

Meeting to discuss the consultation of the guidelines review with Repromed - Auckland

Wednesday 25 October 2017

Proposal 1 Rescinding the biological link policy

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.*

Agree to rescinding the biological link policy to make the environment more equitable for people who cannot gestate a pregnancy, and/or cannot use their own gametes. Repromed sees a handful of people per year that would benefit from the policy change. This number could increase with the proposed change.

Repromed would consider mandatory counselling in a clinic assisted setting to cover off increased complexities in situations where people could go ahead with ART following the removal of the biological link policy. Repromed already provide a holistic perspective in counselling.

Noted that ethical review potentially becomes more important with rescinding the biological link. Noted that independent counselling is difficult in a clinic where there are so many parties involved and likelihood of increased workload required by counsellors or need for increased capacity. Noted that Repromed recognise the benefit of independent counselling that is face to face.

Proposal 2 Access to information held on birth certificates

Agree that it is essential to have annotation/addendum on birth certificate that indicates there is more information available for the birth certificate holder.

In regards to surrogacy we suggest that: (1) the surrogate also be recorded on the HART register along with any gamete donor. Unless a surrogate is also the egg donor her information is currently only captured on a Pre Adoptive Birth Certificate which can be applied for under the Adult Adoption Information Act. (2) As there is no indication on the post adoption birth certificate that a pre adoption birth certificate exists it would be useful to also have something on the adoptive birth certificate that recognises that there exists another birth cert to recognise the surrogate's role in that person's life.

Recognition that we cannot control ARP's that take place overseas.

Recognition that modifying the Birth Certificate has the potential to widen the gap between those who can access the info (those born in NZ and whose parents disclosed their conception) and those who do not know (those who were conceived by ART overseas and do not know their genetic inheritance).

Include an option for The Birth Certificate to say 'donor' rather than 'father unknown' as the latter has negative connotations. Feedback from some parents is that they are happy with including 'donor' on their child's Birth Certificate as it reflects the donorship respectfully and is honest and transparent.

Queried the issue of privacy that putting an obvious insert into an individual's birth certificate may not be appropriate, given that individuals often need to provide their birth certificate in certain situations such as enrolling in school or sports team, and it could be thought of as a breach of that individual's privacy, when they are not able to access further information themselves until they are 18 years old. There could exist 'short' birth certificates in situations like this.

Proposal 3 Format of the proposed guidelines

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.

Support. Amalgamated guidelines will reduce number of forms and generally makes everything simpler.

Recommend ACART should include wording from within the current Family Gamete Donation form"ECART to take into account whether the potential impact of the social, cultural, genetic, and inter-generational aspect of the proposed arrangement safeguards the wellbeing of all parties especially any resulting child" to the proposed form covering all donations

Proposal 4 Justification to use a procedure

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.

Repromed supports the use of "best or only opportunity" as it gives people the chance to put their case to ECART for ethical oversight.

Repromed feels it is good to facilitate a culture of openness.

Case study Single woman A who had "surplus" embryos created from donor sperm. Single woman B who needed donor egg and donor sperm but was on waiting list for donors.*

Single woman A contacted clinic to advise she had recently entered into a relationship with single woman B and wanted single woman B to try for their next pregnancy with the 'surplus' embryos.

This case example demonstrates (as per proposal 10) that if there had been an opportunity for Single woman A to legitimately donate the embryo created for her with donor sperm (with the donors consent), to Single woman B the need for the pretext of a relationship would have been removed.

Due to her own family building journey Single woman A was very empathetic to the obstacles Single woman B was faced with and furthermore Single woman A did not wish to simply dispose of her 'surplus' embryos.

Proposal 5 Consent by gamete and embryo donors

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 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.

Part 1: Repromed believe it is best to have a donors consent closest to the time that the gamete is to be used to create an embryo. Contacting donors to obtain consent specifically for donor egg/ donor sperm in combination is appropriate. Agree that consent of gamete use and conditions can vary up until the time the embryo is created.

Part 2: Repromed notes the distinction between the 2 types of donation: the 'Point of no return' for withdrawal of consent by the donors for ED is at time of embryo transfer; the 'point of no return' for donors of egg and sperm in combination is at time of fertilisation.

The concept of 'point of no return' can be problematic for embryo donors to get their head around - that they can vary or withdraw consent up until implantation especially when they have signed a consent to donate' at the clinic which covers all their embryos This is another reason Repromed supports mandatory legal advice for embryo donors and recipients (refer question 8 and question 12)

Proposal 6 Taking account of potential coercion

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

Repromed already does this, it is good to see it formalised. Counsellors recognise that sometimes it can appear that there is coercion in a certain relationship, but that this is not always the case.

Proposal 7 Limit to number of families with full genetic siblings

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

Yes agree. Appreciate that the reason of complexity is noted in ACART's document first, it shows that ACART upholds the best interests of the resulting children.

Noted that a culture of disclosure and openness to children can reduce the risk of consanguinity in the future.

Important to ensure the wording is right – need to keep reference to “complexity of relationships involved”

Proposal 8 Legal advice

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).***

Agree, and also support the current practice of mandatory legal advice for embryo donation. Recognise that counsellors can cover this off, but legal advice is something different and adds a further element of 'seriousness' (note that when paying for legal advice in embryo donation, recipient couple would need to pay for the embryo donors legal advice too, so about \$3000 more on top of other costs).

Analogous to adoption – legal element is required so it should be for embryo donation too.

2007 – legal advice requirement was not introduced until after this case.

Early embryo donation arrangements did not require legal advice, however there was a situation where a donor couple disputed that they had been advised that they would have no legal rights or responsibilities for a resulting child, including a right of contact.

Note – suggestion legal advice and ECART applications could be publicly funded.

Proposal 9 Regulation of all family gamete donations

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.

Repromed disagree with this proposal. The status quo currently works well. Doing an ECART report will not add anything helpful in terms of ECART deciphering elements of coercion.

Clinics shouldn't need to provide an ECART application unless the donor is under 20 or for inter-generational donations.

If this proposal is enforced, it could result in deceit so that patients can access treatment (which has been known to happen) it will cost donors more (increased ECART applications), and capacity issues in terms of counselling and capacity for ECART!

Proposal 10 Donation of embryos created from donated gametes

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 consent to the specific use.

Noted that this is a very significant change. Repromed support this proposal, provided the consent is freely given by all parties.

Consent by the donor for the donation of an embryo created from donor gametes should be sought at the time of the embryo donation process begins. The record of the gamete donors consent should be valid for 6 months - to be consistent with other ECART reports and documents.

Privacy issues are already considered in counselling.

Supports the donation of these embryos, as time, resource and effort is involved in creating them.

Proposal 11 Embryo on-donation and re-donation

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.***

Yes as long as the 2 family policy applies and there are clear processes for how offspring can access information about their gamete donors. Please consider the implications for embryos created from combined egg and sperm donation

Some donors may have an interest in wanting to know who the embryo is (re) donated to – especially if there are half sibling's as well.

Example: Combined donation from Egg donor A and Sperm donor B to create embryos for Recipient 1. Note: Both donors have children in their families who will be half siblings to any offspring Recipient 1 has.

Recipient 1; when her family is complete, wishes to donate her 'surplus' embryos to Recipient 2. This would be possible with proposed changes outlined:

- : as Recipient 1 is the Embryo donor,
- : full genetic siblings will be limited to 2 families (proposal 7)
- : consent is sought and given by the gamete donors (proposal 5)

Offspring of Recipient 2 need to have clear pathway/ access to information about full siblings in Recipient 1's family and half siblings in Donor A and Donor B families.

Note: could use diagrams in Guidelines to help the reader think through the possible complex scenarios

Need to make sure that donors update their contact details

Proposal 12 Clarification of the status of embryo donation in the regulatory framework

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 one couple is used by one of the couple in a new relationship with the informed consent of the previous partner.***

Agree that all embryo donation guidelines should be regulated by ECART and require legal advice.

If consent is given beforehand then it can go ahead – this is already happening. Consent forms already include a reference to 'in the event of one partner dying are you happy to proceed with donation'. Comfortable with this not being called 'embryo donation' as long as there is appropriate counselling and consent.

Proposal 13 Regulation of all clinic-assisted surrogacies by guidelines.

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

Agree.

Traditional surrogacies are more 'ethically risky' because of the genetic link to the surrogate making relinquishment possibly harder (as she is using her own eggs as well).

Other comments

Repromed would like to see people doing traditional surrogacy coming in for counselling anyway.

What is meant by 'clinic assisted surrogacy' - should ACART give a definition or guidance of what that involves? Does it involve situations where clinics in NZ do preliminary tests for individuals that are having treatment at an overseas clinic?

Why are police checks required for embryo donation, but not for donated gametes? It should be required for donated eggs/sperm too.

Repromed queried the status of the:

- Import and Export of Gametes work
- Research on Viable and Non-viable embryos. Both of these streams are not progressing and it is disheartening for the sector.
- where does the Fertility Standards (10 family max) standard come from? It is not in the HART Act.

National ACART workshop again in 2019 (start advertising in July 2018)

Not discussed on the day – but is there a possibility of a register of donors? This could assist clinics in monitoring the family limits across clinics. We are currently reliant on a donor providing information in regards to whether they have donated to another clinic and how many times.