

**Minutes of the one hundred and second meeting of the**

**Advisory Committee on Assisted Reproductive Technology**

Held online on 27 April 2023.

**Present**

Calum Barrett (Chair)

Seth Fraser

Shannon Te Ahu Hanrahan

Kathleen Logan

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Sarah Wakeman

Debbie Wilson

**Non-members present**

Elsie Coleman. ACART Secretariat.

Chloe Croskery. ACART Secretariat.

John Hancock. Human Rights Commission.

Martin Kennedy. ACART Secretariat.

Jeanne Snelling. ECART.

Lisa Warbrick: Indigenous Genomics Institute.

**1a**. **Welcome**

1.1 The Chair opened the meeting at 9.00 a.m. and welcomed the ECART observer.

**1b.** **Opening comments**

1.2 The member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective provided the opening comments. The member outlined ACART’s Te Tiriti o Waitangi and HART Act Section 4(f) obligations.

1.3 Members discussed opening and closing meetings with karakia. This would set the tone for the work ahead and promote the use of te reo Māori. Members agreed that it would be appropriate to start the next meeting with a karakia. The member with expertise in Māori customary values is to suggest appropriate karakia for ACART. Another member advised that they know of karakia about children which may be relevant.

1.4 The Chair added that it would be timely for the Committee to discuss the welcoming of guests. Members agreed that mihi whakatau (greetings) would be appropriate when welcoming new guests.

**Action**

* + *The member with the ability to articulate the interests of children is to provide relevant karakia about children to both the Chair and the member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective.*
	+ *The member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective is to select appropriate karakia to open and close ACART meetings.*

**2. Apologies**

2.1 Edmond Fehoko

**3. Approval of the agenda**

3.1 Members approved the agenda.

**Action**

* + *Secretariat to add the April 2023 agenda to the ACART website.*

**4. Declarations of Interests**

4.1 The member with expertise in Māori customary values noted that he is one of the directors of the Indigenous Genomics Institute.

**5. Minutes of ACART’s meeting of March 2023**

5.1 Members approved the minutes subject to the change about how PGT is presented in the ANZARD report.

**Action**

* + *Secretariat to publish the March 2023 minutes on the ACART website.*

**6. Actions arising from ACART’s March 2023 meeting**

6.1 Members noted the status of the actions arising from the March 2023 meeting. Many of these items are on this meeting's agenda.

6.2 The Secretariat noted that they have reviewed the Therapeutic Products Bill and concluded that ACART does not need to make a submission. The Secretariat will monitor the next steps for this Bill and let members know if any matters come up that they need to be aware of.

**7. Status of ACART’s work programme**

7.1 Members noted the report. Many of these items are on this meeting's agenda.

7.2 The Secretariat also provided an oral update for this item.

* The consultation on human reproductive research recently closed and is on today’s agenda. Stakeholder engagement and expansion of work with Māori parties was discussed and will need to be revisited.
* Posthumous reproduction will have parallel advice provided by the Ministry of Health (MOH).
* For the guidelines for donation and surrogacy and related advice, the MoH is writing parallel advice. The Minister's office has asked for further information.
* The cover memo from the MoH is being written for the extended storage guidelines.
* For ACART’s advice about testicular tissue, the MoH is writing parallel advice.

**8. Decide meeting dates**

8.1 The August, October, and December 2023 meeting dates need to be reconsidered due to clashes with ECART meetings.

8.2 Members noted the proposed dates and accepted them.

8.3 Members discussed dates for in-person meetings. It would be valuable to have an in-person to welcome new members later in the year, likely in August. Tentative plans for a joint ECART and ACART meeting were made, this will possibly take place in 2024.

8.4 Members also discussed potential working group meetings. One working group would address next steps for the work arising from the amendments to the guidelines for extending storage. The other working group, possibly to be held in person, will consider the submissions on human reproductive research and early draft revised guidelines.

**Action**

* + *Secretariat to circulate ACART meeting dates and schedule meetings.*

**9. Plan next 12 months working groups**

9.1 Members discussed the next 12-month period and what the Committee expected to focus on. Working groups and in person meetings were discussed.

9.2 Human reproductive research is a large item on ACARTs work programme. This will require an in person working group. The Secretariat noted that a summary of submissions will be provided in the next full Committee meeting. Members agreed that the working group could be scheduled for after this full meeting, as the group could identify next steps and develop the summary of submissions to be published. This working group could investigate if and how applications to do HRR would need to be considered by both ECART and an HDEC. This working group will investigate other jurisdictions, ACART limitations, and run through straw man scenarios.

9.3 Members agreed after today’s guest speaker the Committee would have a clearer understand of policy options for extending storage. This item will need a working group.

9.4 The new project, on guidance for culturally appropriate counselling for cases that are considered by ECART, will require a working group.

9.5 The Chair noted that the combined ACART and ECART meeting could be an opportunity for joint training. The member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective noted that a te Tiriti o Waitangi update from the Ministry of Health could also be provided at this meeting.

9.6 The Chair raised the South Pacific Congress for Medical Laboratory Science and Pathology. This would be worthwhile for an ACART member to attend. The member with expertise in human reproductive research expressed an interest in attending this conference.

**Action**

* + *The Chair to send information on the conference to the member with expertise in human reproductive research.*
	+ *The Secretariat to schedule working group meetings.*

**10. Report on ECART’s recent meetings**

10.1 Members noted the report from ECART’s meeting on 24 February 2023.

10.2 Members discussed the significance of biological and cultural links for a child's development. The ECART member in attendance (Jeanne Snelling) said that work on culturally appropriate counselling in fertility clinics would be valuable.

10.3 Members discussed gamete and embryo storage extensions and applicant age. The ECART member in attendance advised ACART that ECART currently do not have an age limit to enforce when considering these applications. There was discussion about the objective of assisted reproductive technologies, and whether it is to extend reproductive lifelines past the ‘normal’, or to solve fertility problems.

**11. Annual report to the Minister for the 2021/22 financial year**

11.1 The Secretariat noted this report was not included when the meeting papers were circulated. In the absence of the report, the Members agreed to review this item at the next meeting.

**Action**

* + *Secretariat to circulate the ACART Annual Report 2021/22 to members.*

**12. Correspondence**

12.1 The Chair discussed a recent submission received from Fertility New Zealand on the Women's Health Strategy. The submission discussed resourcing for assisted reproductive technologies, wellbeing for those living with fertility issues, and that there is no dedicated team at the MoH which deals with fertility issues.

12.2 The Chair agreed to send this submission to any interested members.

**Action**

* + *The Chair will liaise with interested members.*

**13. Review of the guidelines for extending storage**

13.1 Members had noted, in the previous meeting, that the age of both donors and intending parents, and any related storage periods, are relevant to extending storage due to the rights of, and benefits to, individuals to meet their genetic parents and the parents who would raise them. Members discussed whether limitations based on age might therefore be appropriate and justified for the storage of human gametes and embryos.

13.2 The Chief Legal Advisor from the Human Rights Commission spoke to the Committee about the framework for justified discrimination under the New Zealand Bill of Rights Act and Human Rights Act. The most common test for a justified restriction to a service is the Hansen test. The test considers whether a restriction serves a sufficiently important purpose, whether it is rationally connected with the purpose, and whether it is proportional to the objective.

13.3 Members agreed that limiting storage of reproductive material on the basis of age may not be proportional to the objective of protecting the rights of offspring to know their genetic parents. Members noted that there is a distinction between the storage and use of human gametes and embryos, and that individuals may choose to continue storage of material for a range of reasons, such as to donate them to research or because they do not want to destroy them. Members also noted that there are already adequate safeguards for using material as individuals need to go through fertility clinics for this.

13.4 Members noted the importance of providing legitimate expectations for individuals about the likelihood of being able to successfully use their material when an extension of storage is given. Specifically, if storage is approved for individuals of an advanced age, then it should be clearly stated that they would need to discuss use of the material with their fertility provider. Extending storage decision letters could be altered to clarify this distinction between storage and use.

13.5 The Committee agreed to a working group to discuss the extension of storage limits for children/young people storing their gametes for fertility preservation. Also, to discuss discretion around the hard cut-off point at ten years for stored material and the law that does not currently allow ECART to consider late applications. The age of donors and intending parents could also be discussed further at the working group.

 **Action**

* + *Secretariat to organise working group in June 2023.*

**14. Consultation on guidelines for human reproductive research**

14.1 The Secretariat opened this discussion with a brief oral summary of the submissions. They noted that the submissions generally supported an expansion of human reproductive research and most of the research types proposed. There was however a reasonable amount of resistance across the submissions to anything that could result in germline editing (while a few were accepting if it gave healing benefits that are safe). A member observed that CRISPR is already in use and ACART will need to recognise this fact and consider whether to develop advice to the Minister about changing the Act, so that, in future, should the technology become safe to use, and public acceptance also increase, then guidelines could be developed for this technology. Currently, guidelines will never be possible because it is on the schedule of prohibited ARTs.

14.2 Members noted that the submissions will be helpful when formulating the guidelines. A member noted that some submissions stated that if a change to the guidelines will improve people's health, then this that change is ok. The member noted that perhaps now is the time to advocate for a change to the guidelines.

14.3 Members discussed the need for the Committee to understand limitations, as to not inadvertently limit research. Research and guidelines from other jurisdictions may be helpful for the Committee to review. The HDEC processes would also be helpful to review.

14.4 The ECART member in attendance noted the challenges ECART faced while submitting on this consultation. Members discussed summarising the consultation document and noted that it would have been valuable to have a version incorporating te ao Māori principles. The Chair noted that this was a challenge as ACART is required to provide one set of guidelines.

14.5 The Chair welcomed guest speaker Lisa Warbrick from the Indigenous Genomics Institute (IGI). The Chair expressed that ACART would be interested in hearing about the work that IGI does and discussing ways of consultation.

14.6 Lisa outlined how the IGI was formed and the mahi (work) that they do. The institute has a keen interest in exploring how iwi and hapu can become better engaged in discussions about genetic technology.

14.7 A member raised Māori data sovereignty and that sovereignty is individual to each iwi and hapu. Lisa advised that there are challenges to working with the Crown due to its tendency to homogenise approaches, when it is important to acknowledge differences.

14.8 Lisa shared insights from her own mahi on how to create opportunity for conversation with whānau Māori. Lisa highlighted the importance of language and face-to-face conversation.

14.9 The member with Māori customary values noted that the IGI will submit on this consultation.

**Actions**

* + *Secretariat to research other jurisdictions.*
	+ *Secretariat to circulate Monday dates in July for a working group.*
	+ *Secretariat to circulate the remaining submissions to members.*

**15. Advice on culturally appropriate counselling: practice and options**

15.1 Members discussed current ECART requirements for culturally appropriate counselling. Members acknowledged that there is a lot of Kaupapa Māori expertise that may sit outside of the counselling sector.

15.2 Members discussed forming a working group for this item. The member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective is happy to lead this work but asked for more input from people in different communities. The Chair identified that the first step for the working group could be reaching out to clinic counsellors.

15.3 The Chair noted that the benefit of this work would be for fertility treatment consumers. Members discussed other tasks that could be completed by the working group to progress this work. These included:

* creating a plan to approach clinic counsellors
* confidentially talking with Māori who have gone through this process to identify areas that need to be addressed
* talking with Fertility New Zealand, who may have already run focus groups with consumers.

**Actions**

* + *Secretariat to organise working group.*
	+ *Contact Fertility NZ, who may have already run focus groups with consumers.*
	+ *Create a plan to approach clinic counsellors.*
	+ *Talk with Māori who have gone through this process to identify areas that need to be addressed.*

**16. Ethical framework**

16.1 The member with expertise in Māori customary values agreed to spend a half-day reviewing the current section on Mātauranga Māori in the ethical framework.

**Action**

* + *Review the current section on Mātauranga Māori in the ethical framework.*

**17. Chair’s report**

17.1 Members noted the written report.

17.2 The Chair noted that Fertility New Zealand have invited him to several of their board meetings. The Chair will present at one of these meetings.

**18. Members’ reports**

18.1 No items this meeting.

**19. Secretariat report**

19.1 Members noted the report.

**20. Work between meetings**

20.1 Members confirmed the plan for working groups for human reproductive research, advising clinics on cultural considerations, and extended storage guidelines.

**Action**

* + *The Secretariat and Chair will liaise with working group members to progress these items.*

**21. Update on appointments**

21.1 The Secretariat provided an update on the status of appointing new Committee members.

**22. Attendance at ECART**

22.1 Members confirmed their availability.

* 28 June 2023: Calum Barrett
* 31 August 2023: Shannon Hanrahan
* 26 October 2023: Debbie Wilson
* 7 December 2023: Catherine Ryan

 The meeting closed at 2:33 pm