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

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Held online on 17 October 2024.

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**Present**

Calum Barrett (Chair)

Neuton Lambert

Amanda Lees

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Sarah Wakeman

**Non-members present**

Alia Bloom. Observer from Mana Mokopuna / Children and Young People's Commission.

Liz Bohm. ACART Secretariat, Ministry of Health.

Amelia Gill. 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 (part of meeting).

## 1. Welcome and karakia

1.1 The Chair opened the meeting at 9.00 a.m. and welcomed the observer from Mana Mokopuna / the Children and Young People's Commission.

1.2 The Manager of the Ethics team at the Ministry of Health advised committee members that the Ethics team has two new staff and these staff were welcomed to attend the meeting.

## 2. Opening comments

2.1 The member with a consumer perspective spoke about several recent journal articles that discussed the extent to which surplus embryos are, or are not, used in research. He noted that, in some countries which permit research on embryos, people can have embryos surplus to their reproductive needs, but due to inefficient regulatory settings these embryos often do not end up actually being used in research.

2.2 Members briefly discussed bio-banks, noting that the item on today's agenda, about guidelines for research, will address this topic. The discussion included comments that bio-banks are a matter that ACART could advise the Minister about and not create guidelines for.

## 3. Apologies

3.1 Edmond Fehoko, Seth Fraser, Debra Wilson.

## 4. Approval of the agenda

4.1 Members approved the agenda, noting that one item (about the process for extending storage) was from the Ministry of Health.

**Action**

- *Secretariat to add the October 2024 agenda to the ACART website.*

## 5. Declarations of Interests

5.1 The declarations were accepted.

5.2 One member had provided a new declaration (by email, the day before the meeting).

5.3 The Chair informed members he is due to finish with ACART at the end of 2024 and has been nominated to join the board of Fertility New Zealand from January 2025. He noted that, if he is still on ACART in 2025 due to a replacement consumer member not being appointed yet, any potential conflict of interest will need to be managed.

**Action**

- *Secretariat to add the new declaration to the declarations register.*

## 6. Minutes of ACART's meeting of August 2024

6.1 Members approved the minutes.

6.2 The Chair also commented on the summary of submissions, from ACART's first consultation on human reproductive research, saying that it should be published as soon as is practicable.

**Actions**

- *Secretariat to publish the August 2024 minutes on the ACART website.*
- *Secretariat to publish the summary of submissions from the first consultation on human reproductive research.*

## 7. Actions arising from ACART's August 2024 meeting

7.1 Members noted the status of the actions arising from the August 2024 meeting.

## 8. Status of ACART's work programme

8.1 Members noted the report.

8.2 There was a discussion about formalising advice to the Minister about ACART's three new recommendations for changes to the HART Act. The changes are all for the provisions for the storage, and extension of storage, of reproductive material and have not yet been formally sent to the Minister.

**Action**

- *Secretariat to draft the advice.*
- *Members to approve the advice.*

## 9. Report on ECART's recent meeting

9.1 Members discussed some ECART decisions about extending storage. They noted two cases which looked unusual and further information was provided on the circumstances for these cases. It was noted that ECART was contemplating changes to their review processes that would be covered in the agenda item brought by the Ministry of Health.

## 10. Correspondence

10.1 The Chair explained the five items of correspondence.

10.2 The first item was about ACART's response to Fertility Associates who had asked several questions about the new guidelines for posthumous reproduction. The response is about to be sent and will then be shared with members.

10.3 The second item was ACART's response to Fertility Associates' enquiry about a case involving donations within a family and a surrogacy. ECART will also respond to Fertility Associates about this enquiry. Members discussed the way in which

family gamete donations are managed.

10.4 Item three was about the new donor linking process that Fertility Associates will use. ACART will send an acknowledgement directly to Fertility Associates about this matter. Members noted that often people do not know that they might be able to obtain information about gamete donors. Related to this enquiry, at least one ACART member will attend the upcoming meeting of the Donor Identity Aotearoa New Zealand group and can report to ACART in December.

10.5 Item four presented members the final document ACART had submitted to the Parliamentary Petitions Committee about changing section 10 of the HART Act to better enable children / young people to store their gametes for more than ten years. The Chair noted that ACART's submission included three amendments to the act that ACART needs to formally send to the Minister (addressed in paragraph 8.2, above).

10.6 The final item was ACART's response to a public enquiry about the submissions ACART had received for its 2023 consultation on guidelines for human reproductive research. The Chair noted that the summary of submissions should be published as soon as is practicable (also addressed above at paragraph 6.2).

## 11. Human reproductive research

11.1 The Chair introduced this item, suggesting that members settle the various specific matters presented in the cover paper, several of which are policy matters.

HOW TO REFER TO THE NEAC STANDARDS

11.2 Members discussed how the guidelines should refer to the NEAC Standards. The pros and cons of specific and general references were examined, in particular that of the standards are amended then ACART might need to quickly amend its guidelines. Members agreed that the statements, in ACART's guidelines, should be along the lines of "applications must meet the requirements set out in the NEAC Standards" in every instance where the standards are applicable.

11.3 There was also a discussion about the need to ensure that all of the relevant NEAC Standards are referred to in ACART's guidelines. The Principal Advisor from the Ethics team will provide a list of all the relevant standards.

SCOPE AND BOUNDARIES

11.4 The discussion moved on to the scope and boundaries of the guidelines, first addressing whether gonadal tissue would be captured by the guidelines. Members agreed that such tissue would be subject to the guidelines because it has human gametes in it. This led to a discussion about all reproductive tissue having a higher moral status than somatic tissue.

11.5 This discussion then went through some examples of tissue that would not be subject to the guidelines, including the uterus and fallopian tubes. Members

considered the option of using the supplementary advice to explain what research ACART expects ECART to consider and what it does not. This supplementary advice could elaborate on what "use" of human reproductive tissue means.

ALTERNATIVE PATH FOR APPLICATIONS, EXPEDITED REVIEWS

11.6 Members discussed whether some low-risk research might be eligible for an expedited review process by ECART. The member with expertise in fertility treatment noted that even if that were to be an option, the researcher would need to provide the same information as would researchers on higher risk research.

11.7 Members agreed that they need to consider a full summary of the types of likely research, the risk categories, and the possible processes for assessing applications. Members asked the Secretariat to provide this information.

CLINICAL USE OF MATERIAL THAT HAS BEEN BIO-BANKED

11.8 This point comprised two main parts, being (a) that bio-banks are not widely used in Aotearoa New Zealand at present and so this item is largely a theoretical one at present and (b) that people will be able to consent to the future uses of material when they have it stored. ACART's discussion in August 2024, had been about whether bio-banked material could later be used clinically.

11.9 Members agreed that the consultation document does not need to ask what people think about this, but rather to simply include a paragraph explaining that people storing material will be able to specify what future activities they consent to.

NO FUTURE RESEARCH WITH MATERIAL ALREADY USED IN RESEARCH

11.10 Members discussed why there might be a prohibition on research in the future with human reproductive material that had already been used in research. Members agreed it was not entirely clear whether such a prohibition should exist, but possible reasons would be that storing the material for future use was treating it more like somatic tissue which can be argued to have a lower moral status than reproductive tissue. Members also noted that there is a moral argument that we should attempt to maximise the benefit from using such tissue.

11.11 Members agreed that ACART should not place such a limitation on use, and that it is important for people to understand the implications of what they are consenting to and to explain this in the consultation document.

MATERIAL USED NON-CLINICALLY TO THEN BE USED CLINICALLY?

11.12 Members concluded that there is probably no need for ACART to take a position on whether material that had been used in non-clinical research could later be used clinically. The reason for not needing to take a position is that if material was to be used clinically the procedure would be subject to a thorough assessment first for safety — there is nothing to gain by ACART specifying whether or not material that

had been used in non-clinical research could later be used clinically.

RULES FOR FUTURE RESEARCH

11.13 The Secretariat explained that this matter was raised so that the Secretariat could clearly explain the scenarios in the consultation document. In particular, it was not clear whether research could be done posthumously if the deceased had not previously consented to the specific research. The Secretariat observed that in posthumous reproduction, the deceased must have consented to a specific use by a specific person, and asked whether the same criteria should apply for posthumous research.

11.14 Members discussed the importance of consent and that the people, whose tissue is proposed for use, will need to have consented to specific uses. The Chair noted that Belgium uses a system where people providing tissue are asked to specify the *categories* of research, from a list, that they do and do not consent to. This checklist can be used instead of asking people to consent to specific research activities.

11.15 Members agreed to present a provision that for posthumous research the donors must have consented to specific research and to ask the public to comment.

DISPOSAL OF REPRODUCTIVE MATERIAL

11.16 There was a discussion about how people's reproductive material can be disposed of, and that people should be informed of the methods of disposal. Members agreed that the researcher should explain the disposal options to the donors and that ACART's guidelines can refer to the terminology in the NEAC standards. The statement should advise the public that they can request specific disposal methods.

TERMINOLOGY FOR EGG COLLECTION

11.17 Members discussed the terminology for the provision about the collection of eggs, and the associated risks, in situations where women will donated the eggs for research and will not have any fertility treatment. Members agreed that the sentence should say "the risk of collection is justified."

CREATION OF EMBRYOS FOR NON-CLINICAL RESEARCH

11.18 There was a discussion about the *intentional* creation of embryos that would be used only in non-clinical research and whether this activity is morally different from the *incidental* creation of embryos that will be used only in non-clinical research.

11.19 Members agreed that the intentional creation of embryos for non-clinical research would be infrequent and that it could also yield benefits. Members agreed the consultation document should present the activity as one proposed for approval. Members confirmed that the provision must be clear that there is no other way of

doing the research.

SAFETY TO FIRST BE PROVEN IN ANIMAL TESTING?

11.20 The member with expertise in fertility treatment noted that there are various methods for demonstrating the safety of a procedure, and consequently ACART should remove the statement about procedures being proven in animal testing.

11.21 Members agreed the guidelines should refer to the NEAC Standards which says that risks must be acceptable.

11.22 The observer from Mana Mokopuna / the Children and Young People's Commission, offered to discuss with her colleagues the terminology about risk, and "no undue risk," and to report back to ACART.

SHORTEN THE INTRODUCTION TO THE NON-CLINICAL SECTION?

11.23 Members agreed to retain this section in the interim then consider whether to shorten it once the bulk of the content has been confirmed.

REMOVE SEVERAL OF THE RATIONALE SUB-HEADINGS?

11.24 Members agreed that the "rationale" sub-headings could be removed.

TRAINING SECTION

11.25 There was a discussion about whether the guidelines should include a section on training and the Secretariat advised members that an opinion from Health Legal had been sought. Once the opinion has been provided, ACART can consider the matter further.

11.26 Members noted that it might be that ACART could recommend that training to use human reproductive tissue (whether clinically or for non-clinical uses) be subject to some regulatory oversight because of the moral status of the tissue.

THE QUESTIONS

11.27 Members agreed that the questions must be specific and that there should also be an opportunity for submitters to make general comments.

SUMMARY DOCUMENT

11.28 Members agreed it would be useful to have a summary document and that the Secretariat could produce it once the main document has been written.

CONSULTATION OPTIONS

11.29 The Chair commented on how the consultation could run, in particular noting that

ACART should consider using online meetings.

**Actions**

- *The Principal Advisor from the Ethics team to provide a list of all the relevant standards.*
- *Secretariat to collate information about the main types of research, the risks, and the possible processes for assessing applications.*
- *Secretariat to include a paragraph in the consultation document explaining that people storing material will be able to specify what future activities they consent to.*
- *Secretariat to explain, in the consultation document, the importance of understanding the implications of consenting to future activities.*
- *Secretariat to add comments about future research in the section of the consultation document on moral status of human reproductive tissue.*
- *Secretariat to add a provision to the consultation document and guidelines that for posthumous research the donors must have consented to specific research and to ask the public to comment.*
- *Secretariat to add a provision to the consultation document that, for the disposal of tissue, ACART's guidelines will refer to the terminology in the NEAC standards.*
- *Secretariat to amend the provision in the consultation document about egg collection, so that sentence says "the risk of collection is justified."*
- *Secretariat to amend the consultation document to present the intentional creation of embryos, for non-clinical research, as one proposed for approval.*
- *Secretariat to amend the consultation document and the guidelines so that they refer to the NEAC Standards which says that "risks must be acceptable."*
- *Observer from the Children and Young People's Commission, to discuss with her colleagues the terminology about risk and to report back to ACART.*
- *Secretariat to remove the "rationale" sub-headings where appropriate.*

## 12. Extending storage: item from the Ministry of Health

12.1 The Manager of the Ethics team, at the Ministry of Health, introduced this item, explaining that she would like ACART's endorsement of a proposal to change the process used when people apply to extend the storage of their reproductive material.

12.2 The Manager explained that the current process lets people apply directly to ECART, to have storage extended. This method means that the Secretariat has to anonymise the material, and it often has to liaise with both the applicants and the clinic to get the correct information. There is also an increasing number of applications for extending storage. The Manager would like the clinics to manage the applications, submitting all the material to the Secretariat for ECART. There was some discussion about whether a change in the process would result in an increase

of workload for the clinics, and if so, how much extra work this might be.

12.3 Members agreed to support the Ministry's proposal.

## 13. Surrogacy Bill: update

13.1 The Chair briefly recapped the main points that ACART had commented on in its submission to the Health Select Committee. He also noted that the member with expertise in legal matters had made an oral submission in her separate capacity as an academic.

13.2 The Principal Advisor from the Ethics team advised those present that the departmental report was due to be submitted by November 2024 and that the bill was scheduled to return to the house early in 2025.

## 14. Meeting dates for 2025

14.1 Members discussed the proposed meeting dates for 2025, noting that the proposed dates for ECART had also been presented to ensure no overlap of dates.

14.2 Members agreed to meet on the Thursdays of the weeks that had been proposed.

**Action**

- *Secretariat to circulate the dates to members and to inform the ECART Secretariat.*

## 15. Chair's report

15.1 The Chair advised members that the proposed new members and reappointments had been submitted to the Minister for consideration.

15.2 Members discussed options for having some overlap of departing members with new members to ensure continuity of knowledge in the committee. Members agreed this was worth doing and noted that there might be budget limitations to doing this.

## 16. Member reports

16.1 No reports were presented.

## 17. Secretariat report

17.1 Members noted the report.

17.2 The Chair noted that the Secretariat is now less than one full time equivalent staff member and that this could affect the ability of ACART to produce material in a timely manner.

## 18. Work between meetings

18.1 The Chair noted the various actions that had been agreed to in this meeting.

## 19. Update on appointments

19.1 The Secretariat noted that this item had been covered earlier in the day.

## 20. Attendance at ECART

20.1 The member to attend ECART on 24 October is Karaitiana Taiuru, and the member to attend on 5 December is Calum Barrett.

The meeting closed at 1.40 p.m.