

Response ID ANON-FZ4K-4GDA-Y

Submitted to **Proposed Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos**

Submitted on **2020-07-23 09:54:58**

Introduction: Seeking feedback on draft guidelines

Proposal A: All posthumous use should be subject to ECART review

1 Should ethical review by ECART be required for all posthumous uses of gametes or reproductive tissue, even if consent to specific use was given while the deceased person was alive?

No

Comments:

Firstly, thank you for the opportunity to submit on stage two of this consultation process. Some good work has been done and there seems to be some progressive suggestions in the proposed guidelines.

Unfortunately, this guideline I think is not overly progressive. I am not sure why we would go backwards from the current guidelines, where currently if consent is specified, it permits use without an ethics review.

The rationale given that ECART needs to review all posthumous use of gametes, reproductive tissue and stored embryos, I do not agree with. This seems an unnecessary addition of unrelated decision-makers. If it's being proposed that "ACART believes the provisions for counselling remove the need for a specified stand-down period after a person dies before their material or stored embryos can be used" then counselling should also remove the need for an ethical review if "consent to specific use" has been given. Counselling could deal with the "ethical complexities", that are being used as the reason for mandatory review, up front. Counselling plays a major role in the whole process and, in particular, undermines the need for rationale 82 and 85 (page 21 of the proposed guidelines). Counselling is the fence at the top of the cliff rather than ECART being the ambulance at the bottom.

In addition to counselling at the time of donation, the annual review of stored tissue and gametes process should also remove the need for a compulsory ECART consideration. If the collection, storage and review process has been correctly followed and there has been a regular review of the storage and consent for use (as required in 2.2, last paragraph of the current guidelines), then an ethical review is unnecessary, as the intent/wishes of the donor are up-to-date and relevant. If this is not possible i.e. the person has died before their yearly review and the situation has changed that will impede the child's well-being, then perhaps ECART has a role to play here. But only then.

In conclusion, I do not think ECART review should be required for all posthumous uses of gametes or reproductive tissue, when consent to specific use is given while the deceased person was alive.

2 Should ethical review by ECART always be required for the posthumous use of stored embryos, even if consent to specific use was given while the deceased person was alive?

No

Comments:

No. I feel the same way about stored embryos as I do gametes and reproductive tissue. Please see Q1 answer.

3 Do you agree that ACART should recommend a change to the HART Order 2005 to ensure all posthumous use is considered by ECART?

No

Comments:

Refer to Q1

4 Do you agree that the guidelines should allow for the posthumous use of clinic donor sperm or eggs, if there is already a child from the person who donated those gametes and the new child will be in the same family?

Yes

Comments:

Yes. I also think it should be allowed even if there is not another child when the consent to specific use has been given while the deceased person is alive. What about people who may be not have embarked on child rearing yet, but intended to? What about people who may lose their only child and want to have another? There needs to be flexibility to allow for different situations.

Proposal B: Consent must be for use by a specified person/s

5 Do you agree that the deceased person must have consented to a specific use?

No

Comments:

I interpret the intent of this proposed guideline is to provide clarity regarding the donor's consent to a specific use. However, accepting it as it is written is

problematic. The problem with this proposed guideline is the word 'must'. If the consent to a specific use is not given, for reasons beyond the control of the donor, they then 'fail' this guideline and consent will not be granted by ECART. This wording is too restrictive.

Consent to a specific use is ideal and what should always be strived for. It provides clarity and direction rather than adding in subjectivity. However, no process is infallible and there needs to be allowance for such times. From personal experience, the current guideline states "appropriate counselling is mandatory for men donating sperm". This was denied my son. If it had been provided by the clinic, we would not be in a position of having to prove his intent for use. If offered counselling, clarity would have prevailed. Therefore, if the purpose of the HART Act is to "provide a robust and flexible framework for regulating and guiding the performance of assisted reproductive procedures", then these guidelines need to support that. This proposals wording doesn't, therefore I cannot agree.

6 Do you agree with ACART, that the definition of specific use should mean "consent to use by a specific person/s"?

No

Comments:

I don't agree with ACART defining what specific use should be, in this manner. This question is also not complete as the definition goes on to state that intention is that the specified person(s) "would be the intending parents". This may not always be the case. For ACART to define 'specific use' in the guidelines as 'the deceased gave informed consent to posthumous use by a specified person(s) who would be the intending parent(s)' is, again, too limiting.

The donor should be offered the opportunity to define a specified person(s) to use their gametes, reproductive tissue or stored embryos in a preferred manner specified by the donor. I think the donors specified person(s) and the specified use should be asked as two separate questions. With a clarification from the donor that if the situation changes, the specified person can either make the decision of use or the donor has stated an alternative eg discarding or donating to research. Hence, the importance of counselling and guidance at the time of donation.

Furthermore, the specified person may not be the intend parent(s) as the proposed guideline states they must be. A person without a partner may choose a parent to be a specified person and decision-maker but they are not the intended parents. This is particularly the case for younger people (not minors) who don't have a life partner but choose a parent as a specified person with the intent a sibling may become the intended parent. What if the reproductive tissue/ gametes/embryos are able to assist another family member with fertility issues. This is not possible with this definition of 'specific use' and should be the decision of the donor.

Proposal C: Consent to use must be proven

7 Do you agree that the intending parent(s) must provide evidence of consent to posthumous use in order to use gametes, reproductive tissue or stored embryos from a deceased person?

Yes

Comments:

In the absence of written consent to specify use, then evidence of consent or inferred consent is necessary. The wishes of the donor need to be respected and considered. However, it may not be the intending parent(s) that must provide evidence but the specified person. This person may be different to the intended parents.

Proposal D: Consent may be written or oral

8 Do you agree that oral consent is acceptable?

Yes

Comments:

I do, with evidence. This should be extended to inferred consent too.

9 Do you agree that there must be evidence of oral consent for that consent to be acceptable?

Yes

Comments:

Ideally, yes as mentioned in Q8. However, the problem is what evidence will be accepted. True evidence of oral consent would be a tape recording, this is not a reality for many situations. Hence the inclusion of inferred consent is necessary. There needs to be flexibility in the acceptance of evidence.

Proposal E: In most cases, the deceased's consent to retrieval can be inferred from their consent to posthumous use

10 Do you agree that consent to posthumous use of gametes or reproductive tissue can be taken to imply consent to posthumous retrieval of the gametes or tissue?

No

Comments:

I understand the reasoning here is that the expressed desire to posthumously have children would imply consent to retrieval as well. However, some may be happy to donate while alive and then posthumously have children, but due to any cultural beliefs or personal views, may not feel the same way if it means their bodies are altered following death.

I don't think this is clear cut to make this assumption. Perhaps, if they had registered as a 'Donor' on their driver's license, then this consent could be extended to

retrieval following death. Clarify at time of donation. The process of donating, collecting and storing is vital to all these guidelines being effective.

11 Do you agree that there is no need to test whether the deceased person had a full understanding of the method of retrieval of the gametes or tissue?

Yes

Comments:

Yes, there is no need. I don't see this as relevant. We cannot draw the conclusion that if someone "had a full understanding of the method of retrieval of the gametes or tissue", that this would impact their decision to do it or not. I may not be fully informed about many procedures but I would still not choose to do them. Full information, wouldn't change my mind. Therefore, testing whether someone has full information, or not, is not going to provide any sensible conclusion regarding the decision they may have made. A test would be futile.

Proposal F: ECART or the High Court will be able to authorise the retrieval of gametes or reproductive tissue from a deceased person

12 Do you agree that ACART should recommend a change to the HART Order 2005 so that it is clear that posthumous retrieval is never an established procedure?

Yes

Comments:

Yes, that will provide more clarity for the Courts.

13 Do you agree that, subject to the change to the HART Order 2005, ECART could authorise posthumous retrieval? (Note: This would seldom or never actually happen because retrieval cases would usually be decided by the High Court.)

Yes

Comments:

Extending the ability to ECART to also authorise posthumous retrieval would cause no harm, so long as there is consistency in their decision making with the courts. Like a court though, there will need to be the ability to appeal.

Proposal G: Prohibiting retrieval from deceased minors

14 Do you agree that the retrieval of gametes and reproductive tissue from deceased minors, for reproduction, should be prohibited?

No

Comments:

Given, a minor is prohibited by law to have sexual intercourse then it seems consistent to prohibit retrieval of gametes and reproductive tissue, for reproduction, once deceased.

However, this is a very sensitive area, until you have had a child die you don't realise how much you lose. It's not just the child but the loss of possible grandchildren. This is often not realised, or overlooked, but contributes significantly to complicated grief. As reproductive technologies keep improving and changing ACART needs to be flexible enough to adapt with it.

15 Do you agree that if a minor freezes gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue (or can consent as an adult to another use), then the gametes or reproductive tissue are not able to be used by anyone else?

No

Comments:

No. If the minor has specified a person to be the decision-maker of their gametes or reproductive tissue then they could be used by someone else. For example, if siblings have a fertility issue, this reproductive tissue or gametes may be of use to the family. This would however, be subject to an ECART review. There are so many different situations to consider that to make a 'blanket rule' for all is unfair and possibly cruel. Also, contrary to the purpose of the HART Act which is to be "robust and flexible".

Proposal H: One change to the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years

16 Do you agree that ACART should provide advice to the Minister to amend section 12 of the HART Act 2004 to enable people to choose the use of their own gametes/tissue after they reach the age of 16 years?

Yes

Comments:

Absolutely.

Proposal I: No requirement for a specific stand-down period

17 Do you agree that there is no need for the guidelines to include a specific provision about a stand-down period?

Yes

Comments:

Yes. The counselling process should cover this. Furthermore, to state a specific stand-down period is again too arbitrary and inflexible. Another 'blanket rule' that doesn't suit everyone. Grieving is not linear. Someone who is 6 years into grieving is not necessarily in a better place to make decisions than someone who is 6 months in. We all grieve differently and not for anyone else to make a judgment as to when it is a suitable time to make decisions.

18 Do you agree that the counselling provision (7.f), about allowing time for grieving, is adequate for ensuring people make a well-considered decision?

Yes

Comments:

I am not sure what 7f is referring to but in context of the proposal that counselling removes the requirement for a stand-down period, I agree. ACART needs to be careful here. Its very insensitive to make a decision as to what is a suitable amount of time to grieve to ensure people make good decisions. This is like saying 'you must be over it now'. As I said in Q17, some people may be 20 years into their grieving and still not make 'sensible' decisions. No one can decide what is an appropriate arbitrary time that 'good' decision-making will now occur.

The issue of counselling goes wider than just covering a stand-down period and I have already mentioned that in previous questions. However, the bigger issue facing ACART and ECART is how are they going to handle situations when due process has not been followed resulting in an inability for the guidelines to be followed. Times at which donation of reproductive tissue and gametes are done is often a time of shock, stress and confusion. Guidance from those in a trusted position is essential for better decision-making. It will never be perfect but the absence of the guidance, through counselling, has the potential to deny the deceased and their families the potential of future children. There needs to be flexibility and even a non-expensive process to appeal if ECART finds their hands-tied by the guidelines.

Proposal J: No change for the gamete and embryo storage period

Proposal K: The title of these guidelines

19 Do you agree with the proposed title for the guidelines of Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos?

Yes

Comments:

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 and provide a brief description

Organisation name:

Organisation description:

Please explain your interest in this topic

User of fertility services

If you selected Other, please provide more detail:

What is your gender?

Female

Would you like to make a verbal submission in person or using electronic communications?

No

Which of the following age groups do you belong to?

45-54 years

What is your ethnicity? (Tick all you identify with)

NZ European

If you selected other, please specify:

Privacy and publishing submissions

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.: