

**Minutes of the one hundred and third meeting of the**

**Advisory Committee on Assisted Reproductive Technology**

Held online on 29 June 2023.

**Present**

Calum Barrett (Chair)

Edmond Fehoko

Kathleen Logan

Karen Reader

Karaitiana Taiuru (9 am to 10 am)

Debbie Wilson

**Non-members present**

Elsie Coleman. ACART Secretariat.

Chloe Croskery. ACART Secretariat.

Martin Kennedy. ACART Secretariat.

Angela Ballentyne. ECART.

**1a**. **Welcome and karakia**

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

**1b.** **Opening comments**

1.2 The Chair gave the opening comments, first advising those present that five members had given apologies for the day and so the committee would not be able to make policy or reporting decisions. The Chair acknowledged that it was unusual to have five absences for one meeting. He suggested that the meeting continue but with a shortened agenda, specifically that the item on extending the storage of gametes and embryos be deferred to a later meeting. Members agreed.

1.3 The Chair then noted the main topic for the day which is ACART’s work on human reproductive research. In particular, he noted that the draft summary of submissions, to ACART’s recent consultation, was on the agenda for today.

1.4 Members briefly discussed some of the main findings and themes, including:

* the importance of definitions for embryos, synthetic embryos and blastoids
* that any proposed research would need to have clear scientific value
* that no non-clinical research would be permitted beyond 14 days.

**2. Apologies**

2.1 Seth Fraser, Shannon Hanrahan, Catherine Ryan, Sarah Wakeman. Karaitiana Taiuru was present for the first hour but had given his apologies for the day.

**3. Approval of the agenda**

3.1 Members approved the amended agenda. They also noted that parts “a” and “b” of item 12 were separate items — the discussion about “targeted engagement with youth” was for a general discussion about consultation and not confined to the work on human reproductive research.

**Action**

* + *Secretariat to add the June 2023 agenda to the ACART website.*

**4. Declarations of Interests**

4.1 The member with expertise in Māori customary values noted that he had been invited to, and accepted, a short term appointment to be an expert panel member on artificial intelligence and healthcare for the Chief Science Advisor to the Ministry of Health.

4.2 Members discussed the merits of disclosing all possible interests, rather than only the known conflicts of interests, in order to ensure full transparency. Members agreed to do this.

**Action**

* + *Members to send all interests to the Secretariat.*

**5. Minutes of ACART’s meeting of April 2023**

5.1 Members approved the minutes.

**Action**

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

**6. Actions arising from ACART’s April 2023 meeting**

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

**7. Status of ACART’s work programme**

7.1 Members noted the report. The Secretariat gave an oral update, noting that the Ministry of Health (MoH) is yet to provide parallel advice to the Minister for ACART’s advice about:

* posthumous reproduction
* for the guidelines for donation and surrogacy
* for ACART’s advice about testicular tissue.

**8. Report on ECART’s recent meetings**

8.1 Members noted that the report from ECART’s meeting in April 2023 had been seen at ACART’s April meeting. Members discussed the most recent ECART meeting which had been held the day before this ACART meeting.

**9. Correspondence**

9.1 The Chair noted that he had sent correspondence to stakeholders on the publication of the revised storage guidelines.

**10. ACART’s engagement strategy and targeting youth**

10.1 The Chair introduced this item, noting that it is about both ACART’s general strategy for engaging stakeholders, and engagement with youth in particular. Once agreed, the strategy could be applied to ACART’s consultation on human reproductive research to decide whether to seek youth opinions.

10.2 The Chair explained that ACART’s budget is small and that the committee needs to be clear about the value of any engagement activities. Any engagement activity that ACART does will mean that fewer funds are available for engagement on other topics. The Chair explained that ACART needs to be transparent about how it makes its decisions.

10.3 The Chair also suggested that it would be useful for ACART to consider all the expenses that would be likely to come up in the next twelve months and decide which of those the committee would like to prioritise for funding.

10.4 Members noted the following points.

* The committee could identify priority groups.
* It is common for Māori and Pasifika groups to like to have a relationship established first before discussing topics.
* Many Pacific people believe that humans are not to be researched on.
* For the Tongan and other Pacific communities, a good way to establish relationships is through churches and health agencies.
* Getting real, informed, public views is a big task and usually requires large, highly visible campaigns and these need substantial funding.
* Members who work at or have connections to universities probably have networks who could be approached.

10.5 Members agreed to several actions, set out below.

 **Actions**

* + *Secretariat to ask the manager of the Ethics team if the Ministry of Health already has interest groups*
	+ *All members to contact their networks about ACART’s work programme, offering to explain it?*
	+ *The lay member with knowledge of Pasifika to initiate discussions with Pacific churches and health agencies*
	+ *Secretariat to recommence work on ACART’s engagement strategy.*
	+ *The member representing the Office of the Children’s Commissioner and the lay member with Māori heritage to recommence the work to set out options for engaging youth.*

**11. Human reproductive research: summary of submissions and next steps**

11.1 The Chair opened this item, noting that the draft summary of submissions was in the papers and that it was fairly lengthy, at 85 pages. He explained that the Secretariat had done minimal paraphrasing, when drafting the summary, to ensure the submitters’ intended meanings were not lost.

11.2 The Chair noted that the second part of today’s discussion would be about the matters raised by submitters and for ACART to consider possible content of the draft guidelines. The Chair reminded members that no decisions could be reached today as the committee did not have a quorum. The item would be considered again at ACART’s August meeting.

11.3 Members discussed the summary and agreed to send suggestions to the Secretariat. There was a discussion about making the document shorter, by further summarising the submissions. Members agreed that the summary should clearly state the yes/no response for each question, and that members would send the Secretariat their tracked suggestions for the document.

 **Possible guidelines, and research activities that need more investigation**

11.4 Due to the amendments to the agenda, the full committee now had time for all present to discuss the matters that had been scheduled for the working group. Members noted that, in general, submitters had said they would like a more permissive regulatory setting for human reproductive research and that this needs to be clearly stated early in the summary of submissions. At this point, the discussion moved into detail about the various activities that could be enabled and the ethical and clinical pros and cons of enabling or not enabling those activities.

11.5 Members discussed the following matters and agreed that the full committee would probably agree to the following conclusions. All of these items will need to be discussed with the full committee.

1. Amended guidelines should enable *in vitro* research, up to 14 days, on all gametes and embryos that are surplus to the reproductive needs of the donors.
2. The definitions of viable and non-viable embryos could be removed.
3. The prohibitions in the HART Act should remain.
4. The creation of embryos to be used solely in research is scientifically valuable but ethically more difficult to justify due to (a) the moral status of embryos, (b) the risk of coercion and (c) that egg collection involves clinical risk and discomfort for the egg donor. This matter will need further consideration.
5. A member suggested that it might not be necessary to distinguish between clinical and non-clinical research as all *in vitro* research (up to 14 days) will be non-clinical. The Secretariat noted that, for cases of clinical research, it may be useful that the guidelines state what is deemed “innovative” and what is “standard.” This is related to the matter of the distinction between “research” and “practice.” That is, when a new process is being used it could be deemed “research” but once it becomes commonplace, it could be said to be “practice.”
6. More investigation is needed on cloning, blastoids, synthetic embryos, artificial embryos and hybrids. Members noted that the work should be on definitions and how ACART will subsequently address each of these items, especially in the event that any of them would not come under the HART Act.
7. The Secretariat stated that it would look at the Human Tissue Act to see if there were any provisions of it that might apply to any of the matters being discussed here.
8. It would be useful to make a clear distinction between guidelines for clinical research and guidelines for non-clinical research. The distinction might be achieved by having two clearly separate sections in the amended guidelines.
9. Training should be enabled in the guidelines.
10. ACART could make a statement about the moral status of the human embryo, but the statement does not need to be elaborate. Parliament, through the HART Act, has said that human reproductive research is permitted within certain bounds, giving ACART the authority to issue guidelines with details about any such research.
11. ACART will need to confirm the process that will be used to ensure that both ECART and an HDEC will consider any proposed research. The processes will need to be explained and agreed with the HDECs.
12. ACART will need to investigate how people with conscientious objections to a research project would be granted exemptions from participating.

11.6 Members agreed to do a “lessons learned” exercise, about the recent consultation, before the next ACART meeting and also asked the Secretariat to make an early amended draft of new guidelines for members to work on. Members also discussed options for presenting the guidelines to the public not only as a document but in other media.

**Actions**

* + *Members to send suggestions on the summary of submissions to the Secretariat.*
	+ *Secretariat to further summarise the summary.*
	+ *Secretariat to see if the Human Tissue Act has any provisions that might apply to any of the matters being discussed here.*
	+ *All members to discuss points a to l, in the list above, at ACART’s August meeting.*
	+ *Members to take part in a “lessons learned” exercise.*
	+ *Secretariat to make an early amended draft of new guidelines.*

**12. Chair’s report**

12.1 Members noted the written report.

**13. Members’ reports**

13.1 No items this meeting.

**14. Secretariat report**

14.1 Members noted the report.

**15. Work between meetings**

15.1 Members confirmed the next steps for human reproductive research.

The meeting closed at 12:33 pm