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

Held online on 23 October 2025

Present

Debra Wilson (Chair)

Lynsey Cree

Seth Fraser

Amanda B Lees

Kathleen Logan

Andrew Murray

Catherine Ryan

Karaitiana Taiuru

Non-members present

Jeanne Snelling. Ethics Committee on Assisted Reproductive Technology

Kirsten Forrest. Ethics team, Ministry of Health

Ben Clayton. Ethics team, Ministry of Health

Natalia Jefferson. Ethics team, Ministry of Health

Martin Kennedy. ACART Secretariat, Ministry of Health

Saskia Patton. Manager, Ethics team, Ministry of Health

1. Welcome and karakia

1.1 The Chair opened the meeting at 9:00 am and welcomed the new Ethics team member.

1.2 The Chair then invited the secretariat to introduce the new Senior Advisor for the Ethics team. The secretariat advised of a change of portfolios within the team which will mean a change in advisory support for ACART. The committee acknowledged and thanked Martin Kennedy for the work he has done to support ACART in recent years.

2. Opening comments

2.1 The Chair had attended an online seminar on rare disorders and reminded the committee that the Rare Disorders NZ team will be joining after lunch for their presentation.

3. Apologies

3.1 Shalomy Sathiyaraj

Neuton Lambert

4. Approval of the agenda

4.1 Members approved the agenda.

Action

- *Secretariat to add the October 2025 agenda to the ACART website.*

5. Declarations of interests

5.1 No conflicts of interest declared.

6. Minutes of ACART's meeting in August 2025

6.1 Members accepted the minutes.

Action

- *Secretariat to publish the 14 August 2025 minutes on the ACART website.*

7. Actions arising from ACART's 14 August 2025 meeting

7.1 Noted and referred to later in the projects.

8. Status of ACART's work programme

8.1 Referred to later in the projects.

9. Meeting dates for 2026

9.1 Members agreed on the proposed meeting dates for 2026.

9.2 Some members indicated that they haven't received their timetables for 2026, meaning they are unsure of future clashes.

9.3 One member asked if it was possible to combine an in-person ACART/ECART meeting or training day in 2026.

Actions

- *Members to email secretariat once they receive their timetables for 2026 to discuss any potential changes of dates.*
- *Secretariat will discuss the possibility of an in-person training day for both committees with the ACART/ECART Chairs.*

10. Report on ECART's recent meetings

10.1 The ECART Chair noted in the previous ACART minutes that ACART members had agreed to talk to ECART about how it provides information to the committee to help it carry out its monitoring role, and sought clarification as to what would be useful for ACART to have.

10.2 It was noted that while the ECART minutes are of value to ACART, a report on any trends or emerging issues ECART sees could help ACART keep a view on decision-making over time.

10.3 The ECART Chair noted that current informal practice between Chairs involves the raising of trends observed by ECART. Some further thinking around how to formalise this is needed.

10.4 The ECART Chair also referred to a fertility clinic wanting to join an international randomised controlled trial for PGT-A that involves randomising embryos to different groups for comparison. This activity would require ethics committee approval in accordance with the ACART guidelines for research on gametes and non-viable embryos. Because the research involves randomisation of *viable* embryos for which no guidelines exist, ECART will refer the protocol to ACART in accordance with section 18(2) of the HART Act.

Actions

- *Secretariat to discuss how best to report trends or emerging issues ECART is seeing at the next Chairs meeting.*
- *ECART to formally refer the PGT-A research protocol and letter to ACART under section 18(2) of the HART Act.*

11. ANZARD Annual Monitoring Report

11.1 The Chair pointed out the amendments that have been requested for the 2022 report.

11.2 Members approved the report and decided to provide feedback to the University of NSW acknowledging the importance of using neutral language.

Actions

- *Secretariat to publish ANZARD report on the ACART website.*
- *Chair to provide additional feedback about the use of more neutral language.*

12. Correspondence

12.1 The Chair noted the committee's responses to recent enquiries from ECART in relation to donor selection based on ethnicity and ECART's non-binding ethical advice to a fertility clinic about transfer of embryos with a known condition, and to an enquiry from a fertility clinic in relation to applying the ACART guidelines on posthumous use of gametes and embryos.

13. Projects: PGT

13.1 The Chair recapped the last meeting, where it had been agreed to narrow the scope. The committee also decided to put on hold the work on susceptibility in late-onset conditions, and to focus solely on PGT.

13.2 The working group opened the discussion by noting that it had agreed there is a gap in the legislation that prevents some PGT from occurring, and their recommendation to fill this gap in cases where testing is needed. The working group noted it considered a possible next step could be to build a list of criteria to help decide when testing can and cannot take place.

13.3 The Chair asked the secretariat to do a review of other countries' guidelines and use these as a starting point to decide criteria to include in the guidelines. Added to that, the committee agreed on the importance of using case studies to explain PGT and VUS, which in hindsight, would have helped the initial project.

13.4 The Chair opened up the discussion to consider whether progressing a change to the ACART guidelines is needed and what the next steps could be. There was also a reference to the Rare Disorders presentation that could provide a different perspective, which might be useful for this project.

13.5 One member referred to the way in which the amount of PGT is reported in the ANZARD report, noting it likely relates mostly to non-VUS testing, as this is not an established procedure. Another member referred to the VUS threshold for PGT-M and suggested developing a model that considers likelihood of disease, severity, and accuracy of the testing. A member referred to the current challenges, where regulations do not allow for testing of the significance of VUS, and that this is the area that needs to be looked at to determine what to enable in the guidelines.

13.6 The Chair summarised the discussion with two potential items to change: (a) the

guidelines and (b) the language of the HART Order, which refers to the 25% or greater risk and evidence of serious impairment.

14. Projects: Unintended discrimination

14.1 The Chairs of ACART and ECART have discussed this matter. This item is currently being considered by the Ministry, who will provide an update shortly.

15. Human reproductive research: Oral update

15.1 The Chair reported that the Minister had written to her and the committee, outlining her priorities for ACART. The Minister has identified three priorities that should take precedence over HRR in the committee's work programme.

15.2 It was agreed that the Chair would write back to the Minister, acknowledging the letter, and that the committee would discuss how to respond at their December meeting.

Actions

- *Secretariat to review overseas laws (e.g. UK) and criteria regarding PGT.*
- *Secretariat to draft letter to the Minister and send to ACART Chair for review. Secretariat and ACART Chair to also discuss with ECART Chair.*
- *Next step is tabling the letter for ACART meeting in December. Secretariat to find studies to use as background info for letter to Minister.*
- *Members to think of examples to help build the letter.*

Presentation: Rare Disorders NZ

Chris Higgins, Chief Executive of Rare Disorders NZ

Kim McGuinness, Relationship Manager

- The presentation was opened by a round of introductions.
- Kim indicated she liaises with 156 support groups to talk as a collective and to ensure their voices are reflected in RDNZ's advocacy work.
- Chris provided background on the group and opened the floor to any questions from the committee. The Chair shared that at the previous ACART meeting, they had invited scientists who were doing some of the PGT, and ACART had heard from them about what they considered valuable. This time, the committee wanted to hear

another perspective, and what were the advantages and disadvantages of allowing more testing.

- The Relationship Manager noted that the Voice of Rare Disorders Survey is currently taking place, and for the first time, there are more questions about attitudes towards genetic testing, which could provide some insights.
- The RD group expressed that there should be as much technology as possible available to people who live with rare disorders, who think they may have a rare disorder, or even think they may be passing on genes that could cause their children to have a RD in the future. The intent should be to be as permissible as possible, but for this to be done via a fully informed and consented process, with consumers being made aware of the accuracy of testing, as well as what the results mean in terms of impacts on life, future decision-making, and the need to access genetic counselling services.
- The RD group noted that it is hard to obtain accurate data in NZ, because the information they have is based on estimates, which are extrapolated from overseas data. They also estimate that there should be around 10,000 conditions, where 3,000 of those haven't been coded, so there are 7,000 known ones.

Members' questions were:

- When they get enquiries about testing, are people wanting to test themselves, or is this done in relation to assisted reproduction?
- Can the RD group see any downsides to testing?
- Should it be the future parents' choice, or doctors', or should it be in the hands of an ethics committee? On this question, the RD group offered to discuss with their community and see their perspective.
- Chris indicated that in March 2026, they would be able to publicly release the results of the survey and inform ACART.
- The committee discussed the need for pre-consultation information gathering, and surveying the RD community on PGT, how they deal with uncertainty, and whether they consider risk-reduction strategies. Members (Kathleen, Amanda, Debra, and Karaitiana) have offered their assistance considering their background.

Action

- *Working group to produce questions for the pre-consultation survey and circulate these with the committee before the December meeting.*

16. Donation of reproductive tissue after somatic gene therapy: Oral update

16.1 The Minister has requested for this item to be prioritised along with PGT and horizon scanning. These items are on the work programme and will continue.

17. Horizon scanning: Oral update

17.1 There are no updates on this project. The Chair noted a plan for this item that will

be discussed in the future.

18. Chair's report

18.1 The ECART Chair will attend a bioethics conference in Christchurch in December.

19. Members' reports

19.1 There were no updates.

20. Secretariat report: For noting

20.1 The secretariat reminded the committee of the change in portfolios within the team, and that Ben and Kirsten will support ACART from the December meeting onwards.

21. Work between meetings

21.1 No updates, aside from the actions stated in each item.

22. Update on appointments

22.1 Members noted that the terms of five members are due to end in mid-2026.

23. Attendance at ECART meetings in 2025

- 12 December, Shalomy

The meeting closed at 3:00 pm.