

2018-09/002
T:D105

3rd September, 2018

Advisory Committee on Assisted Reproductive Technologies,
Ministry of Health,
Wellington

by email: acart@moh.govt.nz

Tēnā koe

Posthumous Reproduction: Stage 1 Consultation

The New Zealand Nurses Organisation Tōpūtanga Tapuhi Kaitiaki o Aotearoa (NZNO) welcomes the opportunity to participate in the first phase review of the current *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man* (“the guidelines”) taking into account gametes and embryos. We have consulted with members and staff including our 20 colleges and sections, the Board, Te Rūnanga o Aotearoa comprising our Māori membership, and professional nursing, research and policy advisers. We have also encouraged members to respond directly through the survey. The use of assisted reproductive technologies (ART) has been discussed by several Colleges, and we have also received some individual feedback. As anticipated a range of views were expressed, with general consensus on the principles governing access to posthumous reproduction, and the decision-making process.

In general, nurses felt that it was difficult to envisage or anticipate all circumstances in which posthumous reproduction might be feasible, wanted or appropriate, and very few were reluctant to categorically rule it out in all circumstances, particularly considering changes in cultural attitudes, and the potential of new genetic technologies to reduce disease. Confidence was expressed in decision-making processes that were inclusive, and subject to ethical, rather than judicial, review. It was felt that decisions should be made by a Committee such as ACART, rather than a court. However, very strong opposition was expressed by some nurses to retrieval of gametes from permanently incapacitated people, or those in a coma, and there was considerable ambivalence about minors.

It may be worth noting that that this consultation followed considerable discussion on abortion law reform and the role of advanced technologies in expanding access to and clinical practise across the whole continuum of reproduction, from preconception to birth. Posthumous reproduction was considered as a (rarely resorted to) part of this continuum, and for that reason there was general support for clear and consistent principles and guidelines for all ART, and for “case by case” decision-making processes. We also note that new legislation governing therapeutic products, including cell and genetic bio-technologies is reasonably imminent, and we anticipate that this will/should be consistent with the management of ART.

National Office

Level 3
Crowe Horwath House
57 Willis Street
Wellington 6011

PO Box 2128
Wellington 6140

T 0800 28 38 48

www.nzno.org.nz

Te Tiriti o Waitangi

With regard to the Guidelines, NZNO strongly endorses the Tiriti o Waitangi - based bicultural approach to the use of ART outlined in the Guidelines that specifically identifies the importance of:

- *protection of Whakapapa Māori, confidentiality and privacy;*
- *respect for Tikanga Māori and kaumātua counselling. Whānau assistance at the initial interview. Recognition that the donor has the right to refuse or accept this support;*
- *a record of Maori donors be maintained with the following:*
 - *name*
 - *address*
 - *date and place of birth*
 - *name of marae to which donor is affiliated, if applicable, and tribal affiliations*
 - *the names and aliases of an individual's parents and tribal affiliations*
 - *birthplace (if known), iwi [tribal]/hapū contact*
- *and that all information provided by Māori be safeguarded and protected within the health system or as directed by the donor or whānau. (p 2)*

Actual records may need updated and aligned both with Statistics New Zealand and National Health Information data standards, currently being reviewed. The ownership of such data is also important and we refer you to: *Indigenous data sovereignty: a Māori health perspective* (Janson, 2016).

Consultation Questions

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?*

Informed written consent is the basis for all health interventions. However, as indicated above, there may be circumstances in which written consent could be waived on compassionate grounds when it is understood that consent was known and intended. Eg where conversations with people undergoing damaging chemo and radiation therapies about the preservation of their eggs or sperm, may not have been completed. There may also be a correlation here with organ donation? In general, evidence of inferred consent should at least be able to be considered.

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?*

As above.

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

Individual circumstances may dictate whether partners and/or families and whānau should be authorised this, as cultural considerations vary.

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?*

As indicated, this was strongly objected to by some nurses who did not support this in any circumstances.

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?*

As per Question 1

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

Yes

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?*

As per question 3.

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

Yes.

We trust the above will be useful.

Nāku noa, nā



Marilyn Head BA, Dip Tchg, M Sc, PGCert PH

Senior Policy Analyst

DDI: 04 4946372 Marilyn.Head@nzno.org.nz

Reference

Janson, R. (2016). Indigenous data sovereignty: a Māori health perspective. In T. Kukutai & J. Taylor (Eds.), *Indigenous Data Sovereignty: toward an agenda*. Canberra: ANU Press. Retrieved from <https://press.anu.edu.au/publications/series/centre-aboriginal-economic-policy-research-caepr/indigenous-data-sovereignty>

About NZNO

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 52,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements. NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse.*

About the New Zealand Nurses Organisation

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 47,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.

NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse.*