Feedback form

Please provide your contact details below.

Name	Withheld 1
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	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	

Privacy

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If your submission contains commercially sensitive information, please tick this box:

☐ This submission contains commercially sensitive information.

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors.

ECART must be satisfied that:

1. where a procedure will involve the use of an embryo created from donated eggs and/or sperm, the gamete donor(s) has given consent to the use of their gametes at the time of donation

2. implications counselling about the potential use of gametes was provided before the gamete donor gave consent

3. all parties understand that the gamete donor can vary or withdraw consent only up until an embryo is created (in cases where consent is given before the embryo is created)

4. where a procedure will involve the use of a donated embryo, consent to the use of that embryo must have been given by the people who originally had the embryo created for themselves:
   a. at the time of donation, or
   b. if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

5. where a procedure will involve the use of a re-donated embryo, consent to the use of the embryo must have been given:
   - at the time of donation, or
   - if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

   by
   a. the people who originally had the embryo created for themselves whether or not they have had a child that would be a full genetic sibling to a child that would be born from the embryos that are now being donated, and by
   b. the first recipient(s) of the donated embryos if they have already had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated

   but

   a re-donation can only be made if either the original intending parent(s) or the first recipients have not had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos (i.e. the limit of two families that can have full genetic siblings applies)

6. all parties understand that, once an embryo is created, the authority to vary or withdraw consent up to the time the embryo is transferred to the womb remains with the person(s) for whom the embryos were created. However, **if** the original intending parents have no gametes in the embryos **and** they did not have a child(ren) using embryos that would be full siblings to those that would be born from the embryos being donated **and** the first recipients **did** have a child(ren) using embryos that would be full siblings to a child(ren) that would be born from the embryos being donated **then** the authority to consent is with the first recipients.

Commented [MK1]: Submitter suggested “for this purpose”

Do you agree with the proposed consent provisions? Yes ☐ No ☐

Please give reasons for your views.

I am concerned that there is potential confusion within section 5. The “but” clause seems to counter what appears in earlier proposed guidelines.

I remain concerned about the provision for re-donating especially in terms of the understandings and implications for the child. Will they feel that they have been “passed around”?

Question 2: ACART proposes a new position, in which the interest in and authority over embryos would switch to the first recipients of donated embryos if a) they have had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated <u>and</u> b) the original donors do not have any gametes in the embryo(s) to be donated <u>and</u> c) the original embryo donors do not have a child(ren) using embryos that would be full siblings of the embryos.

Do you agree? Yes ☐ No ☐

Please give reasons for your views.

See above comments. How many times has a situation like this occurred? From my experience this would be very rare and again I have concern for the future child.

Question 3: ACART proposes to extend the list of prohibited family gamete donations.

ACART proposes to extend the list of prohibited family gamete donations so that none of the specified closely genetically related family members can use ART.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Avoidance of risk

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Feedback to original consultation very clear on this

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017.

Refer to section 4.

ACART is of the view that, when ECART considers cases involving donations of family gametes, ECART should consider if there is evidence that a) parties are being subject to undue influence, or b) that the health and wellbeing of the offspring and any other parties to the donation are compromised by the procedure, including, for example, by intergenerational complexities.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

This is much more appropriate

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration.

Refer to section 5.

ACART is of the view that the Order should be amended to state that all clinic assisted surrogacies should be subject to ECART consideration.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Clarifies situation.

Question 7: ACART proposes to remove the phrase "the surrogate has completed her family" and replace it with the phrase that asks parties to "consider the risks to the future reproductive capacity of the surrogate".

Refer to section 5.

ACART is of the view that the revised provision manages the risks and does not contain the problematic (unenforceable) provision of requiring family completion.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

More appropriate as it is more general which is welcome

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans.

Refer to section 5.

ACART is of the view that the revised provision gives greater protections to all parties involved.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Question 9: Do you have any other comments about the proposals in this document?

These changes in response to the previous consultation are welcome. Thank you.

Response ID ANON-P1SY-P3WY-Z

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-03-20 12:07:12**

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors

Do you agree with the proposed consent provisions?

Yes

Please give reasons for your views:
I wish to qualify my response. I think I agree but some of the wording, particularly in 6, is complex and hard to follow. For consultation, a diagram demonstrating possibilities could be helpful.
From an ethicist's perspective I recommend explanation of underlying principles. For example, whose interests are being served by these guidelines? Are they those of the embryo? Is safety important and if so of whom?
I think there is an emphasis on genetic relatedness. Why?

Question 2: ACART proposes a new position on interest in and authority over embryos

Do you agree?

Yes

Please give reasons for your views:
Again, I wish to qualify my response.

In b) are the "original donors" the same persons as in c) "the original embryo donors"? If so the terminology needs to be the same in both instances.

I am interested in the consultation document recipients. Is this believed to be full 'community' consultation or are persons on the consultation list mainly users of services and providers of services? I am asking because knowledge seems to be pre-supposed.

How can consultation be carried out to reflect what a largely uninformed society (community at large) understands and wishes to develop a view on? How can consensus be reached? How do New Zealanders want our society to be developing in relation to reproductive technologies? How widespread should consultation be?

Maybe parameters and limitations of this type of consultation should be clarified.

Question 3: ACART proposes to extend the list of prohibited family gamete donations

Do you agree?

Yes

Please give reasons for your views:

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations

Do you agree?

Yes

Please give reasons for your views:

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017

Do you agree?

Yes

Please give reasons for your views:
Yes - but I wonder what "undue Influence" is and how it will be ascertained.

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:
I strongly support the development of recorded precedents and the thinking behind decision making. ECART could keep this kind of record and be guided by it as they continue their work, and in the future recommend any changes to guidelines/legislation. Maybe ECART does this already.

Question 7: ACART proposes to remove the phrase 'the surrogate has completed her family' and replace it with the phrase that asks parties to 'consider the risks to the future reproductive capacity of the surrogate'

Do you agree?

Yes

Please give reasons for your views:
As a contributor to this earlier wording about completion of family I agree with the revised wording. I think that original wording was very strong (and perhaps impossible to have implemented anyway!) Considering risks in the future is essentially the underlying idea of that original wording.

Will parties be guided in their consideration?

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans

Do you agree?

Yes

Please give reasons for your views:
It is good to see the explanation here.

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
These questions have arisen in an area that I thought deeply and read widely about over several years, and discussed at length, before there were guidelines of any kind. (I chaired earlier committees to advise on matters relating to technologies and assisted human reproduction.)

I am not familiar with the deliberations that underlie these consultation questions (but should I need to be to address the questions?).

I have been able to offer comment on some aspects of presentation and wording of questions, and to ask some big questions about principles, and who should be involved in consultation processes that contribute to the shaping of New Zealand societal values and emerging norms into the future.

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:
n.a.

Please provide a brief description of the organisation (if applicable)

Organisation description:
n.a.

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
I am a member of the public, and an ethicist who has experience as such on committees and related work in the area of assisted reproductive technologies.

Publishing submissions and privacy

Publishing submissions

You may publish this submission

Official Information Act responses

Include my personal details in responses to Official Information Act requests

Commercially sensitive information

This submission does not contain commercially sensitive information

If your submission contains commercially sensitive information, please let us know where.:

Response ID ANON-P1SY-P3WM-M

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-03-17 16:02:42**

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors

Do you agree with the proposed consent provisions?

Yes

Please give reasons for your views:
These provisions appear to provide for fully informed consent. However, surrogacy consents also need to do this. The section on surrogacy does not meet fully informed consent requirements. It should be required to much more closely parallel these donor consent provisions - particularly since, in some cases, the surrogate is also effectively the egg donor (although she is not defined as such, and therefore donation regulations do not apply to her or the child/ren she gives birth to.

Question 2: ACART proposes a new position on interest in and authority over embryos

Do you agree?

Yes

Please give reasons for your views:
These provisions appear to be very carefully considered and to protect all those concerned to the fullest extent possible.

Question 3: ACART proposes to extend the list of prohibited family gamete donations

Do you agree?

Yes

Please give reasons for your views:
Again, these provisions appear to take the best interests and both present and future wellbeing of all those concerned into account as fully as possible.

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations

Do you agree?

No

Please give reasons for your views:
The stated exemptions, regarding sisters and brothers, seem sensible, but the potential relationships created in all such situations are extremely complex and need to be very carefully considered - not only in terms of genetics, but in terms of human relationships. Just as all clinically assisted surrogacies are now to be considered by ECART, given their ethical complexity, so all between family donations should also be considered by ECART.

Moreover, the same attention needs to be given to proposed arrangements involving family members acting as surrogates, which require equally careful consideration and clear guidelines.

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017

Do you agree?

Yes

Please give reasons for your views:
These are very important aspects of proposed family donation. Exactly the same provisions should be applied to cases involving proposed family surrogacy, which presents the same or very similar complexities and risks.

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:
This is a very important and sensible change, recognising the ethical and human relationship complexities inherent in all surrogacy arrangements.
\
However, it would be consistent and helpful to explicitly recognise that when a surrogate's own eggs are used, she is also a donor, thus bringing her and the child clearly under the comprehensive provisions governing donors and offspring. This would be particularly important were current campaigns to end the requirement that the intending parents must adopt children born to surrogates, as this is currently the only ongoing legal protection afforded to those involved in this relationship.

Question 7: ACART proposes to remove the phrase 'the surrogate has completed her family' and replace it with the phrase that asks parties to 'consider the risks to the future reproductive capacity of the surrogate'

Do you agree?

No

Please give reasons for your views:
The consultation document appears to envisage the possibility of women who have never experienced pregnancy and birth being able to become surrogates. This is an extraordinary proposal, and the requirement to advise potential surrogates of the risks to their fertility would not even begin to cover the possible dangers and difficulties, physical, mental and emotional, that such a situation could easily involve.

I understand the difficulty of ensuring that surrogates having "completed their families" - i.e. do not intend to have more children for their own family - is in fact the case. But it would be far safer to insist that any intending surrogate has had at least one successful pregnancy and birth before embarking on gestating and birthing a child for others. To permit women who have not done so to embark on surrogacy would seem to be extremely unwise from every possible perspective, including that of the intending parents and the clinicians. It should be explicitly ruled out.

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans

Do you agree?

Yes

Please give reasons for your views:
I strongly agree that residency is an important consideration. The consultation document makes this clear, especially for offspring. However, the proposal as currently worded is, in my view, not strong enough, since it apparently allows ECART to decide not to take residency into account. The word'can' should be replaced with 'should'.

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
The consent provisions for donation have been extensively altered, to good effect. However, in my view serious problems remain regarding ensuring fully informed consent in cases of surrogacy.

The amended guidelines state that the requirements in relation to a proposed surrogacy include the following:

4. all affected parties have received joint counselling.
This wording would appear to allow for all parties to be counselled together, whereas it should be perfectly clear that the proposed surrogate receives counselling separately. This may indeed be the current practice, but it should be clear that this is mandatory.

5. in the opinion of the counsellor the health and wellbeing of the intending surrogate and any resulting offspring is safeguarded
6. affected parties have considered, and in the opinion of the counsellor, have understood:
a. each other's needs and plans for continuing contact
b. specific issues that might affect the health and wellbeing of all affected parties

As worded, these requirements would not ensure fully informed consent. With regard to 5, It is not the counsellor but the surrogate herself, particularly as the risks to her would increase considerably under the current proposals re family completion, who should testify that in her opinion her health and wellbeing is safeguarded. This is essential for fully informed consent.

Similarly, the affected parties themselves should testify that in their opinions, they have considered and understood:
a. each other's needs and plans for continuing contact
b. specific issues that might affect the health and wellbeing of all affected parties. Again, this is essential for fully informed consent. It is not sufficient for the counsellor to speak on their behalf.

In terms of the major proposed change regarding the surrogate and family completion, it is all the more vital to ensure her own fully informed consent. However, as noted in my reply on this issue, the possibility that a woman could become a surrogate before she has had even one child of her own should be clearly ruled out. In this situation, it would be impossible for her to give fully informed consent.

The 'important principles that guide the actions of everyone involved with human assisted reproductive technology and human reproductive research' set out in the HART Act include:
c) while all types of individuals are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and wellbeing of women must be protected in the use of these procedures
d) no assisted reproductive procedure nor human reproductive research should be performed on an individual unless the individual has made an informed choice and given informed consent

Opening the door to women who have not had children becoming surrogates, and the current proposals regarding fully informed consent in cases of surrogacy, are not in line with these principles.

One point re wording: the definitions of surrogacy and surrogate need to both refer to 'intending' (parents). Currently the definition of surrogate says 'intended'.

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:
I am a member of Adoption Action Inc, but this is my own personal submission.

Please provide a brief description of the organisation (if applicable)

Organisation description:
N/A

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
Historian and researcher

Publishing submissions and privacy

Publishing submissions

You may publish this submission

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Commercially sensitive information

This submission does not contain commercially sensitive information

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Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Fertility provider

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Question 1: ACART proposes the following provisions for consent by gamete and embryo donors.

ECART must be satisfied that:

1. where a procedure will involve the use of an embryo created from donated eggs and/or sperm, the gamete donor(s) has given consent to the use of their gametes at the time of donation
2. implications counselling about the potential use of gametes was provided before the gamete donor gave consent

3. all parties understand that the gamete donor can vary or withdraw consent only up until an embryo is created (in cases where consent is given before the embryo is created)

4. where a procedure will involve the use of a donated embryo, consent to the use of that embryo must have been given by the people who originally had the embryo created for themselves:
   a. at the time of donation, or
   b. if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

5. where a procedure will involve the use of a re-donated embryo, consent to the use of the embryo must have been given:
   - at the time of donation, or
   - if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

   by
   a. the people who originally had the embryo created for themselves whether or not they have had a child that would be a full genetic sibling to a child that would be born from the embryos that are now being donated, and by
   b. the first recipient(s) of the donated embryos if they have already had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated

   but

   a re-donation can only be made if either the original intending parent(s) or the first recipients have not had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos (i.e. the limit of two families that can have full genetic siblings applies)

6. all parties understand that, once an embryo is created, the authority to vary or withdraw consent up to the time the embryo is transferred to the womb remains with the person(s) for whom the embryos were created. However, **if** the original intending parents have no gametes in the embryos **and** they did not have a child(ren) using embryos that would be full siblings to those that would be born from the embryos being donated **and** the first recipients **did** have a child(ren) using embryos that would be full siblings to a child(ren) that would be born from the embryos being donated **then** the authority to consent is with the first recipients.

Do you agree with the proposed consent provisions? Yes [✓] No [ ]

Please give reasons for your views.

It is very important that the original intending parents' consent to re-donation.

Question 2: ACART proposes a new position, in which the interest in and authority over embryos would switch to the first recipients of donated embryos if a) they have had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated <u>and</u> b) the original donors do not have any gametes in the embryo(s) to be donated <u>and</u> c) the original embryo donors do not have a child(ren) using embryos that would be full siblings of the embryos.

Do you agree? Yes ☐ No ☑

Please give reasons for your views.

The question is not very clear to me. I think that the original donors must consent if any switch takes place.

Question 3: ACART proposes to extend the list of prohibited family gamete donations.

ACART proposes to extend the list of prohibited family gamete donations so that none of the specified closely genetically related family members can use ART.

Do you agree? Yes ☐ No ☑

Please give reasons for your views.

I think this should be on a case by case basis.

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations.

Do you agree? Yes ☐ No ☑

Please give reasons for your views.

Ethical issues may still arise.

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017.

Refer to section 4.

ACART is of the view that, when ECART considers cases involving donations of family gametes, ECART should consider if there is evidence that a) parties are being subject to undue influence, or b) that the health and wellbeing of the offspring and any other parties to the donation are compromised by the procedure, including, for example, by intergenerational complexities.

Do you agree? Yes ✓ No

Please give reasons for your views.

Undue influence should be awarded at all costs.

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration.

Refer to section 5.

ACART is of the view that the Order should be amended to state that all clinic assisted surrogacies should be subject to ECART consideration.

Do you agree? Yes [✓] No [ ]

Please give reasons for your views.

Surprised to hear about private arrangements are taking place but we can at least ensure clinic assisted surrogacies are subject to ECART consideration.

Question 7: ACART proposes to remove the phrase "the surrogate has completed her family" and replace it with the phrase that asks parties to "consider the risks to the future reproductive capacity of the surrogate".

Refer to section 5.

ACART is of the view that the revised provision manages the risks and does not contain the problematic (unenforceable) provision of requiring family completion.

Do you agree? Yes ✓ No

Please give reasons for your views.

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans.

Refer to section 5.

ACART is of the view that the revised provision gives greater protections to all parties involved.

Do you agree? Yes ✓ No

Please give reasons for your views.

Question 9: Do you have any other comments about the proposals in this document?

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Name	Name withheld 5
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	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Researcher/Senior Lecturer, Clinical Psychologist

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ECART must be satisfied that:

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   - at the time of donation, or
   - if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

   by
   a. the people who originally had the embryo created for themselves whether or not they have had a child that would be a full genetic sibling to a child that would be born from the embryos that are now being donated, and by
   b. the first recipient(s) of the donated embryos if they have already had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated

   but

   a re-donation can only be made if either the original intending parent(s) or the first recipients have not had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos (i.e. the limit of two families that can have full genetic siblings applies)

6. all parties understand that, once an embryo is created, the authority to vary or withdraw consent up to the time the embryo is transferred to the womb remains with the person(s) for whom the embryos were created. However, **if** the original intending parents have no gametes in the embryos **and** they did not have a child(ren) using embryos that would be full siblings to those that would be born from the embryos being donated **and** the first recipients **did** have a child(ren) using embryos that would be full siblings to a child(ren) that would be born from the embryos being donated **then** the authority to consent is with the first recipients.

Do you agree with the proposed consent provisions? Yes [X] No [X]

Please give reasons for your views.

The guidelines do largely clarify consent.

However, in the case of embryos created from donated eggs in conjunction with donated sperm, where these embryos are not used by the people who originally had created the embryos for themselves, and they wish to donate, should the consent for embryo donation not also take into account the views of the gamete donors? Pg. 23, point 75 specifies that it is important that gamete donors are aware that an embryo may be donated and possibly re-donated and that they will have no say in the donation.

Point 2 of the requirements specifies that the gamete donors should receive implications counselling about the 'potential use' of gametes before giving consent to donation, but at that point they may be donating for the purposes of specific intending parents to have children, and they may not be as comfortable with the embryos being donated to others (or indeed, then possibly donated by the first recipients to second recipients where the people for whom the embryos were originally created were unsuccessful in having a child) . Further, research suggests that views about donation are dynamic, and it may be difficult for gamete donors to consent to "potential uses" in the future before an experience of donation. I appreciate the added level of complexity as well as the practical implications for clinics that additional consent would entail – however, I think this may be important for informed consent.

In the case of embryo donation (point 5), the consent process acknowledges the network of relationships created through embryo donation, and where the first recipients have a child through embryo donation, and the people who originally had the embryo created for themselves do not, recognises that the first recipients will have an interest in the outcome of a further donation to a second recipient family. In my opinion, what needs to be considered is further counselling at this point which involves ***both*** sets of recipients in order to discuss issues such as information-exchange and any contact between what will be full genetic siblings should the donation be successful. The potential social ties of such full genetic offspring need to be acknowledged.

As regards point 6), the consent process here recognises the social connections that may be bestowed by genetic connections as well as through gestational connections, and it thus seems appropriate for the first embryo donor recipients (who have a child through donation; gestational and social ties) to have the authority to consent over and above the people for whom the embryos were originally created who have no genetic or gestational ties to the child.

Question 2: ACART proposes a new position, in which the interest in and authority over embryos would switch to the first recipients of donated embryos if a) they have had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated <u>and</u> b) the original donors do not have any gametes in the embryo(s) to be donated <u>and</u> c) the original embryo donors do not have a child(ren) using embryos that would be full siblings of the embryos.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

As above, this position recognises the social connections that may be bestowed by genetic connections as well as through gestational connections, and it is thus appropriate for the first embryo donor recipients (who have a child through donation; gestational and social ties) to have the authority to consent over and above the people for whom the embryos were originally created who in this case (embryos created from donor embryos; no child) have no genetic or gestational ties to the child. My concern would be whether the egg and sperm donors who, in this case, may have donated to specific individuals/intending parents, would be comfortable with the donation and on-donation. See comments for question 1 above – I believe consent would need to be sought for any embryo donation. And of course, there may be complexity for offspring to negotiate in that they share genetic connections within a complex set of relationships.

The continued restriction to embryo donation resulting in full genetic siblings in two families recognises the ties that potential embryo donors may have to embryos remaining even when these were not created from their own gametes. Both Nachtigall et al. (2005) and Hammarberg and Tinney (2006) have indicated that couples who use donor gametes are not necessarily more likely to donate if they have children from the donation, and that any embryos remaining are regarded as full siblings to their existing children – where these couples do not have children through the donation however, and the first recipients of an embryo donation do, it is likely that the first recipients will have stronger ties to the embryos which need to be recognised.

The continued restriction to embryo donation resulting in full genetic siblings in two families also recognises that the donation of embryos created from donor eggs and sperm already links the offspring genetically to the egg and sperm donor, in addition to the full genetic siblings born to embryo donor recipients. Further allowing donation which would result in more than two families with full genetic siblings would create an even more complex chain of relationships. The potential social ties that full genetic offspring may have need to be acknowledged particularly where their only full genetic relationship is to each other, not to genetic ‘parents’.

Question 3: ACART proposes to extend the list of prohibited family gamete donations.

ACART proposes to extend the list of prohibited family gamete donations so that none of the specified closely genetically related family members can use ART.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

I agree that donation should not be allowed between specific family members who have a close genetic relationship carrying significant risk, both medical and psychosocial.

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations.

Do you agree? Yes [ ] No [X]

Please give reasons for your views.

I would prefer to see all family gamete donations being subject to ECART consideration because of the complexity of relationships and the possibility of coercion and obligation. Assuming that families or clinics can manage the risks is, in my opinion, problematic and implies that clinics may be carrying responsibility for risks.

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017.

Refer to section 4.

ACART is of the view that, when ECART considers cases involving donations of family gametes, ECART should consider if there is evidence that a) parties are being subject to undue influence, or b) that the health and wellbeing of the offspring and any other parties to the donation are compromised by the procedure, including, for example, by intergenerational complexities.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Within-family donation involves complex motivations and creates the possibility for complex relationships and potential threats to wellbeing of all parties.

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration.

Refer to section 5.

ACART is of the view that the Order should be amended to state that all clinic assisted surrogacies should be subject to ECART consideration.

Do you agree?	Yes	X	No	

Please give reasons for your views.

Traditional surrogacy may entail significant risk for all parties, which need to be considered.

Question 7: ACART proposes to remove the phrase "the surrogate has completed her family" and replace it with the phrase that asks parties to "consider the risks to the future reproductive capacity of the surrogate".

Refer to section 5.

ACART is of the view that the revised provision manages the risks and does not contain the problematic (unenforceable) provision of requiring family completion.

Do you agree? Yes [ ] No [X]

Please give reasons for your views.

I agree that the provision of requiring family completion is unenforceable and unrealistic. However, I would prefer an option that communicates that having had children would be the *preferred* option, given that it may difficult to ascertain future reproductive needs and fully appreciate risks to future reproductive capacity at the time of undertaking surrogacy - this especially when the surrogate has herself not yet had a child or been in a position to have a child.

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans.

Refer to section 5.

ACART is of the view that the revised provision gives greater protections to all parties involved.

Do you agree?	Yes	X	No	

Please give reasons for your views.

As stated above this could give greater protection to all parties involved.

Question 9: Do you have any other comments about the proposals in this document?

Embryo donation:

Re-donation of embryos: In the case where the first recipients of embryo donation (where they had a child and the people who originally had the embryos created for themselves did not have a child), and a further donation is proposed to a second set of recipients, I would prefer specific requirements to clearly include not only the *consent* of first receptions, but also that they meet in counselling with the original donors and the second set of recipients to discuss information-exchange, contact etc.

Requirements currently state: 2. *The embryo donors and recipients have received joint counselling in relation to the implications of embryo donation* - but this does not include the possibility of two sets of recipients receiving joint counselling. Could it be changed to "all affected parties have received joint counselling" as is the case for surrogacy?

Research suggests that both donors and recipients may need support following donation including when pregnancy is achieved, following birth, and potentially longer-term also. The requirements for surrogacy include that "counselling will be made available to all parties before and after pregnancy is achieved" which goes some way towards acknowledging the potentially longer-term outcomes of third party assisted procedures. Could this requirement be extended to embryo donation?

Surrogacy:

Surrogacy: The role of the 'counsellor' is potentially blurred – I am not sure one clinician can be both a counsellor and fulfil an assessment role as seems to be implied in the requirements. de Lacey S, Peterson K, McMillan J. 2015 has a discussion of some of these issues.

Access to genetic information:

I agree with the rescinding the need for a biological link. However, rescinding the need for a biological link potentially extends the range of people to whom offspring are connected in some way e.g. in embryos which are created from donor gametes and then donated. As started in my previous submission, I believe that ensuring that there are appropriate measures in place to support individuals' access to information regarding their genetic heritage is important. Currently, disclosure depends on parents' willingness to disclose, and offspring are thus not guaranteed the right to access information. The HART Act supports donor offsprings' access to knowledge of their genetic origins. Access is compromised by a lack of measures that will ensure that offspring are aware of their history. In my opinion, policy and practice need to ensure that offspring have access to such information.

Feedback form

Please provide your contact details below.

Name	Name withheld 6
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	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Member of the public

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:

x☐ 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: ACART proposes the following provisions for consent by gamete and embryo donors.

ECART must be satisfied that:

1. where a procedure will involve the use of an embryo created from donated eggs and/or sperm, the gamete donor(s) has given consent to the use of their gametes at the time of donation

2. implications counselling about the potential use of gametes was provided before the gamete donor gave consent

3. all parties understand that the gamete donor can vary or withdraw consent only up until an embryo is created (in cases where consent is given before the embryo is created)

4. where a procedure will involve the use of a donated embryo, consent to the use of that embryo must have been given by the people who originally had the embryo created for themselves:
   a. at the time of donation, or
   b. if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

5. where a procedure will involve the use of a re-donated embryo, consent to the use of the embryo must have been given:
   - at the time of donation, or
   - if consent was not obtained at the time of the donation then it must be obtained when a procedure using such a donated embryo is contemplated

   by
   a. the people who originally had the embryo created for themselves whether or not they have had a child that would be a full genetic sibling to a child that would be born from the embryos that are now being donated, and by
   b. the first recipient(s) of the donated embryos if they have already had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated

   but

   a re-donation can only be made if either the original intending parent(s) or the first recipients have not had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos (i.e. the limit of two families that can have full genetic siblings applies)

6. all parties understand that, once an embryo is created, the authority to vary or withdraw consent up to the time the embryo is transferred to the womb remains with the person(s) for whom the embryos were created. However, **if** the original intending parents have no gametes in the embryos **and** they did not have a child(ren) using embryos that would be full siblings to those that would be born from the embryos being donated **and** the first recipients **did** have a child(ren) using embryos that would be full siblings to a child(ren) that would be born from the embryos being donated **then** the authority to consent is with the first recipients.

Do you agree with the proposed consent provisions? Yes [x] No [ ]

Please give reasons for your views.

I agree with the proposal. It is a challenge to find clear wording that adequately conveys complex requirements.

I suggest some editorial changes:

- Replace the word “can” with “may”. “Can” conveys physical capacity, whereas “may” is about what is allowed and not allowed.
- For consistency, 3. should use the same wording as in 6.: “vary or withdraw consent up to the time…..”. However, for absolute precision and the avoidance of ambiguity I suggest instead, in 3. say “vary or withdraw consent before an embryo….”, with a similar rewording in 6.
- In 6. I note that “womb” is used instead of “uterus”. Checking back, I see uterus is used in the full proposed guidelines.

Question 2: ACART proposes a new position, in which the interest in and authority over embryos would switch to the first recipients of donated embryos if a) they have had a child(ren) that would be a full genetic sibling to a child that would be born from the embryos that are now being donated <u>and</u> b) the original donors do not have any gametes in the embryo(s) to be donated <u>and</u> c) the original embryo donors do not have a child(ren) using embryos that would be full siblings of the embryos.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

I understand the logic of this position.

However, I consider there should be an explicit limit to on-donations, regardless of the outcome of any embryo donation. I consider there should be a maximum of one on-donation, even if the on-donation does not result in a child. To continue on-donating embryos is to treat them as a commodity. Any resulting children need to know their full history, including any on-donation which is part of their history.

A first donation that does not result in a live birth is still part of a child's history. Part 3 of the HART Act requires providers to obtain and record various information about donors. ACART may wish to obtain advice about whether s.48(4) requires providers to keep information about the original donors where a recipient on-donates an embryo.

Question 3: ACART proposes to extend the list of prohibited family gamete donations.

ACART proposes to extend the list of prohibited family gamete donations so that none of the specified closely genetically related family members can use ART.

Do you agree? Yes [ ] No [x]

Please give reasons for your views.

I suggest saying “family members” instead of “relatives”: this wording would be consistent with the subject of the provisions and still enable ACART to restrict the relationships for gamete donation.

However, I don’t understand why the restrictions are only about particular genetic relationships. This presumably has the goal of reducing the health risks associated with reproduction between close biological family members. Has ACART considered whether it would be desirable to have father/daughter sperm and eggs used where the legal and social relationship is formed by adoption?

On the other hand, people may have a biological relationship but not have a legal family relationship, through adoption or gamete donation.

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

I can see the logic of the proposal, but am not entirely convinced that the current relationship exclusions in the HART Order make sense compared to the family donations that are subject to ECART review.

However, I note that while the literature warns of the risks of family donations (eg ASRM and ESHRE ethical reports), I am not aware of case-based evidence that family gamete donations are resulting in substantial difficulties for the parties or offspring.

I therefore agree with ACART's point about proportionate risk. And on this basis, I consider there is justification to not require ECART review of all family gamete donations, but to propose that all clinic assisted surrogacy cases be subject to ECART review.

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017.

Refer to section 4.

ACART is of the view that, when ECART considers cases involving donations of family gametes, ECART should consider if there is evidence that a) parties are being subject to undue influence, or b) that the health and wellbeing of the offspring and any other parties to the donation are compromised by the procedure, including, for example, by intergenerational complexities.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

I agree with the proposal, but note that the proposed wording implies that offspring are parties to the donation, and other people beyond the parties are parties to the donation. I suggest the amendments below.

1. the health and wellbeing of the offspring and ~~any~~ other parties ~~to the donation~~ are not compromised by the procedure, including, for example, by intergenerational complexities

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration.

Refer to section 5.

ACART is of the view that the Order should be amended to state that all clinic assisted surrogacies should be subject to ECART consideration.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

Amending the HART Order appears to be the most practical way to give effect to the proposed change.

Question 7: ACART proposes to remove the phrase "the surrogate has completed her family" and replace it with the phrase that asks parties to "consider the risks to the future reproductive capacity of the surrogate".

Refer to section 5.

ACART is of the view that the revised provision manages the risks and does not contain the problematic (unenforceable) provision of requiring family completion.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

I agree with ACART's reasoning.

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans.

Refer to section 5.

ACART is of the view that the revised provision gives greater protections to all parties involved.

Do you agree? Yes [x] No [ ]

Please give reasons for your views.

The word "residency" appeared in the first guidelines ACART issued in 2007 and has endured since. However, "residency" is very close to "residence" which is a formal immigration status, and thus the term residency is potentially confusing or misleading.

My understanding is that this proposed provision has two main goals:

- for ECART to consider where the parties live now and intend to live in future years, and what this may mean for the child's wellbeing including contact between the parties and for the child. I note this could mean inquiring into a person's immigration status, though I doubt if ECART or a provider has a legal right to ascertain this (an exception for a provider would be where public funding was used for treatment).
- (if a child will be born overseas from a surrogacy established in New Zealand) for ECART to be assured about the child's legal status re citizenship and that the intending parents are eligible, in the view of Oranga Tamariki, to adopt the child and also secure a visa for the child's entry to New Zealand.

Perhaps these ideas could be captured in new wording that does not include "residency", for the avoidance of ambiguity.

Question 9: Do you have any other comments about the proposals in this document?

Paragraph 27 in the consultation document talks about “interim guidelines” without setting out either what these would include or the statutory basis for such guidelines. I take it from the document that the interim guidelines would include new policy that would enable ECART to decide applications that would not meet current guidelines but could be potentially approved under the proposed new guidelines.

References in the HART Act to interim guidelines refer, as I understand it, to the guidelines of the former NECAHR that were in place when the HART Act was passed. The legislation provides for any NECAHR guidelines to be treated as guidelines under the HART Act until ACART issues new guidelines.

While ACART does not require the Minister of Health’s sign off for guidelines to be issued to ECART, ACARET must consult with the Minister and table new guidelines in the House. The idea of interim guidelines appears, without the beneft of explanation, appears to sidestep the formal process.

The way is open for ACART to give advice to ECART, but only where such advice clarifies existing policy set out in guidelines. New policy in guidelines is subject to the statutory process.

I recognise that the notion of interim guidelines may have been addressed through Ministry of Health advice that such guidelines can be issued to ECART.

Response ID ANON-P1SY-P3WD-B

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-03-25 12:16:39**

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors

Do you agree with the proposed consent provisions?

Yes

Please give reasons for your views:

Question 2: ACART proposes a new position on interest in and authority over embryos

Do you agree?

Yes

Please give reasons for your views:
Only as long as the original embryo donors were fully informed of the re-donation

Question 3: ACART proposes to extend the list of prohibited family gamete donations

Do you agree?

Yes

Please give reasons for your views:

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations

Do you agree?

Yes

Please give reasons for your views:

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017

Do you agree?

Yes

Please give reasons for your views:
Yes I feel strongly that the welfare of the unborn child must be considered

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:

Question 7: ACART proposes to remove the phrase ‘the surrogate has completed her family’ and replace it with the phrase that asks parties to ‘consider the risks to the future reproductive capacity of the surrogate’

Do you agree?

Yes

Please give reasons for your views:

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans

Do you agree?

Yes

Please give reasons for your views:
Yes, in our clinic we already conisder this an important factor is counselling surrogacy cases

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
no

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:
submitting my own opinion

Please provide a brief description of the organisation (if applicable)

Organisation description:
submitting my own opinion

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
Health Professional

Publishing submissions and privacy

Publishing submissions

You may publish this submission

Official Information Act responses

Remove my personal details from responses to Official Information Act requests

Commercially sensitive information

This submission does not contain commercially sensitive information

If your submission contains commercially sensitive information, please let us know where.:

Response ID ANON-P1SY-P3WN-N

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-03-25 14:24:37**

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors

Do you agree with the proposed consent provisions?

No

Please give reasons for your views:
I have two points to make about #6
a) That consent can be withdrawn up until the time of transference to the womb.
And
b) That who has the authority of consent changes depending on the presence or absence of a gamete connection between the original intending parents and the embryos.
These are discussed below:

a)
That consent can be withdrawn up until the time of transference to the womb.

Embryo donation requires IVF, which, for the gestation woman requires at least a lead in of a month for medication, tracking etc. It is acknowledged that IVF is a stressful process and time, particularly for straight couples who have a history of infertility. It seems unnecessary to add extra stress during this time, with the right to consent remaining up until transference to the womb, thus meaning the gestational woman has to go through the process aware the transfer might not go ahead.

If the original intended parent(s) agree to re-donate embryos to the first recipients, then the original intended parent(s) should have consent up until their agreement to re-donate the embryos to the first recipients is signed. This can provide a sense of clarity and surety for the first recipients during the IVF process.

b)
That who has the authority of consent changes depending on the presence or absence of a gamete connection between the original intending parents and the embryos. I do not agree with this for the reasons outlined below. This proposal also supports dubious implications that ACART should be aware of.

Page 24 | Embryo re-donation – a new proposal
“then the authority to consent to re-donation should lie with the first recipients. This reflects their stronger interest in the embryos, as a result of the genetic relationship that would exist between their existing children and any child born from those embryos. This proposal is a new position for ACART and we invite comments.”

1.
“ACART has confirmed its intention to progress the most significant policy shift, which is to rescind the mandatory biological link requirement” (p.iii)

Therefore, it seems contradictory to separate out authority of consent depending on whether the intended parents have or don’t have gametes in the embryo i.e. a biological link.

2.
Similarly, ACART recognises:
49 The biological link policy was potentially discriminatory, in the sense that some people wishing to use certain procedures may have been unable to do so because of their biological or social circumstances (page 19).

Thus ACART recognises that people do not need to be biologically connected to be a family, and also recognises that basing access to assisted reproductive technologies around a biological definition of family can be potentially discriminatory.

Separating out authority of consent depending on whether the original intended parents have or don’t have gametes in the embryo (i.e. a biological link) supports a hierarchy of family: those with a gamete connection at the top, and correspondingly have more rights, and those without a gamete connection at the bottom, and have less rights. This Consultation Document is dividing family into two types (those biologically connected and those not), and then also ascribes a hierarchy of family with those at the top (biologically connected) having more rights than those at the bottom (those not biologically connected). And this distinction and hierarchy is based on the assumption that firstly, a biological connection automatically creates both a family and an emotional connection, and secondly, without a biological connection there cannot be a family, nor an emotional attachment.

This is contradictory to the rescinding of the biological link, and potentially discriminatory for families without a biological link, or rather not families, but people who wanted to create a family, but could not, and want to donate their embryos, but are then understood to be less interested in the outcome of the embryos they created, only because they do not share gametes with the embryos.

3.
It also seems unnecessarily complicated to have two different pathways of authority of consent. Given the most complicated pathway of authority of consent is the default (Section 80, page 24: whereby BOTH the original intending parents AND the first recipients are required to give consent) providing another pathway seems even more unnecessary.

4.
Sections 78, 79 and 80 all state: “The original intending parents have authority over the embryos because they were created for them”. This is true for all original intending parents, whether they have gametes in the embryos, or whether they do not.

5.
Page 21 | Re-donation would be permitted, it is stated:
• “The original embryo donors had the embryos created for themselves and therefore have a special interest in them.”

The original intending parents or original embryo donors have a special interest in the embryos. #6 is implying that this ‘special interest’ is negated if there is no gamete connection.

In creating policy and guidelines that uphold a distinction between groups who have and who do not have a connection through gametes to their embryos, and strengthening that distinction through creating different authorities to consent, ACART is stating that intending parents who created embryos without their gametes have no special interest in the embryos, even though they had the embryos created for themselves, to create a family. By including #6, ACART is supporting a view that intending parents who had embryos created for themselves, but not of themselves, cannot and do not care for these embryos, and should not have an opinion, and indeed do not have an opinion, on the future of these embryos, even though they were created in the hope for their own children.

The original intending parents, whether or not they have a connection through gametes to the embryos, created the embyos for the purpose of their family. The embryos were supposed to be their children. In the case of re-donation, unfortunately the original intending parents were not successful in creating their family. Both groups, those with a gamete connection and those without, would have an emotional attachment to these embryos. It is highly insulting to therefore suggest that one group of original intending parents lose the authority of consent over the embryos because they have no connection via gametes, whereas another group of original intending parents retain their authority, purely based on the gamete / biological link, particularly when a primary concern of this consultation is to remove the need for a biological link for people accessing assisted reproductive technologies in fertility clinics.

6.
Page 24 | First embryo donation, it is stated:
“In this situation, ACART considers the fact that the first recipients already have a child that will be a genetic sibling to any child born from the donated embryo gives them a stronger interest in what happens to it.”

Again, ACART is making a (highly contentious) statement that original intending parents without a gamete connection to the embryos they created with the purpose of creating a family, have less of an interest in the embryos than first recipients. Yet in section 80 the original intending parents AND the first recipients are given the same rights and attributed with the same “stronger” interest, based purely on a gamete connection. ACART is ignoring, and continues to ignore, the reality of ‘interest’ based on an emotional connection to the embryos. A genetic connection does not automatically provide people with a stronger interest or stronger sense of responsibility, and similarly, a lack of a genetic connection does not automatically mean there is no interest nor sense of responsibility over embryos that were created with the intention of having children.

In summary:
I suggest removing this second pathway of authority of consent completely. This will also remove the implication that ACART recognises that attachment to and care about embryos can only occur through shared gametes, and the implication that if original intending parents do not share gametes with the embryos created for them, then they cannot and do not care for the embryos. Both the original intending parents AND the first recipients (if they have a child from the embryos of the original intending parents) should have an authority of consent about remaining embryos – whether original intending parents have gametes in the embryos is irrelevant.

Question 2: ACART proposes a new position on interest in and authority over embryos

Do you agree?

No

Please give reasons for your views:
1.
“ACART has confirmed its intention to progress the most significant policy shift, which is to rescind the mandatory biological link requirement” (p.iii)

Therefore, it seems contradictory to separate out authority of consent depending on whether the intended parents have or don’t have gametes in the embryo i.e. a biological link.

2.
Similarly, ACART recognises:
49 The biological link policy was potentially discriminatory, in the sense that some people wishing to use certain procedures may have been unable to do so because of their biological or social circumstances (page 19).

Thus ACART recognises that people do not need to be biologically connected to be a family, and also recognises that basing access to assisted reproductive technologies around a biological definition of family can be potentially discriminatory.

Separating out authority of consent depending on whether the original intended parents have or don’t have gametes in the embryo (i.e. a biological link) supports a hierarchy of family: those with a gamete connection at the top, and correspondingly have more rights, and those without a gamete connection at the bottom, and have less rights. This Consultation Document is dividing family into two types (those biologically connected and those not), and then also ascribes a hierarchy

of family with those at the top (biologically connected) having more rights than those at the bottom (those not biologically connected). And this distinction and hierarchy is based on the assumption that firstly, a biological connection automatically creates both a family and an emotional connection, and secondly, without a biological connection there cannot be a family, nor an emotional attachment.

This is contradictory to the rescinding of the biological link, and potentially discriminatory for families without a biological link, or rather not families, but people who wanted to create a family, but could not, and want to donate their embryos, but are then understood to be less interested in the outcome of the embryos they created, only because they do not share gametes with the embryos.

3.
It also seems unnecessarily complicated to have two different pathways of authority of consent. Given the most complicated pathway of authority of consent is the default (Section 80, page 24: whereby BOTH the original intending parents AND the first recipients are required to give consent) providing another pathway seems even more unnecessary.

4.
Sections 78, 79 and 80 all state: “The original intending parents have authority over the embryos because they were created for them”. This is true for all original intending parents, whether they have gametes in the embryos, or whether they do not.

5.
Page 21 | Re-donation would be permitted, it is stated:
• “The original embryo donors had the embryos created for themselves and therefore have a special interest in them.”

The original intending parents or original embryo donors have a special interest in the embryos. #6 is implying that this ‘special interest’ is negated if there is no gamete connection.

In creating policy and guidelines that uphold a distinction between groups who have and who do not have a connection through gametes to their embryos, and strengthening that distinction through creating different authorities to consent, ACART is stating that intending parents who created embryos without their gametes have no special interest in the embryos, even though they had the embryos created for themselves, to create a family. By including #6, ACART is supporting a view that intending parents who had embryos created for themselves, but not of themselves, cannot and do not care for these embryos, and should not have an opinion, and indeed do not have an opinion, on the future of these embryos, even though they were created in the hope for their own children.

The original intending parents, whether or not they have a connection through gametes to the embryos, created the embyos for the purpose of their family. The embryos were supposed to be their children. In the case of re-donation, unfortunately the original intending parents were not successful in creating their family. Both groups, those with a gamete connection and those without, would have an emotional attachment to these embryos. It is highly insulting to therefore suggest that one group of original intending parents lose the authority of consent over the embryos because they have no connection via gametes, whereas another group of original intending parents retain their authority, purely based on the gamete / biological link, particularly when a primary concern of this consultation is to remove the need for a biological link for people accessing assisted reproductive technologies in fertility clinics.

6.
Page 24 | First embryo donation, it is stated:
“In this situation, ACART considers the fact that the first recipients already have a child that will be a genetic sibling to any child born from the donated embryo gives them a stronger interest in what happens to it.”

Again, ACART is making a (highly contentious) statement that original intending parents without a gamete connection to the embryos they created with the purpose of creating a family, have less of an interest in the embryos than first recipients. Yet in section 80 the original intending parents AND the first recipients are given the same rights and attributed with the same “stronger” interest, based purely on a gamete connection. ACART is ignoring, and continues to ignore, the reality of ‘interest’ based on an emotional connection to the embryos. A genetic connection does not automatically provide people with a stronger interest or stronger sense of responsibility, and similarly, a lack of a genetic connection does not automatically mean there is no interest nor sense of responsibility over embryos that were created with the intention of having children.

In summary:
I suggest removing this second pathway of authority of consent completely. This will also remove the implication that ACART recognises that attachment to and care about embryos can only occur through shared gametes, and the implication that if original intending parents do not share gametes with the embryos created for them, then they cannot and do not care for the embryos. Both the original intending parents AND the first recipients (if they have a child from the embryos of the original intending parents) should have an authority of consent about remaining embryos – whether original intending parents have gametes in the embryos is irrelevant.

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations

Do you agree?

Yes

Please give reasons for your views:
If there is a preference for clinics to be involved so that ethical and legal issues can be better managed, then introducing a regulation for all family donations may prohibit clients from using clinics. In cases of social infertility (i.e. lesbian families), there are already and obviously families being made outside of the clinics and therefore outside of ACART and ECART provisions. By introducing mandatory regulation to social infertility, and making clients pay for it, the risk is that clients will chose to remain outside the jurisdiction of ACART and ECART. Repercussions include children not having access to information because they are not registered on the HART donor list.

By not requiring ethical approval for the cases stipulated under section 98, ACART is recognising a difference between medical and social infertility, and providing fewer barriers for queer women in accessing fertility clinics and their services.

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017

Do you agree?

Yes

Please give reasons for your views:
These are basic ethical considerations.

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:
[Operating on the assumption that the surrogate is never an intending parent]

ALL surrogacy should go through the process. It is not a matter of which eggs or which sperm is used. The priority, presumably, is that the clinic is operating in a manner which most benefits a clear process and pathway for birth of the child by the gestational mother and the subsequent adoption of the baby or babies by the intended parents. If the surrogate is using her own eggs, or the sperm of her partner, it seems even more necessary that they should go through the ECART process to ensure all parties involved are clear about their roles and expectations.

Question 7: ACART proposes to remove the phrase 'the surrogate has completed her family' and replace it with the phrase that asks parties to 'consider the risks to the future reproductive capacity of the surrogate'

Do you agree?

Yes

Please give reasons for your views:
I agree with ACART's rationale.

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans

Do you agree?

Yes

Please give reasons for your views:
Good consideration.

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
1) Overall:
The disparity between
"ACART has confirmed its intention to progress the most significant policy shift, which is to rescind the mandatory biological link requirement." (piii foreword)

And sections such as:
#81 If the original intending parents:
• did not have a child that would be a genetic sibling to a child born from the donated embryo and
• did not have any gametes in the embryos, and
• the first recipients did have a child that would be so related,
then the authority to consent to re-donation should lie with the first recipients. This reflects their stronger interest in the embryos, as a result of the genetic relationship that would exist between their existing children and any child born from those embryos (pages 24 -25 | Embryo re-donation – a new proposal)

It seems incongruent, and disingenuous, to on one hand, allow for intending parents to create embryos which are not genetically related to them, with the hope of creating a family, and on the other hand, write specific guidelines which excludes them from the rights of decision making afforded to other intending parents.

2)
Language.
I strongly advocate for the removal of the word “sibling”.

Language is very considered and deliberate in the Consultation Document, to ensure inclusion. The use of “siblings” is very jolting. It is:
a) definitionally wrong in the context of the document (as siblings have shared ‘parents’ and this discussion is about donors and intended parents. A donor is not ever regarded as a parent)
b) continuing the problematic assumption that a family is based on genetics, and therefore if children are genetically linked they must be related
c) inconsistent with ACARTs proposal to remove the biological link policy.

This is an extension of point 1) above. It is a continuation of an underlying automatic assumption that family is created through a genetic connection, and that a genetic connection automatically creates both family and a sense of care.

“Full siblings” could be replaced with “full genetic children”, or "full genetic offspring" or "genetically matched children" etc.

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:
n/a

Please provide a brief description of the organisation (if applicable)

Organisation description:
n/a

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
Researcher (PhD student looking at lesbians’ decision making around donor sperm, and their experiences of fertility and maternity services).

Publishing submissions and privacy

Publishing submissions

You may publish this submission

Official Information Act responses

Remove my personal details from responses to Official Information Act requests

Commercially sensitive information

This submission does not contain commercially sensitive information

If your submission contains commercially sensitive information, please let us know where.:
n/a

Response ID ANON-P1SY-P3WF-D

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-02-20 09:27:25**

Question 1: ACART proposes the following provisions for consent by gamete and embryo donors

Do you agree with the proposed consent provisions?

Yes

Please give reasons for your views:

Question 2: ACART proposes a new position on interest in and authority over embryos

Do you agree?

No

Please give reasons for your views:

Question 3: ACART proposes to extend the list of prohibited family gamete donations

Do you agree?

No

Please give reasons for your views:

Question 4: ACART proposes not to amend the Order so that ECART is required to consider all between family donations

Do you agree?

Yes

Please give reasons for your views:

Question 5: ACART proposes the guidelines should include the new requirement, for cases involving donations of family gametes, in place of the provision that was consulted on in 2017

Do you agree?

Yes

Please give reasons for your views:

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:

Question 7: ACART proposes to remove the phrase ‘the surrogate has completed her family’ and replace it with the phrase that asks parties to ‘consider the risks to the future reproductive capacity of the surrogate’

Do you agree?

Yes

Please give reasons for your views:

Question 8: ACART proposes to include a provision that ECART can take into account the participants’ residency status and plans

Do you agree?

No

Please give reasons for your views:

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
What needs to be looked at is the donation of embryos made with donor eggs or sperm when the donors are happy for them to be donated and have not donated to the max amount of families . Also the legal parents of a babies born via a surrogate. A surrogate mother still refusing to sign over legal rights to the biological parents 11 months later is not ok.

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:

Please provide a brief description of the organisation (if applicable)

Organisation description:

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
IVF patient

Publishing submissions and privacy

Publishing submissions

You may publish this submission

Official Information Act responses

Include my personal details in responses to Official Information Act requests

Commercially sensitive information

This submission does not contain commercially sensitive information

If your submission contains commercially sensitive information, please let us know where.:

Response ID ANON-P1SY-P3WJ-H

Submitted to **Second round of consultation on the proposed donation and surrogacy guidelines**
Submitted on **2019-03-25 15:25:08**

Question 6: ACART proposes that a change to the HART Order is the best way to ensure all clinic-assisted surrogacies be subject to ECART consideration

Do you agree?

Yes

Please give reasons for your views:
1. I PERSONALLY AGREE WITH THE RATIONALE GIVEN BY ACART AT [116].

I would expand on the rationale that 'all surrogacy can be ethically complex' and suggest that those forms to which the ECART process does not currently apply (where there is a genetic link to the surrogate or her partner) are possibly more ethically and legally complex, particularly should the surrogate change her mind and wish to keep the child.
If we accept that the preference for gestational over traditional surrogacy worldwide arose from a desire to make it easier for the surrogate to see herself as a (valued and trusted) babysitter of another person/couple's future child – and to therefore make any future custody issues easier to determine- then it seems that those cases in which there is a genetic link to the surrogate or partner are those where the ECART process can be the most beneficial in terms of identifying and discussing risks.
I have spoken at over a dozen international conferences about surrogacy regulation in New Zealand over the past five years, and at every conference there are comments from participants about how impressed they are with the ECART process (and as a legal academic, I do take an impartial approach and point out some issues with the process). While other countries struggle to 'unofficially' achieve some of the same steps as our process (by clinics recommending counselling and delaying appointments until this has occurred, or by having numerous medical appointments that double up as 'unofficial' counselling sessions) we have a very good process, and should be taking advantage of it, for the benefit of all parties involved.

The second rationale talks about the idea of the 'relationship between the surrogate and intended parents proceeding as expected'. The problem is, however, that 'as expected' tends to amount to nothing more than 'you'll carry a baby for me and I'll raise it'. As part of my research I have spoken to many lawyers in the UK, and carried out a survey of child and family lawyers in NZ who have dealt with surrogacy cases. There is an unfortunate trend in both countries of viewing surrogacy through rose-tinted glasses. In the UK there are increasing examples of people entering into 'arrangements' with surrogates that they have met online and have known for 48 hours, having had no detailed discussions apart from the amount of reasonable expenses that will be paid and the details around insemination and handing over the child after birth. In NZ, fertility counsellors and lawyers both describe reluctance from potential intended parents and surrogates to consider anything but the perfect outcome (happy surrogate handing over happy healthy baby to happy intended parent(s)). The ECART process creates the impetus for these conversations to take place. While these conversations can be difficult and unpleasant, it is far better to have them before the pregnancy occurs, than to realise that the parties have fundamental differences in opinion later (for example: in what situations, if any, might abortion be considered, and who is involved in the decision? Is selective reduction appropriate? Contact between intended parents/child and surrogate during pregnancy and after birth). The more surrogacy arrangements that are subject to this process, the less likely that issues are to arise later (whether these are issues that end up in court as custody issues, or whether they are issues that just leave one party (likely the surrogate) feeling unsupported or unappreciated).

The third rationale talks about the potential conflict between women's choice and conflicting interests of child/intended parents. As mentioned above, this is an issue that surrogates and intended parents seem to prefer not to talk about. It is, however, one of the most vital conversations to have before entering into a surrogacy arrangement, and not one that can wait until an issue actually arises. The ECART process provides suitable environments for these difficult conversations to happen (independent and joint counselling sessions followed by legal advice) and push factors to encourage these sessions. Counsellors can point out that the parties will next be talking to lawyers, who will bring this up, so why not discuss it in a more 'friendly' (my choice of language) environment first. Both counsellors and lawyer can further point out that it is an ECART requirement. Overall, it seems to me that the best interests of the parties is most effectively served by encouraging these discussions, and this itself is most effectively achieved by having as many surrogacy arrangements as possible being subject to the ECART process. Having all clinic assisted surrogacies being subject to the process seems logical.

For me personally, surrogacy within close family relationships immediately raises red flags in relation to undue influence and coercion, and it does concern me that these are the types of arrangement where it is more likely that the surrogacy will be traditional or the surrogates partner's sperm will be used (so there is a genetic link to the family). Having raised this with fertility clinic counsellors, however, I found it interesting that some agreed with my concern, and would treat these cases more carefully, but others felt less worried about these cases in general (unless, obviously, something specific suggested a cause for concern). Again, I see a real benefit in the ECART process for these individuals.

2. RESULTS FROM THE PUBLIC PERCEPTIONS SURVEY APPEAR TO AGREE WITH THE PROPOSAL

As part of my research, a representative public perceptions survey was carried out of approximately 2000 people, with names taken from the electoral roll. 556 responses were received. The Public Perceptions Survey asked whether "there should be a screening process by an ethics committee to determine the suitability of potential surrogate mothers" and "potential intended parents". While these questions are not directly on point with the ACART proposal questions, they do contain some comments as to the role of an ethics committee in the surrogacy process.
Approximately 80% of respondents thought that potential surrogate mothers should receive both medical and psychological screening before being approved to be surrogate mothers.
Approximately 70% of respondents thought that potential intended parents should receive both medical and psychological screening before being approved to be intended parents.
Survey respondents were also given the options of 'medical screening only', 'psychological screening only' or 'this is a decision for the parties'.
The next most popular answer was that 'this is a decision for the parties' (13.5% in relation to surrogates, 21.8% in relation to intended parents).

Respondents were invited to explain their answers further, and many chose to add additional comments.

*A decision for the parties
Those respondents choosing this answer tended to comment that freedom of choice was most important, and that this was a private decision. Some did, however, see a benefit in counselling, acknowledging that medical counselling and information would be useful in making that decision.
Some who chose this option clarified that they meant their answer to apply in circumstances only where the parties were previously known to each other, or were family.
Others were not comfortable with the involvement of an ethics committee, with some suggesting that medical or psychological professionals would be more appropriate, and one person who had previous experience with the process commenting on the length of time this added to the process.
A third group added that since screening was not required for natural conception, it should not be required for artificial conception

*Screening would identify concerns in relation to the potential surrogate
Some respondents thought that this would ensure that the surrogate was making a free choice, was acting as a surrogate for the right reasons, had thought through the process, or was psychologically able to hand over the child.
In relation to medical screening, some respondents noted that this might identify health issues that might lead to pregnancy complications.

*Screening would identify concerns in relation to the potential intended parent
Some respondents thought that psychological screening would ensure that the intended parents were interested in becoming parents for the right reasons. It was also thought that this would be useful to help determine whether the intended parents were able to cope with the stress of the surrogacy arrangement or of being a parent. Some mentioned using screening as a means of determining suitability for becoming a parent.
In relation to medical screening, some pointed out the importance of ensuring that the surrogacy arrangement was not being entered into for convenience, but for medical necessity. Others thought that it could be used to ensure that the intended parents were physically able to raise the baby, although some pointed out that this could be tricky as it might suggest that someone with, for example, Down Syndrome, should not be a parent.

*Screening would benefit the future child
Some respondents pointed out that medical screening might pick up on genetic or medical conditions that might be passed from the surrogate to the child. One extended this to ‘bad habits’, suggesting that behaviours were also inheritable.

*Screening would benefit all parties
Some respondents simply saw screening as benefitting all parties, recognizing that both the intended parents and surrogate were potentially vulnerable in this relationship

3. DISADVANTAGES OF THE PROPOSAL
I’m not sure of the implications of this proposal in terms of numbers of people affected, but this could be an important consideration, for the following reason:

*Time
The ECART application process is designed to take a certain amount to time, to allow parties to get to know each other (even if they are friends/family they may not know each other in this specific way) and reflect on issues raised in counselling and by lawyers.
The downside of this, however, is that for some groups, surrogacy is the last option after a long and stressful journey towards parenthood. A long, drawn-out process may just be one hurdle too far, particularly if the parties feel like they have already had a lot of the discussions. Alternatively, they might feel beaten-up and traumatized by everything that has occurred so far, and having to go through the ECART process might seem too much. Some comments from the Public Perceptions Survey from people who had experienced the process talked about how the ‘ethics committee delays the whole process a lot’ and one commented that they found the counselling ‘valuable’ but that ‘it does feel like a very long process when time is usually a big issue’.

While these people would likely benefit from the process, they might simply decide to go overseas, or not use a clinic, in order to avoid the process. There is at least one reported adoption decision in NZ in which the intended parents were applying to adopt a child born through a private (non-clinic) surrogacy, having gone through the clinic and ECART route with their first child (there is no explanation as to why they chose a private surrogacy for the second child).

*Cost
There is clearly an additional cost (application fee, various counselling sessions, legal sessions, travel to main centres for these) involved in the ECART process. The concerns raised above about people going private to avoid this might apply here. I have talked to hopeful intended parents who have gone into significant debt in their parenting journey (mortgaging houses, borrowing off family). Several have described feelings of ‘we’ve come too far to really stop trying’ or ‘we’ll just give it one more try with surrogacy’. Will these additional costs outweigh the benefits?

*Resources (counsellors and ECART)
How many more arrangements will this move into the ECART process? From my discussions with fertility clinic counsellors, I noted that there were not many counsellors working at each city. What would the increase on their workload mean in terms of delay?

Depending on the potential number of new applications, I would also wonder if ECART has the capacity to review these in a timely manner?
One comment from the Public Perceptions Survey raised the concern of a ’10 year backlog’.

*Other concerns about ECART
I have heard anecdotal complaints from potential intended parents who have gone overseas because of perceived issues around the ECART process

In the Public Perceptions Survey, there are comments around ECART ‘sound[ing] scary’ and ‘infertility [being] hard enough without having to be before an ethics committee’

Some respondents thought that some screening or decision-maker was a good idea, but that it should not be an ethics committee, but a GP, or Family Planning, or medical/psychological professionals

Question 7: ACART proposes to remove the phrase 'the surrogate has completed her family' and replace it with the phrase that asks parties to 'consider the risks to the future reproductive capacity of the surrogate'

Do you agree?

Yes

Please give reasons for your views:
1. THE SPECIFIC LANGUAGE
I'm actually not sure whether I agree or not.
I'm seeing three different forms of language here:
P35: "replace 'finish family' requirement with a requirement about risk awareness" (heading)
"ACART has proposed a provision that the surrogate should be aware of these risks" (122).

P49: "ACART proposes to … replace it with the phrase that asks parties to 'consider the risks to the future reproductive capacity of the surrogate'"

Proposed amended guidelines:
"2. The risks associated with a surrogacy… are justified in the proposal. These risks are:
a. … risks to the future reproductive capacity of the surrogate"

There is a real difference between being aware of risks, considering them and justifying them. In the current guidelines, the "family first" requirement is not in the section with the language containing the word "justified". While I'm not sure how any of the risks listed can be 'justified' (except to say that the process in the Guidelines has been followed and concerns about relinquishment have been discussed), I have no idea how you justify risks to reproductive capacity.

I think I therefore support the language of risk awareness and consideration but not of justification.
I would suggest that ACART consider replacing 'justified' in the proposed guidelines with 'considered'.

2. THE CONTENT
*The language of 'risk awareness and consideration' seems more appropriate and more consistent with the way the other risks are treated.

A 'Finish family first' requirement seems to suggest that this might be the most devastating outcome, whereas there are reported cases of surrogates dying (and indeed, ECART now often approves applications conditional on life insurance policies being arranged)and issues over the intended parents or surrogates changing their minds can be intensely traumatic (for example the recent Melissa Cook case in the US, which was denied leave to appeal to the Supreme Court). I would add that in interviews and conversations I have carried out with lawyers and fertility clinic counsellors, this is a risk that is almost never mentioned in response to questioning about 'what are the potential risks/issues in relation to surrogacy that you raise with the surrogate/intended parents, or that they raise with you'. Nor did this appear in the public perceptions survey as a risk that appeared to be of concern (exception for the fact that it fell within the scope of the general 'health concerns of the surrogate' type comments). Several other risks were very frequently mentioned (payment, complications during pregnancy resulting in termination decisions, one party changing mind, legal parentage and transfer of parentage). On reflection, I'm not sure whether this means that it is not seen as being as 'risky' as some of the other risks (and should therefore be simply included in the list of other risks as proposed), or whether it is a significant risk that is being overlooked (and therefore needs to be separated in some way to give it emphasis and ensure that this discussion occurs).

*The language of 'risk awareness and consideration' seems more appropriate when possible reasons for this provision are considered

The requirement seems to have been introduced to prevent the situation where a woman acting as a surrogate suffers medical complications and as a result finds herself unable to have children of her own. As discussed above, while the consequences of this occurring can be potentially devastating, this ought to be a risk that the surrogate can weigh up for herself, given the appropriate information. I would therefore support the use of language of risk awareness and consideration in relation to this.

It is alternatively possible that this requirement was introduced in order to ensure that the potential surrogate understood what she was agreeing to. Some scholars have argued that you cannot give informed consent to something (ie becoming pregnant) that you have not experienced. Therefore a potential surrogate should have had at least one pregnancy to experience the physical and mental effects and know whether she is capable of handing over the child. Other scholars add that regardless of experience with pregnancy, it is experience of pregnancy for the purpose of handing over the child that you would need to have experienced before. As most women have not experienced this, it would seem most valuable to ensure that potential issues/concerns surrounding this are discussed in advance. This again supports language of risk awareness/consideration.

*The language of risk awareness is more consistent with preserving the autonomy of individuals
A 'finish family first' criteria is impossible to apply if the potential surrogate is unsure about whether she wishes to have children in the future.
Further, it is potentially unfair on the parties if the potential surrogate is making a conscious decision to delay her own family for personal reasons, but wishes to help a family member. As an example of a story told to me: potential surrogate is a university student, with an older sister who is unable to carry a pregnancy to term. Potential surrogate, who is in her early 20s, wishes to have a family but not until she is in her early 30s and has an established career. Sister (in late 20s) is desperate to start a family soon (and is very keen for the sister to be traditional surrogate as this maintains a genetic/familial link). Potential surrogate is willing to act as surrogate while she is at university, because she believes she can balance pregnancy and study with her sisters' help, but needs this to happen in next 2 years as she feels concerned about possible stigma about applying for job/starting job as unmarried/pregnant young woman. A requirement to 'finish family first' would mean that these sisters would have to wait for ten years for the sister to start her family, then several more years for the surrogate to finish her family. Why make the parties wait, or make the older sister investigate options that neither sister wants (another surrogate who is not genetically related) if it is clear that the

potential surrogate has understood and considered the risks?

Question 8: ACART proposes to include a provision that ECART can take into account the participants' residency status and plans

Do you agree?

Not Answered

Please give reasons for your views:
I'm not really sure how the proposed provision differs from the current one:

CURRENT
Whether the residency of the parties safeguards the wellbeing of all parties and especially any resulting child

PROPOSED
the residency status and plans of the surrogate and intending parent(s) safeguard the health and wellbeing of the child, particularly in relation to being born in New Zealand

I'm not convinced that the change in wording will have any noticeable impact on ECART's decision-making process, or will be particularly useful.
I think that the problem with 'plans' is that for most intended parents, future plans will depend on the outcome of the surrogacy arrangement, or the subsequent adoption proceeding. In Re SCR for example, the intended parents planned to bring their child (born to a surrogate in California) home to NZ, but if the adoption application was not granted, they would view this as a de facto expulsion of their entire family from NZ and the whole family would move somewhere else.

Another problem is that this requirement is asking about the future, but this fails to consider that things change, including laws. In Re CGL for example, a NZ-based surrogate had entered into an arrangement with intended parents in Tasmania. Following the birth of the child, the intended parents sought guardianship orders in the NZ Family Court. The court had to decide as a preliminary matter whether it had jurisdiction to hear this, one issue being that surrogacy had been illegal in Tasmania only three months previously (therefore at the time of the agreement and the conception). If we can assume that ECART is hearing an application at least 1 year before a child is born (and likely longer) then it may well happen that laws in other countries change during this time period.

**Is the question actually about citizenship, not residence?
Para 125 talks about the concern about statelessness. Statelessness and citizenship are two different issues. As an example, consider the first European Court of Human Rights case, Mennenson v France. The Mennesons had twin girls via a surrogate in California, then returned home to France. The French Government refused to allow them to take steps to allow the children to be registered as French citizens, but allowed them residence in France (as wards of the Mennensons) until their 16th birthdays). The twins, by US law, held US citizenship so were not stateless (later, France changed its policy, granting citizenship).

While there is a possibility that children born to overseas surrogates could be stateless, these cases would be unlikely to be subject to the ECART process as the ART would likely also have occurred overseas (although, we do have one NZ reported case in which the ART occurred in Melbourne, the home of the IPs, and the surrogate then returned home to her family in NZ where the child was born).

**Is this question actually about contact with the surrogate?
Para 126 suggests that the concern is that there may be situations in which "the offspring, intending parent(s) and surrogate could have limited, or no, ability to interact with one another."

If this is about contact with the surrogate, this is probably covered in 13k. it is clearly an important matter to take into account, and is something that is frequently raised by judges in their adoption applications (remarking favourably on plans to visit, or to introduce the children to the culture of the surrogate) but I don't think it fits under 'residency status or plans'. With modern technology, contact can be maintained through skype or emails.

Question 9: Do you have any other comments about these proposals?

Please give reasons for your views

Reasons:
I did notice one minor wording change in the surrogacy guidelines

in the 2013 Guidelines:
2 (b) (ii) the surrogacy is not for reasons of personal or social convenience;

Has become
"not for social or financial convenience or gain"

I was wondering why 'personal' was removed. There was clearly meant to be a distinction between 'personal' and 'social' in 2013. Can a woman now argue that she simply doesn't want to be pregnant because she likes looking thin/doesn't want stretch marks? It could be argued that is personal (how she sees herself) rather than social (how she interacts with others). I would be concerned if this was an accidental omission that opened the door to somewhere unintended.

Your details

What is your name?

Name:
[redacted]

What is your email address?

Email:
[redacted]

If this feedback is on behalf of an organisation, please name the organisation

Organisation:

Please provide a brief description of the organisation (if applicable)

Organisation description:

Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)

Interest in topic:
Associate Professor in Law, University of Canterbury, and co-Principal Investigator, Rethinking Surrogacy Laws Project (funded by the New Zealand Law Foundation)

Publishing submissions and privacy

Publishing submissions

You may publish this submission

Official Information Act responses

Include my personal details in responses to Official Information Act requests

Commercially sensitive information

This submission does not contain commercially sensitive information

If your submission contains commercially sensitive information, please let us know where.:

Review of the Donation and Surrogacy Guidelines

Oral submission of a researcher at the University of Canterbury

By teleconference

Date Monday, 18 March 2019

Present: Colin Gavaghan (1), Kathleen Logan (2), Martin Kennedy (3), the researcher.

Notes of phone call by Kathleen with additions from Martin.

1. Deputy Chair of ACART
2. Chair of ACART
3. ACART Secretariat

A. The researcher also made a submission online using the CitizenSpace version of the consultation document.

B. The researcher also submitted two documents to ACART using information from research she has been carrying out with the University of Canterbury. The documents relate to:
   1. ACART's first proposal (that all clinic assisted surrogacies go to ECART) (14pp).
   2. ACART's second proposal (removing the requirement that a surrogate must have completed her family) (35 pp of data).

   The researcher and her colleagues received 500 responses from 2000 random surveys posted to people on the electoral roll.

Re: 1. Questions 59 and 60 of the researcher's survey pertain to ACART's proposal 1.

Generally, public support for screening of sorts, and that meant medical and psychological screening, and psychological screening for intending parent(s). [The researcher has broken down these responses demographically.]

Re:2. Replacing finish family with 'risk awareness': the concerns included: what if someone changes their mind; age limits — minimum age for surrogate, for example, so they are mature enough to understand consequence. Some said you needed to have experienced child-birth to know whether you could go through with a surrogacy; but even if you had, you wouldn't know if you could give up a baby.

Some said commercialising the transaction helped with 'giving up' the child — people separated the process of bearing and labour, from parenting. Idea that contracts 'should be enforceable' only 20% said the surrogate should be allowed to keep the child if they changed their mind. A genetic link to the surrogate was also relevant.

Being aware of risks was really important — by both parties (surrogate *and* intending parents). The researcher interviewed all clinic counsellors (noting there were, actually,

only a few across NZ and she is concerned about workforce planning in this regard). She said counselling needed to be face-to-face. Joint and separate counselling was required. But some clinics appear to have only one counsellor, so you can't get separate counsellor from the other party. Also some (but unclear how much) counselling was done over the phone. This is risky in terms of identifying behaviours that indicate coercion.

Residency provisions

An example was a surrogate who lived in NZ but the children were being raised in Australia — in Tasmania, where surrogacy is illegal. Would ECART have approved this case? Is it NZ's role to police other jurisdictions' legal requirements?

There is a risk of people going overseas if ECART is seen as 'too frightening' (i.e. unlikely to approve an application).

Commercial Surrogacy

The researcher noted that respondents were not hostile to the idea of commercial surrogacy, many people support it. Some were opposed to the commercial aspect, but were okay with payment of expenses, and a gift at the end was considered ok. Only 5% favour the status quo (no valuable consideration).

Q: Kathleen asked whether a 'lighter touch' for surrogacy within families might be suitable. The researcher said that coercion is more likely within families, although at the same time, it tends to be more altruistic (presumably more than commercial surrogacy for non-family). However, she noted that most people agreed that restrictions on surrogacy should be in the direction of making it easier, e.g. having younger age minima, fewer ECART restrictions.

The researcher agreed to send ACART the answers to the open-ended question at the end of her survey that had a significant number of comments. E.g. There is some commentary on ethics committees.

- The researcher's main report (200pp) will be released in a month's time.
- KL agreed to read the two documents she sent, and make a summary for ACART.

PROPOSAL ONE: MAKE ALL CLINIC ASSISTED SURROGACIES SUBJECT TO ECART CONSIDERATION

The Public Perceptions Survey contained two questions that contain potentially useful information.

- Question 59: Should there be a screening process by an ethics committee to determine the suitability of potential surrogate mothers?
- Question 60: Should there be a screening process by an ethics committee to determine the suitability of potential intending parents?

Both of these questions addressed the issue of whether some form of screening would be useful in all surrogacy cases. As can be seen from the answers, the majority of respondents were in support of this, with approximately 80% considering that surrogate mothers should have both medical and psychological screening, and approximately 70% considering that intended parents should have both medical and psychological screening.

In both questions, the overall results were then filtered by age (into 10 year age bands), education level, gender, ethnicity and previous experience with fertility treatment. All of these filters showed results consistent with the overall results.

These results suggest that the general feeling is that oversight through medical/psychological screening and by an ethics committee is beneficial to the parties and the future child.

[Results from the submitter's survey questions were summarized, including some quotes from individuals, and we expect that research to be published academically in due course by the submitter, so are not included here.]

PROPOSAL TWO: REPLACE 'FINISH FAMILY' REQUIREMENT WITH A REQUIREMENT ABOUT RISK AWARENESS

The Public Perceptions Survey contained four questions that contain potentially useful information.

- Question 58: Do you think there should be an age limit on individual entering into a surrogacy arrangement as a surrogate mother?
- Question 64: Should the law allow either the intended parents or surrogate to cancel the arrangement once pregnancy has occurred? (ie can the surrogate decide to keep the child or the intended parents decide not to take custody of the child?)
- Question 65: If the surrogate mother changes her mind and wishes to keep the child, who should the courts grant custody to?
- Question 66: If the intended parents change their mind during the pregnancy or after the birth and do not wish to take the child, who should be responsible for:

  Raising the child?

  Child support?

<u>Question 58 (relevant to bullet points 1, 2, 4, 5 and 7 in para 121)</u>

Of the 522 respondents, 386 thought there should be a minimum age for someone to be a surrogate. 318 thought there should be a maximum age.

The reasons given in relation to the desirability of a minimum age focused on the ability of female to understand the consequences of her decision, and to give informed consent. Common themes included the need: for maturity; for life experience; to have experienced child birth; to be emotionally prepared; and to be protected from exploitation.

The reasons given in relation to the desirability of a maximum age focused on the health of the woman in general due to age (before pregnancy), as well as the health risks during pregnancy, childbirth and recovery. The health risks of the child were also mentioned.

The risk that the surrogate might not be able to have children of her own was not mentioned.

The particular risks involved in a surrogacy arrangement are clearly wider than the 'finish family' requirement currently allows for consideration of, and the majority of the respondents saw other risks as requiring attention to be paid to them

<u>Question 64 (relevant to bullet points 2 and 3 in para 121)</u>

In relation to risks that either the surrogate or intended parents might change their minds, it is interesting to note that some respondents noted that they hoped a proper screening process would prevent this from happening:

> It would be terrible if this happened. With proper psychological checks prior to embarking, this should not happen

Psychological tests should screen out this type of scenario

This is why screening is necessary

Some talked about how unfair it would be if one party was to change their mind, but almost 24% thought that at least one of the parties ought to be able to change their minds (surrogate keep the child, or IP refuse to take the child) and approximately 20% were unsure.

While NZ has not had a case of a surrogate or IP changing their mind (that I am aware of) there is clearly uncertainty as to what should happen if this was to occur, and therefore the parties should be made aware of this risk.

Questions 65-66 (relevant to bullet points 2 and 3 in para 121)

These questions tried to drill deeper into the question of what should happen if one party changed their minds during the surrogacy arrangement. In question 65, 52% thought that custody should go to the IPs if the surrogate changed her mind, with several comments again mentioning the hope that medical and psychological screening. In question 66, 42% thought that IPs should be responsible for raising the child and for child support even if they changed their minds.

The overall picture presented by these two questions is that societal opinion is very unclear as to what should happen if one party (whether surrogate or IP) changes their minds. A requirement that focusses more broadly on 'risk awareness' would provide some reassurance that some of these particular risks are being considered by the surrogate.

[Results from the submitter's survey questions were summarized, including some quotes from individuals, and we expect that research to be published academically in due course by the submitter, so are not included here.]

Review of the donation and surrogacy guidelines

Record of phone calls with *Name withheld 11*

Dates: Monday, 18 February 2019 and Tuesday, 12 March 2019

Calls with Martin Kennedy, ACART Secretariat.

- Overall, ***Name withheld 11*** thinks the proposed guidelines are good and an improvement on those currently in use.

- One matter that ***Name withheld 11*** thought needed further consideration was that of "ownership" of embryos. ***Name withheld 11*** thinking was that if we treat embryos as something that can be "owned" there is a risk that people will treat them as commodities. The differences between ownership, authority and responsibility should be explored. It might be that one of these words will be suitable for the guidelines without establishing any concept of ownership. ***Name withheld 11*** considers this important to fit with other human tissue principles that ensure organs and blood cannot be sold. Also, that any concept of ownership changing would negate the important right of donors to withdraw consent to use by others.

- On the matter of re-donation and/or on-donation, ***Name withheld 11*** thinks that the couple who have had embryos created for themselves should have a say in any re-donations or on-donations , whether or not they had children from embryos that are (would be) full genetic siblings. Martin observed that such scenarios would be managed by people consenting to such possibilities when they first donate embryos. The principle here is autonomy and consent, which should always maintain the right to change your mind, though having a recipient couple who have had a child from donated embryos, also involved in further donation decisions, seems very important too, because of the genetic sibling issue.