



**Advisory Committee on
Assisted Reproductive Technology**

**Posthumous Reproduction:
A review of the current *Guidelines for
the Storage, Use, and Disposal of Sperm
from a Deceased Man* to take into
account gametes and embryos**

**Stage One Consultation:
Submissions Analysis**

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Introduction

This summary of submissions outlines issues raised by submitters to the Advisory Committee on Assisted Reproductive Technology's (ACART's) stage one consultation on posthumous reproduction.

In general, no attempt has been made by ACART to judge the merits of particular viewpoints or arguments. All perspectives are being considered alongside legal and ethical issues, and the principles of the Human Assisted Reproductive Technologies Act, as ACART progresses with developing an updated guideline on posthumous reproduction.

A second phase of consultation will occur when the revised draft guideline has been developed.

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

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



Dr Kathleen Logan

Acting Chair, Advisory Committee on Assisted Reproductive Technology

March 2019

Posthumous reproduction stage one consultation submissions analysis

Submissions received by hard copy or email

- Betty-Ann Kelly
- Debbie Blake
- Debbie Terei
- Fertility Associates
- Family Planning
- Fertility Plus: clinic submission
- John France
- Health and Disability Commissioner
- Hilary Stace (silent on publishing and personal details)
- InterChurch Bioethics Council: Joy McIntosh
- Ken Orr: Right to Life
- Ministry of Justice (email only)
- New Zealand Nurses Organisation
- Office of the Chief Coroner: Judge D Marshal
- Oranga Tamariki Head Office: Paula Attrill
- Peter Le Cren (on behalf of Re Lee) (silent on publishing and personal details)
- Repromed Auckland
- Te Rūnanga o Ngāi Tahu
- The Nathaniel Centre: The New Zealand Catholic Bioethics Centre

Total submissions received: 68

Most submitters used the opportunity to submit through CitizenSpace and chose to be anonymous.

Where possible, submissions received in essay or email form have been incorporated into CitizenSpace to complete the tables.

Face-to-face meetings held

- 22 August 2018 – Auckland Repromed – 1.30 pm
- 23 August 2018 – Auckland Fertility Plus – 10 am
- 23 August 2018 – Auckland Fertility Associates – 12.30 pm

Public consultation

The stage one consultation document was published on 3 July 2018 on both the Advisory Committee on Assisted Reproductive Technology (ACART) website and the Ministry of Health website for public consultation, along with a press release prepared by the Ministry's communications team. Submissions were open for eight weeks, and closed on 3 September 2018.

The Secretariat extended the consultation for another 10 days to allow for a number of further submissions to be received.

ACART is also aware that the consultation generated some media interest, which can be found here:

- <https://www.stuff.co.nz/national/health/105297367/talented-teen-filmmaker-cameron-duncan-died-of-cancer-at-17-15-years-later-he-could-become-a-father>
- <https://www.odt.co.nz/news/dunedin/posthumous-reproduction-needs-ethical-review>

How did ACART consult the public?

The consultation document was emailed to ACART's stakeholder list on 3 July 2018. This contained all fertility clinics, the Ethics Committee on Assisted Reproductive Technology (ECART), and other Government departments such as the Ministry of Justice (which administers the Human Reproductive Technology Act 2004). The list also included ACART's usual submitters, religious and ethnic groups, and medical associations – totalling approximately 300 people/groups. Stakeholders were encouraged to forward the consultation on to their networks.

Submitters could have their say by completing the Citizen Space link through ACART, or the Ministry of Health's web page, or emailing a completed feedback form or comments to acart@moh.govt.nz.

Feedback for this consultation was welcome from any individuals or groups, and the Secretariat invited fertility clinics to make contact with any of their patients that they considered as having an interest in this topic.

Because ACART did not hold open public meetings for this consultation, members included a question in the consultation document for submitters to indicate whether they would like to submit verbally. Three individuals indicated that they would like to submit verbally and the Secretariat organised a time for them to be heard via teleconference on 16 October 2018.

More comprehensive engagement with submitters will be undertaken if the stage two consultation results in draft guidelines.

Consultation with fertility clinics

Members and the Secretariat met with fertility clinics and interested groups during the consultation period. These were attended by a member of the working group and a member of the Secretariat. Clinics then submitted formally after discussing the consultation. Three meetings were held in Auckland at: Repromed, Fertility Plus, and Fertility Associates.

Consultation with young people

Children and young people make up a quarter of the population, and ACART believes that children's voices should be heard on matters that affect them. Therefore, ACART canvassed the views of young people regarding the topic of posthumous reproduction by running targeted and age-appropriate consultation questions with them.

The Centre for Science and Citizenship was commissioned by ACART to run a session with young people on 15 June 2018. Four schools, consisting of young people aged 15–18 (around 120 students) attended the session in Auckland at Maclean's College. These students had an existing relationship with the Centre for Science and Citizenship, and had attended previous sessions regarding beginning- and end-of-life issues. The day was informative and engaging, and students were very thoughtful about the issues around posthumous reproduction. At the end of the day, students could opt to fill out a survey to tell us what they think. The survey had six questions about posthumous use generally, use of embryos specifically, and posthumous retrieval and use of eggs and sperm. While the age range was narrow and the group tended to be from higher socioeconomic backgrounds, there was still a range of socioeconomic groups represented. The group included young people from many ethnicities, religious backgrounds and genders. ACART considers this engagement adequate to ensure it has heard perspectives of young people.

The range of perspectives is reported below under the section on 'Themes from the youth engagement'.

Themes from written submissions

Overall, those who shared their views with the Committee acknowledged there could be circumstances under which it was acceptable to allow posthumous retrieval and/or use of gametes, but that it is an ethically complex area with many factors to consider.

Submissions from fertility clinics and medical professionals showed that posthumous retrieval is a very rare situation.

Retrieval of both sperm and eggs should be legally treated the same

Currently, eggs and ovarian tissue are not legally allowed to be retrieved posthumously. Submitters did not see a good reason for the retrieval of sperm and the retrieval of eggs to be treated differently in law, although they recognised that retrieval of eggs would require abdominal surgery and would need to be performed in a shorter timeframe than retrieval of sperm.

Who may seek posthumous retrieval?

For questions related to authorisation of retrieval and authorisation of use, a number of individual submitters and fertility clinics expressed the view that an individual's family is unlikely to make decisions about a person's reproductive choices while they are alive, therefore there is little rationale for having the control to make a person's reproductive decisions after their death. Some people said, however, they thought the partner *and* family should be in agreement to seek posthumous retrieval of gametes, before such an invasive procedure was permitted.

Who should authorise posthumous retrieval?

ACART sent the consultation document to the Office of the Chief Coroner and the Ministry of Justice. Both submitted in response to question 2, expressing that they were not supportive of the option that coroners should be the ones to authorise the posthumous retrieval of gametes or reproductive tissue. It is their view that coroners are not the right mechanism to hear and determine authorisation to retrieve gametes. Coroners are not involved with all sudden deaths. Coroners have no existing power for posthumous retrieval, and any policy to do this would require an amendment to the Coroners Act 2006.

Grief, and a mandatory stand-down period

Seven submitters expressed support for a mandatory stand-down period before use to be built into any guidelines. Some thought this was necessary because they viewed the desire to use gametes after a partner or child's death as a product of the grief process.

Many people felt strongly that a child should not be produced to meet the desires of a surviving partner or parent that wants to be a grandparent, or to assist the grieving process in any way.

Fertility clinic counsellors also queried whether their role might be extended to assist the grieving process of the deceased person's partner or parents. Submissions relating to use of stored gametes of deceased young people (minors) indicated an unmet need for what the counsellors suggest. Storing gametes of minors after their death leaves unanswered longings of their parents, who want to use the gametes to have 'grandchildren', but are unable to currently.

Processes for fertility preservation in minors could be improved

Many of the submissions received were from parents of deceased children who had frozen sperm or eggs for the purposes of fertility preservation prior to undergoing medical treatment, such as chemotherapy. These submitters were primarily concerned that it was unethical that the rights to their children's gametes were not automatically transferred to them along with their children's other possessions.

On the best interests of children

Many people expressed the idea that the best interests of any resulting children should be the main ethical focus at all times. Oranga Tamariki reiterated ACART's own position that children should be brought up informed of their whakapapa and knowing the true circumstances of their conception. Three submitters expressed their view that posthumous reproduction is not within any resulting child's best interests.

Some submitters were concerned that the consultation document was heavily focused on the rights of those still alive and wanting to use the frozen gametes or reproductive tissue, rather than the best interests of resulting children.

On liberal individuality

Some submitters noted that the scenarios and questions outlined by ACART in the consultation document imply that reproductive decisions are a single person choice (the partner who is alive). Having the 'choice' to create another life utilising the method of

posthumous reproduction, and the principle of ‘individual rights’, come from a Western perspective and focus on the individual and not on whānau.

Choices, decisions and rights for Māori do not operate in an individualistic paradigm, but one that involves recognition of whānau, hapū and iwi relationships and potential impacts on those, including on the whakapapa line (ancestors to descendants).

Some submitters thought that posthumous reproduction is always ethically unacceptable

Six submitters indicated their view that posthumous retrieval on the whole was ethically unacceptable. Two of these submitters (Right to Life and the Nathaniel Centre) had a religious opposition and expressed their view that posthumous reproduction is against God’s will, and they oppose it in all forms.

Some submitters expressed their view that it was ethically unacceptable to deliberately bring a child into the world where one parent is deceased and they will never have a chance to know them. This was referred to as ‘fatherlessness by design’ – but is not just limited to situations where it is the father who is deceased.

On ‘using’ posthumous material

There was a theme among fertility clinics and service providers that if the posthumous retrieval of gametes is permitted, it should be with the understanding that decisions and authority over the use of the gametes is a separate process. Fertility clinics noted they were concerned about being the gatekeepers where retrieval was acceptable, but use was not.

Some submitters thought that the term ‘specific use’ needed to be explicitly defined in any future guidelines so there is no uncertainty between clinics and decision makers.

The use of the term ‘donor’

ACART’s question 8 referred to the deceased individual as ‘the donor’, and this confused a few people.

‘The questions above include reference to “the donor”. I assume the reference is meant to apply to the deceased person, who cannot be described as a donor. The HART Order (s.3) says that donated sperm and donated eggs means sperm and eggs contributed by the spouse or partner of the patient. I recognise that it is arguable whether a person continues to be a partner after death, but the surviving partner’s interest in the stored gametes or embryos is from the perspective of a partnership where the two people hoped to be joint parents of a resulting child.’ (Submitter’s response to question 8)

The use of the term 'partner'

There was a lot of discussion about what constitutes a partner, which loved ones should have authority to make decisions, and many different views about who has a legitimate interest in retrieval and use.

Themes from the verbal engagement

The wishes of the deceased should be upheld

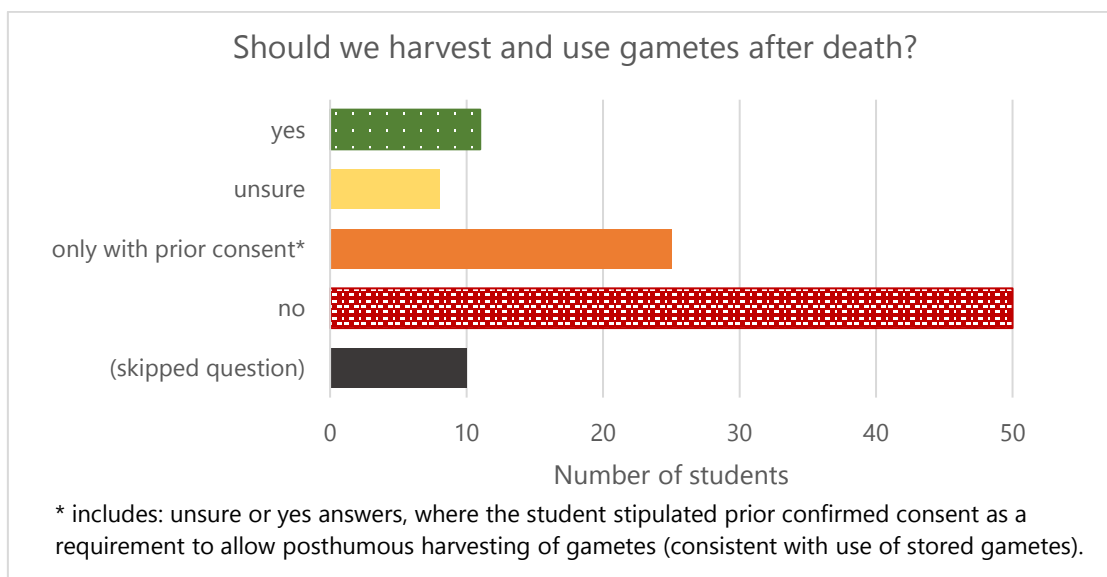
There was a strong theme by families of deceased people that if someone makes the decision to preserve their fertility or store gametes, it implies the deceased would have wanted others to use it.

Themes from the youth engagement

Overarching finding

In general, the majority of the 104 students who participated in the engagement had significant concerns about posthumous reproduction.

Fifty of ninety-five students who answered a question about posthumous retrieval thought it was ethically unacceptable (53%). Only 12% said it should be allowed (just under one in every eight young people – see the green bar in the graph below). 17% were unsure, and 19% said it *could* be ethical only with prior informed, written (provable) consent, which is generally unlikely. 9% didn't answer this question.



Students showed a strong preference for someone's right to be able to consent to what happens to them after death. There was significant discussion about promoting a mechanism (eg, declaration on a driver licence) to indicate whether one is willing for gametes to be extracted posthumously. This idea was raised by several people in the survey responses.

Who should authorise collection

Young people were not specifically asked about who should authorise posthumous retrieval, but some answers in relation to what 'conditions should be met' for posthumous use of gametes harvested after death included that it should be like organ donation, that both partner and parents should agree, and that parents and the partner of the deceased know the deceased best, and what they would have wanted, and so should be able to decide.

Reasons to allow posthumous retrieval of gametes

Only 11 young people expressed the view that posthumous retrieval was acceptable. Reasons given were: 'when you're dead you're dead', 'the dead won't know', 'if there's inferred consent', 'it's their choice [of family or partner] if deceased didn't state preference' and 'wishes of the living are more valuable than the dead'.

'The rights of the deceased should not trump the desires of the living. ... If no-one living will be negatively affected then there is no reason to not do it for the sake of a dead person.' (16-year-old male)

One person suggested the mechanism could be ‘follow the same rules as organ donation. Gametes should not be treated differently to other cells in our body.’ Another person said if the deceased had not indicated their objection, then it should be the choice of relatives of the deceased what they do with his or her body.

‘I believe that respect for the dead is up to the family and/or the partner so I believe they should have the right to have [the] sperm harvested and used as that would be how they deem they should honour the dead person.’ (17-year-old male)

Reasons given to not allow posthumous retrieval of gametes

Most young people said that unless there was prior explicit, written consent from the deceased, it is unethical to take their gametes.

Many said it was a violation of the deceased. They used terms such as selfish, disrespectful, unethical, immoral, unacceptable, strips away dignity, violating to harvest a person’s DNA, against nature, unnatural – death is end of life, seems wrong, deceased are not ‘property’, no choice by deceased, no right of others to take that choice (away from the deceased), it’s not another person’s decision, entering body of deceased is violation, a dead body is tapu, and somewhere a line must be drawn.

‘It shouldn’t be the choice of the family or partner to decide if the deceased create a child or potential child.’ (16-year-old female)

They also pointed to impacts on children: ‘...there will only be unnecessary consequences imposed on the child’ and ‘I don’t think that it’s fair on the child’.

Some young people opposed *all* forms of posthumous reproduction (including use of embryos after death of one partner) for other reasons such as impacts on the child, on the deceased’s body, and because it represents an unhealthy mindset.

‘The practice... disrespects the [deceased’s] existence as an individual (with dignity) and treating the body as just a resource. The body is the vessel for one’s existence, and therefore is sacred, and should not be tampered with, unless specifically instructed to.’ (17-year-old male)

This young person also said that preservation of an embryo after death of one or both contributing parties is pointless. ‘Having a child is a product of two people’s intimacy and a representation of the companionship and love of two individuals. However, after the death of one or both individuals, there is no more meaning in having that embryo become a child.’

He says preservation of the memory of the deceased (through having their child) is an unhealthy mindset (see below under 'Grieving').

Those who were unsure...

Students who were unsure noted that different people have different beliefs, and many struggled with the notion that it was okay 'only with prior written consent' – but realised that was unlikely.

Concept of continual consent

Many said you can't speak on behalf of the dead; the deceased has no chance to say whether they would want their gametes used after their death. During discussion people mentioned that someone could discuss having children in life, but that wasn't the same as being willing to have them after their death. The concept of 'continual consent' was also discussed, and it was clear young people understood that taking gametes from the deceased was a violation of their ability to give informed consent, and that they can't withdraw consent at that point.

'It is, in a sense, unethical to put a person's body through that in order to force them to genetically "parent" a baby when they have already passed on.... unless the deceased person sees to it that their own child is born, they may always change their mind about the process without having expressed so legally. ... It strips away their dignity and they have no say.' (18-year-old female)

Posthumous use of stored gametes

In the case of posthumous use of gametes that were stored, some young people said it is not acceptable to use them after their death, because the eggs or sperm were 'for their personal use', and 'the sperm were stored in the hope/faith of the individual having a child in the future' (17-year-old female).

[This is a valuable perspective to inform policy on posthumous use of gametes collected from minors before they undergo fertility-damaging treatments.]

In contrast, a few people noted the utility of stored gametes, saying if the partner doesn't want them, they can be donated, or that they are useful for research.

Other perspectives expressed included: "shouldn't use gametes posthumously it's against nature"; "if you need a surrogate it's a complication"; "concerns for child"; "embryos are precious" – "can't be used by another; it's ungodly". Many couldn't see the use, thinking it is pointless: it's an unhealthy option to not move on when someone dies, and having

material in storage prevents the family from moving on. One said there are already too many people in the world, and there are other options for family creation.

One said that if using gametes posthumously, then there needed to be explicit proof of consent about who may use the eggs, including a named surrogate and father. They saw a deceased person as an individual not a resource.

Some students expressed concern that a person who is dead would have no say in whether their genetic material is passed down to offspring.

'Forcing a person after they are dead to be a parent is unethical.' (18-year-old female)

Potential conditions of use of gametes or embryos posthumously

The kinds of suggestions people made about potential conditions of use were mainly about the wellbeing of the intending parent and the child. One suggestion was testing first for potential conditions harmful to the child. Many said that users should undergo counselling.

Some indicated there should be ethical review case by case looking at whether the partner's motives are 'sound and moral', their mental health, finances (eg, financial tests to show someone can raise the child, presuming they will be a sole parent), whether the child will have a loving home ('vetting' parents), and whether the parent can look after the child or whether 'they can commit to raising a child'. One said posthumous use of eggs should only be with a social mother – ie, there should be no sole parents for the sake of the child. Another said that opinions of family members of the deceased need to be considered. A few suggested requiring a gap of one year after death before use.

Some said embryos or gametes could be used for research, as they are valuable. Others who disagreed with posthumous retrieval did consider posthumous use to be acceptable because of the 'utility' of gametes stored before death (but they still demanded clear consent by the person stating what should happen to the gametes or embryo if they die).

Interestingly, the majority of those who thought posthumous *retrieval* was acceptable, even without consent of the deceased, were still insistent that posthumous *use* of gametes stored when someone was alive should utterly depend on informed, written consent.

The notion of informed consent was very strong among this group of young people.

Impacts on children

Some the young people involved in the youth engagement agreed that it is not in a child's best interest to be born from posthumous reproduction. One said it would denigrate the child

and have negative impacts on their sense of identity and personality, and could ‘shatter their image’ if they were treated like something ‘of’ the deceased person.

‘It is anything but ethical. ... using [gametes] posthumously is really treating and seeing a child as a memento.’ (18-year-old male)

One said sole parents should not be allowed to create children from deceased person’s gametes, because of the welfare implications for the child. Others said the child bore the consequences. For posthumous use of embryos (where both partners had died) one said only with written consent and the child’s parents should be identified in advance. For example, one young person said they only supported the use of stored gametes posthumously when consent was given in writing, stating precisely what they wanted done with the gametes if they die, and that they should *not* be able to leave it to a named family member to decide, as that could lead to further complications such as the welfare of the child, who would be the other contributing gamete donor and who would look after the child.

Many said you should not have children to be a ‘memory’ or legacy, while one person thought having a child was a good chance for someone to have a legacy if their life was unexpectedly cut short.

One said that if the child is for legacy reasons (maintaining a genetic lineage), expectations will negatively impact the child’s wellbeing, possibly due to restriction of freedoms, and the child becomes merely a ‘tool for the family’s aspirations’.

Some young people said that use of gametes should depend on whether the child would have a loving, supportive environment. One said, in respect of use of eggs posthumously:

‘Only if the surrogate mother would be willing to be the social mother of the child ... or else it would be difficult for a child to be brought up alone.’ (17-year-old female)

... and in respect of use of sperm posthumously:

‘The mental and emotional health ... and financial situation of the mother should be checked to ensure she can bring up a child.’ (17-year-old female)

Grieving

Similar to other submissions, many young people said that people should have to undergo counselling to ensure they were ‘of sound mind’ before being allowed to use gametes posthumously. Some said ‘when you’re dead you’re dead’ and people should go through the grieving process and ‘move on’, and that harvesting gametes or having them in storage just aggravated the grieving process. As mentioned, a grieving period was recommended.

'Not let [it] be used during the grieving period.' (16-year-old female)

'It is unhealthy to keep a part of the partner [after death] – it does not help with their grieving.' (16-year-old female)

High level analysis of ACART's stage one consultation on posthumous reproduction¹

ACART's stage one consultation received a total of 68 submissions via CitizenSpace or by post or email. Some submitters did not fill out the survey but sent an email or letter. Six submitters indicated on the feedback form that they would like to submit verbally to the Committee, and three subsequently chose to make verbal submissions.

Consultation questions 1a and 1b

Do you agree that posthumous retrieval of sperm, eggs or ovarian tissue should only be permitted with the prior **written** consent of the deceased from whom the gametes are to be retrieved?

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of sperm, eggs or ovarian tissue should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that retrieval is consistent with the deceased's wishes, feelings and beliefs prior to death? (inferred consent)
- there is no evidence of consent from the deceased, but there is no reason to think retrieval is inconsistent with the deceased's wishes, feelings and beliefs prior to death? (no consent but no objection)

Submitters generally favour taking sperm or eggs after death if there is some evidence of consent.

In the unlikely event that someone has given written consent before their death then this should be followed. Many people also thought that because of the unexpected nature of the 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, such as discontinuing contraception, or conversations with family or partner.

¹ Where a percentage has been used, this has originated from data that includes people who submitted through CitizenSpace or who filled out a hard copy questionnaire that was able to be added to CitizenSpace.

Meetings with fertility clinics supported the view that even though written consent is their gold standard, in situations of posthumous retrieval or use, written consent does not exist. They thought that evidence of verbal consent could be ethically acceptable. If the stage two consultation resulted in draft guidelines, these would need to be very clear about what constitutes consent.

Most submitters felt that there should be no difference in rights between retrieving gametes from male or females after death (given that they are currently treated differently in law).

Seventy-three percent of submitters strongly agree or agree that posthumous retrieval of sperm, eggs or reproductive tissue should be permitted where there is evidence of verbal consent.

Opinions were split when it came to the acceptability of posthumous retrieval of sperm with evidence of inferred consent – 60% thought it was ethically acceptable and 35% thought it was not. The results were similar for the acceptability of posthumous retrieval of eggs or reproductive tissue with evidence of inferred consent – 48% thought it was ethically acceptable and 38% thought it was not.

On the question of whether the retrieval of gametes is ethically acceptable where there is no consent but no objection, submitters' answers were similar for both question 1a (the retrieval of sperm) and question 1b (the retrieval of eggs).

Consultation question 2

Who should **authorise** the retrieval of gametes or reproductive tissue?

- The deceased's partner
- A close relative of the deceased
- A nominee of the deceased
- ECART
- A coroner (where an individual is recently deceased)
- The Family Court
- The High Court

Should joint authorisation be required?

Four people indicated that it is ethically unacceptable for anyone to authorise retrieval from a deceased person unless there is prior consent.

Regarding who should authorise the retrieval of gametes or reproductive tissue, submitters rated their most to least preferred options as follows:

1. The deceased's partner

2. A close relative of the deceased
3. A nominee of the deceased
4. ECART
5. A coroner
6. The Family Court
7. The High Court.

The submissions show the most supported option for authorisation of retrieval is the partner of the deceased, ideally in conjunction with the wishes of the family, so that any resulting children are able to have a relationship with their whakapapa. This view is shown by the comments – however, the Likert scales show that the majority of submitters disagree with joint authorisation.

Many submitters were more comfortable for a partner (if there is one) to authorise retrieval than they were for family to authorise retrieval.

Submitters indicated that where the person is a minor or had no partner, decision making about retrieval could fall to the family. Many people, including fertility clinics, expressed concern about the family as decision makers, noting that family do not make reproductive choices for their children while alive. Submitters also expressed concern about the family's desire for a replacement to assist the grieving process, which is a narrative referred to by families who had material stored.

There was very little support for authorisation of retrieval by ECART, the Coroner, the Family Court or the High Court. Submitter's rationale for this was that these agencies are not best placed to know the wishes of the individual.

There was a lot of discussion about what constitutes a partner, which loved ones should make decisions, and many views about who had a legitimate interest in retrieval and use.

Consultation question 3

Should others be able to approve retrieval of gametes from a permanently incapacitated person whose death is imminent, in the absence of prior consent by the person?

Opinions were almost exactly split down the middle on the question of whether others should be able to approve the retrieval of gametes from a permanently incapacitated person who has not previously consented.

Those who thought that others should have the right to approve the posthumous retrieval wanted it to be limited to immediate family or a legal partner where a nominee is not specified.

Many submitters (approximately half) took the opportunity to express their views that retrieval without consent is ethically unacceptable.

There was a bit of confusion about why parents are able to approve the retrieval of organs from their children but are not able to consent to the retrieval of their gametes. ACART could explain their rationale for why they think it is different in their final advice.

Consultation question 4

Do you agree that posthumous use of gametes taken or embryos created when the deceased was alive and competent should only be permitted with the **written** consent of the deceased?

If you do not think explicit written consent is always required, do you agree that posthumous use of gametes or embryos should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that use is consistent with his or her wishes, feelings and beliefs prior to death? (inferred consent)
- there is no evidence of consent from the deceased, but there is no reason to think use is inconsistent with their wishes, feelings and beliefs prior to death? (no consent but no objection)

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 written consent option.

ACART heard from a few submitters that their now deceased children (who for a number of reasons didn't give consent for their gametes to be used after their death) would want their stored gametes to be used. These submitters believed that the storage in itself signals an intent for it to be used (in any way – not just by the child when they decide to have children).

A number of people stated in this section that they believe family know what the deceased would have wanted, and to be able to use their gametes would be healing and therapeutic for them.

One submitter stated that 'any health provider offering collection and storage of gametes should be required to put in place legally robust processes that document their consent or dissent'.

Sixty percent of submitters supported posthumous use of stored gametes or embryos where there was evidence of verbal consent. As with questions 1a and 1b, it could be that

submitters did not think the requirement for written consent is workable. There was also strong support for inferred consent for this question (50%).

For females who consent to the use of their eggs after death, there should be evidence that they have considered the implications of a necessary surrogacy arrangement (if she has a male partner).

Consultation question 5

Do you agree that posthumous use of gametes or reproductive tissue taken from a **deceased** or **permanently incapacitated person** should only be permitted with the **written** consent of the deceased?

If you do not think explicit written consent is always required, do you agree that posthumous use should be permitted **without written** consent from the deceased where:

- there is evidence that the deceased gave verbal consent?
- there is no evidence of consent from the deceased, but there is evidence that use is consistent with his or her wishes, feelings, and beliefs prior to death? (inferred consent)
- there is no evidence of consent from the deceased, but there is no reason to think use is inconsistent with his or her wishes, feelings, and beliefs prior to death? (no consent but no objection)

Most people were uncomfortable with only written consent as a requirement and felt strongly that other types of consent could be considered also.

Again, the majority were comfortable for posthumous use where there was evidence of verbal consent (69%) or if there was evidence of inferred consent (57%).

Submitters were not supportive of the option for posthumous use where there was no consent but no objection (33% agree and 62% disagree).

One submitter suggested that consent regarding use should meet a higher test than has been met at the time of retrieval – especially if consent at the time of retrieval was less than clear.

Consultation question 6

Who should authorise the posthumous use of gametes, tissue or embryos?

- The deceased's partner

- A close relative of the deceased
- A nominee of the deceased
- ECART
- The Family Court
- The High Court

Should joint authorisation be required?

Submitters were supportive (in the following order) of authorisation of use by the deceased's partner, a nominee, a close relative, or ECART, but less supportive of the Family Court and the High Court.

There was a very strong theme in the comments that outside parties (eg, anyone who isn't a partner, close family member or nominee) are not placed to make a decision about an individual's reproductive choices. There seemed to be a shared view that ECART or the Family or High Courts should only be involved where an agreement cannot be reached.

Fertility clinics support authorisation for use by ECART as the body to review and authorise. Fertility clinics also support joint authorisation between a partner or close relative and/or nominee for retrieval and use.

Consultation question 7

Who should be permitted to use reproductive material from a deceased person?

- The deceased's partner only
- Family members of the deceased as well as the deceased's partner
- Anybody

Submitters' answers were mixed for the first question of only the partner of the deceased being able to use the reproductive material – 35% strongly agree or agree, 15% ambivalent, 39% disagree or strongly disagree. Those who disagree could be a mix of those do not support posthumous reproduction in any form and those who agree that a deceased person's reproductive material should be able to be used by their partner – but could perhaps be used by a sibling or cousin also.

Fifty-two percent of submitters strongly agreed or agreed that posthumous reproductive material should be able to be used by a family member and/or a partner. Some submitters noted they chose this option for people that did not have a partner.

Only 5% of submitters supported the option of posthumous reproductive material to be used by anybody.

Many people did not understand what was meant by ‘anybody’. No submitter supported this option unless there was prior consent from the gamete provider that they were comfortable donating to ‘anybody’.

Interestingly, many people thought that family should be able to decide, as it was stated that the family knows the person best.

A number of people gave the argument that when a loved one dies, those left behind grieve for not just their life but what could have been their children and grandchildren, and concluded that allowing their life to continue would make it easier for grieving families.

Some people stated that in some circumstances – for example, where a close friend or family member was unable to have their own children – it could be acceptable for them to use the gametes of the deceased person, if it can be agreed among parties that this is what they would have wanted.

Fertility clinics generally supported use by the deceased partner or family with ethics review, and do not support the option of gametes or reproductive tissue being able to be used by ‘anybody’.

Consultation question 8

Should all posthumous use of gametes or embryos be subject to ethics review?

Are there situations in which ethics review should not be required, such as where the person’s partner wishes to use the gametes or embryos?

Interestingly, submitters did not support a requirement that all posthumous use of gametes and embryos be subject to ethics review (46%), but they also did not feel that posthumous use should never be subject to ethics review (60%). It seems as though submitters are looking for a medium of oversight/approval, or a model that is dependent on the situation.

For example, the majority of submitters agreed that ethics review should not be required if the donor’s partner wishes to use the gametes to create a full genetic sibling for an existing child (54%). The existence of a child appeared to have more weight than if the donor’s partner wished to use the gametes to create their first child (36% agree, 29% disagree) – but the results to this were very mixed. The comments section might explain why there was no clear answer for ethics review if the donor’s partner wishes to use the reproductive material.

The majority of submitters agreed that posthumous use should require ethics review if a third party wishes to use them (55%).

There was a bit of confusion about whether ACART intended family to be included in the last option of 'a third party'. A significant number of submitters found this phrase distasteful.

As with all other answers, there was a consensus among submitters that if the deceased's wishes have been written down in a legally recognised document, this takes first priority.

ACART's scenario in the consultation document referred to the deceased individual as 'the donor' and this confused a few people.

Consultation question 9

Considering your responses to the previous questions, would your responses be different if the deceased was a minor?

Should the retrieval or use of gametes from a deceased minor under the age of 16 ever be ethically or legally acceptable?

Should it ever be permissible to use gametes collected from a minor during the minor's lifetime after the minor's death?

Is your answer different if the minors in question are 'mature minors'?

Should the provisions in s 12 of the HART Act apply when the individual concerned is deceased?

Section 12 of the Human Assisted Reproductive Technology (HART) Act 2004 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 the 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.

Most people disagreed or strongly disagreed (67%) that it should be permissible to retrieve and use gametes from a deceased minor, but opinions were about even on whether it should be permissible to use gametes collected while the minor was alive and competent, after their death.

Forty-nine percent of submitters disagreed that the provisions in s 12 should apply to mature minors.

A few people asked for classification of what a mature minor is, and who decides?

Some submitters and clinics also queried the practice of fertility preservation in minors before undergoing treatment, if it is the case that they can't be used after their death.

If the minor had given competent consent to specific uses of the gametes before their death, then most people agreed that this should be honoured.

A number of people believed that minors should be protected from having their gametes retrieved posthumously, and where they have not given consent. Repromed stated that this should still be the case for minors who are judged to be 'mature'.

Consultation question 10

Should ACART consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future?

There was agreement (63%) that ACART should consider the need to regulate posthumous retrieval from permanently incapacitated donors in the future. Five percent strongly disagreed.

Submitters who provided comments did not provide suggestions to ACART about how retrieval from this group could be regulated. Rather, it was recognised that the current regulatory framework has gaps and inconsistencies, and that decision makers need clear guidelines or regulation to point to in the event that a request for retrieval – from someone who is permanently incapacitated but whose death is not imminent – is made.