

ACART meeting minutes

Date: Thursday, 7 May 2026

Time: 9:00 am – approx. 3:00 pm

Location: Online

Present

Professor Debra Wilson (Chair)

Dr Karaitiana Taiuru (Deputy Chair) – left early

Catherine Ryan

Amanda Lees

Kathleen Logan

Dr Lynsey Cree

Seth Fraser – left early

ECART representative: Dr Michael Legge

Secretariat:

Saskia Patton

Ben Clayton

Kirsten Forrest

Guests:

Lucy Bennett (Ministry of Health)

Oliver Poppelwell (Ministry of Health)

Dr Jeremy Tuohy (Ministry of Health)

Mary Silcock (Ministry of Health)

Apologies

Shalomy Sathiyaraj

Dr Andrew Murray

Neuton Lambert

1. Welcome and karakia

- The Chair opened the meeting and welcomed members.
- Opening karakia was given.

2. Opening comments

- The Chair outlined the key focus points for the meeting, including progressing the pre-implantation genetic testing (PGT) work.

3. Apologies

- Apologies were noted and accepted.
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4. Approval of agenda

- The agenda was approved without amendment.
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5. Minutes of 19 March 2026 meeting

- The minutes were approved.
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6. Chair's report

The Chair provided a verbal update, noting:

- A meeting with the Minister is scheduled in the coming weeks.
 - Key topics for discussion with the Minister will include:
 - Human reproductive research, and
 - Consultation on draft PGT guidelines.
 - Early feedback on PGT work has been positive.
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7. Secretariat report

- Updates provided on:
 - Appointments process, and
 - Improving Arrangements for Surrogacy Bill.

Appointments

- Interviews have been completed and advice provided to the Minister.
- Final appointments are subject to Ministerial decision-making and Cabinet approval.
- Members whose terms are expiring were asked to remain in place until replacements are confirmed.

Improving Arrangements for Surrogacy Bill

- The Health Committee has reported back with a revised version of the bill. One member circulated the report prior to the meeting.
- The secretariat noted that future timing is not known.

- If progressed, the bill is likely to generate a significant future work programme for ACART.
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8. ECART monitoring

- Dr Michael Legge attended the meeting as the ECART representative.

The committee noted updates from ECART:

- A high and increasing volume of extended storage applications (approximately 40-50 per ECART meeting).
- A subcommittee has been established to manage straightforward applications.
- Extended storage demand is considered an ongoing trend rather than a short-term increase.

Members discussed:

- The implications of increasing extended storage applications.
 - The importance of ensuring clear processes and adequate resourcing.
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9. Correspondence

Police vetting services

- Email from Police noted.
- Secretariat noted that it had responded to Police to seek further information and is awaiting a response.
- One member provided an example of a Police vetting form.

Action item: Secretariat to prepare some additional information for the committee to discuss Police's request at a future ACART meeting.

Letter to the Minister (22 April 2026)

- Discussed in the context of current work programme and forthcoming meeting.
 - The committee discussed examples of human reproductive research that the Chair could use in her meeting with the Minister.
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10. Extended storage – presentation from Lucy Bennett

- The committee received a presentation from Lucy Bennett.
- Key points included:
 - The Government's response to the Petitions Committee report on the Ann Chapman petition.
 - Issues relating to storage limits and the existing regulatory framework.

- Members discussed:
 - Alignment between ACART’s work and any legislative developments.
 - Ongoing pressures arising from storage-related provisions.
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11. Pre-implantation genetic testing (PGT)

Expert feedback on draft guidelines

- The committee discussed the draft PGT guidelines and expert feedback (senior clinicians and ECART).

Key decisions and agreements

- Title:
 - Agreed to clarify wording to include reference to “for monogenic disorders”.
- Use of terminology (PGD vs PGT):
 - “PGD” will be retained when referring to the Order.
 - “PGT” will be used in all other contexts.
- Definition of disagreement:
 - Confirmed that disagreement between two or more experts is sufficient to trigger escalation under the guidelines.
 - Scope of guidelines not dependent on majority opinion or voting.
- Role of multidisciplinary meetings:
 - Wording updated to include “or an equivalent body” to future-proof guidelines.
- Language and accessibility:
 - ECART feedback indicated technical terms (e.g. “pathogenicity”) may not be well understood.
 - Committee agreed to retain technical accuracy but support this with clearer explanations (e.g. definitions or simplified wording where appropriate).
- Role of ECART and expert advice – the committee confirmed:
 - ECART’s role is ethics-based, not to adjudicate scientific validity.
 - ECART may seek additional expert advice if required under its existing powers.
- Informed consent:
 - Discussion on the absence of explicit consent requirements in draft guidelines (feedback from ECART).
 - Agreed approach – add requirement that:
 - Applicants consent to proceed with testing after taking into account the medical advice and genetic counselling they have received.
 - Specify counselling will come from a genetic counsellor.

Outcome

- The committee agreed that:
 - The draft guidelines are substantially complete, subject to final refinements and circulation with all committee members.
 - The document is ready to progress towards public consultation, pending Ministerial discussion and feedback.

Action item: Secretariat to incorporate changes to draft guidelines and circulate with committee members.

Presentation – Dr Jeremy Tuohy

- Presentation provided an overview of:
 - Advances in genomics and whole genome sequencing
 - Challenges in interpreting variants of uncertain significance (VUS)
 - Emerging issues (e.g. polygenic risk scoring), and
 - Ethical considerations and regulatory implications.
- The committee then had a discussion with Jeremy.

Action item: Committee members to provide the secretariat with any feedback on draft evidence brief (e.g. sections to be developed). Secretariat to pass feedback to Jeremy to finalise brief for future ACART meeting.

The committee lost quorum towards the end of the meeting, limiting formal decision-making.

Consultation approach

- Two options considered:
 - Narrow, targeted consultation, or
 - Broader consultation.
- Committee discussed:
 - Consultation should be targeted at stakeholders likely impacted by the draft guidelines (see below).
 - Include opportunity for broader feedback via some open-ended questions. Answers to these questions would inform second-stage work.
- Stakeholders to consult include:
 - Genetic services
 - Laboratories
 - Fertility providers
 - Relevant agencies and groups
 - ECART, and
 - Royal College of Pathologists – ML to provide contact to secretariat.

Action item: Secretariat to circulate summary of proposed consultation approach with committee members so that the Chair can speak to it at upcoming meeting with the Minister.

Action item: Secretariat to prepare draft consultation material for ACART's July meeting.

12. Closing karakia