

Minutes of the one hundred and sixth meeting of the Advisory Committee on Assisted Reproductive Technology

Held online on 14 December 2023.

Present

Calum Barrett (Chair)
Edmond Fehoko
Seth Fraser
Neuton Lambert
Amanda Lees
Minu Punchihewa
Karen Reader
Catherine Ryan
Karaitiana Taiuru
Sarah Wakeman
Debbie Wilson

Non-members present

Analosa Veukiso-Ulugia. ECART.
Elsie Coleman. ACART Secretariat.
Chloe Croskery. ACART Secretariat.
Martin Kennedy. ACART Secretariat.

1. Welcome and karakia

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

2. Opening comments

2.1 The ECART member in attendance gave the opening comments. She spoke about the differences in access to fertility services between ethnic groups in Aotearoa New Zealand and how the use of Body Mass Index, when assessing possible patients, can affect access. The Chair noted that although ACART is not an advocacy group it could liaise with other groups who work on if and how people engage with fertility services.

3. Apologies

3.1 Shannon Hanrahan.

4. Approval of the agenda

4.1 Members approved the agenda.

Actions

- *Secretariat to add the December 2023 agenda to the ACART website.*

5. Declarations of Interests

5.1 Members agreed to send any conflicts of interest to the Secretariat to be added to the register.

5.2 One lay member declared his HRC Pacific Project exploring Pacific infertility and accessing assisted reproductive technologies.

Actions

- *Secretariat to update the register with the additional declarations of interest.*

6. Minutes of ACART's meeting of October 2023

6.1 Members approved the minutes subject to amending section 14.6 on renaming the human reproductive research project.

6.2 Members agreed to refer to lay members as general lay members in the minutes rather than identifying them according to identity characteristics.

Action

- *Secretariat to make the suggested changes to the October 2023 minutes and publish these on the ACART website.*

7. Actions arising from ACART's October 2023 meeting

7.1 Members noted the status of the actions arising from the October 2023 meeting.

Some of the items were to be discussed further at this meeting.

- 7.2 A member stated that the previous government's bill to amend surrogacy law has been reinstated to the legislative agenda. The priority and timing of progress on the bill are not yet known.

8. Status of ACART's work programme

- 8.1 Members noted the report.
- 8.2 Members agreed to move agenda item 14, about ACART's ethical framework and Te Tiriti, to the February 2024 meeting when the analysis has been completed.

Actions

- *Secretariat to add the item to the agenda for February 2024.*

9. Report on ECART's recent meetings

- 9.1 Members noted ECART's October meeting minutes. The minutes were attached to this (December) agenda for ACART.
- 9.2 Members noted that the time periods given to applicants for extended storage applications were quite subjective. Members discussed this and acknowledged there is little guidance on the duration of extended storage extensions and this could be a work project in the future.
- 9.3 The Chair noted that ECART would be sending a couple of letters to ACART requesting guidance around cultural competency and payments for surrogates.

10. Annual report to the Minister of Health

- 10.1 Members noted the 2022/23 annual report.
- 10.2 Members approved the report subject to changes:
- completing the Chair's foreword
 - additional editing and formatting
 - updating member profiles (the Secretariat will also update member profiles on the ACART website, including adding profiles for the three new members).

Actions

- *Secretariat to make suggested changes to the annual report.*
- *Secretariat to update member profiles on the ACART website.*

11. Opportunity to change the ANZARD reporting process

- 11.1 Members approved the changes to the ANZARD report and agreed to consult the clinics about providing additional reporting information. The Secretariat will work with the University of New South Wales (UNSW) to liaise with the clinics about the

proposed changes to the reporting process.

Actions

- *Secretariat to liaise with UNSW to consult clinics about potential changes to the ANZARD reporting process.*

12. Correspondence

- 12.1 The Chair explained that ACART's guidance for ECART on section 10B of the HART Act was not sent to ECART due to internal advice from the Ministry. This guidance from ACART outlined special circumstances where ACART thought ECART could consider applications submitted after the 10-year storage period. The Chair acknowledged that this guidance will be helpful in the future including for advice to minister on the 10-year limit.
- 12.2 Another item was a letter from the Chair to ECART that supported a broad interpretation of section 12 of the HART Act. The letter acknowledged that a restrictive interpretation would potentially lead to unjust limitation on the autonomy of adults who have reproductive material stored as minors.
- 12.3 The committee also noted an email from the Chair of the Gene Technology Advisory Committee with questions about the implications of somatic gene therapy, which involves gene editing, for the donation of gametes. Members discussed questions about genetic modification and broader questions about societal views of genetic modification. The Chair and three other members (with expertise in fertility treatment, reproductive research, and law) agreed to seek a meeting with the Chair of the Gene Technology Advisory Committee in early 2024.
- 12.4 The final piece of correspondence were the letters from an individual wishing to donate embryos without her ex-partner's consent. Members noted these letters and the responses from the Acting Group Manager at the Ministry.

Actions

- *Secretariat to set up a meeting with the Chair of the Gene Technology Advisory Committee in early 2024.*

13. Extending storage

Draft Advice to the Minister

- 13.1 Members noted the advice to the Minister recommending an amendment to section 10 of the HART Act. The amendment would allow ECART discretion to consider applications submitted after the 10-year expiry date if special, specified, circumstances are present.
- 13.2 Members agreed to the following changes/additions to the advice.
- (a) Add in more context about why the 10-year rule was initially put in place.
 - (b) Add in more justification explaining the risks and consequences of ECART not

having discretion to consider applications past the 10-year cut-off.

(c) Remove example from the appendix about clinics not informing patients about the 10-year rule because this is on the storage consent forms.

- 13.3 Members agreed to review the advice at the February 2024 meeting and send it to the Minister.
- 13.4 The Secretariat confirmed that the letter to the minister was the appropriate way of giving this advice and that the Ministry would likely send parallel advice. The Secretariat has notified the policy team at the Ministry about the advice being sent.
- 13.5 Members agreed to advise the Minister on two topics: giving ECART discretion to consider storage applications as well as on changing the 10-year storage limit. The first piece of advice will be sent to the Minister in February and the second piece will require consultation.

Consultation – changing the 10-year storage limit

- 13.6 Members agreed to do a consultation paper about the 10-year limit and aim to release this in May-July 2024. The consultation paper would cover why ACART wishes to change the 10-year limit and what their proposed change would be. The Committee discussed the options of allowing storage of gametes up until the age of 40 or 50 or allowing 20 years for fertility preservation/minors with discretion for ECART. Members acknowledged that if there was an age limit on initial storage input from the Human Rights Commissioner might be needed to ensure there was sufficient justification to discriminate on the basis on age.
- 13.7 One of the lay members who has been involved in judicial reviews in the assisted reproductive technology space offered to contribute to the Te Tiriti principles section of the consultation paper.
- 13.8 Members agreed that the consultation paper could include multiple options and scenarios demonstrating how the changes would impact people. The committee agreed that this first draft consultation document could be considered at the February meeting.
- 13.9 The Committee also discussed engagement with different groups when consulting on this change to the 10-year limit, such as how to facilitate young people's engagement.

Actions

- *Secretariat to make the suggested changes to the advice to the Minister.*
- *Secretariat to follow up with the policy team at the MoH about the need for parallel advice.*
- *Secretariat to draft the consultation document for consideration at the February 2024 meeting.*

14. ACART's Ethical Framework and Te Tiriti.

- 14.1 Members agreed to defer this item to ACART's meeting in February 2024.

15. Human reproductive research: draft guidelines

Working group

- 15.1 Members agreed that the working group in February would focus on drafting the guidelines. The Chair had noted at the Ethics Sector Day the reproductive researcher used helpful categories, such as ‘future persons’, for explaining human reproductive research and suggested that these categories may be easier to understand for people reading the guidelines. The Secretariat agreed to seek agreement from the researcher to share her presentation slides with ACART members to help inform the categories they include in the guidelines.

Consultation document

- 15.2 Members agreed that the consultation document would provide the guidelines and explain why ACART has decided on the provisions, as well as including broad questions about whether people agree with the approaches. Members agreed to include in the last section of the consultation document the activities that the guidelines would not be enabling – particularly blastoids and artificial embryos – explaining why ACART has not included some activities in the guidelines.
- 15.3 Members discussed how to increase engagement, particularly from Māori, Pasifika, and children. One member suggested talking to the Ethics Principal Advisor about different ways of reaching people in consultations such as over social media. The member representing children’s perspectives noted that a big part of engagement is people being able to understand what is being consulted on and suggested writing a summary document making these ideas more accessible to a wider audience. The member offered to speak with the engagement team at Mana Mokopuna on ways to do this and engage with a wider audience.

Actions

- *Secretariat to email presentation slides from researcher to members.*
- *Secretariat to talk to Principal Advisor Ethics about engagement approaches?*
- *Member representing children’s perspectives to talk to engagement team at Mana Mokopuna for suggestions for engagement?*

16. Guidelines for posthumous reproduction

- 16.1 The ACART Secretariat has discussed the forthcoming guidelines with the ECART Secretariat who are aware that these new guidelines will be published early in 2024. ECART is updating its application process for posthumous reproduction to enable clinics to submit applications. The Secretariat explained that the ECART Secretariat will not create PDF application forms as the new electronic records management system will be in use from March 2024.
- 16.2 The ACART Secretariat is also liaising with the fertility clinics to ensure that their patients can consent as needed in cases involving posthumous reproduction.
- 16.3 The Secretariat noted that the guidelines had been noted by the previous Minister of Health but because they have not yet been published they should be presented

to the new Minister. The Secretariat will work with the Ministry of Health arrange this.

- 16.4 There was a discussion about ACART providing supplementary advice. The advice could include scenarios of activities that are and are not allowed. The Chair asked for a simple document to be drafted explaining what activities will and what will not become Established Procedures.

Actions

- *Secretariat to write a summary of the posthumous guideline changes.*
- *Secretariat to liaise with clinics to update the posthumous ECART forms and publish the posthumous guidelines.*
- *Secretariat to draft supplementary advice for the posthumous guidelines.*

17. Prioritise ACART's work

- 17.1 Members discussed what work they would prioritise and made a timeline for their work programme. Members acknowledged the NEAC prioritisation framework as a guide and agreed that as their programme is less rapid than NEAC's programme, they would not need a scoring framework to work out priority and timelines.

- 17.2 Members noted the guidelines work - posthumous reproduction, human reproductive research, and extending storage.

- Posthumous guidelines – these are close to being published.
- Extending storage - aim to confirm the advice to the Minister in February then the consultation document on changing the 10-year limit in May-July.
- Human reproductive research – aim to get consultation document out at the end of 2024 or early 2025.

- 17.3 Members also noted the increase in correspondence from ECART and that this will likely continue to increase due to the HART Act needing updating.

- 17.4 Members also noted the work on cultural competency and will wait to receive ECART's letter to them to request what ACART should focus on/what some of the key issues are.

- 17.5 Members also noted the Te Tiriti work being done by two of the members and that this would be progressed in the February 2024 meeting. Members agreed to review and update the rest of the ethical framework but that this was not a priority.

Actions

- *Secretariat to update ACART's work programme with this prioritisation framework/timeline.*

18. Chair's report

- 18.1 Members noted the written report.

- 18.2 The Chair noted a recent legal ruling with a sperm donor and the Committee discussed this.

19. Members' reports

19.1 There were no member reports on this occasion.

20. Secretariat report

20.1 Members noted the report.

21. Work between meetings

21.1 Members confirmed next steps for the projects and publications.

21.2 Members confirmed the working group on February 1st 2024.

22. Update on appointments

22.1 No update.

22.2 The Chair noted that many of the members are up for reappointment or finishing their term at the end of 2024. The Secretariat has raised this with the appointments team at the Ministry.

23. Attendance at ECART meetings

23.1 The Chair agreed to attend ECART's February 15th 2024 meeting and one of the lay members agreed to attend ECART's April 11th 2024 meeting.

The meeting closed at 12.40 pm.