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

Held online on 24 August 2023.

Present

Calum Barrett (Chair)
Seth Fraser
Shannon Hanrahan
Amanda Lees
Karen Reader
Catherine Ryan
Karaitiana Taiuru
Sarah Wakeman
Debbie Wilson

Non-members present

Jude Charlton. ECART.
Elsie Coleman. ACART Secretariat.
Chloe Croskery. ACART Secretariat.
Martin Kennedy. ACART Secretariat.
Kathleen Logan. Children and Young Person's Commission / Mana Mokopuna.

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 Chair advised those present that Edmond had been scheduled to give the opening comments but had given his apologies.

2.2 In lieu of the planned opening comments, the Chair commented on a recent news item about womb transplants and members discussed the procedure.

2.3 The Chair also advised those present that three new members had recently been appointed and that one (Amanda Lees) was present today.

2.4 The new member representing the Children and Young People's Commission / Mana Mokopuna had given her apologies and the former member who represented the commission, Kathleen Logan, attended as an observer.

3. Apologies

3.1 Edmond Fehoko, Neuton Lambert, Minu Punchihewa.

4. Approval of the agenda

4.1 Members approved the amended agenda.

4.2 Members discussed whether to have a face-to-face meeting in October and agreed to do so. Doing so would enable the new and existing members to meet one another and make it easier to progress the work on guidelines for human reproductive research.

Actions

- *Secretariat to add the August 2023 agenda to the ACART website.*
- *Secretariat to arrange for an in-person meeting in October.*

5. New members and an introduction to ACART

5.1 The Chair advised those present that the three new members were Amanda Lees (Ethics), Neuton Lambert (general lay person with Māori heritage and legal expertise), and Minu Punchihewa (representing the Children and Young People's Commission / Mana Mokopuna). Neuton and Minu had given their apologies.

5.2 All present introduced themselves.

5.3 The agenda item to give an overview of ACART's functions was deferred to the October meeting when all three new members could take part.

6. Declarations of Interests

6.1 The declarations were accepted.

7. Minutes of ACART's meeting of June 2023

7.1 Members approved the minutes.

7.2 Members noted that the committee had not had a quorum in June and that no policy decisions had been made.

Action

- *Secretariat to publish the June 2023 minutes on the ACART website.*

8. Actions arising from ACART's June 2023 meeting

8.1 Members noted the status of the actions arising from the June 2023 meeting. Some of the items were to be discussed further at this meeting.

8.2 There was a discussion about how ACART can reach more people when consulting. A member noted that some staff at the Ministry of Health have good networks and know people with Māori interests who are likely to be worth approaching. (Item 13, below, explored consultation options in more detail.)

9. Status of ACART's work programme

9.1 Members noted the report.

9.2 The Secretariat advised members that the Minister of Health agreed to ACART's advice on amended guidelines for posthumous reproduction. ACART can now prepare a transition plan and publish those amended guidelines. ACART will liaise with ECART, fertility clinics and the sector to ensure a smooth transition.

Action

- *Secretariat to prepare a transition plan and share it with members.*
- *Secretariat to publish the amended guidelines at the date to be stated in the transition plan.*

10. Report on ECART's recent meetings

10.1 Members noted that the most recent ECART meeting had been held the day before ACART's June meeting, and a brief oral update had been given at ACART. The draft minutes from ECART's June meeting were attached to this (August) agenda for ACART.

10.2 Several cases were noted including (a) people wishing to import gametes that had been stored longer than 10 years, (b) the legality of full genetic siblings being born in more than two families, and (c) options for ECART to consider applications to extend storage after the 10 year limit has been passed.

10.3 The matter of BMI came up and the Chair will discuss it with the Chair of ECART to consider whether ACART should investigate the matter further.

Action

- *Chair talk to the Chair of ECART to consider whether ACART should investigate the matter of BMI further.*

11. ANZARD report for 2020

11.1 Members approved the ANZARD report subject to (a) amendments to the table on ethnicity data, (b) the addition of the foreword and (c) clarification of the columns in table 2. Members also asked that the 10 year trend table be reinstated, for the benefit of ACART members but it does not need to be published.

Actions

- *Secretariat to contact supplier to request two changes. The changes are to a) amend the text that explains the ethnicity data and b) to clarify the meaning of the columns in table 2.*
- *Secretariat to add the foreword.*
- *Chair to approve the foreword and publication.*

12. Correspondence

12.1 The Chair explained that he had been advised about a request, that the ECART Secretariat had received, about a study that would involve synthetic embryos in New Zealand. The Secretariat had advised the person making the enquiry that ECART would not be able to consider an application for such an activity.

12.2 A second item was an enquiry from ECART about how the “two family limit” should be applied and whether ACART’s intention was that it would apply when a potential third family was overseas. The Chair advised members that he is about to send a final ACART statement to ECART that the intention is that the rule applies regardless of which countries the parties are in.

Actions

- *Secretariat to finalise the letter to ECART.*
- *Chair to approve the letter.*

13. Process for planning consultations

13.1 The Chair introduced this item noting that it is, in part, a continuation of the item about engagement strategies that ACART discussed at the June meeting. He suggested that members could now go through a “lessons learned” exercise from the recent consultation on guidelines for human reproductive research.

Lessons learned

13.2 The discussion addressed (a) how to make ACART’s consultation material more accessible (bearing in mind it is often quite technical), (b) how to reach a wider range of people and (c) to acknowledge that much of ACART’s work is in a “niche” area and that it is therefore ambitious to expect large numbers of submissions.

13.3 The Chair observed that when ACART consults it gets responses from the fertility

clinics, consumers, academics and a small number of interest groups. However, the general public make few submissions apart from a small number of interested individuals. Feedback on the HRR consultation included comments that it was long, detailed and hard to follow. Some submitters had suggested that a highly summarised version be made available. Members noted the benefits of opportunistic promotions, such as mentioning ACART's work when attending conferences.

13.4 A member commented that ACART is competing with a range of other parties who seek public comments on a broad range of material. He noted that it would be useful for ACART to know about that range of material in order to help plan when and how to approach prospective stakeholders. Another member suggested that for Māori input, members with contacts in Māori iwi, hapu or other groups approach them directly to establish relationships with a view to then seeking submissions in the future.

ACART's consultation plan

13.5 The Chair moved the discussion on to the draft consultation plan (attached to the paper). Members agreed to the plan and it will be used when preparing consultations in future.

Actions

- *Secretariat to check whether the MoH policy about koha applies to ACART giving koha.*

14. Human reproductive research: summary of submissions, draft guidelines

14.1 The Chair opened this item, noting that the draft summary of submissions had been discussed at the June meeting but that no decision about publication had been made as the committee did not have a quorum at that meeting. However, those who had been present had agreed in principle that the summary was close to ready for publication subject to some amendments. The Chair noted that the committee could now approve the summary.

14.2 The Chair said that the second part of today's discussion would be to consider possible content of the draft guidelines, and related to that how the consultation document might be structured.

14.3 A number of specific research activities, raised at the June meeting, were identified as needing consideration. In particular, members agreed to discuss which activities would likely be included in the draft guidelines, those that might be uncertain, and those that would be explicitly excluded from the guidelines. Some of the activities that would not be enabled in the guidelines could still be consulted on to help inform advice to the Minister about those activities — some of the activities might one day

be enabled through guidelines and/or would first need changes to the HART Act.

Approval of the summary of submissions

14.4 Members approved the summary of submissions for publication, subject to some amendments and formatting changes.

Activities to enable or not enable

14.5 The *intentional* creation of embryos solely for use in research is an activity that might not be socially acceptable and members decided that the consultation document would not suggest it will be permitted. Rather, members agreed that ACART should ask what the public thinks about the activity. Members noted that the *incidental* creation of embryos in research might be an activity that ACART will enable. The consultation document will address the moral and ethical differences between the activities and seek public comment.

14.6 There was a wide ranging discussion about where limits should be set and why, and how clear controls or limits on certain activities would be needed. The distinction between research and therapy was raised, as was the distinction between use and storage.

14.7 Members noted that it would be helpful if ACART could liaise with other experts in HRR to ensure the consultation and guidelines address all the matters they should. Members asked the Secretariat to look into this.

14.8 Members agreed that the consultation document should:

- state that ACART is comfortable that the HART Act retain the 14 day rule and the list of prohibited activities
- distinguish between clinical and non-clinical research
- state that the guidelines would enable training
- state if and how ACART will take into account the difference between standard and innovative research.

The application processes that would be established

14.9 Members noted that many, if not all, applications to do HRR will need approval from both ECART *and* a Health and Disability Ethics Committee. Members agreed that a mapping exercise would help to set out which committees would carry out which activities. Also, ACART needs this information to ensure that the guidelines contain everything they should and that they do not duplicate the considerations that would be made by the HDECs.

14.10 Members discussed the sequence that research applicants would need to use — this will need to be investigated further and discussed with the HDECs. Members asked the Secretariat to check with the manager of the Ethics team whether there would be time to raise this at the “sector Day’ in December.

14.11 ACART will need to liaise with the HDECs and MoH about the processes that would

need to be established. Members asked the Secretariat to liaise with the manager of the Ethics team to ensure the roles of the committees can be clearly delineated. Members also asked the Secretariat to look into the *National Ethical Standards for Health and Disability Research and Quality Improvement* to check for possible areas of overlap.

Actions

- *Members to send final suggestions on the summary of submissions to the Secretariat.*
- *Secretariat to further summarise the summary.*
- *Secretariat to map out the matters that (a) the HDECs consider when assessing research applications and (b) that ECART would consider.*
- *Secretariat to arrange for ACART to liaise with other experts in HRR to ensure the consultation and guidelines address all the matters they should.*
- *Secretariat to liaise with the manager of the Ethics team to ensure the roles of the committees can be clearly delineated.*
- *Secretariat to look into the* National Ethical Standards for Health and Disability Research and Quality Improvement *to check for possible areas of overlap.*
- *Secretariat to check with the manager of the Ethics team whether there would be time to raise the sequence of applications at the "Sector Day" in December.*

15. Extending storage

15.1 This item was introduced by the Chair who summarised the work to date. He recapped ACART's earlier decisions that introducing age limits, for people storing reproductive material, could be legally difficult. He also noted that, generally, clinics can manage the risks of older people using stored material using their standard clinical assessments of cases.

15.2 There was a discussion about the anomalous provision in the HART Act that effectively precludes people from donating their stored reproductive tissue as adults if they had had the tissue stored where they were minors. The discussion led to a quick update on the status of the surrogacy bill that had recently been considered by the Health Select Committee. The committee had made a public update about the bill the same day as this meeting. If the bill continues in the next parliament it might address this anomalous provision about donating stored material.

The hard cut-off at 10 years

15.3 The discussion returned to the topic of the hard cut-off at 10 years, the problems with it and possible ways to address it. Members considered several options, policy intents and the usual legal interpretations of certain words.

15.4 Members agreed that, if certain conditions are met, ECART should be able to consider late applications to extend storage even if the application is not submitted before the end of the ten year period. For example, if a mistake had been made in the administration of a person's stored material, that would be a reasonable basis on which to consider a late application.

15.5 Members agreed they need to specify the types of reasons that would be reasonable for ECART to consider a late application. They also agreed that the language in the guidelines would need to be precise: for example, “exceptional circumstances” has a specific meaning in law and would not be a suitable word for this policy purpose.

15.6 Members asked the Secretariat to arrange for ACART to speak to the patient review panel in Victoria, Australia, about how they apply the test of a “reasonable” reason to consider a late application.

Fertility Preservation

15.7 Members also considered whether the HART Act should provide longer storage options for minors and/or those storing gametes for fertility preservation. Members discussed different time limits such as increasing the initial length of storage for minors to a period of 20 years to allow individuals to be more likely to be in a position to consider use of their gametes.

15.8 In this discussion, members also considered whether the storage of gametes and embryos should be distinguished when determining storage length and allowing a longer storage period for gametes.

Action

- *Secretariat to arrange for ACART to speak to the patient review panel in Victoria, Australia, about how they apply the test of a “reasonable” reason to consider a late application.*

16. Chair’s report

16.1 Members noted the written report.

16.2 The Chair told members he will attend the next board meeting of Fertility New Zealand. He will give them a high-level summary of the submissions on the consultation on HRR.

17. Members’ reports

17.1 The member with expertise in human reproductive research told members she had been to the South Pacific Congress of the NZ Institute of Medical Laboratory Science in Auckland. She presented a summary of the submissions on the consultation on HRR and spoke about the next steps.

18. Secretariat report

18.1 Members noted the report. A Secretariat member also advised ACART members that the Ethics team at the MoH is providing some input to progress the surrogacy bill, mostly focusing on operational matters.

19. Work between meetings

19.1 Members confirmed the next steps for the projects, and publications.

19.2 Members noted who will attend the next ECART meetings. Members also agreed that the ACART agenda for October should include an item to plan the ACART meeting dates for 2024, or at least for the first half of the year.

The meeting closed at 2:25 pm.