



**Advisory Committee on
Assisted Reproductive Technology**

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

**Stage Two Consultation:
Submissions Analysis**

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Introduction

In 2018, the Advisory Committee on Assisted Reproductive Technology (ACART) consulted the public on the ethics of posthumous reproduction. Responses from that consultation informed ACART's development of its Proposed Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos. ACART then conducted a stage two consultation. This publication summarises the submissions received in that consultation.

In the stage two consultation, ACART sought feedback from the interested public on the proposed guidelines and important policy issues, including the consent requirements for the use of gametes, reproductive tissue or stored embryos after someone has died.

In general, ACART has made no attempt to judge the merits of particular viewpoints or arguments. ACART is considering all perspectives, alongside legal and ethical issues, and the principles of the Human Assisted Reproductive Technologies Act 2004 (the HART Act), as it continues to develop its updated guidelines.

ACART would like to thank the Secretariat at the Ministry of Health for its able support in compiling this summary and running the consultation.

We especially thank all those who made submissions for their valuable input.

Ngā mihi ki a koutou



Dr Kathleen Logan

Chair, Advisory Committee on Assisted Reproductive Technology
March 2021



The consultation process

The stage two consultation document was published on 15 July 2020 on both the ACART website and the Ministry of Health website, along with a press release prepared by the Ministry's communications team.

Submissions closed on 30 September 2020 after extending the consultation to allow for a number of further submissions to be received.

ACART emailed the consultation document to its comprehensive stakeholder list, and to all submitters who had engaged with the stage one consultation in 2018. ACART's stakeholder list includes all fertility clinics, the Ethics Committee on Assisted Reproductive Technology (ECART) and other government departments, including the Ministry of Justice (which administers the HART Act). It also includes religious and ethnic groups, and medical associations. In total, ACART emailed the consultation document to approximately 300 people/groups. It encouraged stakeholders to forward the consultation on to their networks.

Submitters could have their say by following the link ACART provided to the online consultation through Citizen Space, a digital platform for consultation, by completing the Citizen Space link through ACART, or through the Ministry of Health's website, or by emailing a completed feedback form or comments to acart@moh.govt.nz.

ACART welcomed feedback from any individuals or groups, and the Secretariat invited fertility clinics to forward the invitation to any of their patients that they considered to have an interest in this topic.

ACART did not hold open public meetings for this consultation, because of the COVID-19 pandemic. Instead, it included in the consultation document a question asking submitters whether they would like to submit verbally. Where submitters did wish to submit verbally, ACART invited them to a Zoom meeting to do so.

ACART received a total of 37 submissions on the stage two consultation, via Citizen Space, post or email. Some submitters did not fill out the feedback form but sent an email or letter providing feedback. Where possible, ACART has manually added these submissions to Citizen Space to enable quantitative analysis. Raw submissions used for this analysis are available to view on ACART's webpage. Personal details have been redacted where submitters requested that their details were withheld before publishing, and some submitters requested that their entire submissions were not made public.

ACART notes that this analysis does not purport to reflect the proportions of views in society, but only of submitters.

Three meetings were held via Zoom with Auckland Repromed, Auckland Fertility Plus and Fertility New Zealand in August 2020, to clarify the rationale for the proposed guidelines and talk through their workability in practice. Each of these meetings was attended by a

member of the ACART working group and a member of the Secretariat. These groups then submitted formally following the meeting.

ACART's feedback form asked for individual submitters to categorise their primary interest in the topic, and to provide their age and ethnicity. The following three tables present total submission numbers broken down by category, age group and ethnicity.

Category	Total	Percent
User of fertility services	9	25.71%
Health professional	12	34.29%
Researcher	0	0.00%
Member of the public	10	28.57%
Other	4	11.43%
Not answered	0	0.00%

Age group	Total	Percent
13–19 years	2	5.71%
20–24 years	2	5.71%
25–34 years	3	8.57%
35–44 years	7	20.00%
45–54 years	11	31.43%
55–64 years	5	14.29%
65–74 years	2	5.71%
75+ years	3	8.57%
Not answered	0	0.00%

Ethnicity	Total	Percent
NZ European	16	45.71%
Māori	5	14.29%
Pacific peoples	2	5.71%
Asian	5	14.29%
Other	13	37.14%
Not answered	0	0.00%



High-level themes

High level themes from the stage two public consultation reflected issues raised in the stage one consultation.

Consent is important

Submitters were generally supportive of retrieval and use of gametes or reproductive tissue after death if there is some evidence of consent.

When a person stores gametes while they are alive, they are asked what they want to have happen to their gametes in the event of their death. Most submitters were familiar with the process of storing gametes while alive for the purposes of fertility preservation, and supported the option of written consent for the use of gametes in this case.

As in the stage one consultation, the majority of submitters supported the posthumous use of stored gametes or embryos where there was evidence of verbal consent. However, most people were uncomfortable with the requirement being for written consent, and felt strongly that other types of consent should be considered also. Many people thought that because of the often unexpected nature of death, written consent should not be mandatory. Submitters expressed that some sort of evidence was vital, and suggested many forms that verbal or inferred consent could take, including an affidavit confirming conversations had with family or a partner.

There was a strong theme that consent of some kind needed to be given for retrieval and use of gametes after death, and many submitters requested clarification from ACART about what acceptable consent for posthumous use might entail.

Not all cases of posthumous use need ethical approval from ECART

In the stage one consultation, ACART found that there was not enough support for a requirement that all posthumous use of gametes and embryos should be subject to ethics review. Submitters seemed to be looking instead for a balance of ethical oversight/approval, or a model that was dependent on the situation. Opinions were mixed, so ACART sought clarification on this question in the stage two consultation.

In this consultation, most submitters and fertility services thought that ECART review should **not** be required for **all** posthumous uses of gametes or reproductive tissue.

The main situation in which submitters thought ethical review by ECART should not be required, was where consent has clearly been given to the specific use of the gamete before the death of the gamete provider and there has been a clear and robust counselling and consent process. In this case, submitters thought that clinics could manage the ethical complexity of posthumous reproduction.

Others noted situations that might meet the threshold of requiring ethical review; for example, where gametes are retrieved posthumously and consent to their retrieval and use is not clear, or where there are additional complex ethical issues to consider, such as inheritance or parentage.

Consistently with the stage one consultation, there was a consensus among submitters that where a deceased person's wishes have been written down in a legally recognised document, this takes first priority, and such cases should not necessarily require ethical review by ECART.

Tikanga

One submitter noted that there should be further careful consideration given to the tikanga and te ao Māori implications of posthumous retrieval of gametes and reproductive tissue in any guidelines issued to ECART.

Who may seek posthumous retrieval and use?

In the stage one consultation, ACART asked submitters who should be permitted to use reproductive material from a deceased person. ACART then proposed that the posthumous retrieval of gametes or reproductive tissue can be requested by the person who intends to use the gametes or reproductive tissue to become a parent, and that that person must be the one specified by the deceased person in their consent. This is most likely to be a surviving partner, but it could be another relative; for example, a sister or brother.

As in the stage one consultation, many submitters agreed with ACART's proposed approach and thought that posthumous reproductive material should only be able to be used by a family member and/or a partner.

Who should authorise posthumous retrieval?

In this stage two consultation, ACART proposed that the posthumous retrieval of gametes or reproductive tissue could be authorised by the High Court, or by ECART in very rare circumstances. ACART proposed this because not specifying this authority might leave a legal gap that ACART has a responsibility to fulfil under the HART Act.

Two submitters noted that they strongly believed that the HART Act did not include any legal mechanism for ECART to lawfully authorise the posthumous retrieval of gametes or reproductive tissue, and that the only avenue for posthumous retrieval should be through the High Court.

Grief, and a mandatory stand-down period

ACART proposed that there is already effectively a stand-down period for posthumous use of gametes if people are undertaking ethical approval for this, and therefore the guidelines did not need to stipulate such a period. Submitters agreed that the guidelines did not need a mandatory stand-down period, and gave reasons for this that a set stand-down period would be too inflexible; having a set stand-down period does not recognise different people's situations; and because they were confident that clinics were able to support families through the grieving process and manage any complex situations in which people wanted to use the stored gametes soon after their loved one has died.

Gametes and tissue should not be able to be retrieved from deceased minors

Section 12 of the HART Act places restrictions on obtaining gametes from minors. The Act states that no person may obtain a gamete from an individual under 16 years of age, or use a gamete obtained from an individual under 16, unless they intend to preserve the gamete for that individual's use, or to bring about the birth of a child likely to be brought up by the individual from whom the gamete was obtained.

In this stage two consultation, ACART proposed that gametes should not be able to be retrieved from deceased minors. Although this question attracted a spectrum of opinions, the majority of submitters agreed that the retrieval of gametes from minors after their death was ethically unacceptable. Interestingly, some submitters thought such retrieval should be allowed in the interests of ensuring an individual's genealogy carries on, if the individual's family was in agreement that this was important.

Using gametes frozen by minors (for their own fertility preservation) after their death

Many of the submissions on this issue appeared to be from parents or family of deceased children who had frozen gametes when they were under the age of 16 for the purposes of fertility preservation prior to undergoing medical treatment. Many of these submitters strongly believed that they (as the whānau of the deceased individuals concerned) should have the authority to authorise the use of that frozen material, even in situations where there was not consent to specific use.

Similarly, ACART heard from families of loved ones who had died, who firmly believed that where a person had made the decision to preserve their fertility or store gametes prior to their death, it could be understood that the deceased person would have wanted others to use those gametes.

Additionally, some submitters argued that if a minor had given their competent consent to specific uses of their gametes before their death, this should be honoured, even if the person was under 16 at the time the gametes were frozen.

A number of submitters included their thoughts on people's competence to make medical decisions and seek sexual health services under the age of 16, and argued that aged 16 is an arbitrary number for legal purposes that does not take into account people's maturity, life experience or competence when expressing their wishes for their gametes.

Alternatively, ECART and fertility providers strongly believed that minors should be protected from having their gametes retrieved posthumously and used by others, and that this should still be prohibited even in the case of minors judged to be 'mature'.

Collective versus individual decision making

Some submitters noted that choices, decisions and rights for Māori (and in other cultures and families) do not necessarily operate in an individualistic paradigm, but in one that involves recognition of whānau, hapū and iwi relationships and potential impacts on those, including on the whakapapa line (ancestors to descendants). Along this line of reasoning, a number of submitters talked about the importance of the support of whānau in using gametes posthumously and in carrying out the wishes of an individual following their death.

Submissions analysis¹

This section provides analysis of submissions on the stage two consultation, set out according to the sections in the proposed guidelines (A–K) and their associated questions.

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?

There were 34 responses to this question.

Option	Total	Percent
Yes	15	42.86%
No	19	54.29%
Not answered	1	2.86%

The majority of submitters and fertility providers thought that ECART review should **not** be required for all posthumous uses of gametes or reproductive tissue.

Two submitters thought that in cases where people have given consent to the posthumous use of their gametes when they are not imminently dying, ethical review for the use should be required due to the change of circumstances (which might affect the validity of that person's consent) that could have occurred in the intervening period.

Some submitters thought that ethical review should not be required because the use of gametes is a personal or family matter and not something that requires review by an external body.

¹ Percentages that appear in this section reflect data received through Citizen Space and also through hard copy questionnaires.

Some submitters also argued that ethical review by ECART would be an unfair and unjustifiable emotional and financial burden in cases where consent had been given to the use of gametes stored while the individual was alive. A few fertility providers and experts thought that there would be nothing more to gain by requiring ethical review in the case of those people who had already undergone a robust consent process at the time of consent and where written consent had been provided before death.

Some submitters agreed with ACART's rationale for ethical review of all posthumous use: that posthumous use is an ethically complex procedure. One submitter thought that ethical review by ECART would be a valuable safeguard to check no coercion had been involved, and would give all parties involved the option for counselling. One submitter and two fertility providers noted that fertility provider counsellors are qualified to decide when a case should be referred to ECART, but that, otherwise, the posthumous use of material that has been stored during an individual's life should be classed as an established procedure.

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?

There were 34 responses to this question.

Option	Total	Percent
Yes	14	40.00%
No	20	57.14%
Not answered	1	2.86%

Submitters answered this question similarly to question 1, which might indicate that those who thought that a clear and robust consent process in deciding on the use of embryos while a person was still alive might eliminate the need for ethical review by ECART.

Similarly, all fertility providers thought that ethical review by ECART was not needed for the approval to use stored embryos after the death of one gamete provider unless that use involved a third person (for example, where a surrogate would be needed to carry the pregnancy).

Alternatively, ECART was of the view that all applications should come before ECART for its consideration with the exception of the situation when a man is dying and gives specific consent to the use of an embryo after his death to a specified person within a specified timeframe. ECART noted that the guidelines should draw a distinction between this situation and the situation in which a man makes such a decision and he is not imminently dying.

Some submitters wished to note that even though they thought that ethical review should not be mandatory, they agreed that in complex situations ECART review could be useful. A few submitters reiterated that they thought ECART approval was needed in cases where the specific use was not clearly agreed to in the original consent, or where situations had drastically changed from when the consent was given.

One submitter said that even if the deceased had noted they wanted the embryos destroyed in the event of their death, ECART should still consider their use so the embryos can be given a chance at life.

A few submitters reiterated that use of embryos is a family matter, and ECART should not be involved in ultimate decisions about it.

Question 3

Do you agree that ACART should recommend a change to the [Human Assisted Reproductive Technology] Order 2005 to ensure all posthumous use is considered by ECART?

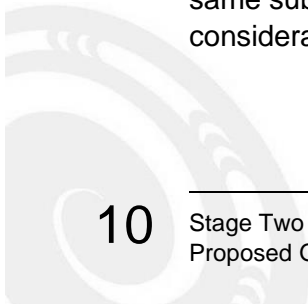
There were 35 responses to this question.

Option	Total	Percent
Yes	22	62.86%
No	13	37.14%
Not answered	0	0.00%

Most people who said yes to questions 1 and 2 consistently said yes to question 3, and vice versa.

Many submitters said that no change should be made to the Human Assisted Reproductive Technology HART Order 2005 (the HART Order) because that would capture cases where consent was given before death, and they did not agree that those cases required ethical review.

However, some of the commentary provided on this question indicated that a few submitters did not understand the implications of the question. For example, some people who answered no to questions 1 and 2 then answered yes to question 3. Taking into account the reasons these submitters gave for answering inconsistently, it appears that some people agreed that a change should be made, and thought this meant that making a change to the HART Order would at least allow a chance for them to try and use their loved one’s gametes (that were frozen for the child’s own fertility preservation) or embryo – even though these same submitters had noted previously that they thought ECART should have no role in the consideration of use, and that the issue was a family matter.



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?

There were 33 responses to this question.

Option	Total	Percent
Yes	31	88.57%
No	2	5.71%
Not answered	2	5.71%

Most submitters agreed that this guideline should be carried over from the current guidelines (written in 2000), and that ACART's guidelines on this should be inclusive of eggs also.

A few submitters considered that there should not be an automatic approval without checking that there was donor consent to the gametes being used after the death of the person concerned.

One submitter and one fertility provider also suggested that the approval to use the gamete should not hinge on the fact that there is an existing child who will be a full biological sibling.

ECART suggested that this provision be widened to include use of:

- embryos already created with donated gametes which have not been used where a child does not yet exist
- 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 (that is, 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).

One submission from a fertility provider also suggested that this provision should include embryos already created using the donor sperm or eggs but not yet used.

B. Consent must be to a specific use

Question 5

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

There were 34 responses to this question.

Option	Total	Percent
Yes	23	65.71%
No	11	31.43%
Not answered	1	2.86%

Most submitters agreed that it was important that an individual had consented to the use of their gametes or indicated how they would like their gametes to be used after their death.

One submission from a fertility provider also suggested that, with the exception of donor sperm, deceased individuals should have consented to use by a named person.

Those who thought that ethical approval by ECART for use should not be required seemed to be more liberal in their answer to this question, saying that consent for use does not need to be so specific.

Some submitters appeared to be of the view that if ethical review by ECART is not always required, then it is more important that consent to use be specific.

Two individual submitters who have gametes stored on behalf of their now deceased children suggested that the wording in this question was too restrictive, and both recalled their relevant experiences, including that there had been no discussion with them or their child about potential uses of the gametes/tissue at the time of freezing. Because applications for use of gametes stored for a child’s own fertility preservation (prior to their death) would not be able to be approved by ECART under the existing HART Act and ACART’s proposed guidelines, these submitters suggested the wording be less restrictive and more in line with the purpose of the HART Act: to ‘provide a robust and flexible framework for regulating and guiding the performance of assisted reproductive procedures’.

A few submitters asked for clarity on what constitutes consent to specific use, and how to prove that had been obtained. There were also concerns that in the absence of clear guidelines for this, use might be unable to be approved by ECART or a review-type process.

Question 6

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

There were 33 responses to this question.

Option	Total	Percent
Yes	18	51.43%

No	15	42.86%
Not answered	2	5.71%

One submitter noted that it was important that a named person was stated, to avoid abuse or misuse of gametes or embryos.

Two submitters noted they particularly disagreed with the idea that the specified person must intend to parent the resulting child themselves.

One fertility provider agreed with ACART's proposal, and reiterated that the specified person should be the partner of the person who dies, and that that person should also intend to parent any resulting child. The provider noted that this did not prohibit donating gametes to another individual, but also commented that a robust consent process for donation should take place before death, at the time of storage.

Feedback from other fertility providers was mixed; there was a general theme that the more specific the individual who dies has been about their wishes in regard to the use of their gametes after their death, the better.

Some submitters noted that the use of the word 'must' and the idea of naming a specific individual and a specific use could not take into account all of the situations in which a gamete or embryo might be used (for example, by a surrogate or a new partner). Some submitters voiced their concerns that this would mean that their consent could be invalidated by ECART.

C. 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?

There were 34 responses to this question.

Option	Total	Percent
Yes	26	74.29%
No	8	22.86%
Not answered	1	2.86%

While the majority of submitters agreed that evidence of consent was required, most people noted that they were unclear about what that would actually entail, as written or oral consent

is unlikely for most cases of unexpected death. Further, two fertility groups suggested that the guidelines should include guidance on what constitutes sufficient evidence from someone who did not leave written consent.

One fertility provider agreed with the proposal and noted that, in its opinion, retrieval of gametes or tissue after death could not meet the threshold of informed consent in almost all cases, and noted its concerns that the guidelines would allow gametes retrieved after death without explicit consent to be used to create a child without the deceased person's consent.

One submitter who agreed with this proposal also argued for the partner of the deceased person to be the only one who could provide evidence of consent.

A few other submitters suggested that it will not always be the intending parent/partner seeking to use the gametes, and accordingly ethical oversight is important.

Those who did not agree with this proposal gave reasons for not requiring evidence of consent, stating that this would set the bar too high and would not allow parents and whānau to have access to their deceased children's stored gametes. They noted that the word 'must' should be removed from this section.

A few submissions noted that a distinction exists between situations where there is a provision of consent at the time of storage and situations where a court authorises posthumous retrieval. One submitter suggested that the guidelines should grant ECART discretion to decide what constitutes sufficient evidence in either situation.

D. The evidence of consent may be written or oral

Question 8

Do you agree that oral consent is acceptable?

There were 32 responses to this question.

Option	Total	Percent
Yes	24	68.57%
No	8	22.86%
Not answered	3	8.57%

Two fertility providers did not agree that oral consent for posthumous use of gametes or tissue was acceptable, and thought that consent should always be in writing. Two other fertility providers thought that oral consent could be acceptable, but along with a number of

other submitters reiterated the need for clearer guidance on what constitutes sufficient oral consent.

Three submitters did not agree with this proposal for the reason that they did not believe that oral consent can meet the requirements of informed consent, and said although oral consent is allowed in other areas of health care, it is not appropriate for posthumous retrieval and use of gametes and tissue.

A few submitters suggested that the guidelines should allow ECART to decide on this issue on a case-by-case basis, stating that they did not want to see some individuals miss out because in their cases there had not been time to obtain written consent.

Question 9

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

There were 29 responses to this question.

Option	Total	Percent
Yes	25	71.43%
No	4	11.43%
Not answered	6	17.14%

Where submitters thought that oral consent was acceptable, they generally saw a need for evidence of that consent; most submitters agreed that evidence of oral consent of some kind was required. Some submitters reiterated that they found it difficult to answer the question without clear proposals of what evidence of oral consent might entail.

ACART heard that evidence of the oral consent should be required for the consent to be recognised as valid – otherwise that consent was simply ‘inferred’. A few submitters stated that oral consent was inferred consent, rather than true and robust consent. One fertility provider reiterated its concern that oral consent was not acceptable as it cannot be informed, and two other fertility providers thought that there should be a level of formality to oral consent, such as an affidavit or an independent witness.

Many people thought that family and friends should be able to vouch for the oral consent. In particular, one submitter suggested the evidence could be informal, such as text or email proof, or statements corroborated by someone who was close to the person. This line of reasoning is in keeping with a theme that emerged in the stage one consultation, that ‘family knows the person best’. However, some submitters specifically noted that the evidence needed to be from someone independent from the person who would benefit from using a deceased person’s gametes, to allow objective proof of the consent, and to mitigate any conflicts of interest.

ECART reiterated that the guidelines should provide it with the discretion to decide what constitutes sufficient evidence for different situations.

E. 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?

There were 32 responses to this question.

Option	Total	Percent
Yes	19	54.29%
No	13	37.14%
Not answered	3	8.57%

Opinions were mixed on this question, but submitters’ comments indicated that they were mostly supportive of the proposal. Those that did not support the proposal commented along the theme that it was wrong to remove someone’s tissue after their death without their explicit consent to do so.

One submitter who agreed that consent for posthumous use would often imply a consent to retrieval further argued that ECART should look for evidence of the individual’s cultural and spiritual beliefs, to ensure that all relevant aspects of an individual’s value system were taken into account.

One submitter who agreed with the proposal also noted that there should be a provision in the guidelines for acceptable methods of retrieval that maintain the dignity of the deceased body.

ECART thought that consent to use without having any frozen material cannot be taken to infer proper informed consent, but noted that if retrieval has been authorised by the Court then ECART could determine on a case-by-case basis whether consent could be inferred.

Two fertility providers thought that where an individual said that gametes could be used after their death knowing that they did not yet have any stored was consent to posthumous retrieval. Two other fertility providers did not share this view.



One fertility provider distinguished the ethical acceptability of the posthumous retrieval of gametes, noting that it did not believe that consent to the use of stored embryos after a person's death implied consent to the posthumous retrieval of further gametes.

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?

There were 32 responses to this question.

Option	Total	Percent
Yes	14	40.00%
No	18	51.43%
Not answered	3	8.57%

Opinions were mixed on this question. Submitters' commentary generally indicated that consent should ideally illustrate that the deceased person had an understanding of what retrieval involves. One submitter noted that it depended on the situation.

One submitter noted that because posthumous retrieval of gametes or tissue is invasive, it should be demonstrated that the person had a good understanding of the method of retrieval.

One fertility provider thought that consent to retrieval after death where a person knew that they did not yet have any gametes or tissue stored inferred consent to whatever method of retrieval was most appropriate for that person and their whānau.

One medical body noted that some people might object to retrieval without consent on the basis of indignity, but said that this should be balanced against the indignity of not being able to contribute to creating a child in situations where it could not be demonstrated that the person fully understood the method of that retrieval.

F. 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?

There were 33 responses to this question.

Option	Total	Percent
Yes	29	82.86%
No	4	11.43%
Not answered	2	5.71%

A strong majority of individual submitters, as well as ECART and all fertility providers, agreed with this proposal.

Submitters who thought that posthumous retrieval should never be an established procedure said that they felt this way because they believed that the legislation as it stood represented the crossing of cultural boundaries, and that important ethical considerations are overstepped if posthumous retrieval was a routine established procedure.

One submitter suggested that if a person had stored gametes while alive, there could be a further option for them to consent to gametes being retrieved after their death also.

A few submitters mentioned that whatever form the authorisation of retrieval took, it simply needed to be clear for the courts and for those who wished to retrieve, due to the small window of time available for viable posthumous retrieval.

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.)

There were 32 responses to this question.

Option	Total	Percent
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Yes	23	65.71%
No	9	25.71%
Not answered	3	8.57%

A number of submitters thought that it was better to keep posthumous retrieval as a matter for the High Court.

Two fertility providers thought that a single pathway through the High Court might make the process clearer and faster; people would not to wait for ECART to convene and decide on a case. They also noted that the cases that could be considered by ECART would be very few.

One submitter suggested that authorisation of posthumous retrieval by ECART would not be appropriate, as it could give people the impression that the use had been pre-emptively approved.

A few submitters suggested that it did not matter which body did the authorising, as long as authorisation was ethically consistent and decision making transparent.

ECART is strongly opposed to any suggestion that it could lawfully authorise the posthumous retrieval of gametes. ECART does not believe that the HART Act gives it this power. The New Zealand Law Society’s submission also argued that the relevant provisions of the Act and Order indicate that ECART’s functions extend only to the posthumous use – and not the posthumous retrieval – of gametes.

G. 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?

There were 32 responses to this question.

Option	Total	Percent
Yes	21	60.00%
No	11	31.43%
Not answered	3	8.57%

The majority of individual submitters, as well as ECART and all fertility providers, agreed with this proposal.

Two different submitters, who both have the gametes of their tragically deceased children in storage, noted that although they agreed that gametes should not be posthumously taken from deceased minors, losing a child meant losing their future also. They expressed that this can complicate the grief process.

One fertility provider made the point that this proposal was consistent with the law that children under 16 are not legally able to have sex to create children. Alternatively, another submitter noted that while the age of consent to sexual activity is 16, a minor of any age can consent to sexual and reproductive health care services; for example, contraception and abortion.

Similarly, a few submitters mentioned Gillick competence (a term used in medical law to decide whether a person aged under 16 is able to consent to their own treatment). Some noted that it would not seem fair for someone to miss out on being able to retrieve gametes or tissue posthumously if a deceased individual was, for example, almost 16.

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?

There were 33 responses to this question.

Option	Total	Percent
Yes	18	51.43%
No	15	42.86%
Not answered	2	5.71%

Just over half of individual submitters, as well as ECART and all fertility providers, agreed with this proposal.

A number of submitters noted that they thought it was ethically unacceptable to use gametes previously stored by a minor where the original intention of storing the gametes of tissue is for that person’s own future fertility preservation. A number of other submitters thought that age did not matter here, and that minors could be mature enough to state their wishes for their stored gametes in the event that they would not be able to use them themselves.

Some submitters thought that the gametes should be able to be used by someone else, and one submitter said that the posthumous use of a deceased minor’s gametes should be able to be used if their whānau were supportive.

Two submitters noted that if a minor wished for their gametes to be used by someone else in the event of their death, or wished for a sibling in need to be able to use them, then that would be “special for the remaining family members”.

A medical body, along with a number of other submitters, said that the ability of minors to consent to sexual and reproductive health services could be consistent with their ability to choose if they would like to donate their gametes to someone else in the event of their death.

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

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?

There were 32 responses to this question.

Option	Total	Percent
Yes	30	85.71%
No	2	5.71%
Not answered	3	8.57%

A strong majority of submitters, as well as ECART and all fertility providers, agreed with this proposal.

The majority of submitters agreed that minors who stored gametes as children for their own fertility preservation and who then reach adulthood should be able to place the same conditions for their stored gametes as other adults. One submitter thought that age 16 was still too young to make the decision to donate, and, further, two fertility providers noted a discrepancy with the age of donation, which is currently aged 20.

I. 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?

There were 32 responses to this question.

Option	Total	Percent
Yes	26	74.29%
No	6	17.14%
Not answered	3	8.57%

Overall, submitters seemed to think some sort of stand-down period was a good idea but did not agree it should be mandated. Many noted that the grieving process was different for everyone, and an enforced stand-down period would be inflexible and arbitrary.

One submitter thought that a stand-down period could be a useful safeguard during the grieving process, but also noted that they were happy to leave these decisions to ECART.

ECART and two fertility providers thought that a stand-down period should not be mandatory, but that ECART should consider it on a case-by-case basis. Some submitters noted that the ECART meetings are infrequent and so there would be a default stand-down period for those going through the process of applying to ECART for posthumous use of gametes or embryos.

Some submissions indicated that they thought clinics could manage any period needed for grief before allowing posthumous use of gametes or embryos.

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?

There were 31 responses to this question.

Option	Total	Percent
Yes	23	65.71%
No	8	22.86%
Not answered	4	11.43%

For this proposal, submitters commented along similar lines to the previous question, and many people noted that a stand-down period needed to be flexible so that where something like age was a factor people did not miss out on the chance to have a child.

One fertility provider and a number of submitters thought that clinics should be able to make the call to defer treatment if a person was not able to make a well-considered decision, or if there was a division among family members about the posthumous use.

Some submitters noted that the notion of counselling is a Western concept that will not suit everyone.

A few submitters said that the extent to which grief *should* impact on fertility treatment was also a matter for case-by-case decisions that clinics could manage.

A few submitters argued that, because grief is not a linear process, it was insensitive to suggest that there should be a 'time limit' on grieving, and that decisions on use should be made case by case.

K. 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*?

There were 33 responses to this question.

Option	Total	Percent
Yes	29	82.86%
No	4	11.43%
Not answered	2	5.71%

A large majority of submitters thought the title of the guidelines was suitable; some submitters suggested the title should include a reference to retrieval if the two-pronged approach to authorisation of retrieval is confirmed in the final iteration of the guidelines.