

Response ID ANON-FZ4K-4GEP-F

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

Submitted on **2020-09-30 15:00:19**

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:

There is NO NEED for ethical review if deceased person, even a minor, expressed their wishes verbally or in written to their loved ones! Their wishes must be honored. Not honoring deceased person's wishes would be UNETHICAL if anything, Ethical review is required when ECART frustrates and denies the loved ones of deceased person's assests!

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:

Saving embryo can be called a "LIVING WISH" comparable to "LIVING WILL" of a person who unfortunately is deceased now. ECART should have NO authority over deceased person's assets, simliarly as laws are when it comes to financial assets. If financial assests are handed over to loved ones after death, why does ECART has hesitations handing PERSONAL and EMOTIONAL assest to the family which are truly invaluable to the family. Stored embryo has invaluable emotional value for the person who decided to save them, and to the loved ones as only living connection to deceased, as every person saves gametes with a wish to be able to use these in case of their untimely demise.

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

Yes

Comments:

Posthumous use of stored embryo is one of the last wishes of the deceased, there should be no question about posthumous use. Going through the difficult process of saving embryo is already a LIVING WISH and CONSENT for future use! It is deceased person's and their loved ones' right, there should not be any hesitations. ECART should not deprive the grieving family of their rights over diseased person's possessions, denial should be considered unlawful and unethical

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:

If I would ever decide to store my gametes, my goal would be, as every person would agree, to have children, even if I/person already has children, why would someone go through the process of saving ganetes which comes with its own set of side effects if they did not wish to extend their family? Saving embryo can be called a "LIVING WISH" comparable to "LIVING WILL" of a person who unfortunately is deceased now.

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:

Saving embryo can be called a "LIVING WISH" comparable to "LIVING WILL" of a person who unfortunately is deceased now. When someone decides to save embryo it is already WRITTEN CONSENT for future use.

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

No

Comments:

Parents, spouse have complete authority to use embryo or stored gametes as a person's "first degree" relatives in all legal languages. In case when a specific person is not appointed first degree relatives should be given complete authority to use gametes to fulfil deceased person's wishes.

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:

Parents are legally considered first degree relatives,
when a parent dies, their children automatically become heirs to all possessions,
similarly if unfortunately a child dies untimely, parents legally have the similar rights to claim their child's possessions including stored gametes, reproductive tissue or stored embryo. ECART in fact should not have any claims to a child's possessions and should not have authority to deny use.
In fact ECART should facilitate the use and handover process to help the grieving parents who are in pain and want to fulfil their child's wish.

Proposal D: Consent may be written or oral

8 Do you agree that oral consent is acceptable?

Yes

Comments:

Oral consent is legally accepted in many major medical decisions worldwide, why not when it comes to posthumous use of stored gametes or embryo?
A dying person does not have time to put their wishes on paper and wait for a lawyer,
oral expression is the only choice at such tragic time, it is inhuman And unethical to expect a dying person to give written consent and fulfillment of their wishes made dependent on unreasonable and impossible requirements!

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

No

Comments:

A person in presence when the wish was made verbally or the person to whom the wish was expressed are THE EVIDENCE themselves.

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:

Absolutely,
why would I consent to save if I do not wish to retrieve?
Why would I retrieve if I do not wish to use?
These terms are interrelated and interdependent,
we should not ignore a deceased person's wish the game of words.

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:

when a consent is obtained to save gametes, it also addresses the process to retrieve during informed consent process. The person who obtained the consent followed the complete informed consent protocol and educated and explained the patient the complete process of saving and retrieval,

then why is additional test/ proof required?

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?

No

Comments:

There is always a first time before procedures become established.

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:

there is no time in this case to go through high court proceedings, this an extremely time sensitive matter, must be addresses at earliest without red tapism

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:

If a minor wishes to their loved ones , retrieval should be considered.

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:

A wish to save means a wish to use,

Saving embryo can be called a "LIVING WISH" comparable to "LIVING WILL" of a person, even a minor, who unfortunately is deceased now.

If a minor has expressed their wish to family, even orally, it must be honored.

specially in cases of minors, their parents are heir to their possessions and assets, this must include stored gametes and reproductive tissue.

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:

Minors should be able to chose even before the age of 16,

Stored gamete is a person's possession and property, they have a right to chose at any age

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:

Prolonging the process and multiple counseling session only add to the pain and grief to the deceased's family. This process should be made easy and helpful to grieving family, not to aggravate those who are already in pain of losing their 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?

No

Comments:

How can someone else decide how to grieve for a family. I agree that well considered decision is important but creating hurdles in the process of retrieval of deceased persons's stored gamete will only add to family's pain. This process should be facilitating and comforting for grieving family. It should be considered "extension of life" process.

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:

This project should be considered extension of life project,
As we plan end of life, hospice and other services , this can facilitate extension of deceased person's life.

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

Health professional

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?

35-44 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

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.: