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

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Question 1: Rescinding the biological link policy

Refer to section **Error! Reference source not found.**

ACART is proposing that:

- the guidelines should no longer require intending parents to have a genetic or gestational link to a resulting child
- instead the guidelines should require ECART to be satisfied that where intending parents will have neither a genetic nor a gestational link to a resulting child, the lack of such links is justified.

(a) Do you agree? (See extensive comment below)

Yes ☒ Y No ☐

(b) Do you believe there are cultural implications associated with the proposed removal of the biological link policy?

Yes ☒ Y No ☐

If so, please describe these implications.

I think there is an important cultural implication for the LGBTI cultural community in that parenting options will become less discriminated against. Also for any single person, gay or straight.

Please give reasons for your views.

See following page

I agree with this change. Any aspect of the current guidelines that is discriminatory should be removed. In this instance the guidelines are discriminatory against people who, because of the disabling nature of infertility and also perhaps because they are in a same sex relationship, particularly lesbian relationship, are unable to gestate or have a gestational link to the resulting child.

In the case of our family, same sex lesbian couple, 11 years ago we used what was defined by the guidelines as 'donated sperm' and what was defined as 'donated embryo', and I was the gestational parent. We had to seek approval. In fact our situation was that of wanting to have two other people as well as us known to the offspring. This has occurred and is quite normal for us and our children

Our family is quite normal to us, and my opinion is that there are very traditional and exclusionist concepts underpinning NZ fertility, and adoption law as well as contraception and sterilisation legislation. These need to be challenged.

I realise that my comments in this section diverge somewhat from specific clauses in the guidelines, however I think this is an opportunity to voice them. There are many variations of parenting, some formalised, others than are out of sight of 'officialdom'.

I challenge state authorities not to see this as 'risky' but as innovative. LGBTI people that I know experience expectations around family that are different to many others. This has enabled us to embrace diverse parenting arrangements. I have seen whangai parenting, fostering, involved donor parent, grandad or uncle/aunty caring as well as single parenting and people just taking on kids otherwise lost in some system.

As examples, my partner and I have been together for 27 years. Our separate and combined family/parenting before and during that time thirty years has included :

- my partner provides support for a person living in a residential disability home. She has been his only external 'family type' support since she started visiting him over 30 years ago. She considers herself to be a part-parent, and there is love
- My partner and I were parents to a child conceived without agency support. The father was known to the child and she had his last name. It was complicated but we managed it outside of any state involvement, which prior to that point had been discriminatory and negative.
- My partner and I have provided respite care for around 13 years to several children, and for one boy consistently for ten years. We remain in contact with the young man he has become and think of ourselves as part parents. Although we looked after straight folks kids we were not able to adopt them
- My partner and I are parents to twins, conceived using embryo from a relative of mine and the sperm of a man they know as dad. They have four parents: three mums and one dad. It is actually not that complicated for us

or for them, though it is important, and could potentially have got complicated or get complicated in the future. We have given them information at different points in their life so far depending on their capacity to understand

The reason I have given these examples is because I want to challenge what I consider and have experienced to be unnecessarily obstructive processes that have an inherent capacity to discriminate against those who are 'diverse'. I also think we need to be open to the shifting nature of parenting, celebrating parenting in all of its forms. It does not need to involve ownership, there can be multiple parents, or part parents. There is, however responsibility. As a foster carer and a teacher I have seen lots of poor parenting in New Zealand, damaged kids, kids who haven't attached, parents who use manipulation to hurt their x partners or current partners.

The common positive element in the diverse relationships that I have seen in LGBTI land, and in most straight families, is that children are cherished, protected and supported to be their own person.

Question 2: Access to information held on birth certificates

*Refer to section **Error! Reference source not found.***

ACART is interested in hearing views about potential strategies to strengthen a donor offspring's access to information about their origins, which is held on their birth certificate.

Do you have suggestions?

Yes

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No

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Please give reasons for your views.

I understand and support the principle of this change. I understand that this may be a deterrent to some donors (probably more specifically sperm donors) but personally I think it is more important for people to be able source their genetic history than to have complete protection of donor privacy.

However I hope that you are actively sourcing a wide cross section of views on this matter. There will be something to learn from those who are using anonymous donors, what this means for them, the issues that are important to them, and how it has worked out for them and their offspring.

I would want to see that the privacy of the offspring is supported in any recording of their origins, so that no automatic printing of any details would occur that might result in discrimination here or overseas. I would suggest that where a person applies for a birth certificate and there is relevant information then they are advised,

separately that relevant information is available, and directed to how to access that if they choose and supports if they need it.

As a matter of information our offspring are able to access their information on the Victorian state registry

Question 3: Format of the proposed guidelines

Refer to section **Error! Reference source not found..**

ACART is proposing to issue one set of guidelines to ECART that encompass family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic-assisted surrogacy.

Do you agree with the format of the proposed guidelines?

Yes

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No

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Please give reasons for your views.

This makes sense

Question 4: Justification to use a procedure

Refer to section **Error! Reference source not found..**

ACART is proposing that ECART should be satisfied the proposed procedure is the best or only opportunity for intending parents to have a child and the intending parents are not using the procedures for social or financial convenience or gain.

Do you agree?

Yes

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No

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Please give reasons for your views.

I think this is an important change, removing the medical reason. It is one way to recognise the diversity of circumstances that exist. It also enables the use of

donated embryo. In our case our 'donor' was willing to donate the remaining embryo, but could not do so, and they were eventually destroyed.

However, I disagree that ECART still needs to decide that the use of a procedure is justified in every case, and my reasons of that are provided in 9 below)

Question 5: Consent by gamete and embryo donors

Refer to section **Error! Reference source not found..**

ACART is proposing that, where a procedure will involve the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes:

- at the time of donation; or
- when a procedure using such an embryo is contemplated.

In either case, the affected parties should receive counselling on the implications of using gametes before the gamete donor gives specific consent.

If consent is given, the gamete donor can vary or withdraw their consent only up until an embryo is created (in cases where consent is given before the embryo is created).

In addition, where a procedure will involve the use of a donated embryo, the person(s) for whom the embryo was created must give consent to the specific use of the donated embryo:

- at the time of donation; or
- when a procedure using such a donated embryo is contemplated.

Once an embryo is created, the decision to vary or withdraw consent up to the time the embryo is transferred to the womb should remain with the people for whom the embryos were created.

Do you agree?

Yes

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No

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Please give reasons for your views.

I agree with this. I think that boundaries do need to be put on the use of gametes

Question 6: Taking account of potential coercion

Refer to section **Error! Reference source not found..**

ACART is proposing that ECART should take account of any factors in a relationship that might give rise to coercion or unduly influence a donor's or surrogate's consent to take part in a procedure.

Do you agree?

Yes ☐ No ☐

Not sure.

Please give reasons for your views.

Whilst I think that ACART is better informed than I am on the need for ECART to take account of factors around coercion, I believe on principle that it needs to be on an actual rather than perceived risk basis. I would be concerned if the potential for coercion meant a 'no' from ECART. All sorts of coercion, mild to large occur in families including in parenting arrangements – the pressure to have children, not have children, to favour and influence procreation within specific cultural groups, to care or not care for aging or disabled or vulnerable family members. There are also lots of examples where grandparents raise the children of their children, for various reasons (to put child parent donations into perspective). My point is that there should not be an automatic rejection of an application on the basis of a potential coercion.

Question 7: Limit to number of families with full genetic siblings

Refer to section **Error! Reference source not found..**

ACART is proposing that full genetic siblings should continue to be limited to no more than two families.

Do you agree?

Yes ☒ Y No ☐

Please give reasons for your views.

Whilst I agree with the principle, I think that ECART ought to be able to consider exceptional cases. There are always exceptional cases.

Question 8: Legal advice

Refer to section **Error! Reference source not found..**

ACART is proposing that ECART must be satisfied that:

- where an application includes a surrogacy arrangement, each affected party has received independent legal advice
- where an application does not include a surrogacy arrangement, each affected party has considered seeking independent legal advice
- any legal reports show that all affected parties understand the legal implications of the procedure(s).

Do you agree?

Yes

Y e s b u t

No

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Please give reasons for your views.

I agree with this change. I think it is worthwhile affected parties being provided with written legal information and expected to consider legal advice. Personally we found the counselling useful and the legal advice much less so. I cannot comment on whether legal advice ought to be compulsory in surrogacy cases because I have no experience of that as a consumer.

BUT..Policy staff need to be aware of the cost to consumers of using fertility services. In our case it was substantial over a period of time, with no state funded support. Our age meant that we slipped down the priority cue. Our sexuality meant that we had to go to additional expense and time to get our specific case approved. What we had going for us was that we had equity behind us (home, jobs, limited debt, mobility) we were Pakeha, and we were possibly better able to navigate the system).

So to my mind an important question that should be asked is, in the aim of minimising a potential risk, how much more financial burden and burden of delay is being placed on people who are already marginalised due to disability or sexuality, or socioeconomic status, education, literacy or culture.

Question 9: Regulation of all family gamete donations

Refer to section **Error! Reference source not found..**

ACART is of the view that all family gamete donations through a fertility services provider should be regulated by guidelines and thus require ECART approval.

Do you agree?

Yes ☐ No ☐ N

Please give reasons for your views.

- I disagree with ECART taking on consideration of every case. I am not clear on the identification of need or risk of this. I see that it would increase the cost and result in at least further 100 people having to have their case considered by ECART, probably growing as the need for fertility support increases by volume and complexity.
- I think that such a move could result in unnecessary delay to the process and the potential for unfair rejection. In some cases this approach could be potentially discriminatory. Bearing in mind that the vast majority of cases involve people who desperately want to be parents but already face challenges and barriers including discrimination around age, gender, sexuality, culture; and that time is sometimes of the essence.
- I think that such a move could result in much more unnecessary scrutiny and exposure of people's personal stories. I found the scrutiny of our very personal and at times traumatic life story, by a remote committee both intrusive and painful. I try to think of other situations where people are required to reveal in this way to a group of strangers. Perhaps women applying for an abortion (which is fundamentally wrong in any case), people before the parole board (they have already committed harm and are being judged against it). In my opinion this a process that should be used sparingly and only when absolutely necessary.
- I also ask policy folks to consider the power imbalance inherent in this process. When fertility consumers are moving through this process there are considerable power dynamics at play and a lot at stake. You don't want to upset the fertility clinic because they have some power over your fertility (perceived or actual); you don't want to upset government administrators because they could perceive you as being difficult; you don't want to upset potential donors. You are often isolated because of your circumstances.
- For our family, we made an application, and it was eventually successful, but by that time because of the delay in consideration we were well down the fertility

path in Australia. There we had no judgement and fabulous clinical support which was comparatively cost effective (considering we had no state funding in NZ or Australia). It was receiving services in Melbourne that opened up our eyes to the problems that existed in NZ.

- I am not saying let's take a hands off approach. I support the requirement for counselling which gives a structured for a for recipients and donors to work through or start to work through the complexities and positions.
- I think that accredited fertility services should be able to process most donor embryo/donor gamete/surrogacy arrangements according to the guidelines, and only refer to ECART cases which are identified as involving more complex elements. Their professional standards, auditing and professional liability should be sufficiently robust to ensure that they are not inappropriately applying rules.
- Where problems are identified during counselling, families and donors should be encouraged to have additional counselling or counsel-mediation to help them work through the areas of complexity.
- I am opposed to any corralling of people into a NZ only fertility process.

Question 10: Donation of embryos created from donated gametes

Refer to section **Error! Reference source not found..**

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships and the gamete donors have given specific consent to the procedure.

Do you agree?

Yes

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No

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Please give reasons for your views.

I agree, it makes sense. We wish we had had this option, as did our donor.

Question 11: Embryo on-donation and re-donation

Refer to section **Error! Reference source not found..**

ACART is proposing that surplus donated embryos:

- should not be able to be on-donated by the recipients

- but can be returned to the donors, in accordance with any agreement between the parties, for re-donation to another party, subject to a new approval by ECART.

Do you agree?

Yes

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No

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Please give reasons for your views.

I can't comment because any opinion would be uninformed

Question 12: Clarification of the status of embryo donation in the regulatory framework

Refer to section **Error! Reference source not found..**

ACART is of the view that the regulatory framework should clarify that:

- all embryo donation cases are regulated by guidelines and thus require approval by ECART
- embryo donation does not include cases where an embryo created for a couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

Do you agree?

Yes

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No

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Please give reasons for your views.

I repeat the comments I made in 9 above. As long as there are clear standards and guidelines then I do not see the need to have to have ECART approval except for exceptional cases

Question 13: Regulation of all clinic-assisted surrogacies by guidelines

Refer to section **Error! Reference source not found..**

ACART proposes to recommend that all clinic-assisted surrogacy cases be regulated by guidelines and thus require ECART approval.

Do you agree?

Yes

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No

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Please give reasons for your views.

On a principle basis I disagree with this, whilst acknowledging that I do not have direct experience of surrogacy. I disagree with this proposal on the same basis as my answer given in 9. I see no reason why clinics are not able to manage surrogacy arrangements independently of an approval process. I think ECART/ACART could beef up standards and auditing, and could either provide directly, or support others such as MoH working alongside Fertility NZ to provide information on surrogacy and both its complexities and its opportunities.

Some of the risk mitigation measures in this document make me reflect on the many people who would make wondrous parents of wondrous children, managing their complexity who will be denied because of potential risk

Question 14: Any other comments

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

Thank you for the time to make a submission.

I was also pleased to have the opportunity to talk with staff at a consultation session. It worried me that there was such light attendance. I wonder if the message got through to the people who are using the services. I would never have known about this if a researcher hadn't informed me. I have tried to let other people know within the limited consultation period left.

Thinking that perhaps you need to broaden the database.