

# Feedback form

Please provide your contact details below.

Name	Sue Gasquoine Nursing Policy Adviser/Researcher
If this feedback is on behalf of an organisation, please name the organisation.	Tōpūtunga Tapuhi Kaitiaki o Aotearoa New Zealand Nurses Organisation (NZNO)
Please provide a brief description of the organisation (if applicable).	<p>NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 51,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.</p> <p>NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.</p> <p>NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is <i>Freed to care, Proud to nurse</i>.</p>
Address/email	Sue.gasquoine@nzno.org.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Represent health professionals

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

### Privacy

We may publish all submissions, or a summary of submissions on ACART's website. If you are submitting as an individual, we will automatically remove your personal details and any identifiable information. You can also choose to have your personal details withheld if your submission is requested under the Official Information Act 1982.

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

- ☐ Do not publish this submission.

Your submission may be subject to requests made under the Official Information Act 1982. If you want your personal details removed from your submission, please tick this box:

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If your submission contains commercially sensitive information that you do not wish to be released, please tick this box:

- ☐ This submission contains commercially sensitive information.

## 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 review should be *recommended* rather than required in these circumstances**

### 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

**The circumstances of use may vary significantly from the 'use' planned when the embryo was retrieved and stored.**

### 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

**ECART is in the best position to consider the wishes and consequences for all parties** involved including the child/ren who result from the **use** of reproductive tissue of deceased persons and so need to be taken into account when changing HART Order 2005

### 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?

Yes

#### Comments

**In these circumstances posthumous use enables a child the benefit of a sibling(s) who share biological parentage.**

## 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

#### Comments

**Can there be more than one use of stored reproductive tissue that could be specified? If not used as specified by the deceased, one NZNO member felt strongly that:**

*'if the deceased is Maori and the preserved samples are from their body, if the partner does not wish to continue with use of the tissue for reproduction (with surviving partner), then the sample should be placed in the casket of the deceased (as a part of their body).'*

### 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

**The same member quoted above also makes the following observation:**

*'In all reality, these very issues should be discussed and contracts written for the clients.'*

## 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?

**Yes**

#### Comments

**One suggestion is the consideration of the use of '*advanced directives*'** in a similar manner to the way organ donation intentions are recorded and updated.

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

### Question 8

Do you agree that oral consent is acceptable?

Yes

#### Comments

**While written/documented consent is desirable, there may be 'emergency' situations where achieving documentation of consent given verbally is impractical. ECART needs to be able to consider these situations on a case-by-case basis so that a whānau is not disadvantaged/excluded from the opportunity to retrieve and use reproductive tissue just because there is no documentation of an earlier decision.**

### Question 9

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

Yes

#### Comments

**As above – evidence of verbal consent can take many forms eg recorded on a device such as a phone, witnessed by others/whānau members,**





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?

**Yes**

**Comments**

**However one member says:**

*'It's not right to retrieve gametes or tissue from a dead person's body...'*

**Question 11**

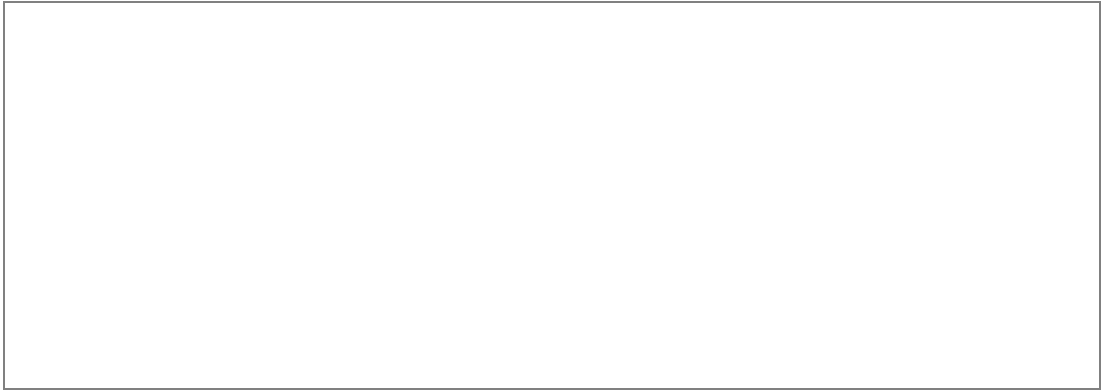
Do you agree that there is no need to test whether the deceased person had a full understanding of the method of retrieval of the gametes or tissue?

**Yes**

**Comments**

**The member quoted above who disagrees with retrieval from a deceased person did not specify if their objection was related to retrieval methods. It seems likely that some will object on the grounds of 'indignity' shown tūpāpaku by posthumous retrieval.**

**However the 'indignity' of not having the opportunity to contribute reproductive tissue to creating a child simply because it cannot be demonstrated that they fully understood the method of retrieval of that tissue, has the potential to exclude some from the benefits of this reproductive technology.**



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**

**Either ECART or the High Court need to consider each situation on a case-by-case basis.**

**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**

**If ECART is unlikely to be asked for a determination, the process will be more robust if the High Court alone is left with this responsibility.**

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## 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?

No

#### Comments

**This issue deserves further consultation. Decisions about the use of stored reproductive tissue from a minor should also involve their whānau who will have assisted the minor with the original decision to have reproductive tissue stored, presumably because of a life and fertility threatening condition and/or treatment.**

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**

## 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

**Given the involvement of ECART and/or the High Court in reviewing/approving the retrieval and use of reproductive tissue from deceased persons there is already a 'default' stand-down period because of the time taken for this process to occur.**

### 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?

No

#### Comments

**The experience of grief is personal, cultural, social and even political. A 'counselling provision' may be useful for some but exclude others because the notion of counselling is originally a middle class western concept and won't necessarily support decision-making for the diverse communities who may wish to access the use of reproductive tissue stored prior to the death of or retrieved on the death of a loved one.**





## 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**