

**Advisory Committee on
Assisted Reproductive Technology**

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

**Consultation document
Stage one of a two-part consultation**

Citation: Advisory Committee on Assisted Reproductive Technology. 2018. 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. Wellington: Advisory Committee on Assisted Reproductive Technology.

Published 3 July 2018 by the Advisory Committee on Assisted Reproductive Technology, PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-98-853961-4 (online)
HP 8857

This document is available on the ACART website: acart.health.govt.nz





Chair's Foreword

The Advisory Committee on Assisted Reproductive Technology (ACART) has prepared this consultation document as the first of a two stage consultation on posthumous reproduction.

Human assisted reproductive technologies are continuously developing and rapidly changing. This context is recognised in New Zealand's Human Assisted Reproductive Technology Act 2004 (HART Act). The HART Act seeks to secure the benefits of assisted reproductive technology while protecting the health and safety of all individuals, particularly women and children, in the use of these technologies. It also requires that ACART provide advice and review relevant Guidelines, to ensure our flexible regulatory framework remains current.

Posthumous reproduction involves the use of a person's sperm or eggs, after their death. In some cases, it also involves the retrieval of these gametes very shortly after death or at a time when death is imminent. While scientific advances have made this form of reproduction possible, there are many complex ethical and legal issues that have not yet been resolved.

ACART is undertaking a two stage consultation to assess the need for change in how we regulate posthumous reproduction in New Zealand. This stage one consultation document presents for public consideration the background, rationale and policy options for a review of the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*¹. The former National Ethics Committee on Assisted Human Reproduction (NECAHR) issued the current Guidelines in 2000, prior to the introduction of the Human Assisted Reproductive Technology Act 2004. Now 18 years old, ACART considers that the Guidelines are no longer fit for purpose. They are narrow in scope and leave many important issues unaddressed, such as the use of eggs after a woman's death.

Recently in the case *Re Lee*,² the New Zealand High Court was asked to authorise the posthumous retrieval of sperm from a man who had died, suddenly and unexpectedly. Like most people, the man had not considered the possibility of his partner wanting to retrieve and use his sperm to have another child, after his death. The Court found that there was a gap in the law as there are no provisions that deal explicitly with retrieval and subsequent use of sperm from a deceased man. While retrieval was authorised by the Court, use of the sperm is not permitted under the current Guidelines due to their narrow scope.

ACART believes the current Guidelines should be reviewed, giving consideration to whether their limited scope should be expanded. A comprehensive regulatory framework

¹ ACART engaged Professor Nicola Peart (Faculty of Law at the University of Otago) as an expert member of the Working Group, which led the Committee's work on the first stage of this review.

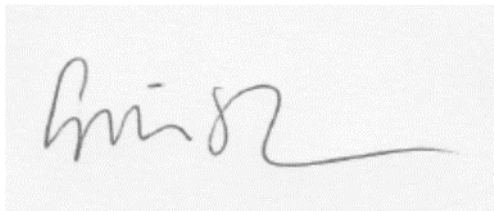
² *Re Lee (Deceased)* [2017] NZHC 3263.

is needed, so that there is consistency and clarity in the way that we deal with requests for the posthumous retrieval and use of gametes and embryos.

We are seeking public feedback on significant policy issues about whether and in what circumstances posthumous reproduction is acceptable. The paper raises important ethical questions about the retrieval and use of gametes from a person who is no longer able to consent. We also raise issues about who should be able to authorise the retrieval and use of gametes, and how any regulatory mechanism might operate.

This document does not contain recommendations, as we are seeking public feedback on these significant policy issues prior to developing any new guidelines.

We appreciate the efforts many people and organisations make to provide valuable feedback to our public consultations and look forward to receiving your submission. Your comments will help ACART to develop a comprehensive framework during stage two of this review, on which public feedback will also be sought.

A handwritten signature in dark ink, appearing to read 'Gillian', followed by a long, horizontal, slightly wavy line.

Gillian Ferguson

Chair, Advisory Committee on Assisted Reproductive Technology

3 July 2018



How to have your say

Your feedback is important to help ACART develop its revised guidelines on deceased and incapacitated persons.

Please take this opportunity to have your say. There is a feedback form at the back of this document. You may give feedback on your own behalf or as a member of an organisation. You can contribute your views by:

1. completing the Citizen Space link through the Ministry of Health's web page, or
2. emailing a completed feedback form or your comments to acart@moh.govt.nz, or
3. posting a completed feedback form or your comments to:

ACART Secretariat
PO Box 5013
Wellington.

ACART welcomes your views on any of the issues this document raises.

Publication of feedback on ACART's website

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.

Official Information Act requests – feedback

Please note that any member of the public may request to see your feedback under the Official Information Act 1982. The Official Information Act requires the Ministry of Health (the Ministry) to release your feedback, including your name and contact details, to the person who requested it unless one of the exceptions set out in Part 1 of the Official Information Act applies.

If you consider that we should withhold any part of your feedback under the Official Information Act, please make this clear on your feedback form, noting the reasons.

Official Information Act requests – name and contact details

In accordance with guidance from the Ombudsman, the Ministry's standard procedure is to not release the name and contact details of a submitter who has given feedback in their private capacity (i.e., not in a professional capacity or on behalf of an organisation) and who has requested that the information not be published by ticking the relevant boxes on the feedback form.

Where a person has given feedback on behalf of an organisation, the Ministry will release the name and contacts details of the submitter and the organisation unless there are other reasons for withholding the information in accordance with the Official Information Act. If you consider that we should withhold your or your organisation's name and/or contact details under the Official Information Act, please make this clear on your feedback form, noting the reasons.

Further guidance on releasing information under the Official Information Act is available at www.ombudsman.parliament.nz/resources-and-publications.

The closing date for feedback is 3 September 2018.

Contents

Chair's foreword	iii
How to have your say	v
Publication of feedback on ACART's website	v
Official Information Act requests – feedback	v
Official Information Act requests – name and contact details	vi
Executive summary	ix
Introduction.....	1
Purpose	1
The consultation process	1
Scope of the first stage of the consultation	1
Posthumous reproduction	3
Permanently incapacitated persons	3
Overview of the issues	4
ACART's role	6
Regulatory setting	8
Human Assisted Reproductive Technology Act.....	8
Human Assisted Reproductive Technology Order.....	8
Code of Health and Disability Services Consumers' Rights	9
Human Tissue Act.....	9
Coroners Act	9
Retrieval of gametes	9
Use of gametes and embryos	10
Recent New Zealand case on posthumous reproduction	11
Posthumous retrieval: scientific details.....	12
Ethical issues.....	13
Securing the benefits of assisted reproduction: s 3(a)	13
Dignity and interest of gamete providers: s 4(d)	14
Dignity and wellbeing of recipient: s 4(c)	14
Status, rights and wellbeing of resulting children: s 4(a)	15
Dignity and interests of existing children: s 4(b)	16
Tikanga Māori: s 4(f) and (g).....	16
Respecting different views about spirituality, culture and mortality: s 4(g)	17
Consent: s 4(d).....	18
Policy options for revised guidelines.....	18

Posthumous retrieval - consent (1a sperm & 1b eggs and ovarian tissue)	198
Authorisation of retrieval of gametes or reproductive tissue from a deceased person	21
Retrieval from a permanently incapacitated person whose death is imminent.....	24
Posthumous use of stored material - consent.....	25
Use of material retrieved after or near to death - consent	27
Authorisation of posthumous use	29
Who should be permitted to use the material	31
When should posthumous use be subject to ethics review	32
Posthumous reproduction involving minors	33
Reproduction involving permanently incapacitated individuals whose death is not imminent.....	35
Glossary	36
Bibliography	38
Feedback form.....	40
Consultation Question 1a.....	41
Consultation Question 1b.....	43
Consultation Question 2.....	44
Consultation Question 3.....	46
Consultation Question 4.....	47
Consultation Question 5.....	48
Consultation Question 6.....	50
Consultation Question 7.....	51
Consultation Question 8.....	52
Consultation Question 9.....	53
Consultation Question 10.....	55



Executive summary

1. This document presents for public consideration the background, rationale and policy options for the review of the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*³ (the current Guidelines). ACART adopted the former NECAHR's Guidelines in 2000, prior to the introduction of the HART Act. The Guidelines subsequently applied to the new regulatory framework of the HART Act. Given societal and technological changes, ACART has determined a need to revisit the existing 2000 Guidelines.
2. ACART is reviewing the current Guidelines on posthumous reproduction to take into account all gametes (not just sperm) and embryos. These existing Guidelines apply only to the posthumous use of sperm that was retrieved prior to the man's death. Relevant issues that the current Guidelines do not address include:
 - retrieval of sperm from a deceased man
 - retrieval and use of eggs from a deceased woman
 - use of stored eggs, after the death of a woman
 - retrieval and use of reproductive tissue from a deceased man or woman
 - use of stored embryos after the death of one or both of the gamete donors
 - retrieval and use of sperm or eggs from a person who has become permanently incapacitated and whose death is imminent.
3. ACART believes the current Guidelines should be reviewed, giving consideration to whether their limited scope should be expanded. We need a comprehensive regulatory framework, so that there is consistency and clarity in the way that we deal with requests for the posthumous retrieval and use of gametes, reproductive tissue and embryos. In particular, we believe that new guidelines should address the use of eggs after a woman's death, and that the legality of retrieving gametes from a deceased person should be clear. ACART proposes that the guidelines should also address the retrieval and use of sperm or eggs from unconscious people who are permanently incapacitated and whose death is imminent. Once a person is deceased, their body tissues deteriorate rapidly. It may be possible to collect better quality tissues or gametes while someone is alive.

³ National Ethics Committee on Assisted Human Reproduction. 2000. *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*. Wellington: Ministry of Health.

4. This document outlines the current regulatory framework for posthumous reproduction in New Zealand. We explain some of the technical and scientific aspects of posthumous reproduction, before describing the key ethical issues that reproduction involving deceased and permanently incapacitated people whose death is imminent raise, and consider how they relate to the purposes and principles of the HART Act. We then consider possible scenarios involving deceased and permanently incapacitated people whose death is imminent, and present a range of policy options to deal with these scenarios.
5. ACART is canvassing public opinion on issues identified in this document. This document does not contain recommendations as we are seeking public feedback on these significant policy issues prior to developing proposed new guidelines. Any revised Guidelines will need to be compatible with legal and ethical precedents. We invite you to complete the feedback form on page 40.



Introduction

Purpose

6. ACART is canvassing public opinion on expanding the scope of the current Guidelines to take into account the retrieval and use of gametes and reproductive material from deceased people. ACART is also seeking feedback on the retrieval and use of gametes from unconscious individuals who are permanently incapacitated and whose death is imminent. The response may inform a proposed new policy and guidelines for posthumous reproduction, which will then go out for a second stage of public consultation.
7. Our recommendations, which we will present in the second stage of consultation, may require amendments to the HART Act or the Human Assisted Reproductive Technology Order 2005 (HART Order), or other legislation, such as the Status of Children Act 1969, or the legislation governing inheritance. Our approach to this first stage has been to focus on the ethical considerations rather than the complex legal position.

The consultation process

8. Our consultation process has two stages. The first stage will seek the public's views on the retrieval and use of gametes, embryos, and reproductive tissue from deceased or permanently incapacitated persons whose death is imminent, and on the type of circumstances in which these procedures would be ethically or legally acceptable, if ever. In this first stage, ACART seeks feedback using tables offering an opinion/response, rather than a Yes/No response. This will assist ACART to gauge views regarding these complex and difficult issues.

Scope of the first stage of the consultation

In scope

9. The scope of reproduction ACART is considering within this consultation document includes:
 - the retrieval, storage and use of gametes or reproductive tissue from a deceased person or a permanently incapacitated person whose death is imminent
 - the use of gametes collected and stored during the lifetime of the person, while the person was capable of giving consent
 - the use of embryos created and stored during the joint lifetimes of the persons, while both persons were capable of giving consent.

10. ACART has identified six relevant scenarios:

1. Posthumous use ⁴ of stored: a) eggs b) sperm c) reproductive tissue taken from somebody while they were alive and had capacity to consent, or d) embryos created while the gamete providers were alive and had capacity to consent	i) With the consent of the person	ii) Without the consent of the person
2. Retrieval of: a) eggs b) sperm c) reproductive tissue from someone who is dead or permanently incapacitated	i) With the prior consent of the person	ii) Without the prior consent of the person
3. Posthumous use of: a) eggs b) sperm c) reproductive tissue retrieved from somebody when they were dead or had become permanently incapacitated	i) With the prior consent of the person	ii) Without the prior consent of the person

Out of scope

11. The scope of reproduction considered within this consultation document excludes human reproductive research carried out using gametes and embryos of somebody deceased.
12. As discussed below, consideration is limited to situations in which a person is deceased or unconscious and permanently incapacitated and their death is imminent. Situations in which somebody is unconscious but is likely to regain consciousness, or is conscious but lacks capacity to provide consent, are out of scope.
13. We invite feedback as to whether there is a need for ACART to address in the future individuals who are in a permanent incapacitated state but whose death is not imminent.

⁴ 'Use' may also include storage, disposal or donation.

Posthumous reproduction

14. Posthumous reproduction is now a realistic possibility and technology will continue to make advances in this area as it develops rapidly. By 'posthumous reproduction' we mean the retrieval of gametes and reproductive tissue after a person's death or at a time when they have permanently lost capacity and their death is imminent, the storage and use of gametes and reproductive tissue after a person's death, and also the creation, storage and use of embryos after a person's death.⁵ In all instances, the person will be deceased at the time their gametes are used and any resulting child is born.
15. In terms of retrieval there is urgency. Gametes need to be retrieved within a short timeframe of 36-48 hours after death, to ensure they remain viable.
16. A person may have consented during their lifetime to the collection, storage and use of their gametes or reproductive tissue after death. It is standard practice in New Zealand for fertility clinics, at the time of storage, to record what people want to happen to their gametes should they die. However there are also some situations where their wishes may not be known.

Permanently Incapacitated Unconscious Person Whose Death is Imminent

17. Our consultation not only addresses the situation in which a person is deceased, but also where a person is unconscious with no prospect of recovery, and their death is imminent. In this document, we use the term 'permanently incapacitated' to refer to such an individual. Whether the person is dead already, or close to death, it is not possible and will never again be possible to ask that person what they want to happen (although in both cases a person may have left evidence of their wishes). Similarly, in both cases, use will occur after death. In other ways, the two situations present different legal and ethical questions.
18. This consultation is concerned only with permanently incapacitated people whose death is imminent. Situations in which somebody is incapacitated but may continue to live for months or years (such as a person in a permanent vegetative state) raise different issues because the person may still be alive when a child is born, and retrieval is not urgent. This consultation focuses only on situations where the gametes will be used following death.
19. Permanently incapacitated persons are patients or 'healthcare consumers' for the purposes of the Code of Health and Disability Services Consumers' Rights (the Code). Under the Health and Disability Commissioner Act 1994, a health consumer is defined as including "any person on or in respect of whom any health care procedure is carried out". There is no further definition of "person". As such,

⁵ The glossary to this document sets out relevant terms and their meaning for the purposes of this document.

anything a health service provider does to them must be done with their consent (at that point in time or in advance) or be in their best interests. It is not legally permissible to carry out procedures on such people just because those procedures will benefit someone else. However, it is assumed that the Code does not apply to deceased persons.

20. In many cases, where a partner requests the retrieval of gametes, the person from whom they are to be retrieved has suffered a recent trauma or medical event and is on life support. For example, in 2014 the High Court authorised the retrieval of sperm from a man who had suffered an irreversible brain injury following a heart attack.⁶ The man was on mechanical life support, and his medical team had agreed to continue mechanical ventilation for a short time while his wife sought approval to retrieve some of his sperm.
21. At present, there is no specific legal framework for this type of situation beyond the law as it generally applies to living persons who lack capacity to give informed consent. In ACART's view, it is important to define a clear and consistent approach to situations where gamete retrieval is a matter of urgency.^{7 8}

Overview of the issues

22. Reproduction involving people who are deceased or near death is one of the most ethically and legally complex issues in the field of assisted reproductive technology.
23. Most of us will not have considered whether we would want our gametes to be retrieved or used when we die or if we became permanently incapacitated so that we are unable to make decisions. Decisions about retrieving gametes shortly before or after death usually need to be made as a matter of urgency to ensure the gametes are viable. For surviving partners and family members, it is a time of great emotional distress. For those who have turned their mind to these questions, such as couples with gametes stored during IVF treatment, the current regulatory framework provides only partial clarity and pathways for action. The existing legislation and guidelines leave many areas unaddressed or unclear. As technology advances and new scenarios become possible, these gaps and uncertainties will only increase.
24. There are many significant legal issues to be considered, such as questions regarding the legality of removing tissue from a person who has died or whose death is imminent, and the posthumous use of that tissue for the purposes of reproduction. Can tissue be taken from a person who has not consented to its retrieval? If tissue is retrieved, who holds responsibility for its storage and use? If a

⁶ *Re M* [2014] NZHC 757.

⁷ Peart N. 2015. Life beyond death: Regulating posthumous reproduction in New Zealand. *Victoria University of Wellington Law Review* 46(3): 725–54.

⁸ Smajdor A. 2015. Perimortem gamete retrieval: should we worry about consent? *Journal of Medical Ethics* 41: 437–42.

child is conceived with a deceased person's gamete, what are that child's inheritance rights?

25. Posthumous reproduction also raises serious ethical concerns for different individuals, including the deceased or incapacitated individual, their partner, their family and any resulting children. Some of these issues include:
 - the significance of consent, and whether it is necessary that the person had agreed that in the event of their death they wanted to become a parent
 - the wellbeing of any children resulting from posthumous reproduction
 - the right of surviving partners to make their own decisions about having children, including using gametes from their deceased or incapacitated partner
 - the impact of posthumous reproduction on the deceased's wider family, including any existing children/siblings.
26. Suppose that a couple is planning on starting a family. Unexpectedly, the male partner falls into a coma and his death is imminent. The female partner wants to have his sperm retrieved, so that she can have his child in due course. Such a scenario raises a number of ethical questions, such as:
 - should the female partner be allowed to have the sperm retrieved?
 - is the male partner's consent important?
 - should anyone other than the female partner be able to use the sperm after the male partner's death?
 - would it make a difference if the male partner had died before his sperm was retrieved?
 - would it make a difference if the couple already had children together?
27. Such issues matter to the people at the centre of them, and raise broader questions for society about how we should frame public policy about posthumous reproduction. It is important that we consider a wide range of perspectives upon these issues.

Actual cases

In the United Kingdom in 1997, following a long legal battle, Diane Blood was granted permission to export and use her dead husband's sperm to have his child. Her case brought worldwide attention to the possibility of retrieving sperm or eggs from a dead or dying spouse in order to have children in the future. As lawyers sought permission for Mrs Blood to use her husband's sperm after his death, debate was sparked about the legal, ethical and religious aspects of posthumous reproduction. There was, and remains, a tension between scientific and reproductive possibilities, and legal and ethical considerations.

Closer to home, in 2017 in *Re Lee* the New Zealand High Court was asked to authorise the removal of sperm from a man who had just died, suddenly and unexpectedly. He had not considered the possibility of his partner wanting to retrieve and use his sperm to have another child, a full sibling for their first child. The Court approved the request to preserve Mr Lee's partner's ability to apply for ethical approval should she wish to use the sperm to have another child.

In 2015 the question of whether Cameron Duncan's gametes could be used after his death was discussed in the New Zealand media. Mr Duncan had banked sperm while undergoing cancer treatment. Several years after his death, his family sought permission for his sister's female partner to use the sperm to have a child.

ACART's role

28. The purposes of the HART Act guide ACART's work. The two purposes relevant to this review are:
- to secure the benefits of assisted reproductive procedures for individuals and for society in general by taking appropriate measures for the protection and promotion of the health, safety, dignity and the rights of all individuals, but particularly those of women and children⁹
 - to provide a robust and flexible framework for regulating and guiding the performance of assisted reproductive procedures.¹⁰

⁹ HART Act, s 3(a).

¹⁰ HART Act, s 3(d).

29. One of ACART's functions is to issue guidelines in respect of any matters relating to assisted reproductive procedures and to keep these under review.¹¹ The current Guidelines were issued in 2000, prior to the passing of the HART Act, in the absence of any legal framework for assisted reproductive technology.¹² They are narrow in scope, and only cover the storage, use and disposal of sperm collected with consent from a man before he died. At that time, it was not possible to allow the efficient freezing and thawing of eggs and grafting of ovarian tissue, processes that now extend the options for posthumous reproduction.¹³
30. Another of ACART's specific functions is to advise the Minister of Health on gametes derived from deceased individuals as they relate to assisted reproductive technology.¹⁴

¹¹ HART Act, s 35(1)(a).

¹² Douglass A, Daniels K. 2002. Posthumous reproduction: a consideration of the medical, ethical, cultural, psychosocial and legal perspectives in the New Zealand context. *Medical Law International* 5(4): 259–79.

¹³ At that time, although it was technically possible to retrieve sperm from a comatose man or within 24 hours of death, the NECAHR had not considered advice on that aspect of posthumous reproduction.

¹⁴ HART Act, s 38(c).

Regulatory setting

31. The current regulatory framework covering deceased and permanently incapacitated persons is piecemeal and unclear. It is a complex blend of the current Guidelines,¹⁵ the Human Assisted Reproductive Technology legislation, the Code, and common law.¹⁶ A recent case in New Zealand, *Re Lee*,¹⁷ highlighted the lack of statutory or regulatory provisions that deal explicitly with posthumous retrieval and use of sperm from a deceased man.

Human Assisted Reproductive Technology Act 2004

32. The HART Act is the key law that regulates assisted reproductive technology and human reproductive research in New Zealand. Paragraph 28 above sets out its relevant purposes. The Act gives ACART the function of providing information, issuing Guidelines, giving advice to the Ethics Committee on Assisted Reproductive Technology (ECART), and if it thinks fit, recommendations to the Minister of Health on gametes derived from deceased persons, in relation to human assisted reproductive technology (s 38(c)).

Human Assisted Reproductive Technology Order 2005

33. The HART Order is established by the HART Act. It lists fertility procedures that do not require approval from ECART because they are 'established procedures': that is, procedures that are done routinely during the course of fertility treatment. Guidelines issued by ACART do not apply to established procedures.
34. The HART Order excludes a number of fertility procedures from being established procedures. This means that even though certain procedures come within the HART Order's broad definition of an established procedure, they are generally seen to be more ethically complex, and still require individual ethical approval from ECART. These include:
- the use of sperm collected from someone who has since died and did not consent to the specific use before their death
 - the use of eggs retrieved from someone who is dead when the eggs are retrieved, or who stores eggs, and dies before they are able to be used.

¹⁵ The Guidelines have been superseded in part by the HART legislation.

¹⁶ As the Human Tissue Act 2008 excludes gametes and embryos from the definition of 'human tissue', it does not form part of the regulatory framework.

¹⁷ See footnote 2

Code of Health and Disability Services Consumers' Rights

35. The Code applies to living consumers, and is assumed not to apply to individuals who are deceased. The Code's consent requirements for health consumers, including those who are permanently incapacitated, are set out in rights 5, 6 and 7.
36. While the Code does not address all aspects of assisted reproductive technology, any regulations or guidelines covering assisted reproductive technology must be consistent with the Code.

Human Tissue Act

37. The Human Tissue Act 2008 explicitly excludes human embryos and gametes from its definition of 'human tissue'.¹⁸ However, some analogous policy considerations underpin this Act. It provides a model for consent and use of human tissue that takes into account the wishes of a deceased's family, and the wishes and interests of the deceased.

Coroners Act

38. The Coroners Act 2006 is relevant as part of the wider context. *Re Lee* confirmed that this Act does not currently give a coroner the power to authorise the retrieval of sperm from a body, while it is within the coroner's custody.

Retrieval of gametes

39. The retrieval of sperm or eggs from a deceased or permanently incapacitated person appears to be an established procedure, provided the person had previously consented to retrieval in such circumstances.¹⁹ This means that where there is prior consent, retrieval can occur without the need to seek approval from ECART.²⁰ The HART legislation does not specify the exact form of the requisite consent, stating only that 'no assisted reproductive procedure should be performed on an individual ... unless the individual has made an informed choice and given informed consent'.²¹ Accordingly, there is uncertainty as to how specific the consent must be and the form it must take.

¹⁸ As the Human Tissue Act 2008 does not exclude ovarian or testicular tissue, there is some overlap.

¹⁹ The HART Order includes the retrieval of sperm and eggs in its list of established procedures. It does not state that the retrieval must be from a *living* person.

²⁰ There is some debate as to whether there should be an additional source of legal authority expressly conferring the legal right to deal with a deceased body for the purposes of retrieving gametes.

²¹ HART Act, s 4(d).

40. In the absence of prior consent to retrieval, there is no clear legal basis for allowing retrieval of gametes from a deceased or permanently incapacitated person. Under the HART Act and HART Order, retrieval without consent would be an assisted reproductive procedure, requiring ECART approval under guidelines or advice issued by ACART. The current Guidelines state that the retrieval of sperm from a recently deceased or comatose person without that person's prior written consent is ethically unacceptable. No guidelines or advice have been issued in relation to the retrieval of eggs from a deceased or comatose person, meaning that ECART cannot approve such retrieval.
41. The legality of non-consensual gamete retrieval from a permanently incapacitated person remains unclear. In 2014, the High Court authorised the retrieval of sperm from a comatose man who had not provided prior written consent.²² However, as the legal basis of the decision is not clear, its precedent value is limited. The Code is relevant with respect to permanently incapacitated persons whose death is imminent. Right 7(4) of the Code provides that where a person is not competent to make an informed choice and give consent, a health care provider may treat the person if it is in the person's best interests to do so and consistent with their views (and in consultation with others), to the extent they can be ascertained. Arguably, the decision as to whether retrieval is in the best interests of the person will depend on individual circumstances.
42. In *Re Lee*, Justice Heath left open the question of whether there was jurisdiction for the Court to make the order in *Re M*.

Use of gametes and embryos

43. Under the HART Order, the posthumous use of sperm is an established procedure, but only if the person consented to the 'specific use' before they died.²³ The Order provides no guidance as to what constitutes specific use. It does not necessarily require a person to identify who may use the sperm, and therefore is inconsistent with the current Guidelines, which limit use of a deceased man's sperm to a 'specific person within a specified timeframe'.
44. Where there is no prior consent, posthumous use of sperm requires ECART approval.
45. The posthumous use of eggs is excluded as an established procedure, even if the woman had consented to such use while she was alive.²⁴ As ACART has not issued guidelines or advice on the posthumous use of eggs, ECART cannot approve such use. At the time the current Guidelines were prepared, egg freezing was not considered a reliable technique.

²² See footnote 6

²³ HART Order, schedule, pt. 2, cl 5.

²⁴ HART Order, Schedule, pt. 2, cl 7 states: 'Despite the descriptions of established procedures in Part 1, a procedure is not an established procedure if it involves the use of eggs collected from a person who is dead when the eggs are collected or who dies before the procedure is carried out'.

46. The HART legislation does not directly address implantation of embryos that were created prior to the death of the egg or sperm provider. It is current clinical practice that posthumous implantation into a surviving partner is considered an established procedure if the now deceased partner had consented to use of the embryos in the event of their death.

Recent New Zealand case on posthumous reproduction

47. In 2017, the High Court in Auckland considered whether it could authorise the posthumous retrieval of sperm without the prior consent of the deceased man.²⁵ Mr Lee²⁶ had died suddenly and unexpectedly. His partner, Ms Long, was pregnant at the time with their first child and wanted to have sperm taken from her partner so that at some point in the future she could have a second child, a sibling for the couple's first born child. This was the first New Zealand case to consider the issue in depth.
48. Justice Heath held that the Court had jurisdiction to authorise the posthumous retrieval of the sperm, because there was a gap in the law. There are no statutory or regulatory provisions that deal explicitly with the ability for a wife/partner to retrieve and use sperm from a deceased person/partner. It was considered appropriate to preserve Ms Long's ability to apply to ECART for approval to use the sperm.
49. While the Court could authorise the retrieval and storage of the sperm, it had no jurisdiction to authorise its use. That was for ECART to determine. In the meantime, the sperm was to be held by Fertility Associates as agent of the Court and not be released to Ms Long without approval from the Court.
50. ACART's current Guidelines on posthumous use of gametes would not allow ECART to approve an application from Ms Long to use her late partner's sperm, because he did not give prior written consent. There was no evidence that he had even considered the possibility of posthumous retrieval and use of his sperm.
51. Given the urgency with which sperm has to be retrieved after death, the Court's decision provides a pragmatic solution in the current inadequate regulatory environment. It preserves the ability of both Ms Long and ECART to address the future use of Mr Lee's stored sperm. In the event that this consultation resulted in changes to the HART Act or Order and ACART issuing revised guidelines, ECART could consider an application to approve the use of Mr Lee's sperm by Ms Long to create a child.

²⁵ See footnote 2

²⁶ All names are pseudonyms.



Posthumous retrieval: scientific details

52. Technically, it is possible to freeze eggs, sperm and embryos and use them after a person's death. In the case of frozen eggs or embryos, if the female partner has died, a surrogate, or new female partner, would be needed to carry the pregnancy.
53. Posthumous retrieval of sperm and eggs is also possible. Sperm can be retrieved from the testis or epididymis of a deceased man via a surgical procedure, such as removing all or part of one epididymis or testis and freezing the tissue at a fertility clinic for later use. In the case of a man who is permanently incapacitated, alternative clinical procedures may be used.²⁷
54. Immature eggs can be aspirated from the follicles in a woman's ovary after surgical removal of one or both ovaries. The eggs can then be frozen or matured in the laboratory of a fertility clinic by In Vitro Maturation (IVM). Currently this process is a lot less successful than the process of retrieving mature eggs in an In Vitro Fertilisation (IVF) cycle: in many cases no mature eggs, or very few, can be retrieved. In addition, the IVM technology is not widely available.
55. It is not currently possible to use testicular tissue from pre-pubertal boys to produce mature sperm. In some countries, the law allows this tissue to be frozen for boys whose fertility is threatened in the hope that advances will be made to allow its use in the future.
56. When there is a request to retrieve sperm or eggs to freeze for posthumous reproduction, the timeframe is critical. Sperm has successfully been retrieved up to 48 hours after a man's death. As eggs or ovarian tissue have rarely been retrieved from women after death for posthumous reproduction, no definite time window is known, but it is likely that the tissue would need to be retrieved within a few hours of death.

²⁷ For example, a procedure called electro ejaculation.

Ethical issues

57. The HART Act sets out principles to guide those performing functions under the Act. ACART's Ethical Framework interprets, explains and elaborates upon the principles in the HART Act.²⁸
58. The following sections set out the purposes and principles of the HART Act that should apply to the retrieval and use of reproductive material from people who are deceased or permanently incapacitated. These purposes and principles will apply in different ways for different circumstances.

Securing the benefits of assisted reproduction: s 3(a)

59. The first purpose of the HART Act is to secure 'the benefits of assisted reproduction', by ensuring that the 'health, safety, dignity and rights' of those potentially impacted by the use of these technologies are protected and promoted.
60. Assisted reproductive procedures enable people who are otherwise unlikely to have children to do so. This is their primary benefit. Whether or not the ability to have children counts as a benefit to a person depends upon whether that plays an important role in how they wish to live their life. Important interests that depend upon the preferences of individuals are best protected by valuing the liberty of people to pursue such activities. Therefore, securing the benefits of assisted reproductive technologies implies giving due weight to procreative liberty as this is the means whereby such benefits can be secured.
61. Retrieving gametes from somebody who is dead or incapacitated could preserve the surviving partner's procreative liberty interest, as it could enable them to have children with their deceased or incapacitated partner.
62. If the deceased had wanted to have children, posthumous reproduction is a way this desire could be fulfilled after their death. While there are reasons for being sceptical about the value of desires being realised after the event of our death, this is analogous to the way in which we view the preferences recorded in a will as important to honour.
63. A person's procreative liberty interests must be considered alongside other interests, such as consent of the person and the interests of the resulting child.
64. Posthumous reproduction might be thought beneficial in that it can:
 - honour the wishes of the person deceased

²⁸ Advisory Committee on Assisted Reproductive Technology. 2012. *Ethical Framework for ACART*. Wellington: Ministry of Health. URL: <https://acart.health.govt.nz/publications-and-resources/acart-publications/ethical-framework-acart> (accessed 1 March 2018).

- create a child who would be a full genetic sibling to any existing children
- create a child who has some aspects of a loved one now deceased.

Dignity and interest of gamete providers: s 4(d)

65. Whether or not a deceased person can be harmed, and whether he or she can have interests that can be realised even after their death, are complex philosophical questions. While it might be difficult to conceive of a deceased person having interests, arguably, dignity can apply to people who are deceased, and does apply to people who are permanently incapacitated.
66. If the deceased does have interests, allowing posthumous reproduction in cases where the person had given consent, might be thought of as a way of respecting their dignity. Conversely, the absence of consent may imply that the retrieval or use of their gametes is undignified, or even harmful to their interests.
67. Even if there is consent, posthumous retrieval of gametes or reproductive material could arguably be considered disrespectful to the deceased. Under s 150 of the Crimes Act 1961 it is an offence to improperly or indecently interfere with or offer any indignity to any dead human body or human remains.²⁹ This section has not often been used, but in Canada, a similar provision was interpreted to require that a defendant intentionally treated the remains in an undignified manner.³⁰ If the same approach were adopted in New Zealand, it seems unlikely that taking gametes with the consent of the deceased would amount to an offence under s 150.

Dignity and wellbeing of recipient: s 4(c)

68. The HART Act requires that due consideration is given to the impact of reproductive technologies upon the health, wellbeing, rights and dignity of those involved.
69. Posthumous reproduction can have implications, both positive and negative, for the dignity and wellbeing of a recipient; that is usually, a surviving partner. The literature indicates that the retrieval of gametes from a recently deceased partner can significantly assist in the grieving process, even if the surviving partner does not go on to use them.³¹ Using gametes from a deceased or incapacitated partner in order to have a child who is genetically related to that partner *might* be considered to contribute to the wellbeing of the recipient and resulting child.
70. Posthumous reproduction is relatively uncommon. There is the potential for the wellbeing and dignity of a child born via such means to be negatively impacted.

²⁹ Crimes Act 1961, s 150.

³⁰ *R v Mills* (1992) 77 CCC (3d) 318 (CA).

³¹ Bahadur G. 2002. Death and conception. *Human Reproduction* 17(10): 2769–75.

Status, rights and wellbeing of resulting children: s 4(a)

71. The wellbeing of any children resulting from posthumous reproduction should be considered in terms of not only the use but also the retrieval of gametes from deceased or incapacitated people.
72. Research indicates that psychological outcomes for a child who is created from material retrieved posthumously are no different from a child produced by other assisted reproductive technologies.³²
73. The wellbeing of resulting children will be influenced by the motivations of the intending parents. For example, a child could be negatively affected if the child was intended as a replacement for the deceased person, or if the parent's grief had an impact on their parenting capacity. Conversely, a child might benefit from knowing their genetic origins and from having a positive image of the deceased person, where the alternative is a parent who was an anonymous donor. The significance of such factors will be highly dependent on individual situations.
74. Posthumous reproduction also raises issues of inheritance rights and the legal status of the child. Currently, under the Status of Children Act,³³ if a woman uses the sperm of her deceased partner to conceive a child, the law will not regard her late partner as the father of the child. His name will not be entered onto the birth certificate. If the woman had not re-partnered at the time of the child's birth, the child will be deemed not to have a father and will have no rights in respect of their father or their father's estate. If the woman re-partnered before using her late partner's sperm to have a child, her new partner would be deemed to be the father of the child.
75. If the deceased is a woman and her surviving male partner wishes to use her eggs to have a child, he will have to re-partner or enter into a surrogacy arrangement. Either way, under the Status of Children Act, the resulting child will be deemed to be the child of the birth mother, not the deceased woman from whom the eggs were retrieved. The child will have no rights in respect of the deceased woman or her estate.
76. It may be appropriate for the child to share in the distribution of their mother's or father's estate, or have a claim for provision under the Family Protection Act 1955 for support and maintenance. If a parent's estate is to be divided among their

³² Robson SJ, Campbell S, McDonald J, et al. 2015. Pregnancy and childhood health and developmental outcomes with the use of posthumous human sperm. *Human Reproduction* 30(10): 2259–62.

³³ Status of Children Act 1969, as amended in 2004, which deems certain persons to be the parents and others not to be parents. Relevant provisions include the following.

- Section 17 deems the birth mother to be the mother of the child, regardless of whose gametes were used to conceive the child.
- Section 18 states that if the mother has re-partnered since the death of her husband, her new partner is the parent of the child if the new partner consented to the assisted reproductive procedure.
- Section 21 states that the man who provided the semen (the mother's late husband) will not be the father of the child for any purpose.
- Section 14 deems a mother who has not re-partnered to be a 'woman acting alone'.

children and it is possible that they parent further children at an undetermined time after their death, there may be a delay in the administration of the estate and the rights of existing children may be adversely affected.³⁴ The existing children may have to wait for their inheritance and would receive less if siblings could be conceived after their parent's death.

77. The United Kingdom and Australia have addressed these issues in legislation. The United Kingdom allows the deceased father of a posthumously conceived child to be entered on the birth register, while in some Australian jurisdictions the child has succession rights as well, subject to time limits to avoid extensive delays to the administration of estates.³⁵
78. A posthumously conceived child might also be eligible for 'fatal entitlements' from ACC under the Accident Compensation Act 2001 if their parent died in an accident. The Act provides for children born posthumously, but there are questions around definitions and time limits that might make the situation of the posthumously conceived child more complicated.

Dignity and interests of existing children: s 4(b)

79. Posthumous reproduction will have an impact on existing children within a family unit, and their interests should be taken into account. For example, the relationships between existing children and younger siblings conceived posthumously or after a parent became incapacitated should be considered.

Tikanga Māori: s 4(f) and (g)

80. The HART Act recognises the principles of the Treaty of Waitangi. Māori values and cultural practice are relevant to how we think about posthumous reproduction in New Zealand. ACART acknowledges that respecting the needs, values and beliefs of Māori does not mean that a pan-Māori perspective exists; nor do we promote such a perspective.
81. Traditional Māori belief holds that death is not an instantaneous process, but a progression from life to full death, and that life does not cease at the point of physical death.³⁶ Additionally, the wairua (spirit) is thought to begin the process of leaving the body at death, but to come and go from the corpse as it explores its new spiritual realm. Retrieving gametes and material from a deceased person could be seen to interfere with this process, or be disrespectful to the body or wairua.

³⁴ Peart N. 2015. Life beyond death: Regulating posthumous reproduction in New Zealand. *Victoria University of Wellington Law Review* 46: 725–54.

³⁵ See footnote 34

³⁶ Douglass A, Daniels K. 2002. Posthumous reproduction: A consideration of the medical, ethical, cultural, psychosocial and legal perspectives in the New Zealand society. *Medical Law International* 5: 259–79.

82. Traditional Māori society is often described as holistic. What affects one part is deemed to affect the whole. This includes individuals and families. The body of an individual can be seen as a physical manifestation of whakapapa. To bury a body that is not whole (because something has been taken from it), or to have parts living on outside the body, might be seen as disrespectful, and have ramifications for the ancestral line³⁷. This could have implications for the retrieval of ovarian or testicular tissue, and, depending on how the tissue is viewed, potentially gametes as well.
83. Tapu is the web of observances and rules that applies to this world and the next, ensuring consistency and safety for those who adhere to and respect it. Seeking to retain the life of an individual or to create a new life by retrieving and using gametes can be viewed as creating an interplay between the living and the dead that some Māori may view as upsetting the spiritual order.
84. A significant part of tikanga is that it facilitates and encourages collective decision-making. In traditional Māori society, the individual gained importance through being a member of the collective, and individual identity was defined through that individual's relationships with others. This has implications for posthumous reproduction, and for the decision as to who should be able to authorise the retrieval or use of gametes.

Respecting different views about spirituality, culture and mortality: s 4(g)

85. The 2013 Census found that just over one-quarter of people living in New Zealand were born in another country. Section 4(g) of the HART Act recognises the diversity resulting from migration and a pluralistic, multicultural society, and requires different ethical, spiritual and cultural perspectives to be considered and treated with respect in the context of assisted reproduction. An example of such respect might be an acknowledgement that, in general, Pasifika communities have a holistic perspective of health and wellbeing: they see an interconnectedness between spiritual/religious, cultural, emotional and social dimensions, and consider that health and wellbeing are often heavily influenced by family and community. As is true for Māori, we acknowledge that a pan-Pasifika perspective does not exist.
86. Different communities and different families hold different views about reproduction, spirituality, religion and mortality, which may affect their views on posthumous reproduction. For example, traditionally, social status in Pasifika cultures has been closely linked to family size and there may be specific protocols to be considered relating to issues regarding reproduction³⁸. Family members can have a significant influence on people's health decisions and the wishes of a deceased person's family are important.

³⁷ Lewis G., Pickering N (2003) Maori spiritual beliefs and attitudes to organ donation. *New Zealand Bioethics Journal* (February) 31-35.

³⁸ Paterson J, Tautolo E-S, Iustini L, et al. 2016. Pacific islands families studies: intimate partner stressors and psychological distress among pacific adults. *Sexual Relationship Therapy* 31(3): 301–11.

Consent: s 4(d)

87. Posthumous reproduction raises a number of issues about consent. There is a question as to whether consent is always required. The HART Act provides the principle in s 4(d) that those taking part in reproductive procedures must have made an informed choice and given informed consent. This implies that reproduction involving a deceased or incapacitated person should only ever occur in cases where they had specifically consented to posthumous retrieval and use.
88. In order to give informed consent, it is essential that individuals receive adequate information. For the gamete provider, this means they must receive information before their death or loss of capacity, and make a decision about events that will occur after their death.
89. There is a question about what counts as evidence of consent. This might include written or spoken formal consent (as in the Human Tissue Act), a presumption of refusal unless it can be shown on a balance of probabilities that the deceased would have consented, or a presumption of consent.
90. Analogies can be drawn between posthumous organ donation and the posthumous retrieval of gametes and reproductive material. Relatives play a large role in authorising organ donation after a person has died, even when the deceased had previously given consent. However, as previously noted, gametes are expressly excluded from the Human Tissue Act and this reflects the different ethical and public interest issues raised by retrieval of gametes and other types of tissue.³⁹
91. Despite the differences between gametes and other types of tissue, the Human Tissue Act provides a useful example of an approach to consent. In particular, it provides for others to give consent on behalf of a person if the person has neither consented nor objected to the posthumous retrieval and use of their tissue.⁴⁰
92. The Human Tissue Act gives primacy to the consent or objection of the deceased before they died, or of somebody nominated by that person to consent or object on their behalf. Legally, this consent is all that is required. In reality, however, certain complications can arise, including the following.
- It is not always clear how valid consent should be expressed or recorded
 - In practice, the wishes of the deceased's family are sought and followed, even when there is no legal necessity to do so.
93. Whatever position is favoured with regard to gamete donation, we need to pay attention to the practical realities of implementing it.

³⁹ See footnote 2

⁴⁰ Human Tissue Act 2008, s 31(2)(b)(i) and (ii).

Policy options for revised guidelines

94. This section addresses the following issues:

- 1) Posthumous retrieval - consent (1a sperm & 1b eggs and ovarian tissue)
- 2) Authorisation of retrieval of gametes or reproductive tissue from a deceased person
- 3) Retrieval from a permanently incapacitated person whose death is imminent
- 4) Posthumous use of stored material - consent
- 5) Use of material retrieved after or near to death - consent
- 6) Authorisation of posthumous use
- 7) Who should be permitted to use the material
- 8) When should posthumous use be subject to ethics review
- 9) Posthumous reproduction involving minors
- 10) Reproduction involving permanently incapacitated individuals whose death is not imminent.

1. Posthumous retrieval – consent (1a sperm & 1b eggs and ovarian tissue)

95. When we refer to posthumous retrieval of gametes, we are primarily referring to cases in which a man dies suddenly and unexpectedly, and his partner asks for his sperm to be retrieved for later use to have his child. In practical terms, it is unlikely that he will have given consent.
96. As technological and scientific advances are made, a wider range of options may become available for posthumous reproduction. We are therefore considering the underlying issues that apply to all possible scenarios, current and future.

Case illustration

Mr and Mrs D have been trying unsuccessfully to have a child for six years. They have seen a fertility specialist, and are about to begin fertility treatment. Mr D is in an accident and dies. Mrs D asks if his sperm could be retrieved to enable her to have the child they both wanted.

Consent

97. Where there is no prior consent, there is currently no clear legal basis for allowing retrieval of gametes from a deceased person. Under the HART Act, retrieval without consent would be an assisted reproductive procedure, requiring ECART approval under guidelines or advice issued by ACART. The current Guidelines state that the

retrieval of sperm from a recently deceased person without that person's prior written consent is ethically unacceptable.

98. In most cases where the posthumous retrieval of gametes is requested, the person has died suddenly and unexpectedly. If the deceased person had never thought about posthumous reproduction, their wishes on the matter will not necessarily be known. The fact that someone wanted to have children during their lifetime does not necessarily mean that they would have consented to their reproductive material being retrieved and used to conceive a child after death.
99. In the absence of explicit written consent, one policy option is to accept evidence of verbal consent from the deceased, or to infer consent from surrounding circumstances. For example, it may be reasonable to infer consent in circumstances where all involved agree that the deceased would approve, and their views are based on conversations with the deceased. Consent may also be inferred from someone's views and values, and surrounding circumstances. This is a type of substituted judgement approach to assessing a person's previously expressed wishes and preferences. It can also be argued that it seems harsh to refuse requests for posthumous gamete retrieval due to the absence of written consent in cases where those involved are confident of the deceased's wishes.
100. Other policy options include viewing posthumous retrieval as ethically permissible when:
 - there is no evidence of consent but reasons to suppose that having children is what the deceased wanted, or
 - there is no evidence of consent but no evidence that retrieval contradicts what the deceased would have wanted, or
 - a third option is to prioritise the autonomy of the person requesting the retrieval of the gametes ahead of the wishes of the deceased. This option might involve permitting posthumous retrieval in cases in which there is evidence of objection from the deceased. ACART is not promoting this approach. We note that it would be a significant departure from what happens in other areas after someone has died (such as organ donation).
101. Evidence of the wishes of the deceased can take many forms, such as conversations with GP or others, awareness that the deceased was trying to have children, prior IVF treatment or noting in one's will about future children. It might be that any one of these reasons is not indicative that the deceased wanted to have children, but collectively they could be an indicator of implied consent.
102. We acknowledge that people may have different responses to the questions depending on whether the material to be retrieved from the deceased is sperm, eggs or ovarian tissue.

Sperm

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).

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Posthumous <u>retrieval</u> of sperm should be permitted:</i>					
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

Eggs and ovarian tissue

If eggs and ovarian tissue are retrieved, their subsequent use will inevitably require a surrogate or new female partner, unless the person was in a same-sex relationship.

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).

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Posthumous retrieval of eggs or ovarian tissue should be permitted:</i>					
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

2. Authorisation of retrieval of gametes or reproductive tissue from a deceased person

103. If it is agreed that, in some instances, gametes and reproductive material could be retrieved posthumously without requiring prior written consent from the deceased, the question arises as to who should authorise the retrieval.
104. There are technical problems associated with the retrieval of gametes that make it very time-sensitive. After somebody has died, there is a small window of time in which gametes can be retrieved. Any mechanism for the authorisation of retrieval will need to enable decisions to be made quickly.
105. As previously noted, though the Human Tissue Act explicitly excludes human embryos and gametes from the definition of 'human tissue', its approach to consent may provide a useful model for authorisation of posthumous gamete retrieval.
106. The Human Tissue Act gives primacy to the wishes of the individual. However, it also provides for a hierarchy of other people who may consent or object to the retrieval of human tissue, provided nobody above them in the hierarchy has consented or objected. The four parties who may, in order, give consent or raise an objection are:

1. the individual
2. the individual's nominee/s
3. the individual's immediate family
4. a close available relative of the individual.

107. In addition to the parties identified in the Human Tissue Act, there are a number of other options:

- ECART to authorise the retrieval of gametes. (It may be impractical to assign ECART this responsibility, as it may be difficult to arrange a meeting of ECART within the requisite timeframe).
- Coroners to authorise the retrieval of gametes. (Giving coroners the power to authorise retrieval of gametes would extend their existing role. This option would not be appropriate in cases where retrieval is sought from an incapacitated person whose death is imminent.)
- The Family Court to authorise the retrieval of gametes.
- The High Court to authorise retrieval. (This court deals with matters that exceed the jurisdiction of the Family Court, particularly where complex issues are involved.)
- Joint authorisation: for example, from both the deceased's partner and the coroner.

108. We recognise that some of these options may have practical challenges or require changes to the existing jurisdiction or range of functions.

Consultation Question 2

Who should **authorise** the retrieval of gametes or reproductive tissue from a deceased person?

- 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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Gamete or reproductive tissue retrieval should be <u>authorised</u> by:</i>					
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

3. Retrieval from a permanently incapacitated person whose death is imminent

109. When somebody is permanently incapacitated and close to death, although there may be more time than in the case of a deceased person, there is still a limited timeframe in which their gametes can be retrieved, as in the case of *Re M*. In this situation too, the process of applying for consent or authorisation needs to be quick.
110. The existing legal framework on incapacitated individuals must be taken into account when considering how we should deal with requests for retrieval of gametes from an incapacitated person. Where a person no longer has capacity to provide consent, others may have legal authority to consent on their behalf. For example, the incapacitated person may have a welfare guardian or person with an enduring power of attorney. These people must act to promote the welfare and best interests of the incapacitated person and – as far as this can be determined – to act consistently with what the incapacitated person would have wanted.⁴¹
111. Where a person is incapacitated and no one else has authority to provide consent on their behalf, Right 7(4) of the Code provides that treatment can only be given where:
- (a) it is in the best interests of the consumer; and
 - (b) reasonable steps have been taken to ascertain the views of the consumer; and

⁴¹ Right 7(4), Code of Health and Disability Services Consumers' Rights.

- (c) either, –
- (i) if the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - (ii) if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

112. A question arises as to whether retrieving gametes from a permanently incapacitated person is in their best interests. There is also a question as to whether it is ever appropriate for another person to make decisions about the retrieval of gametes from living persons.

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?

Consultation 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

4. Posthumous use of stored material - consent

113. When we refer to the posthumous use of stored material, we are primarily referring to cases in which a man has stored sperm with a fertility clinic and his partner wishes to use it after his death.
114. There may also be instances in which a couple has stored embryos, and the surviving partner wants to use them after the other partner has died. In the event that both partners died, for example in a car accident, it is possible that a third party, such as a parent or sibling, could want to use a stored embryo.

115. There are also scenarios where a woman freezes eggs while she is alive and competent to consent to the retrieval. In this instance, if her surviving partner is a male, and she has consented to their use in the event of her death, a surrogate will be needed to carry the pregnancy.

Case Illustration 1

A man has his sperm stored prior to undergoing cancer treatment. After his death, his partner asks to use the sperm to have a child.

Case Illustration 2

A couple have been undergoing fertility treatment, and have eggs stored at a clinic. The woman dies suddenly. Knowing that the couple have been trying to have a child, a close friend offers to carry a baby for the surviving partner. The arrangement complies with the appropriate surrogacy guidelines.

Consent

116. When people arrange to store sperm, eggs or embryos at a fertility clinic, they sign a consent form specifying what they would like to happen in the event of their death.
117. Currently, the posthumous use of sperm is an established procedure, provided that the deceased person consented to its 'specific use' before he died. However, there is no guidance as to what constitutes 'specific use' under the HART Order.
118. Where there is no prior consent to the specific use, the posthumous use of sperm is an assisted reproductive procedure that requires ECART approval. The current Guidelines state that, where consent has not been obtained, an application for ethical review must be submitted, and a counselling report should be included as part of the application.
119. For the interests of completeness, ACART is considering and consulting on:
- what should happen in instances where there is written consent
 - what should happen in instances where there is no written consent.
 - ACART is also consulting on whether there should be new guidelines that include the posthumous use of eggs and embryos.

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).

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<u>Posthumous use of stored gametes or embryos should be permitted:</u>					
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

5. Use of material retrieved after or near to death - consent

120. When we refer to the use of material retrieved posthumously, we mean instances where gametes or reproductive tissue have been retrieved from somebody after or shortly before their death, and there is subsequently a request for the material to be used.

Case Illustration 1

A woman was permitted to have sperm retrieved from her partner after his death. Two years later, she wants to use his sperm to try and have a child.

Case Illustration 2

A man was permitted to have eggs retrieved from his wife after her death. Several years later, he is convinced that he will not want to re-partner. Knowing of his strong desire to have a child, and that his wife had also wanted to become a mother, his wife's sister offers to act as a surrogate, carrying a baby created from the man's sperm and the wife's egg. The man considers this offer and agrees.

Consent

121. As outlined above under *Use of gametes and embryos*, currently, the posthumous use of sperm is an established procedure, provided that the deceased person consented to its 'specific use' before he or she died. In the absence of such consent, posthumous use of sperm requires ECART approval. The posthumous use of eggs is expressly excluded from being an established procedure and would also require ECART approval as an assisted reproductive procedure.
122. Because, in this situation, the material has been retrieved posthumously or following permanent loss of capacity, rather than being stored at a clinic while the deceased was still alive, it is very unlikely that written consent to its posthumous use will exist.
123. For the interests of completeness, ACART is considering, and consulting on, what should happen in instances where there is written consent and also in instances where there is not written consent. The same policy considerations as outlined above under *Posthumous retrieval/consent* also apply here.
124. We anticipate that the approach taken to consent, in the context of posthumous retrieval, would be the same as that taken to consent, in the context of posthumous use. This is because posthumous retrieval must presuppose that use could be approved.

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).

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Posthumous use of gametes or reproductive tissue retrieved after or near death should be permitted:</i>					
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

6. Authorisation of posthumous use

125. The HART Act and Order provide a framework for authorising the posthumous use of gametes, tissue or embryos. Under this framework, an application must be made to ECART as the ethics body that considers applications for assisted reproductive procedures. In contrast to authorisation of posthumous retrieval, time sensitivity is unlikely to be an issue in an application for posthumous use.
126. It could be considered that a different mechanism is appropriate for authorisation of the posthumous use of reproductive material. The Human Tissue Act's hierarchy of consent, discussed above, could be one alternative mechanism we could use in determining who should authorise the use of reproductive material.

127. In addition to the considerations the Human Tissue Act takes into account, there is an additional aspect pertaining to the use of reproductive material that we need to consider: some people (for example, the deceased's partner and family) will have a vested interest in the outcome that will influence their judgement. For instance, a partner could wish to use the material to have a child, or a parent could wish to use it to have a grandchild.
128. Another option is for the Family Court to authorise posthumous use, because its purpose is to assist New Zealanders with family issues, and it deals with issues relating to the welfare of children.
129. Another option is for the High Court to authorise posthumous use, because it deals with matters that exceed the jurisdiction of the Family Court, particularly where complex issues are involved.
130. Joint authorisation could also be required for the posthumous use of gametes, embryos or tissue: for example, from both the deceased's partner and ECART.

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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Posthumous use should be authorised by:</i>					
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

7. Who should be permitted to use the material

131. It is generally the surviving partner of the deceased, or a family member of the deceased, who wants to use the deceased's reproductive material.
132. One policy option would be to restrict the posthumous use of reproductive material to the partner of the deceased only. This would mean that, genetically speaking, any resulting children would be akin to those who would have come about had the deceased lived. If the couple already had a child, as in *Re M* and *Re Lee*,⁴² any posthumously conceived child would be a full sibling of the existing child.
133. Another policy option would be to also allow family members of the deceased to use the material. Requests from family members who are not partners of the deceased can come about when someone (for example, a sibling) wants to have children but their own gametes are unsuitable, or they have no partner, or they are in a same-sex relationship, and they wish to be genetically related to their children.
134. Another policy option would be to not restrict the use of reproductive material, and allow anybody to use it regardless of their relation or lack of relation to the deceased. For example, the deceased's partner might want to donate sperm to a friend who is in need of donor sperm.

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?

Consultation responses

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Reproductive material should be permitted to be used by:</i>					
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

⁴² See footnote 6; See footnote 2.

8. When should posthumous use be subject to ethics review

135. Currently, ECART approval is required for all posthumous use of gametes, other than the use of stored sperm where there is consent to the specific use. There may be other situations in which ethics review should not be required.

136. There are four main options:

- a) to require ethics review for all posthumous use of gametes and embryos
- b) to never require ethics review
- c) to require ethics review only in certain situations, such as if the gametes or embryos are to be used by a third party
- d) to exempt certain uses from ethics review, such as if the gametes or embryos are to be used by the person's partner to create a full sibling for existing children.

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 require ethics review if a third party wishes to use them	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

9. Posthumous reproduction involving minors

137. 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.
138. This provision could be interpreted as a blanket ban on any posthumous use of gametes obtained from a minor, even if the minor had become an adult and consented as an adult and then died. Obviously, gametes belonging to somebody who is deceased could never be used by the individual, or to bring about the birth of a child to be brought up by that individual.
139. This section is aimed at protecting the vulnerability of minors, while preserving their reproductive capability. It may be that the vulnerability of an individual under 16 does not exist after their death. There may be reason to remove these restrictions.
140. Another consideration is that of 'mature minors': children or young people who are considered to have the capacity to consent to medical treatment or procedures on their own behalf, because they are able to fully understand what will happen. On this consideration, it could be that obtaining or using gametes from mature minors is acceptable.

Case Illustration 1

A 15 year old minor banked sperm prior to undergoing cancer treatment. Before his death at age 17, he gave his mother written authority to determine what should be done with his sperm in the event of his death. His sister and her female partner want to use his sperm to have a child.

Case Illustration 2

Eggs are retrieved from a 14 year old minor prior to undergoing cancer treatment. 10 years later as an adult she dies, and her husband wants to use her previously stored eggs to create a child.

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?

Consultation responses

	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

10. Reproduction involving permanently incapacitated individuals whose death is not imminent

141. Situations in which a potential gamete donor is conscious with no imminent likelihood of death but has permanently lost capacity to provide consent are beyond the scope of this consultation. However, ACART would like to obtain feedback as to whether there is a need to consider permanently incapacitated individuals, whose death is not imminent, in the future.

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

Glossary

This glossary is a list of terms used throughout this document. It does not present technical definitions.

Advisory Committee on Assisted Reproductive Technology (ACART)	The advisory committee established under New Zealand's Human Assisted Reproductive Technology Act. The Minister appoints members. See www.acart.health.govt.nz
Assisted reproductive procedure	The Human Assisted Reproductive Technology Act defines an assisted reproductive procedure as a procedure performed for the purpose of assisting human reproduction that involves: the creation of an in-vitro human embryo, or the storage, manipulation or use of an in-vitro human gamete or an in-vitro human embryo, or the use of cells derived from an in-vitro embryo, or the implantation into a human being of human gametes or human embryos; but does not include an established procedure.
Capacity to consent	The ability to make and communicate an informed decision.
Cryopreservation	The process of freezing and storing cells, gametes and embryos at very low temperatures to maintain their viability when thawed for use. Typically storage is in liquid nitrogen at -196C.
Donation	The giving of gametes or embryos for reproductive purposes.
Donor	A person whose gametes or embryos are given to another person for use in assisted reproduction. See s 5 of the HART Act.
Ethics Committee on Assisted Reproductive Technology (ECART)	The ethics committee established under the HART Act. On a case-by-case basis, ECART reviews and decides applications to undertake assisted reproductive procedures, to undertake human reproductive research and to extend the statutory storage period of gametes and embryos. The Minister of Health appoints members. See www.ecart.health.govt.nz
Electro ejaculation	A medical procedure to obtain semen/sperm when a man is unable to provide it. A mild rhythmic delivery of an electric current is used to induce the ejaculation of semen/sperm.
Established procedure	A procedure declared in the HART Order that does not require ECART review and approval. See s 6 of the HART Act.
Gamete	An egg or sperm, whether mature or not, or any other cell (whether naturally occurring or artificially formed or modified) that contains only one copy of all or most chromosomes and is capable of being used for reproductive purposes.
Genetically related	Where an embryo is created by the sperm and/or eggs of the intended parent/s.
Human Assisted Reproductive Technology (HART) legislation	The Human Assisted Reproductive Technology Act 2004 and Human Assisted Reproductive Technology Order 2005. ACART and ECART were established under the HART Act.

Human reproductive research	Defined in the HART Act as research that uses or creates a human gamete, a human embryo or a hybrid embryo.
Incapacitated	Lacking the ability to make legally binding decisions. The term 'diminished capacity' is sometimes used with a similar meaning to reflect that capacity or incapacity is not an absolute concept and is decision-specific.
Imminent	Of an event etc. (almost always of evil or danger): Impending threateningly, hanging over one's head; ready to befall or overtake one; close at hand in its incidence; coming on shortly (<i>Oxford English Dictionary</i>).
Implantation	For the purposes of assisted reproduction, the transfer and attachment of an embryo to the uterus.
Posthumous reproduction	The retrieval or use of gametes or tissue from somebody who has died for the purpose of reproduction.
Procreative liberty	An individual's freedom to make their own decisions about having children.
Reproductive tissue	Tissue that is used for the purposes of reproduction, includes testicular and ovarian tissue.
Surrogacy	The process whereby a woman becomes pregnant, carries and delivers a child on behalf of another person or couple (the intended parent/s).
Surrogacy guidelines	Guidelines issued by ACART relating to surrogacy – currently the <i>Guidelines on Surrogacy Arrangements involving Assisted Reproductive Procedures</i> .

Bibliography

American Society for Reproductive Medicine. 2004. Posthumous reproduction. *Fertility and Sterility* 82: S260–2.

American Society for Reproductive Medicine. 2013. Posthumous collection and use of reproductive tissue: a committee opinion. *Fertility and Sterility* 99(7): 1842–5.

Bahadur G. 2002. Death and conception. *Human Reproduction* 17(10): 2769–75.

Collins R. 2005. Posthumous reproduction and the presumption against consent in cases of death caused by sudden trauma. *Journal of Medicine and Philosophy* 30: 431–42.

Crimes Act 1961.

Douglass A. 1998. *Assisted human reproduction: posthumous use of gametes*. (Master's thesis.) University of Otago, Dunedin, New Zealand.

Douglass A, Daniels K. 2002. Posthumous reproduction: a consideration of the medical, ethical, cultural, psychosocial and legal perspectives in the New Zealand context. *Medical Law International* 5(4): 259–79.

Health and Disability Commissioner (*Code of Health and Disability Services Consumers' Rights*) Regulations 1996.

The Human Assisted Reproductive Technology Act 2004.

Human Assisted Reproductive Technology Order 2005.

Human Tissue Act 2008.

Jones S, Gillett G. 2008. Posthumous reproduction: Consent and its limitations. *Journal of Law and Medicine* 16(2): 279–87.

Kindregan CP Jr. 2009. Dead dads: Thawing an heir from the freezer. *Suffolk University Law School Legal Studies Research Paper Series* 35: 433–48.

Knapp C, Quinn G, Bower B, et al. 2011. Posthumous reproduction and palliative care. *Journal of Palliative Medicine* 14(8): 895–8.

Kramer AC. 2009. Sperm retrieval from terminally ill or recently deceased patients – a review. *Canadian Journal of Urology* 16(3): 4627–31.

Landau R. 1999. Planned orphanhood. *Social Science and Medicine* 49(2): 185–96.

Lewis G, Pickering N. (2003) Maori spiritual beliefs and attitudes to organ donation. *New Zealand Bioethics Journal* (February) 31–35.

Middleton SL, Buist MD. 2009. Sperm removal and dead and dying patients: a dilemma for emergency departments and intensive care units. *Medical Journal of Australia* 190(5): 244–6.

Moore A. 2000. Posthumous Reproduction. *Otago Bioethics Report* 9/1 (February): 11–14.

Moore A. 2005. Postmortem Reproduction, Consent, and Policy. In Aiken W, Haldane J (eds) *Philosophy and its Public Role*, Exeter (UK) and Charlottesville (VA), Imprint Academic 105–121.

- National Ethics Committee on Assisted Human Reproduction. 2000. *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*. Wellington: Ministry of Health.
- National Ethics Committee on Assisted Human Reproduction. 2005. *Guidelines for Research on Gametes and Non-viable Embryos*. Wellington: Ministry of Health.
- Orr RD, Siegler M. 2002. Is posthumous semen retrieval ethically permissible? *Journal of Medical Ethics* 28(5): 299–303.
- Paterson J, Tautolo E-S, Iustini L, et al. 2016. Pacific Islands families studies: intimate partner stressors and psychological distress among pacific adults. *Sexual Relationship Therapy* 31(3): 301–11.
- Peart N. 2015. Life beyond death: Regulating posthumous reproduction in New Zealand. *Victoria University of Wellington Law Review* 46: 725–54.
- Pennings G, de Wert G, Shenfield F, et al. 2006. Taskforce on ethics and law: posthumous assisted reproduction. *Human Reproduction* 21(12): 3050–3.
- Re M* [2014] NZHC 757.
- R v Mills* (1992) 77 CCC (3d) 318 (CA).
- Re Lee (Deceased)* [2017] NZHC 3263.
- Robson SJ, Campbell S, McDonald J, et al. 2015. Pregnancy and childhood health and developmental outcomes with the use of posthumous human sperm. *Human Reproduction* 30(10): 2259–62.
- Shefi S, Raviv G, Eisenberg ML, et al. 2006. Posthumous sperm retrieval: analysis of time interval to harvest sperm. *Human Reproduction* 21(11): 2890–3.
- Smajdor A. 2015. Perimortem gamete retrieval: should we worry about consent? *Journal of Medical Ethics* 41: 437–42.
- Status of Children Act 1969 as amended in 2004.
- Strong C, Gingrich JR, Kuttah WH. 2000. Ethics of post-mortem sperm retrieval. *Human Reproduction* 15(4): 739–45.
- Strong C. 2006. Gamete retrieval after death or irreversible unconsciousness: what counts as informed consent? *Cambridge Quarterly of Healthcare Ethics* 15(2): 161–71.
- Swinn M, Smith M. 1998. Retrieving semen from a dead patient: Utilitarianism in the absence of definitive guidelines. *British Medical Journal* 317: 1583–5.
- Thomas C. 2006. *A framework for the collection, retention and use of human body parts*. (PhD thesis.) Victoria University of Wellington, Wellington, New Zealand.
- Victorian Law Reform Commission. 2007. *Assisted Reproductive Technology and Adoption: Final Report*. Melbourne: Victorian Law Reform Commission.

Feedback form

Please provide your contact details below.

Name	Dr Joy McIntosh, Rev Dr Graham O'Brien
If this feedback is on behalf of an organisation, please name the organisation	InterChurch Bioethics Council, New Zealand
Please provide a brief description of the organisation (if applicable)	The InterChurch Bioethics Council (ICBC) is an ecumenical, cross-cultural body elected and supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand (www.interchurchbioethics.org.nz). ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education.
Address/email	jrjak.mcintosh@xtra.co.nz
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Our science, ethics and medical fields include assisted reproductive technologies, with ICBC aiming to present information on the background science and accompanying ethical questions to allow informed discussion in our faith congregations and the general 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

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
<i>Posthumous <u>retrieval</u> of sperm should be permitted:</i>					
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.

Four fundamental concerns ICBC have identified for this entire ethical review are:

- a) this document does not provide any question from the perspective of, or about the rights of, any future child, or the need to provide a community for any future child. Future uncertainty and a supportive community for any child born using posthumous reproduction needs to be ethically considered, with first priority on non-harm and thriving of the child.
- b) counselling and grief support must surround the partner/family during posthumous decisions.
- c) from both Western and Māori views, these are not individual rights or decisions to be made alone.
- d) key questions that Māori would ask need to hold equal priority in this enquiry.

Our comments for this section 1a) on sperm posthumous retrieval also apply to our answers for 1b) egg and ovarian tissue retrieval, and are pertinent for several of the other consultation questions:

- We believe explicit consent is critical for this practice to gain approval ie no consent, no retrieval. Written consent already allows legal retrieval, evidence of verbal consent would require thorough ethical examination and clear evidence must be ascertained through previous discussions with the spouse, significant other and/or family, and friends. Absence of donor intent may be tantamount to invasion of privacy, hence, would therefore be a ground for denial of request.

- Due to the nature of the request, despite the short time frames involved for successful retrieval, ethically it is important to identify the motives of the request for retrieval both with written and verbal consent eg. wanting to hold onto the deceased or provide a reminder, or denial of death. We note here that grief support through nursing, social services, spiritual care and mental health services needs to be offered to families during and after bereavement, including while making posthumous reproduction requests with both written and verbal consents. A minimum time before gamete use might allow time for counselling, and a maximum storage limit could reduce potential legal problems.

- The future uncertainty for any child born under circumstances using posthumous reproduction needs to be ethically considered, eg under current law would not have a father noted on the birth certificate. Legislation should address the rights of the children who through no fault of their own, often become victims of new reproductive technologies, rather, than beneficiaries.

- This is not an individual right or decision. Having the 'choice' to create another life utilizing the method of posthumous reproduction, and the principle of 'individual rights,' come from a Western perspective and focus on the individual and not on whānau. This 'choice,' this 'decision,' this 'right to choose,' for Māori does not operate in a vacuum. The impact of this type of decision affects not only whānau, but hapu and iwi. Any decision affecting a whānau member, needs to incorporate all whānau in making the decision. As whānau, we are also answerable to our Atua, our Tupuna, and our people for any decisions we make that impact on all those we whakapapa to. We are also answerable to our mokopuna and future generations. What we decide now impacts on the present, but also the past and the future.

- Even in Western culture there needs to be a strong community ethic as families and communities and society, will be impacted at some stage. The scenarios outlined and questions imply this is a single person choice (the partner who is alive).

- Issues of justice – will this be a procedure only accessible to the wealthy since the collection and storage are costly, as is IVF (and possible screening depending on the nature of conditions leading to death of parent).

- Throughout reflecting on these consultation questions, there is a sense of extending our human penultimate role into areas of the ultimate (to use Bonhoeffer's distinction) in the decisions to create life. Moana Jackson asked a key question during the debate around the relevance and significance for Māori of genetic engineering and genetic modification, especially during the Royal Commission on Genetic Modification. His question was: "Always go back to the same question: Do you think our tupuna [ancestors] would have agreed to putting [human] genes in sheep?" A similar question could be asked here: "Do you think our tupuna would have agreed to the creation of life from the method and process of posthumous reproduction?" Similarly, another question posed during this period of the Royal Commission on Genetic Modification, was a question posed by Angeline Greensill: "Tampering with whakapapa is likely to have a negative effect on the mauri of the species involved as well as on the whānau and hapu." This question has relevance with regards to posthumous reproduction.

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
<i>Posthumous <u>retrieval</u> of eggs or ovarian tissue should be permitted:</i>					
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 comments for egg and ovarian tissue posthumous retrieval are the same as for 1a) sperm posthumous retrieval.

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
<i>Gamete or reproductive tissue retrieval should be <u>authorised</u> by:</i>					
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.

- Only the legal spouse or partner should be allowed to be the primary requestor for posthumous retrieval of sperm or eggs/ovarian tissue with consent of the deceased person. In no situations should this be a decision for a direct relative eg mother or father retrieving/using gametes of a deceased child, as this directly risks a “replacement” mentality, with psychological risk to any resulting child.
- After the partner’s request, consent allowing retrieval (written or verbal) needs to be verified and authorised - written consent by coroner and partner, verbal consent by ECART or Family Court with the partner.
- If time is too short for ECART/family Court decision, then a coroner could authorise retrieval, but ethical decision by ECART/Family Court would be required for use of retrieved material.
- the partner’s request also requires whānau/community input and support/counselling where possible.

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.

- Others (whether legal partner or authorisation group) should not be allowed to retrieve gametes from a dying person without their consent because the focus would become what is beneficial for others, rather than what is good for the incapacitated person who is about to die. Without written or strong evidence for verbal consent from a partner, the retrieval process would be invasive and not give dignity to, or be in the best interests of, the dying person.
- Instead, processes of verification of consent and therefore authorisation (to ECART/family court/coroner) by partner could be initiated, for possible and timely gamete retrieval after the person's death.
- There needs to remain the separate policy (as in the Human Tissue Act) between posthumous reproductive tissues and organ donation. As in this Act, gametes, reproductive tissues and embryos have a different value than other organs and tissues, which retrieval and donation can be consented to by next of kin.

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
<i>Posthumous use of <u>stored gametes</u> should be permitted:</i>					
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.

- Posthumous use of stored gametes should be permitted only with consent, as shown by the score above. Upon collection and storage of gametes, fertility clinics should register (ie written consent) a client's wishes as to what can happen to their gametes if they should die.
- The production of embryos is different and would be the strongest case for verbal and inferred consent to be accepted. Storage of embryos implies a future desire for children and action has already been taken (ie IVF and storage) to indicate this. Presumably in this context – the desire for children was shared by both partners, prior to incapacitation or death.
- However, fertility clinics should be required to have a full record of both parent's wishes upon death. These records should be explicit and in enough detail to clarify all situations (death, incapacitation etc) and be updated if a parent's consent changes.

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
<i>Posthumous use of gametes or reproductive tissue retrieved after should be permitted:</i>					
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.

- As noted in question 3, we do not believe the retrieval (and hence use) of gametes from incapacitated people near death should be allowed, so the above score is only for 'after death'.
- There should be linking of the authorisation of gamete/tissue retrieval and the authorisation of gamete/tissue use, since retrieval implicates a request for a potential future use.
- When a deceased person has consented to sperm/egg/embryo retrieval and 'specific use' before he or she died, this should be verified allowed (as is currently the case with sperm use).
- Without written consent, the process permitting gamete/tissue use should also be tied in with any permission for posthumous retrieval, eg. partner+ECART/Family Court.
- We note here that some couples might be currently planning a family or are in the middle of having a family already with a child or children, when one partner suddenly dies, and it is unlikely there is written consent as there would be in the case for stored gametes. Close ethical consideration is required for verbal consent of the deceased partner; inferred consent would be too open to manipulation and incorrect estimation of consent. This consideration also has to weigh the benefit for resulting children and their siblings, the emotional health/strength/support of the family for future children, as well as the 'procreative liberty interest' of the surviving partner.

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
<i>Posthumous use should be authorised by:</i>					
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.

- In cases where posthumous retrieval of gametes and tissue has occurred, authorisation of gamete/tissue/embryo use should be linked in with the retrieval authorisation. - Where gametes/tissue/embryos were stored prior to death, authorisation of deceased person's consent recorded by fertility clinic would be required jointly by partner and ECART or Family Court. This ethical check even with written consent gives the best protection for any unborn child(ren). - As commented before, close relatives and nominees should not be allowed to request use.
--

Consultation Question 7

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

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

Response

	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree
<i>Reproductive material should be permitted to be used by:</i>					
the deceased's partner only- gametes	1	2	3	4	5
family members of the deceased as well as the deceased's partner – for embryos	1	2	3	4	5
Anybody	1	2	3	4	5

Please add comments about your response if you wish.

- For gametes and reproductive tissue, only the surviving partner should be permitted to use this material. Sibling use of deceased siblings gametes without explicit consent of the circumstances would be unacceptable.
- For embryos, the surviving partner would have priority choice for use. There may be a case for a sibling of deceased or surviving partners to surrogate for a surviving male parent, or a sibling to surrogate then parent if no partners are surviving – this would require considerable ethical deliberation. We do not believe this use should be granted to parents of the deceased.

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.

- We strongly agree that all posthumous use of gametes and embryos should be subject to ethics review. This could be carried out with the retrieval authorisation (joint partner and ECART/Family Court) or separately to ensure the situation is the same as when the initial authorisation for retrieval was carried out.
- This ethical consideration over all use of posthumous tissues and embryos ensures best ethical process and consideration of family outcomes for resulting children and to reducing potential harm. Since request for posthumous use is small, this should not prove unsustainable to authorising bodies.
- There should be no posthumous use of gametes by a third party. Ethical consideration is required if use of embryos is requested by a family member with consent from the deceased.

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.

- Our responses to the previous questions would change if the deceased person was a minor, since the minor would not have been planning a family with a legal partner during their lifetime as a minor.
- The provisions in s12 of the HART Act should continue to apply when the individual concerned is deceased ie 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 (or legal partner) from whom the gamete was obtained.
- In no cases should material be collected posthumously from a minor.
- In no cases should material collected while a minor was alive, be used if death has occurred as a minor. As with Case 1 supplied for this question, this scenario implies no partner, so parents or others would be making the requests, which we do not agree to. Case 1 highlights the difference between the value and potential of reproductive tissues compared to other organs and tissues (as noted by the Human Tissues Act not including reproductive
- e tissues), and so responsibility for those tissues should not be allowed to be transferred to next of kin.
- In cases where gametes have been retrieved as a minor for medical reasons, and the person dies later as an adult having given consent to a partner for use of those gametes (as in supplied Case 2), ethical consideration should follow a request.
- The provisions of s12 Hart Act should remain if the minor is considered 'mature' ie estimated maturity of a minor would not alter authorisation.

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.

- This would only affect a small number of people but is worth considering in the future.
- Prior consent of the incapacitated person would be at the core of this consideration, evidenced by storage of material or by partner’s evidence. Dignity of the incapacitated person and benefit to resulting child need to be considered as well as how this incapacitation impacts ability of partner ever to have a child (procreative liberty interest of the partner with capacity).
- The reason for incapacitation also needs to be considered ie genetic conditions that could affect the offspring, accident which interrupts future hopes for a family for both incapacitated person and partner.