

ACART meeting minutes

Thursday 19 March 2026 (9:00 am – 4:00 pm)

Location: Online

Attendees:

- Professor Debra Wilson (Chair)
- Kathleen Logan
- Catherine Ryan
- Dr Lynsey Cree
- Neuton Lambert
- Shalomy Sathiyaraj
- Amanda Lees
- Dr Karaitiana Taiuru (Deputy Chair)

- Associate Professor Jeanne Snelling (ECART)

- Saskia Patton (Secretariat)
- Ben Clayton (Secretariat)
- Kirsten Forrest (Secretariat)

Apologies:

- Dr Andrew Murray
- Seth Fraser (TBC)

1. Welcome and karakia

- The Chair welcomed members and opened with the karakia.

2. Opening comments

- Opening comments included noting the day's major discussion items and the intention to progress work programme items where possible.

3. Apologies

- One apology (AM) was noted.

4. Approval of the agenda

- The agenda was reviewed and approved.

5. Declarations of interest

- No new declarations of interest were made.

6. Minutes of the 18 December 2025 meeting

- The minutes of the 18 December 2025 meeting were approved as a true and correct record.

7. Chair's report

- The Chair provided a verbal update on work between meetings, including progressing the work programme and preparation of draft materials for discussion (including draft guidelines for pre-implantation genetic testing).
- The Chair also noted an upcoming conference presentation relating to UK storage consent issues and would update the committee on any relevant developments. The Chair gave her conference presentation to the committee and answered questions.

8. Member reports on research/papers

- No additional member reports were recorded.

9. Secretariat report

- The Secretariat summarised the Government response to the Ann Chapman petition and noted the commitment to a policy review of section 10 of the HART Act. The Secretariat advised that the Ministry policy team would attend the next ACART meeting to outline their work and discuss how the committee may contribute.
- Discussion included practical issues relating to storage consent and communication practices (including the use of letters, emails, and patient portals), and why '10 years' is the existing statutory storage period (noting the historical origin of the limit).

- The Secretariat also provided updates on appointments (interviews underway) and the Improving Arrangements for Surrogacy Bill (Select Committee report-back date extended to 1 April 2026).
- The Secretariat confirmed the schedule for ACART member attendance at ECART meetings and noted it would be reconfirmed when circulating the minutes.

Action item: Secretariat to coordinate with the Ministry policy team for attendance at the next ACART meeting, and to clarify scope of section 10 review (including whether section 12 is within scope).

Action item: Secretariat to include/reconfirm the ECART attendance schedule in the email circulating the minutes.

10. ECART's recent meetings (monitoring and reporting)

- The committee discussed recent ECART meetings. Discussion included a surrogacy case where the clinical justification for surrogacy was contested (including interpretation of the 'best or only opportunity' test), and a complex case involving a progressive neurological condition where views evolved after further discussion.
 - Members noted the value of understanding ECART's decision-making processes and the balance between clinical and ethical considerations.
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11. Correspondence

11.1 Letter to Rare Disorders NZ

- The committee noted the letter to Rare Disorders NZ and discussed the subsequently published survey/paper. Members highlighted findings (including the prevalence of misdiagnosis) and noted potential relevance for later-stage work on pre-implantation genetic testing. The Secretariat noted it would circulate the paper with the minutes.

Action item: Secretariat to circulate the Rare Disorders NZ survey/paper link with the minutes.

Action item: KL to circulate the draft document of potential survey questions/ideas relating to pre-implantation genetic testing.

12. ACART response to October 2025 letter from the Minister

- The committee discussed the draft substantive letter to the Minister regarding human reproductive research. Members agreed to seek ministerial agreement to progress a scaled-back project focused on the first two categories of research previously proposed, with the third category deferred. Members discussed strengthening the letter by emphasising clinical relevance and clarity, and by explaining limitations of the current guidelines.
- Members agreed to provide suggested edits to the Secretariat. The Chair and the Secretariat will consolidate changes, circulate a final draft for sign-off, and send to the Minister as soon as possible before the next meeting.

Action item: Members to provide suggested edits on the draft ministerial letter to the Secretariat.

Action item: Chair and Secretariat to consolidate edits, circulate a final draft letter for sign-off, and send to the Minister before the next meeting.

13. ACART work programme for 2026

- The committee noted the summary of the 2026 work programme and discussed the three current projects: (1) pre-implantation genetic testing (two-stage approach), (2) emerging assisted reproductive technologies, and (3) donation of gametes from patients of somatic gene therapy. The Chair also noted that her students' work on womb transplants was underway and would be presented to the committee.
- Members discussed the value of maintaining a separate 'watch list' of prior advice and long-standing legislative recommendations (e.g. sections 10 and 12), and suggested an annual check-in/paper to brief the Minister and refresh priorities.

Action item: Secretariat to maintain (and periodically bring to ACART) a list of prior advice/long-standing legislative recommendations for annual check-in.

14. Pre-implantation genetic testing

- The committee confirmed a two-stage approach: (1) develop narrow guidelines to enable ECART to consider the current case type (where experts do not agree on the pathogenicity of the variant/s), and (2) undertake a broader review of regulatory settings for pre-implantation genetic testing.
- For the narrow guidelines, the committee discussed framing the scope around situations where two or more experts disagree on whether a genetic variant is

pathogenic/whether the HART Order criteria apply in that case, rather than limiting to a single named condition.

- The committee discussed whether disagreements about severity should be included at this stage, and noted the option of consulting on the narrower scope while asking questions about wider issues (including severity) through consultation.
- The committee discussed ECART's role as being focused on best interests and informed consent in the context of conflicting expert advice, rather than determining which expert is 'right'.
- Members discussed and agreed to a number of refinements to the draft stage-one guidelines.
- The committee discussed the draft consultation plan, including testing the workability of the draft guidelines through a mid-April workshop with relevant stakeholders and through the April ECART meeting, before bringing a revised draft back to ACART in May for agreement on the consultation version.

Action item: Secretariat to revise the stage-one draft guidelines to reflect agreed wording and scope changes, and circulate to members for review between meetings.

Action item: Secretariat to progress the consultation plan for the stage-one guidelines, including a mid-April workshop with key stakeholders and discussion at the April ECART meeting prior to the May ACART meeting.

15. Work between meetings (and closing karakia)

- The Secretariat will revise the draft guidelines to reflect agreed changes and circulate for committee review between meetings.
- The Chair noted the next ACART meeting would be in May. Members also discussed the possibility of a future in-person shared meeting/training day, noting this would depend on budget.
- The meeting closed with the karakia.

Action item: Secretariat to update members on feasibility of an in-person/shared meeting or training day, subject to budget.