later in life can have significant implications in terms of identity, psychosocial health, and family relationships. The HART Act also draws on principles that recognise the needs and rights of offspring to access information, and the need to consider the health and wellbeing of children that result from ART's. Asserting the importance of access to genetic history, but not creating conditions for offspring to access such information, is contradictory (see Allan, 2010). Blyth et al. (2009) in the UK argue that this has the potential to make the state complicit in acts of deception (Blyth et al., 2009), and may undermine the ability to respect the best interests of children born from ARTs. The NZ Law Commission considered the question of access to information in 2005 and made proposals in terms of recording information – this needs to be revisited.

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.

This will simplify the guidelines which is appropriate.

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.

I agree in principle with the removal of the medical need criteria, as this may enable further third-party assisted procedures for those wishing to become parents. It will be important to ensure that the psychosocial issues and complexity of relationships are well managed, and especially take into account the needs of potential offspring.

Point 102 (4.2.2.) suggests that lesbian or single women who cannot access donated sperm may then be able to receive donor embryos, reducing the need for using donor sperm outside the clinic setting. It is worth noting that recent research (See Goedeke, 2014; Goedeke and Daniels, in print) suggest firstly, that embryo donation is not a frequently chosen option for surplus embryos, and secondly, that donors typically wish to donate to individuals they consider to be similar to themselves – ED is thus not necessarily likely to be a solution for the lack of availability of sperm.

Note that the removal of the need for medical reasons for embryo donation opens the possibility that a small number of individuals currently unable to access embryo donation may consider it. In recent research (Goedeke, 2014) for example, some donors spoke of wishing to donate their embryos to family members who would be willing recipients, even if not necessarily infertile. Some recipients may also be invested in 'providing embryos with a home'.

It may also be important to clarify the parameters of ECART's role in evaluating applications. In my research (Goedeke, 2014) there was some suggestion that participants regarded ECART's role as akin to a government agency that holds responsibility for child welfare and protection, and that when decisions were made in favour of an application, ECART was confident of positive outcomes. Removing the need for medical criteria opens the possibility for applications from a greater range of individuals and increased complexity of cases.

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 ☐ X

Please give reasons for your views.

I agree with the need for informed consent, but am unclear if the proposal includes considering the need for donors to give consent for **each** specific procedure for which the gametes are used, **and** (not 'or') at the time they are used. Research suggests that donors (e.g. in embryo donation) may change their minds and that donation is a dynamic process – initial decisions to donate may change with life circumstances, experiences of donation, and reproductive journeys (e.g. Blyth et al, 2011; De Lacey, 2005). It thus seems important that consent for procedures are sought with **each** new procedure undertaken and **at the time** it is undertaken. This may seem impractical, but nonetheless, important for informed consent.

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 nature of the relationships and the consequences of donation need to be carefully considered.

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.

The potential complexity of relationships resulting from third party assisted reproductive procedures is significant.

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.

I agree that surrogacy applications should include a need for independent legal advice. I also agree that in many cases, legal advice in embryo donation may be unnecessary as the rights and responsibilities of donors and recipients are clear. However, donors may continue to assume a degree of responsibility for offspring and not always fully appreciate their lack of rights in relation to offspring (see Goedeke, 2014). Removing the need for independent legal advice potentially shifts the responsibility for ensuring donors and recipients have clarity about their rights to the clinic, and the counsellors involved in embryo donation applications?

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.

Family gamete donations are potentially complex and have implications for family relationships, and the wellbeing of offspring. Impacts of the proposal are stated to include an increase in ECART's workload, which presumably will also lead to an increase in the workload of clinic counsellors?

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.

I agree with this in principle, as it also allows potential embryo donors who find the option of discarding morally unacceptable with a viable option. However there may be three important issues to consider:

1. As acknowledged in the proposal, allowing embryo donation created from donor gametes increases the potential complexity of relationships – As discussed above, research suggests that many donors have an interest in information about or even contact with offspring and vice versa, and the same applies to donor siblings. How will this complexity be managed? Who will provide support, on an ongoing basis, for the various parties in managing these complexities? The HART Act is guided by principles that include considering the health and wellbeing of children, present and future generations, and all persons affected.
2. The HART Act supports donor offspring's access to knowledge of their genetic origins, which in the case of embryos formed from donor gametes includes additional parties. Access is compromised by a lack of measures that will ensure that offspring are aware of their history. Policy and practice need to ensure that offspring have access to such information.
3. Consent – the section on consent specifies that donors have given consent **either** at the time of donating **or** later – this may not adequately take into account the dynamic nature of donation (discussed above). Consent at each point and for each new procedure would be ideal.

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.

On-donation: New Zealand research (Goedeke, 2014; Goedeke & Daniels, in print) suggests that donors invest considerable time and emotional energy in making a disposition decision, and in choosing recipients for their surplus embryos. They are concerned about choosing recipients that they consider will make suitable parents, and with whom they feel they can form sound relationships. Many donors construct the offspring that may result from donation as still part of their family in some way, and thus assume a degree of responsibility for attempting to ensure their welfare. This ability would be removed from them should recipients be able to on-donate. This is particularly important given many donors' concerns about the lack of parenting assessments.

Re-donation: Donors may be very heavily invested in their embryos, the disposition decision may be very difficult, and for some, embryos are constructed as life (Goedeke, 2014). Discarding embryos may not be a morally acceptable option. For these donors, the ability to donate to a second family where the first donation was not successful, may be useful.

Note that the responsibility that donors assume for selecting suitable recipients is of concern, and may represent a burden for them – re-donation require donors to undergo this process again, and it is important the donors have adequate support.

Where re-donation refers to the relinquishing of embryos to the original intended parents for a second donation, and may also be important to seek renewed informed consent. While this may be a frustrating process for donors and recipients where there is sound relationship, and both parties remain committed, research (Goedeke, 2014) suggests that for some donors the reality of the donation differs from what is envisaged. Donation may be fraught with ambivalent feelings, and donors may not wish for the original recipients to make another attempt to achieve a pregnancy or have another child. It is also important to recognise that some donors, while originally indicating that their embryos were surplus to their needs, go on to have children after their donation. Views regarding family completion may change, especially in the context of ambivalence around donation. Seeking informed consent gives donors a further opportunity to consider if they would like to use the embryos themselves.

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.

Embryo donation has significant implications for all parties involved: donors, recipients, offspring, and their family members. It is important to approach ED cautiously.

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.

Yes. Surrogacy may involve a complex set of relationships and the possibility of coercion is present. Practical issues such as the increase in workload for counsellors would need to be addressed.

Question 14: Any other comments

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

The need for counselling: Counselling requirements are currently suggested to be “available throughout the donation/treatment process”. There may be a significant need for counselling *following* donation, as well as longer term, as the implications of donation become more apparent and as the various parties involved in donation manage the complexity of relationships that may ensue (Goedeke, 2014; Goedeke, Daniels & Thorpe, 2016) Counselling provision should ideally include *future* provision. Requirement 11(j) calls for implications counselling to address ‘their feelings now and possible feelings in the future’. Future feelings are difficult to predict, as donation is a dynamic process the outcomes of which are uncertain.