

# Feedback form

Please provide your contact details below.

Name	ECART
If this feedback is on behalf of an organisation, please name the organisation.	
Please provide a brief description of the organisation (if applicable).	
Address/email	ecart@health.govt.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	ECART is the ministerial committee that reviews, determines and monitors applications for assisted reproductive procedures.

Are you:

☐ Male ☐ Female ☐ Other gender identity

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

☐ Yes ☐ No

Which of the following age groups do you belong to?

☐ 13–19 years ☐ 20–24 years ☐ 25–34 years  
☐ 35–44 years ☐ 45–54 years ☐ 55–64 years  
☐ 65–74 years ☐ 75+ years

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

☐ NZ European ☐ Māori ☐ Pacific peoples  
☐ Asian ☐ Other

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If you do not want your submission published, please tick this box:

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## A. All posthumous use should be subject to ECART review

### Question 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

ECART agrees that approval is needed with the exception of circumstances in which a man is dying and gives specific consent to the use of his sperm after death to a specified person within a specified timeframe, which currently falls within the definition of an established procedure.

ECART is of the view that a distinction needs to be drawn between people who are making decisions in the context of situations where they are not, at that point in time, dying and someone who is imminently dying.

In circumstances where a person has made a decision about the future use of their gametes in circumstances where they are **not** imminently dying, ECART considers it appropriate to consider the application for posthumous use, due to the variety of circumstances which may have occurred in the intervening period which may raise questions about the ongoing validity and applicability of the consent.

### Question 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

ECART is of the view that all such applications should come before ECART for its consideration, with the exception of circumstances in which a man is dying and gives specific consent to the use of the embryo after death to a specified person within a specified timeframe.

This is because ECART is of the view that a distinction needs to be drawn between people who are making decisions in the context of situations where they are not, at that point in time, dying and someone who is imminently dying.

Where a person signed a consent form a long time previously, many factors may have intervened which may give rise to a question about the validity and applicability of the consent. That is much less likely to be the case where a person is imminently dying, and gives consent to the posthumous use of his gametes/an embryo created with his gametes.

### Question 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

Yes, with the exception of cases where sperm or egg donors have consented to use of their donation for the creation of embryos and the embryos exist.

### Question 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?

**Comments**

ECART also suggests that this provision be widened to include use of:

- embryos already created with donated gametes which have not been used where a child doesn't yet exist; and
- sperm from a personal sperm donor who has consented to posthumous use but where there are no offspring in the recipient family at the time the donor dies (i.e. cases where the donor has consented to be a personal sperm donor and says in his consent form signed after implications counselling, that he consents to the use of the sperm in the event of his death).

## B. Consent must be to a specific use

### Question 5

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

**Yes / No**

#### Comments

With the exception of donor sperm (as covered in question 4), ECART agrees that the person who dies must have consented to use by a specific person.

ECART notes that the framing of this consultation document narrows the decision-making situation to one where there is express consent to any posthumous use. This does not allow for a situation where consent could be inferred. ECART considers that there may be circumstances where it could be ethically appropriate to approve an application for posthumous use of gametes where the person hasn't provided written consent to posthumous use of their gametes and/or their embryos by a named person.

The possible situations where this could be the case include:

- when a consent form is signed at the time of collection and storage and it is not clear or it hasn't been updated
- when gametes have been retrieved without the signing of any consent form.

ECART suggests that the consent forms people are asked to sign are very clear about intended future use of eggs/sperm/embryos and that people could be asked to revise their consent on a yearly basis when clinics contact them to ask whether they want to continue to store their reproductive material.

### Question 6

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

**Yes**

#### **Comments**

With the exception of donor sperm (as covered in questions 4 and 5), ECART agrees that the person who dies ought to have consented to use by a specific person.



## Consent to use must be proven

### Question 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?

#### Comments

A distinction exists between situations where there is provision of consent at the time of storage and situations where posthumous retrieval has been authorised by the Court.

ECART is of the view that the Guidelines ought to provide it with the discretion to decide what constitutes sufficient evidence of consent/withdrawal of consent/inferred consent in either situation.

## C. The evidence of consent may be written or oral

### Question 8

Do you agree that oral consent is acceptable?

#### Comments

A distinction exists between situations where there is provision of consent at the time of storage and situations where posthumous retrieval has been authorised by the Court.

ECART is of the view that the Guidelines ought to provide it with the discretion to decide what constitutes sufficient evidence of consent/withdrawal of consent/inferred consent in either situation.

A useful example of a situation where it may be appropriate for ECART to exercise its discretion in this regard involves an application for use of gametes by the surviving partner of a deceased man. The man had consented to his previous partner using the stored sperm posthumously but had since married a new partner. ECART considered that the previous consent indicated that he was open to posthumous use of his sperm. Coupled with evidence about the man's intentions to have a child with his new partner, ECART considered that the posthumous use of his gametes was likely to be consistent with his wishes and preferences or, in other words, it was likely that he would have consented to the posthumous use of his sperm by his new partner had he been asked.

**Question 9**

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

**Yes / No**

**Comments**

Please see comments made in response to question 8.

## D. In most cases, the deceased's consent to retrieval can be inferred from their consent to posthumous use

### Question 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

ECART is of the view that agreement to posthumous use of stored gametes or embryos in the event of someone's death cannot be taken to infer consent to retrieval.

In relation to the rare situation where a person consents to use if they were to die but there is no reproductive tissue/gametes stored then ECART would expect that there would be a discussion with the individual about what that would involve before they could be considered to have validly consented to retrieval after death.

ECART considers that it ought to be able to consider situations where a person has not expressly consented to retrieval after death, but retrieval has been authorised by the Court. In such circumstances, ECART sees its role as determining whether or not consent can be inferred in the circumstances.

### Question 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 / No**

#### Comments

Please see comments made in response to question 10.

## E. ECART or the High Court will be able to authorise retrieval of gametes or reproductive tissue from a deceased person

### Question 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

### Question 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.)

**No**

#### Comments

ECART is strongly opposed to any suggestion that ECART could lawfully authorise the posthumous retrieval of gametes. ECART is of the very strong view that the HART Act does not give ECART the power to authorise the posthumous retrieval of gametes.

ECART appreciates that one of the reasons that ACART may wish to suggest that ECART is able to undertake this role might be because it would allow ACART to issue guidelines which apply to the posthumous retrieval of gametes. However, ECART suggests that the guidelines could, in any event, address the considerations which ECART ought to take into account when considering an application for use of gametes retrieved posthumously by order of the Court. The Court is likely to attribute some weight to any such guidelines when considering whether or not to authorise posthumous retrieval of gametes in relation to a particular case before it.

## F. Prohibiting retrieval from deceased minors

### Question 14

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

**Yes**

#### Comments

### Question 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

ECART is of the view that it is not ethically appropriate to use a minor's gametes for any purpose other than their own unless they subsequently consent to a specific use when they become an adult.

G. 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

**Question 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**

ECART notes that regulations being passed for the use of ovarian tissue also state 'no' to use by another person without the consent of the minor once she is over the age of 16.

## H. No requirement for a specific stand-down period

### Question 17

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

**Yes**

#### Comments

ECART is of the view that there shouldn't be a specific stand down period but that the length of time since someone has died should be one of the factors that is taken into consideration by ECART.

### Question 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. The title of these guidelines

### Question 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

ECART is of the view that the proposed title for the guidelines of *Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos* is appropriate.

ECART makes the following additional general comment that these Guidelines ought to extend beyond the posthumous use of gametes and embryos to address storage of gametes and embryos where the person who stored their gametes has died. For example, what do clinics do in cases where sperm or eggs have been collected after accidental death and there is no route to use them because ECART has declined an application for use?