

Minutes of the Eighty-ninth Meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 19 February 2021, online, by telephone, with secretariat and Chair at the Office of the Children's Commissioner, Wellington.

Present

Kathleen Logan (Chair)
Calum Barrett
Rosemary de Luca
Seth Fraser
Colin Gavaghan (Deputy Chair)
Karen Reader
Catherine Ryan
Analosa Veukiso-Ulugia
Sarah Wakeman

Apologies

Karaitiana Taiuru
Iris Reuvecamp (Chair, ECART)

Non-members present

Zoe Bengé, ACART Secretariat
Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat
Mike Legge, ECART Member

1. Welcome

- 1.1 The Chair opened the meeting at 9.00 am and noted the apology from the Māori expert member who had been scheduled to give the opening comments.
- 1.2 The ECART member in attendance was Mike Legge.
- 1.3 The meeting was held primarily online (Zoom), and the Secretariat joined with the Chair at her office in Wellington, while the Ethics expert member joined by telephone.
- 1.4 The Deputy Chair made opening comments, focusing on the recent meeting (on 16 February 2021) between some members of ACART and ECART and the University of Otago to discuss the legality of the proposed guidelines for posthumous reproduction. That meeting had addressed whether the HART Act authorises ACART to make guidelines for the posthumous collection of gametes and noted that it is not clear, due to the wording of the Act. That meeting had addressed whether to seek a High Court declaration about this matter and noted that, if they do so, they could seek declarations on other unclear parts of the Act. The Disability expert member can help with the request as he is a barrister.
- 1.5 The opening discussion moved on to the limited value of online meetings as members felt that it is difficult to discuss complex ethical matters when members are not in a room together. Members felt that the timing and interactions of a normal discussion can't be replicated online. The Chair advised members that Ministry of Health policy is now that all committee meetings are to be held online unless there is a clear need to meet in person. Members discussed holding working groups, in person, more often and also the option of doing more work out of session, noting that payment for such an approach needs to be consistent with the fees that members can be paid.
- 1.6 The Chair offered to meet the manager of the Ethics committees team to discuss amending ACART's Terms of Reference to give the committee more flexibility in its working arrangements, in particular to enable members to be paid for work completed out of session.

Action

- *Secretariat to draft a letter to the Ministry of Health asking for agreement to seek a High Court declaration.*
- *Chair to discuss modus operandi of Committee with Ethics manager.*

2. Approval of the agenda

- 2.1 The Chair proposed members accept the agenda but that the committee should not make a conclusion about item 9 (governance) as the Māori expert member's input is essential to that item. Members approved the agenda with the change the Chair requested.

Action

- *Secretariat to add the February agenda to the ACART website.*

3. Declarations of Interests

3.1 No conflicts of interest were declared at this meeting.

4. Minutes of ACART's meeting of December 2020

4.1 The minutes were approved.

Action

- *Secretariat to add the minutes to the ACART website.*

5. Actions arising from ACART's December meeting

5.1 Members noted the status of the actions from the December meeting.

6. Work programme status

6.1 Members noted the status of items on the work programme.

7. Review of the guidelines for posthumous reproduction

7.1 The Chair advised members that the working group at the December meeting had progressed the guidelines with one outstanding matter which was subsequently addressed at the legal discussion on 16 February 2021 (see item 1.4, above).

7.2 There was a discussion about offspring being able to learn who their genetic parents are and the various ways that family and whānau are formed. The Chair observed that the guidelines are for ECART and cannot require such information to be recorded, but agreed that it is important that offspring be able to obtain this information. The Chair noted that work is underway with the Department of Internal Affairs and the Ministry of Justice to address this matter. The discussion addressed whether an interim measure could be put in place to ensure offspring have access to information about their genetic parents, but no practical solution was agreed.

7.3 The Chair advised members that the Births, Deaths and Marriages Act requires the recording of the living partner of the birth mother but does not allow for the recording of the source of the gametes if a gamete donor is deceased.

7.4 The Chair advised members that the Minister of Health has agreed to meet her and there was a discussion about the Chair raising matters such as this with the Minister when she meets him.

7.5 Members discussed the meaning of "specific use" in the proposed new guidelines for posthumous reproduction. They agreed that if ECART requested advice about the intended meaning of this phrase that ACART could provide it. The ECART member in attendance agreed that ECART would request such advice. ACART's legal expert member noted that if the advice constituted a change in policy that ACART would need to consult on it. He also noted that the guidelines need to give ECART enough flexibility to be able to consider each case on its merits.

7.6 Members worked through the proposed guidelines suggesting specific changes. In

particular, they asked the secretariat to:

- (a) remove the last sentence in the first part of the preamble as that point is addressed in the consent section
- (b) remove the definition of specific use
- (c) simplify the final two provisions
- (d) remove reference to authorisation of posthumous retrieval.

Actions

- *Chair to raise with the Minister the matter of offspring being able to learn their genetic heritage.*
- *Secretariat to draft advice to ECART about the intended meaning of “specific use”*
- *Secretariat to amend the guidelines as requested.*

8. ACART’s obligations, as a Crown entity, under Te Tiriti o Waitangi

- 8.1 The Chair introduced this item, noting ACART’s obligations to the Treaty of Waitangi/Te Tiriti as it is a Crown entity. She noted that the Māori expert member was not present today and that it was important he be able to take part in discussions about governance, and therefore the committee should not make a decision about co-governance options today.
- 8.2 Members noted various points about co-governance, in particular that if ACART wanted to institute co-governance it would have to be agreed by the Minister. There was discussion about co-governance being operationally difficult, due to the need for the committee to have a single decision maker and person who reports to the Minister. Members discussed whether having a co-Chair could also call into question the role of the Deputy Chair — the deputy carries out the Chair’s functions when the Chair is unavailable, but if there was a co-chairing arrangement what then would be the role of the deputy?
- 8.3 Members agreed that ideally ACART would have greater input from Māori and that having another member with expertise in tikanga Māori would be a great benefit to ACART. The discussion addressed the point that, at present, members do not *represent* the groups they have expertise on and that they should not be referred to as “representative.” To appoint an official representative for Māori would need to be done democratically and with the appropriate consultation of relevant parties. A member also noted that by improving consultation processes ACART could benefit from more meaningful engagement with Māori.
- 8.4 The Chair proposed that a paper be presented at the April meeting setting out (a) ACART’s purposes, (b) options for honouring the treaty, (c) possible content for a briefing to the Minister about changing ACART’s terms of reference so that ACART could have official Māori representation and (d) noting that all members would like the committee to have more engagement with, and input from Māori.

The new Deputy Chair was chosen

- 8.5 The Chair advised members that the current Deputy Chair was not seeking renewal of his term and that members could choose a new deputy at this meeting. Members noted the importance of the deputy having a detailed working knowledge of the

HART Act, the current work programme, and the committee. The member with a consumer perspective was unanimously supported as the new Deputy Chair and will assume this role following today's meeting.

Actions

- *Secretariat to draft a letter from the Chair to the Minister about governance options.*
- *Advise the Minister and Ministry that the consumer representative is the new Deputy Chair*
- *Update ACART's website about members' roles.*

9. ACART's consultation process

- 9.1 There was a discussion about ACART's consultation process, noting it varies depending on the nature of the topic being consulted on, and members noted the importance of, in general, consulting widely and authentically.
- 9.2 Members agreed they would like greater engagement with Māori and suggested the committee should establish relationships with Māori who either might wish to make a submission or who could suggest other Māori who might like to be involved in ACART's work.
- 9.3 A member asked that the stakeholder list be amended to show the categories into which the stakeholders fit. For example, whether they have a clinical, academic, religious, cultural interest or so on. Stating the criteria used to create the groups would be useful to ensure that the stakeholder list is comprehensive. Members agreed to send the secretariat suggestions of people and networks who could be useful additions to the stakeholder list.
- 9.4 There was a discussion about how the submissions are analysed and the secretariat drew members' attention to ACART's ethical framework and noted that all decisions must be in accord with the HART Act. The ECART member in attendance explained how some guidelines are developed afresh when, for example, a new technology allows a new procedure to be used as in the case of the use of cryopreserved ovarian tissue.

Actions

- *Secretariat to amend the stakeholder list to show the categories into which the stakeholders fit.*
- *Secretariat to list the criteria used to create the stakeholder groups.*
- *Secretariat to send the amended list to all members.*
- *Members to send the secretariat suggestions of people and networks who could be useful additions to the stakeholder list.*

10. Confirm the consultation document for guidelines for extending storage

- 10.1 The Consumer member — who led the working group meeting — spoke about the changes to the draft consultation document that the working group had made at the December meeting. The changes were primarily to simplify the document and remove repeated points.

- 10.2 The working group had decided to remove the question about the ten-year storage period as the guidelines would not have any provisions about that period, and any question about it had the potential to confuse readers or raise their expectations. Members then agreed that in the final question, asking if people had ‘any other comments’, the document could give the ten-year limit as an example.
- 10.3 Members worked through the document requesting changes or additions as follows.
- (a) The document should elaborate on why intending parents have sole authority over an embryo once they have had an embryo created for their own use.
 - (b) Add more text about the Treaty of Waitangi/Te Tiriti to ACART’s online reference document that explains the regulatory and ethical setting within which ACART works.
 - (c) Add a definition of “donated embryo.”
 - (d) In the guidelines, change the heading for “storage history” to “Consider storage history.”
 - (e) Remove references to “re-consenting” as this may cause confusion.
 - (f) Several minor formatting changes.
- 10.4 Members agreed the document does not need to come back to the full committee for approval but noted that the April meeting needs to agree on the consultation process. Members agreed to ensure the consultation process would adequately engage Māori before publishing the document.

Actions

- *Secretariat to update the draft consultation document as requested.*
- *Secretariat to liaise with members to amend the consultation plan and process.*
- *Members to review the consultation plan at the full meeting in April.*

11. Member reports on papers/research

- 11.1 No items were presented on this occasion. The secretariat had recently circulated several journal articles.

12. Report on ECART’s October 2020 meeting

- 12.1 Members noted the report and the Chair observed that ECART appears to be encouraging people to use their own gametes if they can, consistent with ACART’s position.
- 12.2 There was a discussion about whether clinics are advocates for patients. Members were advised that when a case comes to ECART and the patient’s clinician is on ECART and is present at the ECART meeting, that clinician will excuse him/herself from the meeting to avoid any conflicts of interest.
- 12.3 The matter of unjustified discrimination was raised, and what the legal position of clinics is, as ‘intermediary service providers’ in relation to altruistic gamete donations. ACART’s disability expert member noted that the New Zealand Bill of Rights Act only applies to the Crown whereas the Human Rights Act applies to all people in New Zealand.

13. Correspondence

13.1 No items.

14.a. Chair's report

14.a.1 The Chair's report was taken as read.

15. Secretariat report

15.1 The Secretariat report was taken as read.

15.2 Members asked about progress on appointments and the Secretariat advised that the Ministry of Health team that manages appointments gives the secretariat updates when significant progress has been made or changes have happened. The most recent update was that all of the appointments were going smoothly through the process, but the timing was uncertain due to Ministerial priorities.

16. ANZARD report 2017

16.1 The Secretariat advised members that the 2017 report was almost ready for publication, the outstanding matters being to confirm the foreword and for members to approve the document. The Secretariat advised members that this report does not contain ethnicity data but that the Secretariat had been working on options for having such data included in future reports.

16.2 There was a discussion about if and how an alternate provider of the report might be identified, especially given the cost of the report. This discussion begged the question about whether an alternate provider could save ACART enough money for the change to be justified. The Secretariat agreed to discuss the matter further with the lay member with Pasifika health expertise, and to report back to the committee.

Actions

- *Secretariat to discuss, with the lay member with Pasifika expertise, options for alternate report providers*
- *Secretariat to report back to the committee.*

17. Work between meetings

17.1 Identified in the various action points.

18. Attendance at ECART meetings

18.1 The member with expertise in disability perspectives confirmed that he will attend the ECART meeting on 8 April 2021.

The meeting closed at 2.40 pm.