

## Response ID ANON-FZ4K-4GE1-G

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

Submitted on **2020-09-29 16:19:04**

### 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:**

Don't complicate things for grieving family members. Be respectful and compassionate.

The cost associated with ECART and legality may be widening up equity gaps for many.

**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:**

Don't complicate things for grieving family members. Be respectful and compassionate. Stored assets belong to the loved ones

**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:**

ECART has costs involved and incurred privately, and these are not covered by public funding as well. ETHICS Applications Fee starts with \$3,090 not including legal and other costs. This is further widening the equity gap. Does that mean that people need to have at least 15-20 K to initiate something that is very personal, emotional and close to their hearts? Only rich people can and afford to fulfil the wishes /consent and of the deceased and desired by the family left behind!!

**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:**

The guidelines should also allow for the posthumous use of clinical donor sperm or eggs in all cases. Even if there is not an existing child from a person who donated those gametes/eggs/sperms and can be in a different family. The family left behind is capable and committed to raising the child using posthumously gametes/ sperms should be allowed keeping the resulted child safe and protected.

I am a sibling who has lost her sister very young and is left lonely, depressed as she was my best buddy. I wish to fulfil my sister's wish to have her baby in this world and also to have her legacy complete our family. No one wants to see self, their family going through depression every day for something they were helpless and can't do anything and for current things they are not able to do now !! The family should be allowed to have to use the eggs/sperms retrieved/donated eggs/sperms to bring completeness and sense of belongings to the family too -

#### 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:**

If they have consented ( verbally , implied , expressed) to its use, must allow use. How many think about or consider using preserved fertility after their death??

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

No

**Comments:**

#### 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?**

No

**Comments:**

Please take the must off then it is yes, there can be many circumstantial reasons and evidence and various means to interpret written, implied and verbal consent.

Yes, it can be legally binding from committed families as they can give affidavits, stat declarations and any other modes of commitment to be put forward as evidence and commitment and be able to fulfill the wish/consent of their lost one, which will help bring solace by carrying on the legacy along with other family members.

**Proposal D: Consent may be written or oral**

**8 Do you agree that oral consent is acceptable?**

Yes

**Comments:**

Yes, when other family, friends and/or relative evidence should carry the same weight and validation to provide an affidavit that is not just limited to the Doctor evidence only.

Common people are not aware of such requirements and read ACART guidelines and explanations when going through a rough time with their loved ones and that

Verbal consent has to be in front of a doctor only! No such things are planned and thought of when unexpected deaths happen.

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

Yes

**Comments:**

Yes, when other family, friends and/or relative evidence should carry the same weight and validation to provide an affidavit that is not just limited to the Doctor evidence only.

**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?**

Yes

**Comments:**

**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?**

No

**Comments:**

**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:**

**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:**

**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:**

Wishes and consent are important at all ages and must be fulfilled.

- Yes, a 9-10-year-old or someone who did not hit puberty should not be stressed for such procedure.

This should be considered case by case situation. There is just bleak numerical difference between 15 years and 16 years old, this should be considered ensuring someone is not disadvantaged due to few month here and there.

**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:**

'It's not in normal circumstances that this permission or procedure is done. There are always special circumstances when fertility preservation methods are administered. So

- If a boy and girl were allowed to preserve their fertility and reproductive tissues, they should also be allowed to use them when alive and if they wish to have them used posthumously like any other individuals aged over 16 years or into adulthood.

Wishes and consent are important at all ages and must be fulfilled.

**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, there is no rationale for restricting how an adult uses their own gametes just because those gametes were preserved when the person was a minor. Anyone who reaches adulthood, even close to that, should be permitted to consent to a different use of their stored gametes or reproductive tissue that was collected when they were a minor.

Much appreciated this amendment.

**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:**

Honestly, by not putting these unnecessary restrictions and letting families find their hope and peace with going ahead with using the deceased gametes/sperms.

Grief is not time-bound and I do not expect anyone to understand who has not been hit so hard by the loss and grief of losing a loved one.

**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:**

If that is to help grieving family members. It should just be a tick box or slapped on.

One size does not fit all. Being compassionate, kind and respectful is definitely a therapy ACART and ECART can use through their compassionate policies.

**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:**

No fuss

**Your details**

**What is your name?**

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