



Advisory Committee on Assisted Reproductive Technology

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

Stage two consultation document

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Foreword

In New Zealand, fertility services are regulated through the Human Assisted Reproductive Technology Act 2004 (HART Act). The HART Act requires the Advisory Committee on Assisted Reproductive Technology (ACART) to develop guidelines and review them as needed. ACART must do this with respect for both the HART Act and, as a Crown-appointed body, for the principles of the Treaty of Waitangi. This includes consulting with the public in a meaningful manner.

This consultation document seeks your thoughts on proposed guidelines for posthumous reproduction.

Posthumous reproduction involves using a person's reproductive tissue, sperm, eggs or stored embryos after their death. While scientific advances in retrieving and freezing gametes have made this form of reproduction possible, there are complex ethical and legal issues that have not yet been resolved. The uses of stored gametes, embryos and tissues depend heavily on what a person consented to at the time of storage.

ACART adopted the existing Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man in 2000, developed before the HART Act was passed. These guidelines have a limited scope and do not address recent technological developments, such as egg freezing. ACART believes they should be replaced, and the scope expanded to include eggs, reproductive tissue and embryos stored before a person's death and the potential for gametes or reproductive tissue to be retrieved after a person's death.

ACART consulted the public in 2018 on posthumous reproduction, and the responses from that consultation have informed the development of the guidelines proposed here.

ACART seeks your feedback on the proposed guidelines and important policy issues, including the consent requirements for the use of gametes, reproductive tissue or stored embryos after someone has died. Your submissions will be carefully considered while finalising new guidelines and advising the Associate Minister of Health.



Dr Kathleen Logan

Chair, Advisory Committee on Assisted Reproductive Technology

July 2020

How to have your say

Your feedback can help ACART develop appropriate and effective guidelines on posthumous reproduction.

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 ACART or the Ministry of Health's web page, or
2. emailing a completed feedback form or your comments to acart@health.govt.nz, or
3. posting a completed feedback form or your comments to:

ACART Secretariat
PO Box 5013
Wellington.

ACART welcomes your views on the proposed guidelines and related issues.

Publication of feedback

We may publish all submissions, or a summary of submissions on ACART's website.

Official Information Act requests – name and contact details

In accordance with guidance from the Ombudsman, the Ministry of Health's (the Ministry's) standard procedure is to not release the name and contact details of any submitter who has given feedback in their private capacity (ie, not in a professional capacity or on behalf of an organisation) and who has requested that their personal 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 1982. If you consider that we should withhold your or your organisation's name and/or contact details under the Official Information Act 1982, please make this clear on your feedback form, noting your reasons.

Further guidance on releasing information under the Official Information Act 1982 is available from the Ombudsman's website at:
www.ombudsman.parliament.nz/resources-and-publications.

The closing date for feedback is 30 September 2020.

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Executive summary

1. This consultation document seeks feedback on draft guidelines for the use of gametes and reproductive tissue from deceased people and already stored embryos from the now deceased. These are proposed to replace the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*¹ (the current guidelines).
2. The current guidelines were published by the National Ethics Committee on Assisted Human Reproduction (NECAHR) in 2000, before the Human Assisted Reproductive Technology Act 2004 (HART Act) was introduced and subsequently adopted by ACART. Given societal and technological changes, ACART has been reviewing the current guidelines.
3. ACART believes the new guidelines should take into account stored embryos, reproductive tissue (from ovaries and testes) and all gametes. The current guidelines apply only to the posthumous use of sperm that was retrieved before a 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
 - retrieval and/or use of reproductive tissue from a deceased man or woman
 - use of stored eggs after the death of a woman
 - use of stored embryos after the death of one or both of the gamete providers or intending parent(s).
4. New Zealand needs a comprehensive regulatory framework to ensure consistency and clarity in the way that we deal with requests for the posthumous retrieval and/or use of gametes and reproductive tissue and the posthumous use of stored embryos. In particular, ACART has placed weight on the consent of the deceased, both to honour their wishes and to avoid use without their explicit consent.
5. As part of ACART's review of the current guidelines, a stage one public consultation was undertaken in July 2018 to seek the public's views about whether the guidelines' limited scope should be expanded. This consultation document and the proposed guidelines are informed by the views expressed in that original public consultation.
6. This stage two consultation presents draft guidelines for public feedback. We invite you to complete the feedback form starting on page 43 of this consultation document.

¹ 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

Introduction

Seeking feedback on draft guidelines

7. ACART is seeking feedback on the proposed draft guidelines for posthumous reproduction, which are intended to replace the Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man² (the current guidelines). The content in these draft guidelines is informed by ACART's stage one consultation in 2018.
8. ACART's approach in the stage one consultation focused on ethical considerations rather than the anticipated regulatory changes. This stage two consultation looks more closely at the changes to the regulatory regime.
9. The draft guidelines presented here would require amendments to the Human Assisted Reproductive Technology Act 2004 (HART Act) and the Human Assisted Reproductive Technology Order 2005 (HART Order). There may be implications for the Status of Children Act 1969 and possibly inheritance law, but we make no recommendations about those pieces of legislation here. A change to the HART Act would be needed for minors to decide what would happen to their stored tissue once they turned 16 years of age. The HART Order would need to be amended to clarify that established procedures relating to the collection and use of gametes and reproductive tissue apply only to people who are alive and to make all posthumous use of stored embryos subject to ethical review.
10. For the purposes of this consultation document, the terms 'man' and 'woman' refer to biological sex, consistent with the HART Act. We acknowledge not all people have a gender identity that falls within the binary categories of male and female and that people may have gender identities that differ from their biological sex.

ACART's definition of posthumous reproduction

11. In 'posthumous reproduction,' it is important to keep in mind that the person will be deceased when their gametes or reproductive tissue are used and when

² 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

any resulting child is both conceived and born. In this document, the term 'posthumous reproduction' includes:

- the retrieval, storage and use of gametes and reproductive tissue after a person's death
- the use of gametes, embryos or reproductive tissue frozen before death
- the creation, storage and/or use of embryos after a person's death.³

12. A person may have consented during their lifetime to the posthumous collection, storage and use of their gametes or reproductive tissue. Where gametes are collected and stored during a person's lifetime, it is standard practice in New Zealand for fertility clinics, at the time of storage, to record what the person wanted to happen to their gametes in the event of their death.

³ See also the glossary at the end of this document.

Overview of the legal, ethical and cultural issues

13. Posthumous reproduction is now a realistic method of assisted reproduction. Reproduction involving deceased people is one of the most ethically and legally complex issues in the field of assisted reproductive technology. However, the existing legislation and guidelines leave many areas unaddressed or unclear. As technology advances and new fertility treatment scenarios become possible, these gaps and uncertainties will only increase.
14. Purposely creating a child from the gametes of a person who has died is ethically more complex than when a baby is conceived before the death of one of their parents (or gamete providers). The decision to knowingly create offspring who will never be able to meet a genetic parent should not be made lightly. As with donor-conceived children, the consequences can be significant. It is well known that donor-conceived people are interested in the traits and medical history of their donor, and many express interest in meeting the donor. Ethical oversight of such decisions is a good way to ensure that the interests of all parties, particularly offspring, are considered.
15. Most of us will not have considered whether we would want our gametes (or reproductive tissue) to be retrieved after our death for the purpose of posthumous conception and will not have left clear instructions. Decisions about retrieving gametes after death usually need to be made as a matter of urgency to ensure they remain viable. For surviving partners and family members, it is a time of great emotional distress.
16. For those who have turned their mind to these questions, such as couples with gametes stored during fertility treatment, the current regulatory framework provides only partial clarity and pathways for action. People sign consent forms outlining what they want to happen with their gametes, embryos and reproductive tissue in the case of their death. However, consent forms may be poorly completed, the patients may not have full information, and when reproductive material is stored before treatments such as cancer therapy, it may be done hurriedly with little time to consider the implications of consenting to posthumous use of the material.
17. There are significant legal issues to be considered, such as questions regarding the legality of removing reproductive tissue from a person who has died⁴ and

⁴ Section 150 (b) of the Crimes Act 1961 states that a person commits an offence if that person 'improperly or indecently interferes with or offers any indignity to any dead human body or human remains, whether buried or not'.

the posthumous use of that tissue for the purposes of reproduction. Is it legal to take reproductive tissue from a person who has not consented to its retrieval? If reproductive tissue is retrieved, who holds responsibility for its storage and use? If a child is conceived with a deceased person's gamete, is the deceased person the child's parent and, if so, what are that child's inheritance rights?

18. In summary, posthumous reproduction raises serious ethical concerns for different individuals, including the deceased individual's partner, other family members and any existing or resulting children. These issues include:
 - the wellbeing of any resulting children who will never have the chance to meet their deceased genetic parent
 - the significance of consent and whether it is necessary that the person agree that in the event of their death they may become a parent to a child they can never meet
 - the interests of surviving partners to make their own decisions about having children, including using gametes from their deceased partner
 - the impact of posthumous reproduction on the deceased's wider family, including any existing children/siblings.
19. Posthumous reproduction also raises societal ethical concerns, such as:
 - the social taboo, tapu or spiritual offence of disturbing the body of a deceased person in an invasive way to retrieve gametes or reproductive tissue
 - the effects of using stored gametes long after someone has died, so the offspring's genetic connections may become more inter-generationally distant
 - social concerns about how a child should be conceived and the use of technology that challenges social 'norms' about conception or reproduction.
20. This consultation document seeks your views on clarifying existing uncertain legal interpretations, such as recommending that the HART Order be changed so it is explicit that the posthumous retrieval of gametes and tissue is now an assisted reproductive procedure and that the use of gametes and embryos posthumously requires ethical approval.

Cultural considerations

21. For people generally, and Māori in particular, the recognition of the importance of relatedness and connection to others expressed through values such as whānau (family), whakapapa (genealogy) and whanaungatanga (kinship) is relevant to gamete and embryo donation and posthumous use. Māori have been influential in shaping non-Māori views on the significance of whakapapa,

- and this has arguably led to New Zealand having a more open attitude to the knowledge of genetic parentage than exists in some other countries.⁵
22. Principle 4(f) of the HART Act requires the needs, values and beliefs of Māori to be considered and treated with respect. This is further developed in the New Zealand Fertility Services Standard (1.1.2), which requires consumers who identify as Māori to have their health and disability needs met in a manner that respects their individual values and beliefs.
 23. These draft guidelines acknowledge the importance of te ao Māori (Māori world view). Specifically, ACART has considered the way in which whakapapa connects people to their genetic lineage as well as their whānau. Even if one cannot meet one's genetic parent, one can still connect with the whānau of one's genetic parent (providing the now deceased consented to this connection).
 24. There is a view in Māori culture, that an individual can be understood only in relation to their social and cultural contexts and relationships.⁶ Principles central to these relationships include interdependence, connectedness and whānau commitment. One's decision-making influences the whānau, hapū and iwi. Care must be taken when considering how practices will impact on whakapapa — honouring both ancestors and descendants. In te ao Māori, the wairua (a person's spirit or essence of being) is considered to leave a body over a period of time after death, and the moment of death is not an instant in time. The body, during this time, is considered tapu (sacred). The nature of tapu may differ between different iwi, hapū and whānau. There may be specific tikanga (customs or protocols) necessary to deal with the wairua (spirit) and tapu that sits with the tūpāpaku (corpse/body) after death. There are likely to be varied views on posthumous retrieval of gametes or reproductive tissue from someone who has only just died.
 25. New Zealand is a culturally and ethnically diverse country, and ACART has considered this in its deliberations. Principle 4(g) of the HART Act requires the different ethical, spiritual and cultural perspectives to be considered and treated with respect in the context of assisted reproduction.

Disability perspective

26. People with disabilities are entitled to the same consideration as all people in fertility treatment. The Human Rights Act 1993 prohibits discrimination against individuals on the basis of disability, and New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities.

⁵ Dyall L, Keith J. 1994. Analysis of written submissions made to Ministerial Committee on Assisted Reproductive Technologies. In B Atkin and P Reid, *Assisted Human Reproduction: Navigating our future*. Wellington: Ministry of Justice. www.moh.govt.nz/notebook/nbbooks.nsf/0/8E8C59B6E4F845EE4C2565D70018BEB1 (accessed 27 July 2017)

⁶ Houkamau CA, Sibley CG. 2010. The multi-dimensional model of Māori identity and cultural engagement. *New Zealand Journal of Psychology*, 39(1), page 12

The purpose and findings of the first round of consultation

27. The purpose of ACART's stage one consultation⁷ held in July and August 2018 was to canvas public opinion on issues related to posthumous reproduction. ACART consulted on the posthumous use of embryos, the retrieval and use of gametes and reproductive tissue from deceased or permanently incapacitated people whose death is imminent and on the circumstances in which these procedures would ever be ethically or legally acceptable.
28. The stage one consultation did not contain recommendations as ACART sought public feedback on the significant ethical and policy issues before developing draft guidelines.
29. The stage one consultation received a total of 68 submissions. A submissions analysis and the raw submissions are published on ACART's website.⁸

Consultation with young people aged 15 to 18 years

30. Children and young people make up one-quarter of New Zealand's population, and ACART believes that young people's voices should be heard on matters that affect them. ACART canvassed the views of young people regarding posthumous reproduction by running a targeted and age-appropriate consultation with them.
31. The individual perspectives received from the young people have not been published online, but a summary has been incorporated into the summary of submissions, which is published on ACART's website. Names and email addresses have been redacted and the young people's written material is stored on the Ministry's secure filing system for future reference.

⁷ For more details, see *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* on the ACART website at: <https://acart.health.govt.nz/posthumous-reproduction-review-current-guidelines-storage-use-and-disposal-sperm-deceased-man-take>

⁸ For more details, see ACART's Past consultations page at: <https://acart.health.govt.nz/consultations/past-consultations>

The scope of the draft guidelines

32. The reproductive procedures that ACART thinks should be covered by these draft guidelines include:
- the posthumous use of gametes or reproductive tissue collected and stored during the lifetime of the person
 - the posthumous use of embryos created and stored during the lifetimes of the people whose gametes were used to create the embryos
 - the posthumous retrieval and use of gametes or reproductive tissue collected shortly after a person's death
 - the posthumous retrieval and use of gametes from minors.

What is out of scope of the guidelines

33. The reproductive procedures that ACART considers should not be covered by the proposed guidelines are:
- human reproductive research carried out using gametes and embryos of a deceased person
 - the retrieval (while alive) and storage of gametes or reproductive tissue from an individual who is permanently incapacitated or unconscious.

Why incapacitated people whose death is imminent would not be covered by the guidelines

34. ACART's stage one consultation addressed not only the situation in which a person is deceased but also the situation in which a person is unconscious with no prospect of recovery, and their death is imminent. The rationale for seeking feedback about people in this situation was that, once a person is deceased, their body tissues deteriorate rapidly, and it could be possible to collect better quality tissues or gametes while someone is alive.
35. However, ACART has no authority to regulate the retrieval of gametes from comatose people. How people are treated in these circumstances is defined by the Code of Health and Disability Services Consumers' Rights (the Code) and by common law, and clinical practice is based on what is in the best interests of the incapacitated person. In practice, if a person's death is imminent and the presiding clinician knows that gametes or tissues are to be recovered, they

could do so shortly after the person dies if they are authorised to do so (eg, by the High Court).

36. It would potentially be possible, while someone is incapacitated/unconscious, for their partner (or the intended parent named in the consent) to apply for approval to retrieve gametes, but that retrieval would happen after death, to avoid contravening the Code.
37. At present, there is no specific legal framework for this type of situation other than the law as it generally applies to living people who lack the capacity to 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.^{9, 10}
38. Retrieval from those who are comatose or permanently lack the capacity to consent when they have **not** previously consented raises very different legal issues from those relating to deceased people. Additionally, such retrievals were not supported by respondents to the stage one consultation.

⁹ Peart N. 2015. Life beyond death: Regulating posthumous reproduction in New Zealand. *Victoria University of Wellington Law Review* 46(3): 725–54

¹⁰ Smajdor A. 2015. Perimortem gamete retrieval: should we worry about consent? *Journal of Medical Ethics* 41: 437–42

Why ACART proposes the guidelines be amended

ACART's statutory role to update the guidelines

39. The purposes and principles of the HART Act guide ACART's work. The purposes relevant to the current guidelines' review are:
- to secure the benefits of assisted reproductive procedures for individuals and for society in general by taking appropriate measures to protect and promote the health, safety, dignity and rights of all individuals, but particularly those of women and children.¹¹
 - to provide a robust and flexible framework for regulating and guiding the performance of assisted reproductive procedures.¹²
40. The principles relevant to this review are:
- the health and wellbeing of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure.¹³
 - the human health, safety and dignity of present and future generations should be preserved and promoted.¹⁴
 - no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent¹⁵
 - the needs, values and beliefs of Māori should be considered and treated with respect.¹⁶
41. 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.¹⁷ The current guidelines were issued in 2000, before the HART Act was passed, in

¹¹ HART Act, s 3(a)

¹² HART Act, s 3(d)

¹³ HART Act, s 4(a)

¹⁴ HART Act, s 4(b)

¹⁵ HART Act, s 4(d)

¹⁶ HART Act, s 4(f)

¹⁷ HART Act, s 35(1)(a)

the absence of any legal framework for assisted reproductive technology.¹⁸ They have a narrow scope and only cover the storage, use and disposal of sperm collected with consent from a man before he died.

42. 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.¹⁹

The origins of these draft guidelines

Communications from the sector about using gametes from deceased people

43. The current guidelines are very limited. Clinics and consumers have told ACART that they would value a clearer regulatory framework that specifies who can ethically and legally use reproductive material, and under what circumstances. For example, currently, if an individual dies, the gametes or embryos stored during their lifetime cannot be used without that individual's prior written consent.

Changes in technology mean eggs can now be stored and used years later

44. Posthumous reproduction has become possible as a result of technological advances. For example, it is now possible for eggs to be frozen and subsequently thawed and used in in-vitro fertilisation (IVF), whereas when the current guidelines were written that technology was experimental. There is also an increase in long-term storage of frozen eggs.

Case involving posthumous retrieval and use of gametes/reproductive tissues

45. The only relevant, publicised case in New Zealand was *Re Lee* in 2017, in the High Court in Auckland, in which Justice Heath ruled that the High Court could authorise the posthumous retrieval of sperm without the prior consent of Mr Lee who had died suddenly and unexpectedly.²⁰ (The case is discussed in more

¹⁸ 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

¹⁹ HART Act, s 38(c)

²⁰ *Re Lee* [2017] NZHC 3263; *Re Long* [2018] 2 NZLR 731

detail in the next point and under section 6: Proposals for revising the guidelines: The *Re Lee* case.)

46. Justice Heath ruled that the court had the jurisdiction to authorise the posthumous retrieval of the sperm because there was a gap in the law. However, the court concluded that only ECART could authorise the **use** of the sperm. Given the urgency with which sperm has to be retrieved after death, the court's decision was pragmatic and preserved the ability of both Ms Long and ECART to address the future use of Mr Lee's stored sperm.

Matters ACART has taken into account when developing the guidelines and other advice

47. In developing the proposed guidelines and advice, ACART has taken into account:
- the principles and purposes of the HART Act
 - other common ethical principles, including autonomy, wellbeing and transparency
 - wider legal and public policy considerations, including the right to informed consent to health care under the Code
 - feedback from public consultation on related matters
 - evidence and information from local and international sources.
48. When considering these matters, ACART referred to its ethical framework, which incorporates the principles of the HART Act and generally accepted ethical principles. The ethical framework considers the welfare of those affected by the procedure and the autonomy of those involved, as well as altruism; social trust and responsibility; the special status of the embryo; justice and equality.²¹

²¹A copy of ACART's ethical framework can be found at the ACART website: www.acart.health.govt.nz

Current regulatory setting

49. The current regulatory framework covering retrieval and use of gametes from deceased people and the use of embryos belonging to now deceased people is piecemeal and unclear. It is a complex blend of the current guidelines,²² the HART Act and Order, the Code and common law.²³ The recent case in New Zealand, *Re Lee* (discussed above and in more detail under section 6: Proposals for revising the guidelines: The *Re Lee* case), 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

50. The HART Act is the key piece of law that regulates assisted reproductive technology and human reproductive research in New Zealand. The Act gives ACART the function of providing information, issuing guidelines, giving advice to ECART and, if it thinks fit, providing recommendations to the Minister of Health on gametes derived from deceased people, in relation to human assisted reproductive technology (s 38(c)).

Human Assisted Reproductive Technology Order 2005

51. The HART Order was passed under 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. Collection and use of sperm are listed as established procedures, as is collection of eggs for the purpose of donation.

52. The HART Order excludes some circumstances from being established procedures. This is because such procedures are generally considered to be

²²The current guidelines have been superseded in part by the HART legislation.

²³As the Human Tissue Act 2008 excludes gametes and embryos from the definition of 'human tissue', it does not form part of the regulatory framework.

more ethically complex and so require individual ethical approval from ECART. With relevance to posthumous reproduction, they 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 was dead when the eggs were retrieved or who stored eggs and died before those eggs could be used.

53. The Order does not explicitly address the posthumous collection of sperm or the subsequent use of that sperm. ACART has, however, taken the view that collection of sperm is only an established procedure when it is collected from a living person.

54. In effect, the present position is that the only permitted form of posthumous reproduction is when sperm was stored before death and the deceased gave specific consent.

Code of Health and Disability Services Consumers' Rights

55. 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.

56. While the Code does not specifically refer to assisted reproductive technology, any regulations or guidelines covering assisted reproductive technology must be consistent with the Code.

Status of Children Act

57. The Status of Children Act 1969 determines who a child's parents are at the child's birth. Under that Act, a child conceived naturally by a man and a woman but born after the death of the father and/or mother is deemed to be the child of the father and the mother.²⁴ Both the father and the mother will be named as the parents on the child's birth certificate under the Births, Deaths, Marriages, and Relationships Registration Act 1995.

58. Different rules apply when a child is conceived by means of an assisted reproductive procedure. In that case, the Status of Children Act, as amended in 2004, provides that the birth mother is deemed to be the mother of the child, even if the embryo implanted used the egg of another woman.²⁵ If the birth mother has a partner at the date of conception and that partner consented to the reproductive procedure, the partner is deemed to be the child's other

²⁴ Status of Children Act, 1969, s 5

²⁵ Status of Children Act, 1969, s 17

parent.²⁶ If the birth mother has no partner, or the partner did not consent to the procedure, the woman will be deemed to be acting alone and the child's birth mother will be the child's only parent.²⁷

59. If a woman conceives a child after the death of her partner, using sperm of her deceased partner, the deceased will not be the father of the child under the Status of Children Act and cannot be registered as the father of the child.²⁸ If the woman has a new partner, that partner will be deemed to be the parent of the child and registered as such under the Births, Deaths, Marriages, and Relationships Registration Act.

Inheritance rights

60. It is uncertain whether a child conceived after the death of the sperm provider will legally be the child of the sperm provider. Therefore, the child may have no right to inherit from the sperm provider under the current law, unless the sperm provider made a will in which they made provision for a posthumously conceived child to inherit from their estate.²⁹ In the absence of a will, the child may not be treated as a child of the deceased for purposes of inheriting from the deceased under the intestacy rules that apply when there is no will.³⁰
61. A child conceived after the death of an egg provider could be born either to the female partner of the egg provider, or to another woman, i.e. through surrogacy. The birth mother is the legal parent of the child unless and until an adoption occurs. Again, the child may have no automatic right to inherit from the egg provider unless specifically provided for in her will.

The storage period of gametes and embryos

62. The storage period of gametes and embryos is defined in section 10 of the HART Act, and ECART can consider applications for extending storage under the *Guidelines on Extending the Storage Period of Gametes and Embryos*.³¹
63. ACART does not propose a different storage limit for gametes stored posthumously than provided for in the Act. People can stipulate a shorter period of storage if they wish, and they can apply for extensions to storage. For

²⁶ Status of Children Act, 1969, s 18

²⁷ Status of Children Act, 1969, s 22

²⁸ Status of Children Act, 1969, s 22; Births, Deaths, Marriages, and Relationships Registration Act 1995, s 9(4)

²⁹ Status of Children Act, 1969, s 7

³⁰ Administration Act 1969, ss 77 and 78 refer to 'Issue living at the death' of the person who died intestate. Section 2 of the Act defines 'living at the death' of any person to include a child who is conceived but not born at the death of the deceased and is subsequently born alive.

³¹ ACART. 2012. Guidelines on Extending the Storage Period of Gametes and Embryos. Wellington: Advisory Committee on Assisted Reproductive Technology. URL: <https://acart.health.govt.nz/system/files/documents/publications/acart-guidelines-extending-storage-gametes-embryos-2012.pdf> (accessed 11 March 2020)

more details, see "Section 6: Proposals for revising the guidelines: J: No change for the gamete and embryo storage period," below.

Summary of proposed guidelines

64. This section summarises ACART's proposals for new guidelines and the rationale for each proposal. 'Section 6: Proposals for revising the guidelines' then explains the proposals in more detail.

A. All posthumous use should be subject to ECART review

65. In view of the additional ethical complexities involved (as discussed above in section 2: Overview of the legal, ethical and cultural issues), all posthumous use of gametes, reproductive tissue and stored embryos should be subject to ECART consideration. ACART proposes that this should be required even where there is prior consent.

B. Consent must be for a specific use by a specified person

66. The HART Act does not specify how detailed or specific a person's consent must be. Therefore, it is important for the guidelines to be clear about what must be specified in the consent. Specific consent might also help safeguard any potential offspring because the gametes, stored embryo or reproductive tissue would be used to create a child in a family known to the deceased in circumstances the deceased had considered: that is, the intending parent will have been specified by the now deceased.

C. Consent to use must be proven

67. The principle of the HART Act at s 4(d) states that 'no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent'.

68. This principle implies that reproduction involving a deceased person should only ever occur in cases where the deceased person had specifically consented to posthumous use.

D. The evidence of consent may be written or oral

69. The HART Act does not specify the form in which consent must be expressed³² and does not stipulate that consent must be written. ACART has said previously that 'ideally written consent should be given for all ART processes,'³³ while acknowledging that 'there may be instances where written consent is not practicable and that oral consent is sufficient'.³⁴ If consent is oral (or in any other form), there must be evidence of it.

E. In most cases the deceased's consent to retrieval can be inferred from their consent to posthumous use

70. ACART proposes that it is logical to presume that the deceased's consent to the **posthumous use of their gametes or tissue** implies their consent to **retrieval** after death if the retrieval has not already been done. While it would be ideal to have evidence that the deceased was 'fully informed' about the details of what retrieval involves, ACART does not propose that evidence of this should be a requirement for retrieval to be authorised.

F. ECART or the High Court will be able to authorise the retrieval of gametes or reproductive tissue from a deceased person

71. In cases where a person dies suddenly and gametes or reproductive tissue were not already stored, it is most likely that the High Court would consider the application for retrieval. In cases where a person makes arrangements in advance to have gametes or reproductive tissue retrieved shortly after death, ECART might be in a position to authorise that retrieval. It is unreasonable to expect ECART members to convene at short notice to consider an urgent application for posthumous retrieval.

72. While the guidelines will set the parameters for authorising posthumous use and retrieval, ECART will most likely have the following main functions for posthumous reproduction. They will consider applications for use of gametes, reproductive material or embryos after death. They might also consider applications for retrieval while a person is still alive in anticipation of retrieval of gametes or tissue once the person has died.

73. ACART takes the view that collection of gametes is only an established procedure under the HART Order when the gametes are collected from living

³² HART Act, s 4(d)

³³ ACART, Advice to the Minister of Health about informed consent and assisted reproductive technology (October 2016), at [66]

³⁴ ACART, Advice to the Minister of Health about informed consent and assisted reproductive technology (October 2016), at [67]

people. This also appears to have been the view taken by Justice Heath in the only legal case to have considered posthumous gamete collection.³⁵ ACART does, however, recognise that the HART Order could be seen as ambiguous on this point and that the question of whether ACART can validly issue guidelines to cover such collection is not entirely certain. ACART proposes to recommend that the HART Order be amended to remove any ambiguity about this, making it absolutely clear that no posthumous reproduction is ever an established procedure. All assisted reproductive procedures that are not established procedures are required to be reviewed by ECART using guidelines issued by ACART.

G. Prohibiting retrieval from deceased minors

74. Obtaining gametes from minors who are already deceased is prohibited by the HART Act, as doing so could not be for the purpose of preserving the minor's own reproductive capacity.

H. One change to the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years

75. Section 12(3) of the HART Act only allows gametes collected from minors (under age 16) to be used to bring about a child they are likely to raise themselves. This means that such gametes cannot be donated to other people, even if the minor survives to adulthood. ACART considers this to be an anomaly and proposes that when a person reaches the age of consent (16), they should be permitted to consent to a different use of their stored gametes or reproductive tissue that was collected when they were a minor (for their own reproduction according to the HART Act). This would require an amendment to the HART Act and accordingly, advice would be provided to the Minister and Associate Minister of Health.

I. No requirement for a specific stand-down period

76. ACART believes the provisions for counselling remove the need for a specified stand-down period after a person dies before their reproductive material or stored embryos can be used. The counsellor would need to be satisfied that relevant parties have considered the advisability of waiting before having a child, to allow time for a grieving process that can ensure more considered decision-making. Also, the process of application to ECART creates a natural delay before posthumous use.

³⁵ Neither the collection nor use of sperm from a deceased person is listed in schedule 1 to the HART Order. Clause 5 of point 2 to the same schedule confirms that such processes are not 'established procedures'. *Lee v Long* [2017] NZHC 3263 at [55]. See also [95], where Justice Heath reiterates this understanding.

J. No change for the gamete and embryo storage period

77. ACART does not propose a different storage limit than that provided for in the HART Act and it does not propose a shorter period in cases where people seek extensions to stored reproductive material. Imposing a shorter period for posthumous storage would be arbitrary, the current situation is adequately flexible and well managed, and therefore limits for posthumously-stored material do not need to be different.

K. The title of these guidelines

78. The title of the guidelines should be consistent with the content, which is primarily the use of embryos, gametes and reproductive tissue for posthumous reproduction. ECART might, in some cases, also consider applications to retrieve gametes or reproductive tissue posthumously, but such cases are likely to be rare and so are not included in the proposed title.

Proposals for revising the guidelines

A. All posthumous use should be subject to ECART review

Proposal

79. ACART proposes that **all** posthumous **use** of gametes, reproductive tissue and stored embryos be subject to ECART consideration because of the ethical complexities involved (as discussed above in section 2: Overview of the legal, ethical and cultural issues). ACART also proposes that the posthumous retrieval of gametes or reproductive tissue is an assisted reproductive procedure and requires authorisation by the High Court or by ECART. See paragraphs 108 to 115 for more details.
80. ACART recognises that, in the majority of cases of posthumous retrieval of gametes or reproductive tissue, it will not be practical for ECART to convene in time to consider such applications, and that it will be more common for these applications to be decided in the High Court. Nonetheless, ACART believes that ECART should be able to grant authorisation to posthumous retrieval should circumstances arise where this is practical. For that reason, ACART proposes to issue guidelines for ECART to apply in such cases.

Rationale

81. ACART's proposed guidelines would address the use of sperm, eggs, reproductive tissue and stored embryos. ACART notes that, due to technological changes, human eggs and reproductive tissue (both male and female) can now be safely retrieved, stored and used. ACART's first round of consultation showed that submitters did not see a reason to continue under the current system where sperm could be used posthumously but eggs could not. They believed that, provided the conditions for retrieval and use were met, both should be allowed to be retrieved and used if doing so were ethical, clinically safe and effective.
82. ACART proposes that, even where there is prior consent to a specific use of gametes, stored embryos or reproductive tissue stored before death, their use will require ethical approval from ECART. ECART will assess whether explicit consent has been given for posthumous use and whether all ethical matters have been addressed.
83. 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. ACART is aware that under current practice, clinics generally do not use donor ('clinic')

sperm after a donor has died (when the clinic knows that the donor has died) unless there is already a baby born from that donor and the family want a sibling using the same donor.

84. ACART proposes that the guidelines allow for posthumous use of clinic donor sperm or eggs, if there is already a child from the person who donated those gametes and the new child will be in the same family. This provision would allow for family completion using the same genetic material, which is desirable by some families. This provision is an exception to the requirement of having a recipient specified by the deceased in their consent, and it is consistent with the policies fertility clinics currently have for clinic sperm. It is standard practice for clinics to ask donors if they consent to their gametes being used after their death.
85. ECART would assess whether adequate provisions have been made to address the potential impacts of posthumous reproduction on the child that would be born and that those provisions took account of the child's health and wellbeing. For example, ECART may enquire about arrangements that have been made in case the offspring want to be able to make contact with the family/whānau of their deceased genetic parent (if the family/whānau are not already part of that child's life).
86. Although this requirement for ethical review of all posthumous cases will be new, the cases are infrequent. Question 1 seeks your feedback on this policy.
87. The HART Act and Order do not address the use of embryos that were created before the death of the egg or sperm provider. In the current regulatory setting, the posthumous use of an embryo in a specified person (usually the deceased person's partner or a family member) is an established procedure **if** the deceased person had consented to the specific use of the embryos in the event of their death. In this case, the complexity of posthumous **retrieval** is not present because the embryos have already been created and stored with the informed consent of the people who produced them and the authority over the embryos lies with the surviving intending parent.
88. However, it is arguable that the posthumous use of embryos has characteristics (in particular, the complexity of relationships) similar to other assisted reproductive procedures that are subject to ECART consideration. Furthermore, if a woman dies and the surviving intending parent needs to use a surrogate, those cases will most likely be reviewed by ECART under the surrogacy guidelines. ACART proposes that it is better for all cases to be reviewed by ECART due to the ethical complexities involved. Question 2 below seeks your feedback on this policy for stored embryos.
89. To achieve clarity on requirements for ethical review, it would be best if the Order were explicit and clear about posthumous reproduction. Question 3 seeks your feedback on ACART's proposal to recommend a change to the HART Order to that effect.

Question 1. Should ethical review by ECART be required for all posthumous uses of gametes or reproductive tissue, even if consent to specific use was given while the deceased person was alive?

Question 2. Should ethical review by ECART always be required for the posthumous use of **stored embryos**, even if consent to specific use was given while the deceased person was alive?

Question 3. Do you agree that ACART should recommend a change to the HART Order 2005 to ensure all posthumous **use** is considered by ECART?

Question 4. Do you agree that the guidelines should allow for the posthumous use of clinic donor sperm or eggs, if there is already a child from the person who donated those gametes and the new child will be in the same family?

B. Consent must be for use by a specified person/s

Proposal

90. ACART proposes that when a person consents to the posthumous reproductive use of gametes, reproductive tissue or embryos, that consent must be to a specific use. ACART's proposed definition of 'specific use' in the guidelines will be that 'the deceased gave informed consent to posthumous use by a specified person(s) who would be the intending parent(s)'.
91. Note that people are permitted to specify a time period during which use must occur, within the 10-year storage limit, and they can specify what procedures they consent to, for example, IVF or surrogacy. While such specifics are permitted, these are not requirements for consent.
92. ACART proposes that, when assessing the validity of such consent, ECART must be satisfied that the deceased person is likely to have intended it to apply to the present circumstances and proposed fertility procedure. In some instances, the deceased's personal circumstances may have changed after recording or expressing their consent. Sometimes those circumstances will have changed to such an extent that doubts arise as to whether the earlier expression still reflects the deceased person's final wishes. For example, they may have separated from their partner of that time and/or entered a relationship with someone else. In such situations, ECART will have to consider whether the original consent is still a valid basis to authorise use of the deceased person's gametes. This is consistent with the approach New Zealand law takes towards advance directives or 'living wills'.³⁶
93. ACART proposes that the posthumous retrieval of gametes or reproductive tissue can be requested by the person who intends to use the gametes or reproductive tissue to become a parent, and that person must be the one specified by the deceased person in their consent. This is most likely to be the surviving partner, but it could be another relative, for example, a sister or brother. If a person other than the partner of the deceased person requests posthumous retrieval and use (ie, as a 'specified person'), they too would need to be able to show evidence that the deceased person had consented specifically to that person's use and, either explicitly or by inference, to retrieval.

Rationale

94. To be consistent with the HART Act (see paragraph 97), the deceased person must have made an informed choice and given informed consent to the posthumous retrieval and/or use of their gametes, reproductive tissue or stored embryos before they died.

³⁶ See also, Advance Directives & Enduring Powers of Attorney on the Health & Disability Commissioner website, at: www.hdc.org.nz/your-rights/about-the-code/advance-directives-enduring-powers-of-attorney/

95. However, the HART Act 2004 does not specify how detailed or specific a person's consent must be. It is important for the guidelines to be clear about what must be specified in a deceased person's consent.
96. Some submitters from the first round of consultation told ACART that the term 'specific use' needed to be explicitly defined in any guidelines so that there could be no uncertainty about the term and clinics and decision-makers would have a shared understanding of the phrase.
97. The key idea is to enable a surviving partner or other specified individual to use the reproductive material or stored embryo to have a child to parent. That might include the involvement of a new partner or surrogate, which would be acceptable if the deceased person had consented to such involvement. Whatever the circumstances, the deceased person must have been clear about the specifics of the posthumous use of their reproductive tissue, gametes or embryos created using their gametes. In particular, ACART proposes the focus should be on consent specifying who will be the parent.

Question 5. Do you agree that the deceased person must have consented to a specific use?

Question 6. Do you agree with ACART, that the definition of specific use should mean "consent to use by a specific person/s"?

C. Consent to use must be proven

Proposal

98. ACART proposes that the posthumous use of gametes, reproductive tissue or stored embryos may occur only when there is evidence that the now deceased person had consented to that use. In the case of posthumous **retrieval** of gametes or reproductive tissue, consent will similarly be required.³⁷ In the absence of evidence to the contrary, consent to that retrieval will be **presumed** when the deceased has consented to **use** (see section E below). The consent must be specific, and the characteristics of the specificity are discussed in section B above.

Rationale

99. ACART believes that proving consent to posthumous use is consistent with the principles of the HART Act, in particular principle 4(d): 'no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent'.

100. This principle implies that reproduction involving a deceased person should only ever occur in cases where the deceased person had specifically consented to posthumous use.

101. In ACART's first round of consultation on this topic, many submitters stated that in cases of unexpected death, written consent should not be mandatory, but that some sort of evidence was vital. They suggested many forms that oral or implied consent could take but also that any guidelines would need to be very clear about what constitutes consent.

102. In ACART's consultation with young people, most said that unless there was prior explicit, written consent from the deceased person, it would be unethical to take their gametes. ACART agrees that the deceased person's consent holds significant weight but recognises the legal status of oral consent, too.

103. It is worth noting that these proposed guidelines are more lenient than the standards in the United Kingdom, Canada and some Australian jurisdictions, in that ACART is not insisting on written consent (see point 105 below).

104. ACART concludes that consent must be mandatory and specific. (Section B above discusses the specifics that consent must contain.)

³⁷ Note section D, below, in which ACART states that consent to **retrieval** can be assumed if a person consents to posthumous use, unless there is reason to believe otherwise. If the High Court approved the retrieval, ECART would subsequently require evidence of consent to **use** and assume the consent to the associated act of retrieval.

Question 7. Do you agree that the intending parent(s) must provide evidence of consent to posthumous use in order to use gametes, reproductive tissue or stored embryos from a deceased person?

D. Consent may be written or oral

Proposal

105. ACART proposes that consent can be either written or oral.

Rationale

106. The HART Act does not specify the form in which consent must be expressed.³⁸ In particular, it does not stipulate that consent must be written. ACART has previously said that 'ideally written consent should be given for all ART processes,'³⁹ while acknowledging that 'there may be instances where written consent is not practicable and that oral consent is sufficient'.⁴⁰ There must be evidence of the oral consent, for example, it could be witnessed by a doctor who then provides an affidavit outlining what the deceased consented to, or a recording of the oral consent could be provided.
107. While ECART will be required to cite evidence of consent if the committee is ever involved in authorising posthumous retrieval, ACART notes that the High Court can set its own standard of consent requirements and evidence when authorising posthumous retrieval of gametes or reproductive tissue.
108. As noted above, ACART recognises the legal status of oral consent but also that not everything that people say in conversation about their future wishes to have children counts as informed consent to posthumous reproduction.

Question 8. Do you agree that oral consent is acceptable?

Question 9. Do you agree that there must be evidence of oral consent for that consent to be acceptable?

³⁸ HART Act, s 4(d)

³⁹ ACART, Advice to the Minister of Health about informed consent and assisted reproductive technology (October 2016), at [66]

⁴⁰ ACART, Advice to the Minister of Health about informed consent and assisted reproductive technology (October 2016), at [67]

E. In most cases, the deceased's consent to retrieval can be inferred from their consent to posthumous use

Proposal

109. In some cases, a deceased person may have left evidence of their consent to posthumous reproduction but not have explicitly addressed the matter of gamete retrieval. ACART is proposing that, in the absence of evidence to the contrary, consent to retrieval can be **presumed** when the deceased has consented to posthumous use. It will not be necessary for the deceased to have been precise about the means of retrieval. However, that presumption will **not** apply where there is reason to believe that the deceased would have objected to the methods of retrieval. (See the Glossary for methods of retrieval).

Rationale

110. It is logical to presume that the deceased's consent to posthumous use implies their consent to retrieval, if gametes had not already been stored. This is because posthumous reproduction in such cases obviously could not take place without posthumous gamete retrieval. While it would be ideal to have evidence that the deceased was informed about the details of what the act of retrieval involves, ACART does not propose that evidence of this knowledge should be a requirement for accepting the evidence of consent. However, there may be instances where evidence exists that the deceased held religious or other views likely to be incompatible with the reality of retrieval or with certain methods of retrieval. Where such evidence exists, the presumption of consent to retrieval will not apply.

Question 10. Do you agree that consent to posthumous use of gametes or reproductive tissue can be taken to imply consent to posthumous retrieval of the gametes or tissue?

Question 11. Do you agree that there is no need to test whether the deceased person had a full understanding of the method of retrieval of the gametes or tissue?

F. ECART or the High Court will be able to authorise the retrieval of gametes or reproductive tissue from a deceased person

Proposal

111. ACART recognises that, in the majority of posthumous retrieval cases, it will not be practical for ECART to convene in time to consider such applications and that it will be more common for them to be decided in the High Court. Nonetheless, ACART believes that it should also be open to ECART to grant authorisation, should circumstances arise where this is practical. For that reason, ACART proposes to issue guidelines for ECART to apply in such cases.
112. While ACART takes the view that posthumous collection of sperm requires authorisation, it notes that neither the HART Act nor Order explicitly addresses this question. ACART therefore proposes to seek an amendment to the Order removing any doubt on this matter.

Rationale

113. Retrieval after death must be done within 36 to 48 hours of death. On the assumption that such collection constitutes an assisted reproductive procedure under the law, it will need to be authorised either by ECART or the High Court. Furthermore, posthumous collection of gametes could amount to an offence of 'offering any indignity to any dead human being or human remains' (Crimes Act 1961, s 150(b)). In *Lee v Long* (discussed in more detail under *The Re Lee* case below), the judge expressed the view that this offence would not be committed if there were authorisation by the court or ECART.
114. Authorisation of retrieval by the High Court would enable the gametes or tissue to be retrieved while they were still viable for subsequent assisted reproduction. A decision about **use** would need to be made later by ECART. This is consistent with Justice Heath's view (stated in the case *Lee v Long*, discussed below) that the High Court can authorise the retrieval and storage of gametes or reproductive tissue and ECART can consider use of the material under guidelines issued by ACART.
115. It is unlikely that the High Court will authorise retrieval in circumstances where there is no prospect of future use. However, where use is not precluded, the High Court could authorise retrieval where the use would subsequently be considered by ECART. Authorisation of retrieval will not necessarily mean use is permitted as that is a decision yet to be made by ECART.
116. The proposed guidelines mean that ECART could review the **retrieval** of gametes or reproductive tissue (even if in practice it is unlikely to do so, due to the practical limitations of convening the committee at very short notice). The High Court will most likely make decisions about **retrieval** and could do so irrespective of the guidelines. ACART's proposed guidelines build on the High Court's jurisdiction for retrieval and create a pathway for use. ECART will not

need to determine if the High Court saw evidence for retrieval but will need to see evidence of consent to posthumous use.

The *Re Lee* case

117. In 2017, the High Court in Auckland authorised the posthumous retrieval of sperm from a deceased man without his prior consent.⁴¹ Mr Lee⁴² had died suddenly and unexpectedly, and his partner, Ms Long, was pregnant at the time with their first child. Ms Long wanted to have sperm taken from Mr Lee so that at some point in the future she could have a second child as a sibling for their first child. This was the first New Zealand case to consider in depth the lawfulness of retrieving sperm from a dead man without his consent.

118. Justice Heath noted that there were no statutory or regulatory provisions dealing explicitly with this issue.⁴³ On his interpretation though, posthumous collection of sperm was not an established procedure. Therefore, authorisation was required before it could take place.⁴⁴ While that authorisation should technically come from ECART, Justice Heath ruled that the High Court could also authorise the posthumous collection of sperm as part of its inherent jurisdiction. This was necessary, he decided, because 'there is no realistic prospect that an ethics committee could be convened in every case where an application of the type made by Ms Long was made on an urgent basis'.⁴⁵

119. Authorisation of *use* of such gametes, however, would have to come from ECART. The Court's authorisation was limited to collecting the sperm. The Court ordered the sperm to be held by Fertility Associates as an agent of the Court until guidelines were published, and not to be released to Ms Long without approval from the Court.

There is no role for the Chief Coroner to authorise retrieval

120. The Office of the Chief Coroner told ACART that authorising posthumous retrieval of gametes or reproductive tissue would extend their existing role. *Re Lee* had confirmed that the Coroners Act 2006 does not give a coroner the power to authorise the retrieval of sperm from a body while it is in the coroner's custody. For coroners to have that role, the Coroners Act 2006 would need to be amended.

Question 12. Do you agree that ACART should recommend a change to the HART Order 2005 so that it is clear that posthumous retrieval is never an established procedure?

Question 13. Do you agree that, subject to the change to the HART Order 2005, ECART could authorise posthumous retrieval? (Note: This would seldom or never actually happen because retrieval cases would usually be decided by the High Court.)

⁴¹ *Lee v Long* [2017] NZHC 3263

⁴² All names are pseudonyms.

⁴³ *Lee v Long* at [26.]

⁴⁴ *Lee v Long* at [55]. See also [95], where he reiterates this understanding.

⁴⁵ *Lee v Long* at [101]

(Note: The High Court can consider the retrieval of gametes or reproductive tissue from deceased people regardless of any guidelines.)

G. Prohibiting retrieval from deceased minors

Proposal

121. ACART proposes that:
- a) a 'minor' means an individual aged under 16 years (consistent with the HART Act)
 - b) neither gametes nor reproductive tissue can be retrieved from deceased minors
 - c) if a minor freezes gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue (or can consent as an adult to another use), then the gametes or reproductive tissue cannot be used by anyone else.

Rationale

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

123. Obtaining gametes from minors who are already deceased, then, is prohibited by the Act, as this could not be for the purpose of preserving the minor's own reproductive capacity. ACART has no proposal to amend the Act in this respect. The current law strikes an appropriate balance between protecting minors and preserving their reproductive capability. It is consistent with the New Zealand legal position with regard to consent to sexual acts and reproduction.

Question 14. Do you agree that the retrieval of gametes and reproductive tissue from deceased minors, for reproduction, should be prohibited?

Question 15. Do you agree that if a minor freezes gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue (or can consent as an adult to another use), then the gametes or reproductive tissue are not able to be used by anyone else?

H. One change to the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years

Proposal

124. ACART does propose one change to section 12 of the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years.

Rationale

125. At present, section 12(1b and 3b) only allows gametes from minors under the age of 16 to be used to bring about a child they are likely to raise themselves. This means that such gametes cannot be donated to other people, exported or donated for research, even if the minor survives to adulthood. ACART considers this to be an anomaly and proposes that when someone reaches adulthood, they should be permitted to consent to a different use of their stored gametes or reproductive tissue that was collected when they were a minor. This would require an amendment to the HART Act and advice would be provided to the Minister and Associate Minister of Health.

126. A person who had their gametes or reproductive tissue stored when they were a minor may, on reaching the age of consent, wish to donate those gametes or reproductive tissue to someone instead of using them themselves. ACART has identified age 16 as being consistent with section 12 of the Act, and the age of consent to sexual acts and reproduction⁴⁶. ACART believes there is no rationale for restricting how an adult uses their own gametes just because those gametes were preserved when the person was a minor.

127. ACART believes that, on turning 16 years of age, such people should have the same range of options regarding their stored gametes as any other adult.

Question 16. Do you agree that ACART should provide advice to the Minister to amend section 12 of the HART Act 2004 to enable people to choose the use of their own gametes/tissue after they reach the age of 16 years?

⁴⁶ 16 is the age at which people can consent to most other medical procedures (Care of Children Act 2004).

I. No requirement for a specific stand-down period

Proposal

128. ACART considers that the counselling provisions in the guidelines are adequate to remove any requirement for a stand-down period after a person dies, before their reproductive material can be used.
129. Under the proposed guidelines, counselling would need to include implications counselling for all relevant parties and, in the counsellor's opinion, all relevant parties have considered the advisability of waiting before having a child to allow time for a grieving process. This will help relevant parties make a considered decision.

Rationale

130. After the stage one consultation, some people recommended a stand-down period to allow time for grieving before using the deceased's gametes or embryos for reproduction. However, ACART agreed it would be arbitrary to set a 'stand-down' period before allowing an intending parent to use a deceased person's reproductive material. There may be valid clinical reasons both for proceeding quickly or for delaying use. Clinics manage cases of posthumous reproduction well, and decisions about each case depends on individual circumstances. Also, the process of application to ECART creates a natural delay before posthumous use. Issues such as the appropriateness of allowing more time to grieve can be addressed through counselling.

Question 17. Do you agree that there is no need for the guidelines to include a specific provision about a stand-down period?

Question 18. Do you agree that the counselling provision (7.f), about allowing time for grieving, is adequate for ensuring people make a well-considered decision?

J. No change for the gamete and embryo storage period

131. ACART does not propose a different storage limit than that provided for in the HART Act, and it does not propose a shorter period in cases where people seek extensions to stored reproductive material. Imposing a shorter time period for posthumous storage would be arbitrary, the current situation is adequately flexible and well managed, and therefore no specific limits need apply to posthumously-stored material.

K. The title of these guidelines

Proposal

132. ACART proposes that these draft guidelines be named *Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos*. We are open to feedback on this proposed title.

Rationale

133. The name of the guidelines should be consistent with their content, which is primarily the **use** of embryos, gametes and reproductive tissue for posthumous reproduction. Although the guidelines also address the retrieval of gametes and reproductive tissue, in most cases, ECART will not be the entity that authorises retrieval (for practical reasons).

Question 19. Do you agree with the proposed title for the guidelines of Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos?

Draft guidelines for consultation

Guidelines for the Posthumous use of Gametes, Reproductive Tissue and Stored Embryos

Preamble
<p>ACART can issue guidelines</p> <p>ACART is appointed by the Minister of Health. One of its functions is to issue guidelines on any matter relating to any kind of assisted reproductive procedure (s.35(1)(a) of the HART Act, including in respect of gametes derived from deceased people: s.38(c) of the HART Act).</p> <p>All posthumous use of stored embryos, gametes and reproductive tissue requires ECART approval.</p> <p>Where there is insufficient evidence of consent from the deceased, the procedure cannot be approved.</p>
Guidance on terms used
<p>In these guidelines, unless specified otherwise, words should be interpreted in accordance with definitions given in the Interpretation Act 1999, HART Act 2004 and the HART Order 2005.</p>
Scope of the guidelines
<p>These guidelines set out the requirements that ECART must ensure are met if a person applies to ECART for permission to:</p> <ol style="list-style-type: none">use the gametes or reproductive tissue of a deceased person, or embryos formed from that person's gametes, to create offspringhave gametes or reproductive tissue retrieved from a recently deceased person. <p>A High Court judge may choose to consider these guidelines when assessing an application to authorise the retrieval of gametes or reproductive tissue from a recently deceased person.</p>

If the gametes or reproductive tissue were retrieved after death, ethical approval of use would only be possible if ECART were satisfied that the person from whom the gametes or reproductive tissue were extracted had consented, before death, to the specific use of those gametes after death.

Specific use

The HART Order uses the phrase 'specific use' in connection with the deceased's consent. For ACART's purposes, 'specific use' means that the deceased gave informed consent to the use of their gametes by a specific person/s.

Principles

When considering an application to carry out any of the following procedures ECART must be guided by the principles of the HART Act. The principles state:

'All persons exercising powers or performing functions under this Act must be guided by each of the following principles that is relevant to the particular power or function:

- a) the health and well-being of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure
- b) the human health, safety, and dignity of present and future generations should be preserved and promoted
- c) while all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and well-being of women must be protected in the use of these procedures
- d) no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent
- e) donor offspring should be made aware of their genetic origins and be able to access information about those origins
- f) the needs, values, and beliefs of Māori should be considered and treated with respect
- g) the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect.'

PROVISIONS THAT APPLY TO ALL PROCEDURES COVERED IN THESE GUIDELINES

Posthumous retrieval of gametes or reproductive tissue

Requirements

The posthumous retrieval of gametes or reproductive material can be approved by ECART only if:

1. the person from whom the gametes or reproductive tissue will be extracted had consented, before death, to the specific use of those gametes or reproductive tissue after their death
2. the deceased was not subject to undue influence.

Posthumous use of stored embryos or gametes or reproductive tissue

Consent requirements

ECART must be satisfied that:

1. the person from whom the gametes or reproductive tissue were extracted, or from whose gametes the stored embryos were formed, had consented before their death to the specific use of those gametes, embryos or that reproductive tissue after their death
2. the consent to posthumous use for creating offspring must be for a specific person(s) who will be the intending parent(s)
3. neither the deceased nor the intending parent(s) have been subject to undue influence
4. the intending parent(s) and the deceased considered and understood the potential risks to the child(ren) and demonstrated why the risks are justified.

Notes

Ethical approval is required for all posthumous use of stored embryos, gametes and reproductive tissue, even if the deceased had consented to the specific use,

If assisted reproductive procedures that require ECART approval are involved, such as surrogacy or within-family gamete donation, the relevant guidelines will also apply.

Counselling requirements

ECART must be satisfied that:

1. The intending parent(s) and any other relevant parties have received counselling in accordance with the current standards for fertility services
2. Counselling will be available to all relevant parties before and after pregnancy is achieved
3. The counselling has covered the fact that any resulting children may only have one, or no, living genetic parent
4. The counselling is culturally appropriate
5. The counselling has included the whānau or extended family of the intending parent(s) where desired by the intending parent(s)
6. Children have been invited to join counselling
7. The counselling has included implications counselling for all relevant parties, and in the opinion of the counsellor the parties have considered:
 - a) the wellbeing of any resulting offspring, including the right of children to know about their posthumous conception and/or birth from an early age
 - b) requirements for information sharing under the HART Act 2004
 - c) any specific issues that might affect the health and wellbeing of all parties and especially the offspring
 - d) issues related to use, storage and disposal of gametes, embryos and reproductive tissue

- e) the relevant parties' reasons for wishing to use posthumously derived (when relevant) sperm or eggs to create a child
- f) the advisability of waiting before having a child, to allow time for a grieving process that can ensure more considered decision-making
- g) the relevant parties' current and possible future feelings about posthumous reproduction.

Legal advice requirements

ECART must be satisfied that:

1. The counselling has encouraged the intending parent/s to seek independent legal advice, in particular to ensure that they understand the legal status of any resulting child, or implications for inheritance rights, and other family relationships.

Health/medical advice requirements

ECART must be satisfied that:

1. All relevant parties have received independent medical advice
2. Medical reports show that the relevant parties have been informed of the health implications of the procedure(s).

ADDITIONAL PROVISIONS THAT APPLY TO SPECIFIC PROCEDURES

Posthumous reproduction and minors

For the purpose of these guidelines:

- a) A 'minor' means an individual aged under 16 years (consistent with the HART Act 2004)
- b) Gametes obtained from minors may only be used by the individual from whom the gamete was obtained.⁴⁷
- c) Neither gametes nor reproductive tissue can be retrieved from deceased minors
- d) If a minor has frozen gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue, such gametes or reproductive tissue are not able to be used by anyone else.

⁴⁷ If the HART Act is amended, following ACART's recommendation in section H, bullet point b (above) will be altered in any final guidelines.

Glossary

This glossary explains terms relevant to 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 2004. The Minister of Health appoints the members of this committee. For more information, see www.acart.health.govt.nz
Assisted reproductive procedure	The Human Assisted Reproductive Technology Act 2004 defines an assisted reproductive procedure as a procedure performed for the purpose of assisting human reproduction that involves: <ul style="list-style-type: none">• 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 (excluding an established procedure).
Capacity to consent	The ability to make and communicate an informed decision.
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 section 5 of the Human Assisted Reproductive Technology Act 2004.
Ethics Committee on Assisted Reproductive Technology (ECART)	The ethics committee established under the Human Assisted Reproductive Technology Act 2004. 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 the members of this committee. For more information, see www.ecart.health.govt.nz
Established procedure	A procedure declared in the Human Assisted Reproductive Technology Order 2005 that does not require ECART review and approval. See section 6 of the Human Assisted Reproductive Technology Act 2004.

Fertility services provider	A clinic that provides a range of fertility services. These services include, but are not limited to: assessing people's fertility; assisting people to achieve pregnancies/have children; collecting, storing and using sperm, eggs and embryos; providing counselling on people's fertility and their options.
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, the offspring are genetically related to that parent/s. Where a person provides gametes to produce more than one offspring, those offspring are genetically related to one another and that person.
Human Assisted Reproductive Technology (HART) legislation	The Human Assisted Reproductive Technology Act 2004 (HART Act) and Human Assisted Reproductive Technology Order 2005. ACART and ECART were established under the HART Act.
Human reproductive research	Defined in the Human Assisted Reproductive Technology Act 2004 as research that uses or creates a human gamete, a human embryo or a hybrid embryo.
Implantation	For the purposes of assisted reproduction, the transfer and attachment of an embryo to the uterus.
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.

Methods of retrieval	<p>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.</p> <p>Testis biopsy – where a piece of testicular tissue removed from a testis, usually via a small incision (cut) through the scrotal skin.</p> <p>Ovary biopsy – where a piece or pieces of ovary are removed in an operation through the lower abdomen, either via laparoscopy (key hole surgery) or a small incision (cut) in the lower abdomen.</p> <p>Egg aspiration - eggs can be aspirated from follicles in ovaries as in IVF treatment – this is done with a vaginal ultrasound scan and a needle through the vaginal wall into the ovary. When ovarian tissue has been removed for freezing and storage it may be possible to aspirate eggs from the larger follicles in the tissue in the laboratory.</p>
Posthumous reproduction	The retrieval or use of gametes or tissue from a person 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, including 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 involving Assisted Reproductive Procedures</i> . ⁴⁸

⁴⁸ ACART. 2013. *Guidelines on Surrogacy involving Assisted Reproductive Procedures*. Wellington: Advisory Committee on Assisted Reproductive Technology.

Feedback form

Please provide your contact details below.

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

Are you:

Male Female Other gender identity

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

Yes No

Which of the following age groups do you belong to?

13–19 years 20–24 years 25–34 years

35–44 years 45–54 years 55–64 years

65–74 years 75+ years

What is your ethnicity? (Tick all you identify with)

NZ European Māori Pacific peoples

Asian Other

Privacy

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

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

Do not publish this submission.

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

Remove my personal details from responses to Official Information Act 1982 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.

A. All posthumous use should be subject to ECART review

Question 1

Should ethical review by ECART be required for all posthumous uses of gametes or reproductive tissue, even if consent to specific use was given while the deceased person was alive?

Yes / No

Comments

Question 2

Should ethical review by ECART always be required for the posthumous use of **stored embryos**, even if consent to specific use was given while the deceased person was alive?

Yes / No

Comments

Question 3

Do you agree that ACART should recommend a change to the HART Order 2005 to ensure all posthumous **use** is considered by ECART?

Yes / No

Comments

Question 4

Do you agree that the guidelines should allow for the posthumous use of clinic donor sperm or eggs, if there is already a child from the person who donated those gametes and the new child will be in the same family?

Yes / No

Comments

B. Consent must be to a specific use

Question 5

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

Yes / No

Comments

Question 6

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

Yes / No

Comments

Consent to use must be proven

Question 7

Do you agree that the intending parent(s) must provide evidence of consent to posthumous use in order to use gametes, reproductive tissue or stored embryos from a deceased person?

Yes / No

Comments

C. The evidence of consent may be written or oral

Question 8

Do you agree that oral consent is acceptable?

Yes / No

Comments

Question 9

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

Yes / No

Comments

D. In most cases, the deceased's consent to retrieval can be inferred from their consent to posthumous use

Question 10

Do you agree that consent to posthumous use of gametes or reproductive tissue can be taken to imply consent to posthumous retrieval of the gametes or tissue?

Yes / No

Comments

Question 11

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

Yes / No

Comments

E. ECART or the High Court will be able to authorise retrieval of gametes or reproductive tissue from a deceased person

Question 12

Do you agree that ACART should recommend a change to the HART Order 2005 so that it is clear that posthumous retrieval is never an established procedure?

Yes / No

Comments

Question 13

Do you agree that, subject to the change to the HART Order 2005, ECART could authorise posthumous retrieval? (Note: This would seldom or never actually happen because retrieval cases would usually be decided by the High Court.)

Yes / No

Comments

F. Prohibiting retrieval from deceased minors

Question 14

Do you agree that the retrieval of gametes and reproductive tissue from deceased minors, for reproduction, should be prohibited?

Yes / No

Comments

Question 15

Do you agree that if a minor freezes gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue (or can consent as an adult to another use), then the gametes or reproductive tissue are not able to be used by anyone else?

Yes / No

Comments

G. One change to the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years

Question 16

Do you agree that ACART should provide advice to the Minister to amend section 12 of the HART Act 2004 to enable people to choose the use of their own gametes/tissue after they reach the age of 16 years?

Yes / No

Comments

H. No requirement for a specific stand-down period

Question 17

Do you agree that there is no need for the guidelines to include a specific provision about a stand-down period?

Yes / No

Comments

Question 18

Do you agree that the counselling provision (7.f), about allowing time for grieving, is adequate for ensuring people make a well-considered decision?

Yes / No

Comments

I. The title of these guidelines

Question 19

Do you agree with the proposed title for the guidelines of *Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos*?

Yes / No

Comments