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29 August 2018

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Kia ora

Thank you for the opportunity to provide comment on the issue of posthumous reproduction. In lieu of providing answers to each of the consultation questions, Family Planning will focus our comments on the broad issues of informed consent and the evolving capacity of young people.

Family Planning is the largest provider of sexual and reproductive health services in New Zealand. We are a stakeholder in this conversation because of our commitment to promoting sexual and reproductive health and rights of all people. We believe that reproductive rights – the right to freely decide if and when to have a child - includes the use of gametes and embryos.

As explained in the consultation document, the original guidelines for posthumous reproduction only address the *Storage, Use, and Disposal of Sperm from a Deceased Man*. We agree with the Advisory Committee on Assisted Reproductive Technology (ACART) that the scope of the revised guidelines should be expanded. The guidelines should also include the retrieval of sperm, the retrieval and use of eggs and reproductive tissue from someone deceased or a person who is permanently incapacitated and death is imminent, and the use of stored eggs and embryos.

ACART may want to consider using person instead of man or woman throughout the document so it is inclusive of transgender and gender diverse people. For example, sperm may come from someone whose biological sex is male, but the person identifies as a woman.

Informed consent

Reproductive rights are described in the Programme of Action adopted at the International Conference on Population and Development (ICPD) in 1994. The Programme of Action was agreed by 179 countries, including New Zealand.

> *"These [reproductive] rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so...." –ICPD Programme of Action, paragraph 7.3.*

In other words, reproductive rights relate to an individual's autonomy over decisions about if and when to reproduce. Once a person is deceased, or incapacitated, they no longer have the ability to make decisions about reproduction. In the absence of explicit consent to reproduce posthumously, Family Planning believes it is unjust and counter to current understanding of reproductive rights and autonomy to authorise reproduction on another person's behalf.

Family Planning believes that posthumous reproduction should only occur when written informed consent for the specific use of sperm, eggs, embryos and/or reproductive tissue has been obtained prior to a person dying or becoming incapacitated.

Specific use should be clearly defined in regulation and guidelines so there is no uncertainty for decision makers – including health providers and the courts. A person must describe exactly who could use their gametes or embryos to reproduce, within what timeframe, and whether they could be retrieved posthumously if they aren't already stored. The same approach should apply regardless of the reproductive material – eggs, sperm, embryos and reproductive tissue. Reproductive rights apply to all people, regardless of sex or gender.

Explicit written consent is important for a number of reasons. A person's views about reproduction are not necessarily fixed. A person who would like their gametes or embryos to be used by their partner in the event of their death when they are 20 or 30 years old, may feel differently when they are 40 or 50 years old. It is essential that a timeframe for use is made clear when consent is obtained.

Privacy may be another important consideration as reproductive decisions are private and personal – sometimes even between partners. For example, unless requested through a court order, Family Planning would not release information about a person – alive or deceased - having an abortion, even to a partner or other family member. A surviving partner may not

know if their partner has made a decision to end a pregnancy, nor do they have any legal right to have this information.

In our view, an approach where informed consent is paramount would be consistent with current law and guidelines, including the principles of the HART Act which states: "no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent."[1] The current guidelines on *Storage, Use, and Disposal of Sperm from a Deceased Man* state "the retrieval of sperm from a recently deceased or comatose person without that person's prior written consent is ethically unacceptable."[2] There do not appear to be sufficient benefits of posthumous reproduction to individuals and society to override informed consent in new guidelines.

It appears that the approach taken by most Western jurisdictions[3] is to require explicit informed consent for posthumous reproduction. The European Society of Human Reproduction and Embryology (ESHRE) states that written consent from the deceased is a condition that needs to be met in order for posthumous reproduction to take place.[4] While Australian laws vary by state, and some states do not specifically address posthumous reproduction, where they do, the majority appear to require written informed consent.[5]

While the Ethics Committee of the American Society for Reproductive Medicine (ASRM) takes a slightly broader approach, the Committee still states that informed consent should be a requirement in most situations:[6]

> *"Posthumous gamete (sperm or oocyte) retrieval or use for reproductive purposes is ethically justifiable if written documentation from the deceased authorizing the procedure is available."*

While the Committee opinion also leaves room for health providers to consider the use of gametes and embryos without express written consent, if allowed by local law, the Committee notes:

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[1] HART Act, s 4(d). Retrieved from: file:///C:/Users/Amyb/Downloads/Human%20Assisted%20Reproductive%20Technology%20Act%202004.pdf
[2] Posthumous Reproduction consultation paper, pg. 9.
[3] Kroon, F (2016) Presuming consent in the ethics of posthumous sperm procurement and conception. *Reproductive Biomedicine and Society*. May. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6001348/
[4] ESHRE Task Force on Ethics and Law 11: Posthumous assisted reproduction (2006) Retrieved from: file:///C:/Users/Amyb/Downloads/Task%20Force%2011%20(1).pdf
[5] Health Law Central: http://www.healthlawcentral.com/assistedreproduction/post-humous-use-gametes/.
[6] ASRM Committee Opinion (2018) Retrieved from: https://www.asrm.org/globalassets/asrm/asrm-content/news-and-publications/ethics-committee-opinions/posthumous_retrieval_and_use_of_gametes_or_embryos.pdf.

"Moreover, the Committee discourages posthumous assisted reproduction unless there is clear evidence that it would have comported with the decedent's wishes."

The views of the partner or family of the deceased person should not be used as a proxy for consent from the deceased person. As stated previously, with regard to reproductive decisions, an individual's feelings are fluid, and may be distinct and unknown to even a partner or family.

Evolving capacity of young people

The issue of posthumous reproduction involving the sperm or eggs of a minor is raised in the consultation document.

The document states:

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 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.

This law is not consistent with accepted legal interpretations of young people's right to provide informed consent for health care.

Where a young person is under 16 years of age, the Health and Disability Commission states: "the general view, then, is that a child may consent themselves if and when the child achieves sufficient understanding and maturity to understand fully what is proposed."[7] This opinion is based on the understanding that young people have "evolving capacity,"[8] which does not necessarily align with a specific age. This was the conclusion of a 1985 court case before the House of Lords, *Gillick v West Norfolk and Wisbech Area Health Authority*, upon which New Zealand bases its legal interpretation of young people's right to provide informed consent to health care, including sexual and reproductive health care services.

It is important that new guidelines align with current understanding of a young person's right to provide informed consent for health care. It is accepted practice that a young person who is capable of providing informed consent, can manage all aspects of their health care.

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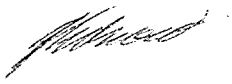
[7] Health and Disability Commissioner (2014). Fact Sheet 3: The Age of Consent and Informed Consent for Children. Retrieved from: http://www.hdc.org.nz/media/266086/fact%20sheet%203%20-%20the%20age%20of%20consent%20and%20informed%20consent%20for%20children.pdf.

[8] Lansdown, G. (2005) *The Evolving Capacities of the Child.* United Nations Children's Fund (UNICEF) and Save the Children Sweden. Retrieved from: http://www.unicef-irc.org/publications/pdf/evolving-eng.pdf.

In summary, Family Planning believes that it is important to expand the scope of current guidelines related to posthumous reproduction. We believe that reproductive autonomy should be paramount and that posthumous reproduction – including the retrieval and use of sperm, eggs and stored embryos – should not occur without current, written informed consent of the deceased individual. The new guidelines should align with current understanding of a young person's right to provide informed consent for health care.

Thank you for the opportunity to make a submission.

Ngā mihi nui



Jackie Edmond
Chief Executive

FERTILITY associates | a better understanding

Fertility Associates
Private Bag
Remuera
Auckland

31 August 2018

ACART Secretariat
PO Box 5013
Wellington

Dear Gillian, members of the ACART and the ACART Secretariat

Thank you for the opportunity of responding to the submission on Posthumous Reproduction, and to committee members for spending time with members of our Medical Directors Meeting Group. As we discussed then, we are submitting our response in the form of principles and their corollaries, rather than answering the specific questions in the discussion document.

Since our meeting, we have shared the principles with all staff for their contribution too.

Best wishes

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Feedback form

Please provide your contact details below.

Name	Fertility Associates
If this feedback is on behalf of an organisation, please name the organisation	Fertility Associates
Please provide a brief description of the organisation (if applicable)	Fertility provider, undertaking about 75% of the fertility treatment in NZ
Address/email	Private Bag Remuera Auckland
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Fertility provider

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Principles

We have based our response on principles, which can then be applied to any situation. For simplicity, we have sometimes used the term 'material' rather than repeating 'sperm, eggs and tissue'.

1) Same approach for sperm, oocytes, ovarian tissue and testicular tissue
   - Embryos are different since they will always have been created before a person dies, and the consent before creation will ask the person or couple what they want done with embryos should one of the partner die. Current embryo donation guidelines do not allow donation after death, so the options are discarding or making them available the surviving partner.

2) Separate guidelines for retrieval and for use
   - Guidelines for seeking permission and the process for retrieving sperm, eggs or tissue from a dead or dying person should be different from those for using the stored material. A decision to retrieve will usually need to me quickly while the sperm, eggs or tissue is still potentially viable, with limited time for reflection, consideration of issues and implications, and access to counselling and advice.

3) There should be a reasonably high barrier/threshold for retrieval and use, otherwise clinics will be asked to store more material than can never be used
   - Holding material with an uncertain future can be emotionally draining for people. We have seen this when young men or women without a partner die after cancer treatment, and their parents and family are left with deciding what to do with their stored material. There are also financial costs for preparing sperm, eggs or tissue for freezing and for storage.

4) Guidelines for retrieval need to be framed with the knowledge that there will almost never be written consent, since sudden death or coma are unlikely to be foreseen.

5) The partner should be the person who decides whether to retrieve material
   - We hold this view because, following the principles below, other parties are unable to use the material.
   - There is some diversity of opinion among us whether the dead person's family should also have some say.
   - In support of the family having some say is:
     - There are different types and levels of relationship, and the term 'partner' may not imply a person with whom the dead person was planning to have children
     - Close family members may have knowledge of and insight into the dead person's wishes
   - In support of the family not having a say is:
     - Family do not have a say whether or when a couple have children when the partners are alive, so why should family have a say after a death
   - A corollary is that parents or family cannot initiate retrieval
     - When a person is alive, they can have offspring in two ways using Assisted Reproductive Technology (ART):
       - As an intending parent, either with an opposite sex partner, or using a gamete donor with their partner or as a single person, OR
       - As a gamete donor

- There are requirements (eg. covered in the NZ Fertility Standards NZS8181) which describe what must be done before a person can become a gamete donor, including counselling and giving informed consent. These cannot be met if a person is dead, and we do not think the requirements for being a donor should be weaker if a person is dead.

6) There must be a route for the tissue's use (see below)
   - A corollary is that ECART has to decide what uses are potentially permissible
     - At present the road to use for a partner can be complex.
     - For instance, a gay man cannot leave his sperm to his gay male partner, because use would either require insemination of a woman, in which case the dead person would have had to become a donor, or IVF surrogacy. But surrogacy guidelines do not allow a single person to undertake surrogacy unless he or she is providing a gamete, so the surviving gay male partner cannot become an intending parent in IVF surrogacy.

7) Who can authorise retrieval will be determined by law, and we understand that this currently requires a injunction.
   - It would be sensible if a coroner could authorise retrieval from a dead person, since a coroner is already involved in sudden deaths, and would be required to remove tissue.
   - The clinician responsible for a comatose person could authorise retrieval in that scenario. However, we think this scenario would be seldom necessary (see below).

8) It is preferable that tissue be retrieved after the person has died, rather than while alive but in a terminal state
   - Sperm will be viable and testicular tissue will hold viable sperm for 24-48 h. Temperatures of 4-25'C are beneficial. Hence, retrieval while the man is alive is not needed.
   - Ovarian tissue, and the oocyte within, are likely to be viable for 12 h if the body is not chilled, considering the recovery of ovaries from ovarian torsion, and the ability to retrieve viable oocytes from animals after death. When ovarian tissue is removed before cancer treatment, tissue processing often takes several hours at room temperature and this does not reduce the viability of the tissue. Removal as soon as possible after death would be a precautionary advantage.

9) Normally only a partner should be able to use material
   - There may be occasional exceptions – we know ECART has considered and given provisional approval for a sister to use stored sperm with her female partner after a young man's death, where he had not consented to this in writing.

10) The partner must intend to be a legal parent of any child resulting from use of the material in ART

11) If consent for use after death was made in writing, ECART approval for use is not required
   - This is the situation now
   - People in this situation will nearly always be partners of men and women who stored sperm or eggs or ovarian tissue before cancer treatment, and specified that their partner could use their material should they die.

12) If a use is not permitted or possible when the person was alive, it should not be permitted when the person is dead

- For instance, parents of the dead person should not be able to retrieve or use tissue with intention of having a grandchild. Parents cannot use ART to commission grandchildren now using sperm or eggs donated by their living son or daughter.
- This is a practical issue, since several parents have asked that their son's sperm or daughter's eggs be made available to a family friend so that the parent(s) may have grandchildren.

13) If there is no written consent for use after death, then a request for use should be considered by ECART
    - It is important that the forum for considering use has expertise in ethics and ART
    - It is important that all decisions are made by the same body to build expertise and for consistency, at least until it can create detailed guidelines based on practical experience and real cases
    - There is some diversity of opinion on whether, or to what extent, the family should be involved in contributing to decision-making, as covered in principle 5.

14) A stand-down period for use should be considered in each case but not be mandatory
    - A stand-down period can be beneficial because sometimes the surviving partner will make a different decision after a period of grieving and reflection
    - On the other hand, for older women, a delay may reduce the chance of success using ART due to the woman's age

15) If there is no route for use, then the material should be disposed of after a period.
    - This scenario arises from tissue stored before cancer treatment
    - Family members sometimes find it hard to 'let go' even when there is no route for use, so guidelines for disposal would be helpful

16) Consent trumps a will, and ECART trumps an executor's wishes
    - When there is stored material, it should not be considered 'property' under the control of the executor
    - This is a practical issue. We have had cases where a mother disapproves of her dead son's partner and has wished to dispose of stored sperm so the partner could not have her son's child.

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation	
Please provide a brief description of the organisation (if applicable)	
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Retired senior policy analyst, supported ACART for 8 years

Are you:

☐ Male x Female

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

☐ Yes x 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
x 65–74 years	☐ 75+ years	

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Summary of my current views:

- The current work is needed because of substantial gaps, inconsistencies and uncertainties in the regulatory framework.
- The gametes and embryos of vegetative and deceased individuals should not be treated as resources for the use of others. The posthumous use of reproductive material differs from organ donation in that the use may result in a child, with various legal and relationship consequences.
- The only justification for the retrieval and use of such gametes and embryos is to continue a parental project where the partners made an informed decision to consent to use in the case of the death of a partner.
- Ideally, consent should be in a written form, though evidence of verbal consent may be satisfactory. Because the timeframe for retrieval is brief, the test for informed consent may be less stringent than for any subsequent use.
- Retrieval and subsequent use are separate decisions.
- Applications for retrieval and use should be made by partners only.
- The authority to make decisions (where procedures are not established procedures) should lie with an appropriate disinterested accountable statutory body.
- Posthumous use of donated gametes held by clinics needs to be considered as part of this project.

I look forward to ACART's consultation on specific proposals.

Consultation Question 1a

Do you agree that posthumous retrieval of sperm 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 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of sperm should be permitted:					
only when there is written consent	X	2	3	4	5
when there is evidence of verbal consent	1	X	3	4	5
when there is evidence of inferred consent	1	2	3	4	X
when there is no consent but no objection	1	2	3	4	X

Please add comments about your response if you wish.

I understand that in law verbal as well as written consent may be valid. The act of interfering with a body, where the intrusion is not lawfully required (eg an autopsy), is very significant, and therefore ideally should be done only if the consent is positive and unambiguous.

However, the timeframe for retrieval is short, and confirmation of the consent may not be possible in the timeframe, though there should be good reason to believe that the deceased individual had consented. If retrieval is permitted, it should be with the understanding that use of the sperm is a separate decision.

Consultation Question 1b

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

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of eggs or ovarian tissue should be permitted:					
only when there is written consent	X	2	3	4	5
when there is evidence of verbal consent	1	X	3	4	5
when there is evidence of inferred consent	1	2	3	4	X
when there is no consent but no objection	1	2	3	4	X

Please add comments about your response if you wish.

My response to this question is the same as to 1a. An additional factor in this scenario is that any subsequent use of the eggs or the ovarian tissue would require a surrogate or a new partner to gestate the pregnancy. However, unless future policy precluded such use, I think a common policy should cover the retrieval of eggs, sperm and ovarian tissue.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Gamete or reproductive tissue retrieval should be <u>authorised</u> by:					
the partner of the deceased	1	2	3	4	X
a close relative	1	2	3	4	X
a nominee	1	2	3	4	X
ECART	1	2	**X**	4	5
a coroner (where an individual is recently deceased)	1	**X**	3	4	5
the Family Court	1	**X**	3	4	5
the High Court	1	**X**	3	4	5
Joint authorisation should be required	1	2	3	4	**X**

Please add comments about your response if you wish.

There are two aspects to this issue: who ahould be able to request retrieval, and who or what should decide a request for retrieval. My responses above address the matter of authority to decide a request.

Request for retrieval

A partner of the deceased arguably has the only justifiable interest in requesting retrieval, though the request might certainly be informed by family/whanau discussion. Any anticipated parental project by the partner and the deceased person would have been between them. If both partners were alive, other family members or friends would not have had the right to be part of their family creation plans, including overriding any decisions *not* to have children.

If a deceased person did not have a partner, retrieval should not take place. Retrieval in this case would be treating the gametes as a spare resource.

Authority to make decision

The authority to make the decision about retrieval should rest with a disinterested statutory body that is accountable. I have no strong views about what body should make the decision, though agree that ECART may not be in the best position to convene members at short notice to make a quick decision. However, ECART has the advantage of being the statutory ethics committee for assistted reproductive technology, and therefore an authority on the ethical implications and wider legal context of decisions about assisted reproduction.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Other people should be able to approve the retrieval of gametes from a permanently incapacitated person who has not previously consented	1	2	3	4	X

Please add comments about your response if you wish.

While the person is still alive, they continue to have interests regarding their wellbeing. Retrieval of gametes in the absence of consent could not be said to contribute to their wellbeing.

While the Human Tissue Act provides for some wishes of deceased persons to be overridden by a surviving family member, public policy re organ donation is nevertheless based on an "opt in" approach (eg on a driver's license), not an "opt out" approach. This suggests that gamete retrieval should also be based on a positive decision expressed when a person had capacity.

The discussion does not appear to take into account stored donated sperm (donated eggs are more likely to be used fresh by a nominated individual, not stored in anticipation of future use by an unknown individual). There are some different issues arising with donated sperm (see below).

Use of stored gametes and embryos which are part of a parental project

Use should be able to be approved where the use is part of a parental project, and also where there is written informed consent to posthumous use: "The presence of cryopreserved gametes or embryos shows that a parental project existed, but it does not demonstrate that the deceased accepted the continuation of the project after his or her death".[1] In some cases evidence of verbal consent may be sufficient.

Kroon[2] argues that posthumous reproduction should be considered in a relational context. People have interests in potential offspring that extend beyond the death of a parent. From this perspective, informed consent is important because it ideally comes from consideration of the circumstances in which a potential child is born and raised.

In the case of stored embryos and where a female partner has died, there should be evidence that she has considered the implications of a necessary surrogacy arrangement (though in some lesbian partnerships the surviving partner may be able to gestate the embryo).

Where the use is covered by guidelines, consent would be a necessary but not sufficient reason for ECART approval. ECART's consideration would take into account all provisions in the relevant guidelines.

Specific use

The discussion document notes the lack of definition of "specific use". I concluded some years ago that at times the word "use" is less than helpful in interpreting the regulatory framework. This issue particularly arose when ACART discussed what counted as the "use" of gametes, and the point at which a donor should be able to withdraw or amend consent: creation of an in vitro embryo? Transferring an in vitro embryo to the womb of a recipient woman?

Re "specific use", I have taken it to refer to the specific procedure in which gametes or embryos are used eg surrogacy, donated eggs with donated sperm. For instance, this was the meaning in a proposal in the consultation on combined guidelines: ACART proposed that where a procedure involved the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes. However, for the sake of transparency it would be useful to have a clear definition in the Act or the Order.

Use of stored donated sperm

In many cases a clinic will not know of a donor's death, and so it is appropriate for a clinic to use donated sperm for insemination or IVF with the assumption that a donor is alive. If a clinic is advised of a donor's death, the question of consent to posthumous use is perhaps not so clear. Where a donor has specifically indicated that his sperm should not be used after his death, his decision must be honoured.

However, I suspect that in many cases sperm donors will not have made a decision about whether their stored sperm could be donated after their death. This situation may have been influenced by a provision in the Fertility Standard. The Standard in 1.11 says that donors must be informed what will happen with their gametes if they die.

ACART submissions to reviews of the Standard have noted that donors have the right to make decisions about what should happen to their gametes after their death. ACART's 2016 advice on informed consent recommended that gamete donors should continue to be allowed to place conditions on their donations, and also recommended that gamete donors should be able to withdraw or vary consent up to the point of fertilisation or insemination. The position that gamete donation is based on consent should extend to posthumous use of donated gametes.

(Continued on next page)

[1] ESHRE Task Force on Ethics and Law. 2006. "Posthumous assisted reproduction" Human Reproduction 21:12 3050-3.

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)

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of stored gametes or embryos should be permitted:					
only when there is written consent	X	2	3	4	5
when there is evidence of verbal consent	1	X	3	4	5
when there is evidence of inferred consent	1	2	3	4	X
when there is no consent but no objection	1	2	3	4	X

Please add comments about your response if you wish.

(Continued from previous page)

I am inclined to think there is justification for using donated sperm from a deceased donor where the sperm of the same donor has already been used to create children and where the clinic has no evidence that the donor did not wish his sperm to be used after his death. The parents involved (who may be in more than one family) should be able, if they wish, to use the sperm in efforts to have biological siblings to the existing child/ren. They should be informed that the donor is deceased.

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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of gametes or reproductive tissue retrieved after or near death should be permitted:					
only when there is written consent	X	2	3	4	5
when there is evidence of verbal consent	1	X	3	4	5
when there is evidence of inferred consent	1	2	3	4	X
when there is no consent but no objection	1	2	3	4	X

Please add comments about your response if you wish.

[2] Kroon F. 2016. "Presuming consent in the ethics of posthumous sperm procurement and conception". Reproductive BioMedicine and Society Online 1 123-30.

The consent re use should meet a higher test than has been met at the time of retrieval, if the consent at the time of retrieval was less than clear.

The issue of a time period between retrieval and use should be considered, either setting a mandatory minimum period, or requiring ECART to take account of the time that has passed since the retrieval.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use should be authorised by:					
the partner of the deceased	X	2	3	4	5
a close relative	1	2	3	4	X
a nominee	1	2	3	4	X
ECART	1	2	3	4	X
the Family Court	1	2	3	4	X
the High Court	1	2	3	4	X
Joint authorisation should be required	1	2	3	4	X

Please add comments about your response if you wish.

As with an earlier question, there are two aspects: who should apply to use the gametes or embryos, and who or what should make the decision re use.

An application or request for use should be by the remaining partner, though if an application is made to ECART, the application will be in the name of a responsible person at the clinic which has assisted to prepare the application and would carry out an approved procedure.

If decisions are made by ethical review, ECART should make the decision using guidelines issued by ACART.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Reproductive material should be permitted to be used by:					
the deceased's partner only	X	2	3	4	5
family members of the deceased as well as the deceased's partner	1	2	3	4	X
anybody	1	2	3	4	X

Please add comments about your response if you wish.

As noted earlier, the deceased person's partner should be the only party able to use the reproductive material. It is possible that the partner may wish to use the material with the intention of parenting a resulting child with a new partner. While such a situation would not be the same parental project as originally planned or embarked on, there may be justification for such use eg where embryos have been created and stored that would become full siblings for existing children.

I am unaware of any empirical research re outcomes for children who are created from the posthumous use of gametes and embryos, and I recognise the challenges of researching a sufficiently representative group. However, children have interests in having a positive view of the history of their creation, including knowing that a deceased parent was willing for the surviving partner to use his/her reproductive material.

The commentaries re posthumous assisted reproduction from the ASRM and ESHRE ethics groups both briefly note the risk of family members, eg grandparents, wishing to create "commemorative" children. I do not know whether this is a purely speculated risk or whether the situation arises in practice.

While my current view is that a partner should be the only person able to use the reproductive material, I can see that the use by a close family member could be a positive outcome provided that the deceased person had given specific informed consent to such use. However, I do not think that reproductive material should be treated as the property of the surviving partner to donate to anyone he/she chooses.

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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
All posthumous use of gametes and embryos should be subject to ethics review	X	2	3	4	5
Posthumous use of gametes and embryos should never be subject to ethics review	1	2	3	4	X
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them to create a full genetic sibling for an existing child	1	2	3	4	X
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them	1	2	3	4	X

Posthumous use of gametes and embryos should require ethics review if a third party wishes to use them	1	2	3	4	X

Please add comments about your response if you wish.

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.

My current view is that all posthumous use should be subject to ethical review, whether or not the particular use would require ethical review if posthumous use was not part of the circumstances. There appears to be a general international view that posthumous use is ethically complex.

However, my view might change if the regulatory framework was very tight, providing a very limited and unambiguous set of circumstances in which posthumous use was possible. In such cases, eg written consent for specific use by partners only, there may be a case for continuing to treat established procedures as established procedures regardless of the posthumous element. If the requirements were no more than a checklist, ethical review might appear to be superfluous. Clinics could, as now, ask ECART for a non-binding view on individual cases.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
The provisions in s 12 of the HART Act should apply to deceased individuals	1	2	X	4	5
It should be permissible to retrieve and use gametes from a deceased minor	1	2	3	4	X
It should be permissible to use gametes collected while the minor was alive and competent after the minor's death	1	2	3	4	X
The provisions in Section 12 of the HART Act should apply to mature minors	1	2	X	4	5

Please add comments about your response if you wish.

My responses to previous questions could be read as tantamount to reflecting aspects of s.12, because my current view is that use should be restricted to a surviving partner.

However, retrieval and posthumous use of gametes from minors would in my view be treating minors as genetic resources. I note that s.12 includes prohibition and offence provisions, and then sets out a defence to a charge against the section. The prohibition reflects the vulnerability of minors, while making provision for the future use of the gametes.

My concern is that unused gametes (eg stored after a person's death and which cannot be lawfully used) are seen as "wasted" becaue the demand for gametes exceeds the supply of donated gametes or embryos. The matter of appropriate use of any gametes or embryos, regardless of the age of a gamete provider, should be entirely divorced from a demand/supply framework.

Re the issue of maturity of consent givers: it may be helpful to look at a Ministry of Health publication "Consent in Child and Youth Health: Information for Practitioners".

Consultation Question 10

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

Consultation response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
There is a need to consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future.	1	2	X	4	5

Please add comments about your response if you wish.

This current ACART project is justified because the current regulatory framework on the matter has substantial gaps and inconsistencies. While relevant cases are not common, they do happen in New Zealand. The public and decisionmakers need clear policy that is adequate to address the dliversity of circumstances which can arise.

I assume the question above is about regulation of the retrieval and use of gametes from such individuals. Decisions about any future ACART consideration should be informed by any evidence about whether there is a problem to be addressed eg are there reports that requests are made for retrieval of gametes in such cases? And if there are such requests, are clinicians faced with challenges in responding, and/or are responses in different cases inconsistent and therefore potentially unfair or ethically troubling? If there is a justification for the work, the priority would presumably be assessed in light of other potential ACART projects.

Does ACART have in mind those who may be surviving in long term coma where the clinical judgement is that they are unlikely to recover consciousness? The definition of "permanently incapacitated" individuals unable to give consent would include some severely developmently disabled individuals (by birth, illness or accident) who are not comatose and where death is not imminent, and who lack capacity to give consent. I suspect that any definition of permanent incapacity and the implications would be troubling for many in the disability community.

My current view on the matter is that retrieval of gametes from such persons would be treating them as a resource to be harvested from. Retrieval could not be argued to be in their best interests, and could be seen as an assault.

I presume that it would be possible to remove one kidney or part of a liver from such an individual for the use of another person, but I think that would be generally seen as unacceptable, regardless of the relationship or need of a potential recipient. The same norm should inform the removal of gametes from a person who cannot give consent.

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation	Terei Whanau (family)
Please provide a brief description of the organisation (if applicable)	Whanau (family)
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Member of the public and our son has his sperm stored with Fertility Associates.....please refer to my cover note attached.

Are you:

☐ Male X☐ Female

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

☐ Yes X☐ 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 X☐ 55–64 years
☐ 65–74 years ☐ 75+ years

Privacy

We may publish all submissions, or a summary of submissions on the Ministry of Health'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 on the Ministry's website, please tick this box:

☐ Do not publish this submission.

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

☐ Remove my personal details from responses to Official Information Act requests.

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.

Consultation Question 1a

Do you agree that posthumous retrieval of sperm 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 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of sperm should be permitted:					
only when there is written consent	(X1)	2	3	4	(X5)
when there is evidence of verbal consent	(X1)	2	3	4	5
when there is evidence of inferred consent	(X1)	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

If all decisions totally rely on written consent then potentially there could be a missed opportrunity and this outcome would be absolutely devastating. Verbal consent expressed to legal guardian/partner/parent MUST BE taken into account.....most definitely.

Consultation Question 1b

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

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of eggs or ovarian tissue should be permitted:					
only when there is written consent	1	2	3	4	(X5)
when there is evidence of verbal consent	(X1)	2	3	4	5
when there is evidence of inferred consent	(X1)	2	3	4	5
when there is no consent but no objection	(X1)	2	3	4	5

Please add comments about your response if you wish.

If all decision totally relies on written consent, potential there could be a missed opportunity and the this outcome would be devastating. Verbal consent expressed to legal guardian/partner/parent MUST BE taken into account.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Gamete or reproductive tissue retrieval should be authorised by:					
the partner of the deceased	1	2	3	4	(X5)
a close relative	1	2	(X3)	4	5
a nominee	1	2	3	4	(X5)
ECART	1	2	3	(X4)	5
a coroner (where an individual is recently deceased)	1	2	3	4	(X5)
the Family Court	1	2	3	4	(X5)
the High Court	1	2	(X3)	4	5
Joint authorisation should be required	(X1)	2	3	4	5

Please add comments about your response if you wish.

Once again my response is the same as my comments in 1a.....such a critical decision can not be totally relied on to be written.

Joint authorisation could be a priority for our situation, this could be between guardian/parent/siblings, as our son did not have a partner, but they could also b e included in this process. The joint decision makers would not be someone ACART or National Ethics Committee deem to be suitable, it must be to the guardian/parent/siblings/partner.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Other people should be able to approve the retrieval of gametes from a permanently incapacitated person who has not previously consented	X1	2	3	4	5

Please add comments about your response if you wish.

So imperative that these decision makers are the absolute perfect person to do so, after indepth consultation of course.

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)

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of stored gametes or embryos should be permitted:					
only when there is written consent	1	2	3	4	X5
when there is evidence of verbal consent	X1	2	3	4	5
when there is evidence of inferred consent	X1	2	3	4	5
when there is no consent but no objection	X1	2	3	4	5

Please add comments about your response if you wish.

Most definitely there needs to be an annual review of the consent forms, and certainly more regular updates done of the guidelines.....18 years is ridiculously too long.

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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of gametes or reproductive tissue retrieved after or near death should be permitted:					
only when there is written consent	1	2	3	4	(X5)
when there is evidence of verbal consent	(X1)	2	3	4	5
when there is evidence of inferred consent	(X1)	2	3	4	5
when there is no consent but no objection	(X1)	2	3	4	5

Please add comments about your response if you wish.

My views are very clear in how I have rated my answers above.....definitely NOT by written consent only.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use should be authorised by:					
the partner of the deceased	1	2	3	4	(X5)
A close relative	1	2	(X3)	4	5
a nominee	(X1)	2	3	4	5
ECART	1	2	(X3)	4	5
the Family Court	1	2	3	4	(X5)
the High Court	1	2	(X3)	4	5
Joint authorisation should be required	(X1)	2	3	4	5

Please add comments about your response if you wish.

Joint authorisation is imperative with nominated whanau/partner/guardians/parents, but not a delegated person from outside party like ECART or High Court.

Only time would be a split decision and te guardians/parents/siblins/partners can not agree to the best outcome, so this is when a 3rd part I would involve like ECART OR HIGH COURT.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Reproductive material should be permitted to be used by:					
the deceased's partner only	1	2	3	4	(X5)
family members of the deceased as well as the deceased's partner	(X1)	2	3	4	5
anybody	1	2	3	4	(X5)

Please add comments about your response if you wish.

Again our decision is based on the fact that there was no partner or certainly not one that was a long term stable relationship.

Your option 'anybody' feels very vague and not something I would want to commit to without some serious rewriting of this section.

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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
All posthumous use of gametes and embryos should be subject to ethics review	1	2	3	4	X5
Posthumous use of gametes and embryos should never be subject to ethics review	1	2	3	X4	5
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them to create a full genetic sibling for an existing child	1	2	X3	4	5
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them	1	2	3	X4	5
Posthumous use of gametes and embryos should require ethics review if a third party wishes to use them	X1	2	3	4	5

Please add comments about your response if you wish.

Each situation is so unique to all. Not all of these shall require an Ethics Review (and how many times will the Ethics Review hear each case?). Most definitely there may be situations where a 3rd party is required (again this was something that was covered in Question 6 in my comments.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
The provisions in s 12 of the HART Act should apply to deceased individuals	1	2	3	4	(X5)
It should be permissible to retrieve and use gametes from a deceased minor	(X1)	2	3	4	5
It should be permissible to use gametes collected while the minor was alive and competent after the minor's death	(X1)	2	3	4	5
The provisions in Section 12 of the HART Act should apply to mature minors	1	2	3	4	(X5)

Please add comments about your response if you wish.

The question is why are we retrieving the gametes, and lets not dismiss any actions/decisions because of the fact that they are only a minor.

Totally object to any 'blanket ban' of use of gametes, case by case is how I see. Individuals have no choice but to store gametes prior to treatmentas they are protecting their option to reproduce.

Consultation Question 10

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

Consultation response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
There is a need to consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future.	1	2	3	4	X5

Please add comments about your response if you wish.

ACART

Must always consider the regulation of permanently incapacitated individuals whose death is not imminent in their future.

Fertility Plus / 23 August 2018

Anything that comes out of this needs to be consistent across clinics and needs to be something solid they can reference.

Comment that it is important to survey different age groups for ACART's consultations to get a good public sample.

Informed consent – any resulting guidelines need to be clear about what exact procedures an individual's material can be used for.

Considers the wellbeing of any children born when one parent is deceased (either by posthumous retrieval or by stored material) the most important consideration.

Fertility plus commented that they were pleased to note ACART's reference that psychological outcomes from children born after one parent is deceased - is positive or neutral.

There was consensus that a one year stand down period is important to establish, though this may be difficult to impose if the fertility window is decreasing.

Note that it is impossible to expect written consent in situations where material is retrieved posthumously – it may be that inferred consent is appropriate under strict guidelines.

A policy option could be to survey the number of people requesting that their material be destroyed in the event of their death and see how common it is for people to be comfortable with posthumous use.

Fertility Plus noted that your family doesn't make your reproductive decisions while you're alive – so there is little rationale for them to be making these decisions after death.

Possible policy option: to retrieve (because time is of the essence) – then have a robust mechanism for use.

Question 1a and 1b: any resulting guidelines should treat retrieval of sperm, eggs, and reproductive tissue the same.

Question 2: there should be a hierarchy like the Human Tissue Act, a nominee to be consulted first (if that person has one) otherwise a high court injunction + partner for authorisation of retrieval.

Question 3: to retrieve from a permanently incapacitated individual might mean in some situations to keep that individual on life support while they wait for a surgery slot for the retrieval to take place. Concern that this is an unnecessary burden to the taxpayer.

*Note in relation to question 3 above that although in questions 1a and 1b there is no rationale to treat sperm retrieval as different from egg and reproductive tissue retrieval – however in reality, it is not the same. This is because in retrieving ovarian tissue, there is a tighter timeframe as blood supply to the ovary ceases upon death. Ovarian tissue collection will also require anaesthetic for abdominal surgery if the individual is permanently incapacitated.

Question 4: there should be the same provisions for the posthumous use of eggs after death. Written consent is best in this situation, as the use requires another woman/surrogate

Question 5: if there is written consent for retrieval – then this consent should extend to any use. But in reality there is likely to not ever be written consent to PR or PVS retrieval.

Question 7: consider it okay that material is used by ones partner or siblings same sex partner.

Question 9: both Repromed and Fertility Plus acknowledged that banking material for minors has a lot of existing problems and didn't feel that the ground work was even laid to answer this question. Eg: Repromed suggested a policy option of taking materials from minors and re-consenting them at age 20 for use. In the event of their death before age 20, material should be destroyed.

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation	Repromed Auckland
Please provide a brief description of the organisation (if applicable)	Fertility provider
Address/email	105 Remuera Rd, Remuera, Auckland Or
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	

Are you:

☐ Male ☐ Female

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

Privacy

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If you do not want your submission published on the Ministry's website, please tick this box:

☐ Do not publish this submission.

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

☐ Remove my personal details from responses to Official Information Act requests.

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.

Consultation Question 1a

Do you agree that posthumous retrieval of sperm 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 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of sperm should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Our first preference is for written consent (1).

We are not supportive of no consent/no objection (5)

We note for the other 2 options: intent/action can have more bearing than verbal consent. Intent may include that contraception has been stopped or that someone may have made an appointment at a fertility clinic.

We agree that sperm may be retrieved however we recognise that for some people having gametes retrieved but not being able to use them may create a moral/ethical dilemma.

Consultation Question 1b

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

If you do not think explicit **written** consent is always required, do you agree that posthumous retrieval of 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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous retrieval of eggs or ovarian tissue should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Responses as per Question 1A

Our first preference is for written consent (1).

We are not supportive of no consent/no objection (5)

Please note; we determine no difference between retrieval of sperm and eggs – both genders should be treated equally under the law.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Gamete or reproductive tissue retrieval should be authorised by:					
the partner of the deceased	1	2	3	4	5
a close relative	1	2	3	4	5
a nominee	1	2	3	4	5
ECART	1	2	3	4	5
a coroner (where an individual is recently deceased)	1	2	3	4	5
the Family Court	1	2	3	4	5
the High Court	1	2	3	4	5
Joint authorisation should be required	1	2	3	4	5

Please add comments about your response if you wish.

Joint authorisation should be required (strongly agree: 1) between either the partner of the deceased, a close relative or a nominee AND either the coroner (for expediency purposes) or a nominated person of the High Court.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Other people should be able to approve the retrieval of gametes from a permanently incapacitated person who has not previously consented	1	2	3	4	5

Please add comments about your response if you wish.

Strongly disagree (5) as the person in question is still alive and no previous consent has been given.

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)

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of stored gametes or embryos should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Our first preference is for written consent (1) for specific use. This should be defined in the consent.

We are not supportive of no consent/no objection (5).

Note: If embryos have already been created and are stored in a fertility clinic (when the person was alive and competent) the process included consent being sought and documented. It would be rare that there are stored gametes or embryos in a clinic which were taken/created when the deceased was alive and competent without written consent existing regarding their wishes around posthumous use.

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).

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use of gametes or reproductive tissue retrieved after or near death should be permitted:					
only when there is written consent	1	2	3	4	5
when there is evidence of verbal consent	1	2	3	4	5
when there is evidence of inferred consent	1	2	3	4	5
when there is no consent but no objection	1	2	3	4	5

Please add comments about your response if you wish.

Our first preference is for written consent (1).

We are not supportive of no consent/no objection (5)

A 2-step process needs to be formalised:

1) Gametes may be retrieved either with existing written consent or if a decision is made to allow retrieval with the joint authorisation of an interested party and the coroner /High court, then
2) the interested party/s would need apply to ECART for use (unless there is existing written consent with specific instructions). ECART would need their guidelines to include a process to be able to manage conflicting requests if more than one party eg the partner could apply to use (see Q7.)

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Posthumous use should be authorised by:					
the partner of the deceased	1	2	3	4	5
a close relative	1	2	3	4	5
a nominee	1	2	3	4	5
ECART	1	2	3	4	5
the Family Court	1	2	3	4	5
the High Court	1	2	3	4	5
Joint authorisation should be required	1	2	3	4	5

Please add comments about your response if you wish.

We strongly agree (1) Joint authorisation should be required between the deceased's partner, or close relative or a nominee (as applicants) and ECART as the body to review and authorise.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
Reproductive material should be permitted to be used by:					
the deceased's partner only	1	2	3	4	5
family members of the deceased as well as the deceased's partner	1	2	3	4	5
anybody	1	2	3	4	5

Please add comments about your response if you wish.

We agree that reproductive material should be permitted for use for both:
The deceased partner
And Family member of the deceased (with ECART review)
We strongly disagree (5) with '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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
All posthumous use of gametes and embryos should be subject to ethics review	1	2	3	4	5
Posthumous use of gametes and embryos should never be subject to ethics review	1	2	3	4	5
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them to create a full genetic sibling for an existing child	1	2	3	4	5
Posthumous use of gametes and embryos should not require ethics review if the donor's partner wishes to use them	1	2	3	4	5
Posthumous use of gametes and embryos should require ethics review if a third party wishes to use them	1	2	3	4	5

Please add comments about your response if you wish.

The posthumous use of gametes and embryos should require ethics review accept if the deceased's partner wishes to use them to create a full genetic sibling for an existing child and there is consent.

We note this question refers to a 'donor's' partner; our assumption is that ACART means the deceased person partner.

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?

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
The provisions in s 12 of the HART Act should apply to deceased individuals	1	2	3	4	5
It should be permissible to retrieve and use gametes from a deceased minor	1	2	3	4	5
It should be permissible to use gametes collected while the minor was alive and competent after the minor's death	1	2	3	4	5
The provisions in Section 12 of the HART Act should apply to mature minors	1	2	3	4	5

Please add comments about your response if you wish.

Strongly agree (1) that the provisions in s 12 of the HART Act should apply to deceased individuals, including "mature minors"

We do not support a proposal to retrieve and use gametes from a deceased minor as it is essentially a proposal to create a child from a child without consent.

If gametes from a minor have been collected for the purposes of fertility preservation these cannot be used without a second consent given at the time the minor turns 20.

Consultation Question 10

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

Consultation response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
There is a need to consider the regulation of permanently incapacitated individuals, whose death is not imminent, in the future.	1	2	3	4	5

Please add comments about your response if you wish.

(2) Agree, so that regulation and clear guidelines can be established for this group.

He tono nā

Te Rūnanga o NGĀI TAHU

ADVISORY COMMITTEE ON ASSISTED REPRODUCTIVE TECHNOLOGY

e pā ana ki te

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

21 Rima/September 2018

contact person
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1. GENERAL STATEMENT OF POSITION ON THE REVIEW

1.1. Te Rūnanga o Ngāi Tahu (Te Rūnanga) supports the review of posthumous reproduction guidelines (the current review) in New Zealand being undertaken by the Advisory Committee on Assisted Reproductive Technology (the Committee). This review is both timely and necessary, in order to better enable the New Zealand health system to meet the needs of whānau in the twenty-first century.

1.2. Whilst this response does not seek to supplant the ability of specifically affected parties to make decisions, there are several points we would speak to in order to enhance the delivery and support of those affected moving forward.

1.3. Te Rūnanga o Ngāi Tahu also strongly recommends the Committee consider the National Ethics Advisory Committee's (the NEAC) 2018 Draft National Ethical Standards for Health and Disability Research: Consultation document in order to meaningfully give effect to the Crown's Te Tiriti obligations.

1.4. Te Rūnanga thanks the Committee for their efforts, and looks forward to its response.

2. TE RŪNANGA INTERESTS IN THE REVIEW

2.1. Te Rūnanga is the mandated representative of te iwi o Ngāi Tahu. Ngāi Tahu whānui comprises some 60,000 registered iwi members, all of whom are linked by their whakapapa to our eponymous ancestor, Tahu Pōtiki. It is whakapapa that places a duty upon Te Rūnanga to safeguard and advocate for the interests of each and every individual of our iwi, living, dead, and those yet to be born. This is captured in our guiding whakatauākī:

"Mō tātou, ā, mō kā uri ā muri ake nei – For us, and our children after us."

2.2. Additionally, as Mana Whenua over a region which encompasses the largest proportion of New Zealand territory, Te Rūnanga has a responsibility to ensure the well-being of all those who live in our takiwā in accordance with the tikanga of manaakitanga.

3. GENETIC MATERIAL

3.1. Te Rūnanga commends the Committee's acknowledgement of the relevance of tikanga Māori to posthumous reproduction considerations.

3.2. For Ngāi Tahu, as for other iwi, human genetic material (te ira tangata) carries whakapapa, and is therefore tapu. This places on individual iwi members an additional layer of ethical responsibility towards the iwi collective in respect of the way in which their genetic material is provided to third parties.

3.3. Te Rūnanga affirms the right of iwi members to make their own, individual choices in respect of their personal genetic material, especially when this comes to issues as

sensitive as those contemplated by the current review.

3.4. However, Te Rūnanga considers that genetic material retrieved or used for posthumous reproduction must be subject to strong protections. Te Rūnanga strongly opposes the exploitation of whakapapa for any other purpose than the very limited conditions under which it is collected, for use by a very specific group of affected individuals.

3.5. Access to human genetic material collected for posthumous reproduction must therefore be restricted to the immediate family of the deceased, including their partner.

3.6. Te Rūnanga opposes Ngāi Tahu whakapapa information being provided to anyone non-Ngāi Tahu for any other purpose. Te Rūnanga requires that no genetic material from Ngāi Tahu iwi members retrieved for posthumous reproduction is to be accessed, stored, utilised, databased (including databanking and biobanking), or otherwise provided to any third party for any reason.

4. NEAC DRAFT NATIONAL ETHICAL STANDARDS

4.1. At 4.5 of the National Ethics Advisory Committee's 2018 Draft National Ethical Standards for Health and Disability Research: Consultation document (the NEAC draft standards), the NEAC states that, although the NEAC draft standards are specifically aimed at researchers who are conducting health research, *"from an ethical point of view, the principles and the standards apply to all practices where they are relevant"*. Te Rūnanga endorses this provision, and considers this approach to be highly applicable to the current review.

4.2. As such, Te Rūnanga recommends that the Committee particularly have regard to Part 6 of the NEAC draft standards, which specifically speaks to ethical requirements in health practices involving Māori. Of particular note are 6.3-6.6 and 6.14.

4.3. Te Rūnanga also endorses 2.3 of the NEAC draft standards which provides suitable formulation of the Principles of the Treaty not only in respect of health research, but in terms of the current consultation:

> *The three Treaty of Waitangi principles of partnership, participation and protection should inform the interface between Māori and research:*
>
> - *Partnership working together with iwi, hapū, whānau and Māori communities to ensure Māori individual and collective rights are respected and protected.*
> - *Participation involving Māori in the design, governance, management, implementation and analysis of research, especially research involving Māori.*
> - *Protection actively protecting Māori individual and collective rights, Māori data, Māori culture, cultural concepts, values, norms, practices and language in the research process.*

5. DECISION MAKING

5.1. The tikanga which arise in questions of posthumous reproduction will vary depending upon the individual circumstances in a specific case. In order for this to be appropriately managed, Te Rūnanga recommends the establishment of a Iwi Advisory Committee, the membership of which should comprise appropriate iwi representatives possessing a high level of expertise in tikanga Māori.

5.2. Te Rūnanga further recommends that an interim Iwi Advisory committee be established in line with the above, in order to assist ACART during the subsequent stages of the current review process, prior to its conclusion. This will ensure that the Treaty partnership is given proper effect, and also provide the Committee with necessary cultural assistance in the design and delivery of the new Posthumous Reproduction guidelines.

5.3. Te Rūnanga recommends that there be provision for mana whenua representatives to sit on the Iwi Advisory Committee when specific posthumous reproduction issues arise within any given iwi region. It is the position of Te Rūnanga that this provides a suitable level of consultation as required by the Treaty partnership obligations of the Crown, while still appropriately upholding the right of affected individuals to privacy in what can be times of significant emotional distress.

5.4. Te Rūnanga requires that mana whenua must be notified of the policies and practices relating to storage and disposal of human genetic material in their iwi region, regardless of whether this belonged to deceased Māori individuals or non-Māori, due to the significant cultural and spiritual implications this has. Te Rūnanga believes that the Māori Advisory Committee would be a useful party in order to facilitate these conversations, possessing the appropriate tikanga Māori and ethical acumen to navigate what can be quite complex issues.

6. MANAAKITANGA

6.1. Te Rūnanga wishes the guidelines to acknowledge the severe emotional toll these processes can place upon the bereaved.

6.2. As such, Te Rūnanga recommends that the guidelines provide for support services, including Māori advocates, to assist the affected parties as they consider their options.

APPENDIX ONE: TEXT OF CROWN APOLOGY

The following is text of the Crown apology contained in the Ngāi Tahu Claims Settlement Act 1998.

Part One – Apology by the Crown to Ngāi Tahu

Section 6 Text in English

The text of the apology in English is as follows:

1 The Crown recognises the protracted labours of the Ngāi Tahu ancestors in pursuit of their claims for redress and compensation against the Crown for nearly 150 years, as alluded to in the Ngāi Tahu proverb 'He mahi kai takata, he mahi kai hoaka' ('It is work that consumes people, as greenstone consumes sandstone'). The Ngāi Tahu understanding of the Crown's responsibilities conveyed to Queen Victoria by Matiaha Tiramorehu in a petition in 1857, guided the Ngāi Tahu ancestors. Tiramorehu wrote:

"'*This was the command thy love laid upon these Governors ... that the law be made one, that the commandments be made one, that the nation be made one, that the white skin be made just equal with the dark skin, and to lay down the love of thy graciousness to the Māori that they dwell happily ... and remember the power of thy name.*"

The Crown hereby acknowledges the work of the Ngāi Tahu ancestors and makes this apology to them and to their descendants.

2 The Crown acknowledges that it acted unconscionably and in repeated breach of the principles of the Treaty of Waitangi in its dealings with Ngāi Tahu in the purchases of Ngāi Tahu land. The Crown further acknowledges that in relation to the deeds of purchase it has failed in most material respects to honour its obligations to Ngāi Tahu as its Treaty partner, while it also failed to set aside adequate lands for Ngāi Tahu's use, and to provide adequate economic and social resources for Ngāi Tahu.

3 The Crown acknowledges that, in breach of Article Two of the Treaty, it failed to preserve and protect Ngāi Tahu's use and ownership of such of their land and valued possessions as they wished to retain.

4 The Crown recognises that it has failed to act towards Ngāi Tahu reasonably and with the utmost good faith in a manner consistent with the honour of the Crown. That failure is referred to in the Ngāi Tahu saying 'Te Hapa o Niu Tireni!' ('The unfulfilled promise of New Zealand'). The Crown further recognises that its failure always to act in good faith deprived Ngāi Tahu of the opportunity to develop and kept the tribe for several generations in a state of poverty, a state referred to in the proverb 'Te mate o te iwi' ('The malaise of the tribe').

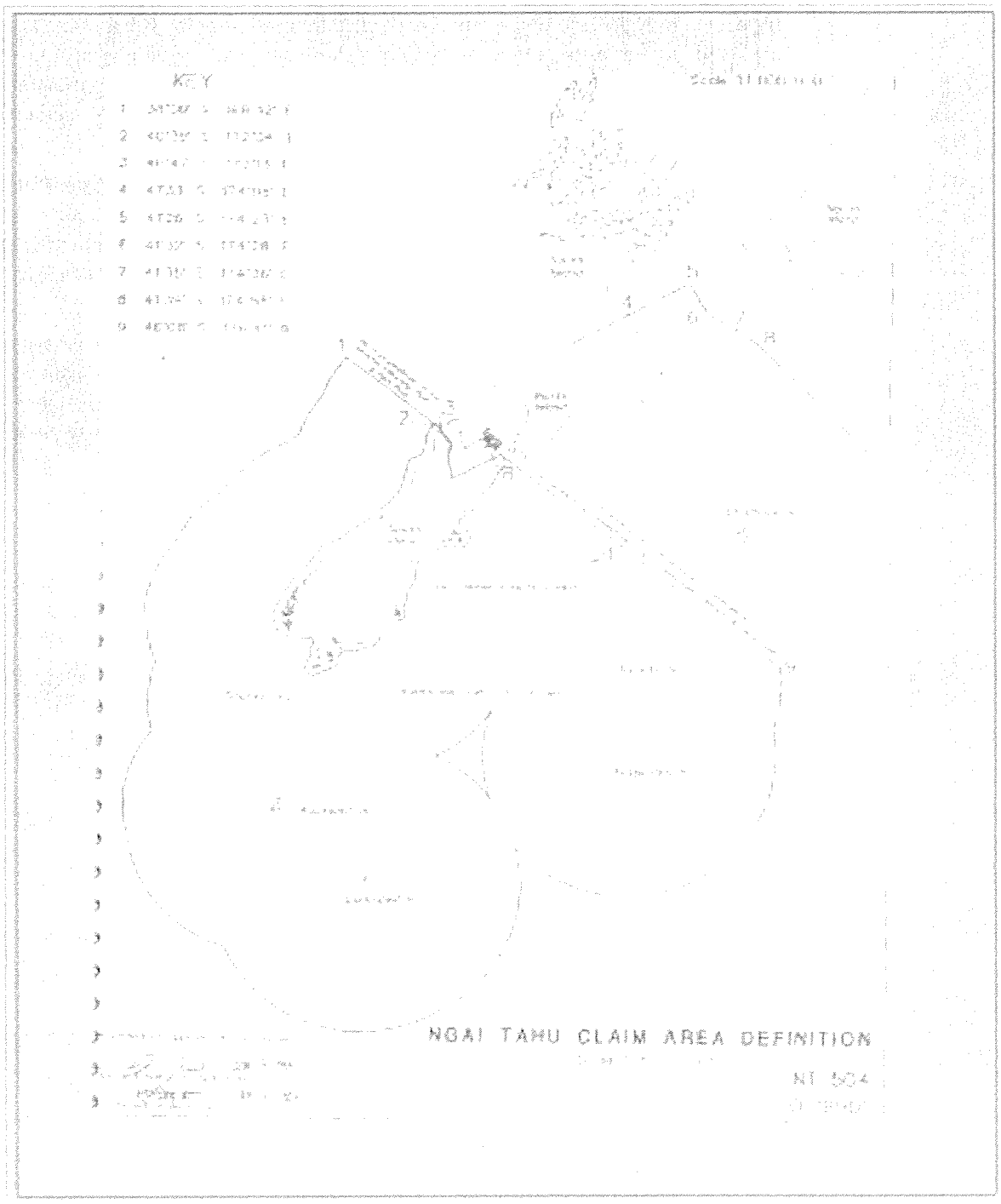
5 The Crown recognises that Ngāi Tahu has been consistently loyal to the Crown, and that the tribe has honoured its obligations and responsibilities under the Treaty of Waitangi and duties as citizens of the nation, especially, but not exclusively, in their active service in all of the major conflicts up to the present time to which New Zealand has sent troops. The Crown pays tribute to Ngāi Tahu's loyalty and to the contribution made by the tribe to the nation.

6. The Crown expresses its profound regret and apologises unreservedly to all members of Ngāi Tahu Whānui for the suffering and hardship caused to Ngāi Tahu, and for the harmful effects which resulted to the welfare, economy and development of Ngāi Tahu as a tribe. The Crown acknowledges that such suffering, hardship and harmful effects resulted from its failures to honour its obligations to Ngāi Tahu under the deeds of purchase whereby it acquired Ngāi Tahu lands, to set aside adequate lands for the tribe's use, to allow reasonable access to traditional sources of food, to protect Ngāi Tahu's rights to pounamu and such other valued possessions as the tribe wished to retain, or to remedy effectually Ngāi Tahu's grievances.

7. The Crown apologises to Ngāi Tahu for its past failures to acknowledge Ngāi Tahu rangatiratanga and mana over the South Island lands within its boundaries, and, in fulfilment of its Treaty obligations, the Crown recognises Ngāi Tahu as the tangata whenua of, and as holding rangatiratanga within, the Takiwā of Ngāi Tahu Whānui.

Accordingly, the Crown seeks on behalf of all New Zealanders to atone for these acknowledged injustices, so far as that is now possible, and, with the historical grievances finally settled as to matters set out in the Deed of Settlement signed on 21 November 1997, to begin the process of healing and to enter a new age of co-operation with Ngāi Tahu."

APPENDIX TWO: NGĀI TAHU TAKIWĀ



Ngāi Tahu claim area definition

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

ACART Secretariat
PO Box 5013
Wellington

2 October 2018

By email: acart@moh.govt.nz

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

Thank you for the opportunity to comment on the Advisory Committee on Assisted Reproductive Technology (ACART) review of the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man* (the Consultation Document) to take into account gametes and embryos.

The Consultation Document seeks submissions on whether the collection of gametes should be permitted where a donor is recently deceased and also where a person is unconscious with no prospect of recovery and their death is imminent. I have focused my comments on the situation where the donor is unconscious with no prospect of recovery and has not given prior informed consent to the retrieval of gametes.

The first part of this submission restates my previous comments regarding the fact that the issue of the collection of gametes is a sensitive matter in situations where the consumer is alive and able to consent. It is therefore a matter of even greater sensitivity when it is proposed to be performed on those who are unable to consent. I have then set out my comments directly in response to the issues raised in the Consultation Document.

The Health and Disability Commissioner (HDC), is charged with promoting and protecting the rights of health and disability services consumers in New Zealand, as set out in the Code of Health and Disability Services Consumers' Rights (the Code). One of my functions under the Health and Disability Commissioner Act 1994 (the Act) is to make public statements in relation to any matter affecting the rights of health or disability services consumers. Please note the Code refers to the rights of 'consumers' and I have used this term in this submission.

The Act and the Code apply to consumers of health and disability services. 'Health consumer' is defined in section 2 of the Act as including 'any person on or in respect of whom a health care procedure is carried out'. A 'health care procedure' is defined as including 'the provision of health services', which include fertility services.

For the purposes of the Consultation Document, this means that every person undergoing an assisted reproductive procedure has all the rights in the Code including the right to effective communication, full information, to make an informed choice, and to give informed consent to that procedure.

Reproductive procedures involve more than one consumer. I understand that there are several processes involved in the procedure of assisted reproduction such as the extraction, storage, and use of gametes, and the creation, storage and implantation of embryos, the use of surrogates and donors. Different processes focus on different consumers (surrogate, donor, potential parents). The design of the set of events/procedures needs to anticipate that informed consent will be required by each consumer subject for each of the events/processes/procedures in which they have the relevant interest. Many of these decisions (events/steps/procedures) will clearly be covered by the Code.

Clarity as to the steps involved throughout the processes, through to and including the relevant end point/s, is critical in order to obtain the required informed consent from the relevant individuals for the relevant activities.

It is clear that the extraction of gametes is a health care procedure for the purposes of the Act and Code and that the gamete donor is a consumer for the purposes of these procedures.

The requirements of informed consent are at the heart of the Code and trigger a number of rights (Right, 5, 6, and 7).

The Act in section 2 defines informed consent in relation to a health care consumer as consent to that particular health care procedure that is:

- Freely given by the consumer, or where applicable by any person who is entitled to consent on that consumer's behalf; and
- Is obtained in accordance with the requirements of the Code.

Under the Code, every consumer must be presumed to be competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent (Right 7(2)).

Right 6(2) of the Code provides that every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive. In my

view, a reasonable consumer undergoing an assisted reproductive procedure, where the purpose of that procedure is to remove gametes for future use, would expect to know what will happen to those gametes, including any embryos created from them. In most circumstances, the disclosure of such information would, in fact, be required in order for that consumer to be able to give informed consent, in accordance with Right 7 of the Code.

Right 7(5) provides that a consumer who is not competent at the time of treatment to make an informed choice or give informed consent may set out his or her views regarding particular services in an advance directive prior to receiving treatment.

However, services may still be provided to consumers who are not competent to make an informed choice and consent to those services (for example, a person who is unconscious) provided certain requirements set out in Right 7(4) are met. However, from a starting point it would appear that Right 7(4) precludes gamete retrieval in a situation where a consumer is not competent to give informed consent as it requires that the procedure provided be in the best interests of the consumer. Given that the consumer's death is imminent it would be difficult to justify that gamete retrieval would be in their best interests.

Right 7(9) and 7(10) of the Code contain requirements in relation to the use, return, and disposal of body parts and bodily substances removed or obtained in the course of a health care procedure. There is no definition of 'body part' or 'bodily substance' in either the Act or the Code, however sperm and eggs would be considered 'bodily substances' and therefore Rights 7(9) and 7(10) provide additional specific protections in relation to the use, return, and disposal of gametes removed or retained in the course of a health care procedure.

Paragraph 57 of the Consultation Document states that the Human Assisted Reproductive Technology Act 2004 sets out principles guiding those performing functions under that Act and ACART's Ethical Framework provides more details of those principles. I note that it is also a requirement of Right 4(2) that services provided must comply with legal, professional, ethical, and other relevant standards. Many of the purposes and principles discussed in the 'Ethical Issues' part of the Consultation Document are also rights in the Code such as the right for a consumer to be treated with dignity (Right 3), the right to be treated with respect (Right 1(1)), the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethical groups, including the needs, values, and beliefs of Maori (Right 1(3)).

Conclusion

I observe that the law in New Zealand rightly places a very high value on informed consent. The proposal to take gametes without consent from an unconscious individual ought to be approached with high degrees of caution, and in order to implement the proposal will require change to the current legal environment.

The Code does not apply to those who are deceased. Nonetheless, the legal restrictions evident prior to death invite the conclusion on public policy grounds that any proposal to

act in a way after death that immediately before death would clearly be unlawful should also be approached with high degrees of caution.

I trust that you find these comments of assistance. Please do not hesitate to contact Senior Legal Advisor, Jen Feltham on (04) 494 7925 or by email at jen.feltham@hdc.org.nz if you have any questions about this submission.

Yours sincerely

Anthony Hill
Health and Disability Commissioner