

## Response ID ANON-FZ4K-4GEE-4

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

Submitted on **2020-09-30 23:58:33**

### 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?**

Yes

##### **Comments:**

Review should only be allowed with the following objectives:

The consent to the specific use of reproductive tissue and gametes given by the deceased person (adult) is respected, upheld and allowed. The ethical review by ECART should not be a situation where ECART make a decision which can override the consent given by the deceased person (adult) in question - Human and reproductive rights of the deceased should be respected, in regards to the consent given by the deceased in question, and not disrespected and therefore denied by ECART in regards to the review process.

If it is merely a 'rubber stamping', then that would be more sensible, where consent of the deceased person (adult) is upheld. There should be no allowance for conflict of interest from ECART themselves, or other parties (i.e: relatives, extended family, friends, church etc) to be involved or cause interference who may have a religious or personal agenda.

To avoid abuse and misuse of deceased person's (adult) gametes or reproductive tissues, or to prove consent actually was given, review process would be vital. But, not to make the consent given by the deceased void, as that contradicts the original reason for consent in the first place.

Also, it would only be sensible and natural for posthumous use of a deceased adult's reproductive tissue and gametes by a de facto partner or spouse, where consent has been given or implied in some capacity. It would be nonsensical for other parties besides partner or spouse to use said gametes or tissue.

The review process should filter out any forms of abuse, manipulated consent or forced consent - in terms of a deceased person being part of an abusive relationship or marriage, parents retrieving their deceased child's gametes or reproductive tissue to ensure grandchildren, or other parties (relatives, extended family, church, community) being involved who do not have consent, and are not specified as being the specified persons allowed by the deceased for retrieval purposes.

More clarity and precise terms of what the review process entails is important.

In regards to my specifying a deceased adult above - the use of gametes or reproductive tissue of a minor (underage person) is a different matter and should not be allowed.

##### **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?**

Yes

##### **Comments:**

I refer to my answer to the previous question.

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

Yes

##### **Comments:**

It is vital this change is made.

It will enable adult women to have the choice to have their gametes retrieved and used in the event of sudden or impending death by their partner or spouse, where consent is given or implied. Personally I would benefit from this change, in the event of my impending death or sudden death if that were to occur, I would want my spouse to have the consent from myself to make it possible to retrieve my gametes and/or reproductive tissue to use, so our intentions and plans for a family can be accomplished, should this situation happen unfortunately.

Furthermore, this change should enable the retrieval and use of all types of gametes and reproductive tissue from a deceased adult for use by their spouse or partner, where consent is implied or given and can be possibly proven.

The change would also bring the HART Order 2005 under a more modern umbrella, which would reflect the progression at which families and couples have evolved and changed over the past several decades, and also reflect the progression of technology and medicine in regards to fertility and reproductive assistance.

**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:**

### **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?**

Yes

**Comments:**

More clarity and specificity needs to be given on how to prove this consent, and what this consent is, and what types of consent there are.

There could/will be situations where there is implied and/or verbal consent, where proof isn't available, in the event of the deceased person dying suddenly.

Consent given must be upheld and respected, and not declared void by ECART in regards if there is a review process - To do such would undermine and disrespect the human rights of the deceased person, even in death. The consent and human rights of the deceased person in question should be upheld.

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

Yes

**Comments:**

This is vital to avoid any misunderstanding, and avoid abuse by other parties, family, etc. More clarity on this is needed, and how to consent to specific person or persons. This consent to use by a specific person/s must be upheld, to avoid abuse by outside parties or persons.

### **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:**

More clarity, is required. As sometimes consent can't be proven in some situations, where a deceased person dies suddenly before creating evidence. Or consent isn't able to be proven, even if implied or given. What is the evidence of consent? What types of evidence of consent are there? More information is needed.

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

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

Yes

**Comments:**

In some cases oral consent may be the only consent given. Especially when deceased person in question died suddenly, or prior written consent was misplaced or not made. Oral consent must be acceptable, as situations sometimes only allow for oral consent, where further planning isn't made. More details are required on what defines oral consent. In some cases, a brief conversation may be defined as oral consent, or something else. More clarity is needed.

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

Yes

**Comments:**

More specificity and clarity is needed on what constitutes proof of oral consent, and what oral consent may actually be.

### **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:**

It makes sense, the consent to posthumous use of gametes or reproductive tissue implies consent for retrieval - otherwise the point of retrieval is nonsensical.

**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:**

To give consent properly, is to given informed and total voluntary consent - Consent of the deceased must be upheld and respected. To test whether the consent is valid, could result in the consent itself being made void, and would be an abuse of the deceased's prior consent and dignity in regards to their human rights and dignity as a deceased person.

**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:**

**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?**

Yes

**Comments:**

**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?**

Yes

**Comments:**

**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:**

**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:**

**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:**

This could create an issue in terms of time constraints for retrieval from a deceased person, especially where the deceased has died suddenly, and be seen as a way to block retrieval, where consent has been implied or given for said retrieval.

If counselling is done after the retrieval process, then that would be more acceptable, but counselling should not be compulsory and forced to allow for the retrieval. If consent is given or implied by the deceased, there is no need for counselling to create a block to the retrieval process or manipulate the process or ethical review by ECART.

In all retrieval situations, counselling should not be made mandatory.

## **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?**

35-44 years

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

NZ European, Asian, Other

**If you selected other, please specify:**

Australian, English, Irish

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