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

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Held online on 11 December 2024.

Present

Calum Barrett (Chair)

Amanda Lees

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Sarah Wakeman

Debra Wilson

Non-members present

Annabel Ahuriri-Driscoll. Ethics Committee on Assisted Reproductive Technology.

Liz Bohm. ACART Secretariat, Ministry of Health.

Lewis Forsyth. Ethics team, Ministry of Health (part of meeting).

Beth Harman. Ethics team, Ministry of Health (part of meeting).

Natalia Jefferson. Ethics team, Ministry of Health.

Martin Kennedy. ACART Secretariat, Ministry of Health.

Kathleen Logan. Observer, Mana Mokopuna / Children and Young People's Commission.

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 observers. The observers were from Mana Mokopuna / the Children and Young People's Commission and from the Ethics Committee on Assisted Reproductive Technology.

1.2 Two staff who are new in the Ethics team at the Ministry of Health attended the meeting as observers.

2. Opening comments

2.1 The member with expertise in law spoke about a conference on surrogacy she had attended and about the surrogacy bill that is at the select committee stage.

2.2 The member reported that the conference included presentations from several countries revising their surrogacy laws at the same time. Of those countries, most are not introducing a requirement for the ethics committee to assess whether the proposed compensation (in a case) is reasonable. Similarly, most countries are not proposing that the ethics committee make decisions about the legality of the contracts between the parties. The member commented on the difficulty of requiring the committee to carry out such functions due to the level of technical legal knowledge that the committee members would need.

2.3 The member explained that the surrogacy bill, that is at select committee, has created a lot of interest and many people have been able to comment on it. The select committee invited the member to appear twice, the second time for a longer session in which she was able to elaborate on several matters that need more consideration.

2.4 There was a brief discussion about the increasing use of "support plans" for surrogacies in Aotearoa New Zealand. Although these plans are not required by the regulations ECART considers them to be useful.

3. Apologies

3.1 Edmond Fehoko, Seth Fraser, Neuton Lambert.

4. Approval of the agenda

4.1 Members approved the agenda, including a late item that the Chair had circulated separate to the agenda pack.

Action

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

5. Declarations of Interests

5.1 The declarations were accepted.

6. Minutes of ACART's meeting in October 2024

6.1 Members approved the minutes.

6.2 Members discussed the summary of submissions, from ACART's first consultation on human reproductive research. Members agreed it should be published as soon as is practicable.

Actions

- *Secretariat to publish the October 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 October 2024 meeting

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

8. Status of ACART's work programme

8.1 Members noted the report.

9. Report on ECART's recent meeting

9.1 Members discussed the minutes and noted that, on this occasion, the cases had been straight forward with few matters needing ACART's attention. There was a discussion about a traditional surrogacy and the circumstances in which cases must be considered by ECART — the discussion was prompted by a case in which it was not immediately clear that it was a traditional surrogacy.

9.2 Members noted that the method for numbering cases has been changed and now the date, on which the case was considered, is not immediately obvious.

10. Correspondence

10.1 The Chair explained the five items of correspondence.

10.2 The first item was about Fertility Associates' new donor linking process. The item presented ACART's formal response to Fertility Associates, endorsing their proposed new process. There was a brief discussion about whether or not it was easy for consumers / interested parties to find information, on Fertility Associates' website, about donor linking.

10.3 The second item was ECART's letter to Fertility Associates about reasonable expenses. ECART's letter to Fertility Associates had been copied to ACART. Members discussed how reasonable expenses can be defined and they noted that the surrogacy bill will include some details on what payments could be considered reasonable.

10.4 Item three was ACART's response to Fertility Associates about the guidelines for posthumous reproduction. The item was included for members' information and no further discussion was needed.

10.5 Item four was the response from the Director General of Health to ACART's letter which had commented on the need for ACART to be supported by the Ministry of

health.

Fifth item of correspondence: using PGD in assisted reproduction

10.6 The fifth item, which had been sent to members separately from the agenda pack, was about if and how PGD could be used in assisted reproduction and, if it is to be more widely used, how it might be regulated.

10.7 The Chair told members that he and the Chair of ECART had recently had a meeting with Dr Richard King (a geneticist). Dr King had enquired about which activities might come within the uses of PGD that are regulated under the HART Order. The Chairs' meeting with Dr King had addressed matters such as Variants of Unknown Significance.

10.8 Members noted that the regulation of PGD is no longer fit for purpose and that changes to the regulations need to be considered. Members noted that one option would be to adopt a regime similar to that in the United Kingdom, where clinicians refer to a substantial list of conditions to guide their decisions about applying the technology.

10.9 There was a discussion about the role of uncertainty and how criteria could be set for deciding whether or not embryos should not be used in reproduction. Members commented on the need for an in depth review including the state of and options for regulation, and the associated ethical questions. Members agreed to add an item to ACART's agenda for February 2025 to do initial scoping on the topic.

Clinic query about PGD and non-binding advice

10.10 Closely related to the discussion about PGD was a query a clinic had sent to ECART. The clinic had asked ECART for non-binding advice about a case in which a genetic condition (that could cause serious illness) was present in embryos. The clinic had sought ECART's non-binding advice about deciding whether to proceed with the assisted reproduction. Subsequently, ECART had asked ACART for its opinion, with ECART noting that it has no authority to make policy and that, depending how ECART responds to the clinic, the response could be seen as ECART setting a policy.

10.11 Members had a wide ranging discussion about the ethics of enabling a pregnancy where there was a significant risk of the offspring having, or developing, ailments which could be serious and in some cases fatal. Members commented on the draft response from ECART to the clinic and suggested that ECART's proposed response would enable a pregnancy that was too risky.

10.12 The Chair said he would discuss the case with the Chair of ECART directly. He also concluded that ACART and ECART have identified a gap in the regulations and

confirmed that ACART should look into how the gap could be addressed.

Actions

- *Secretariat to add an item to ACART's agenda for February 2025 to do initial scoping on the topic.*
- *Chair to discuss the case with the Chair of ECART directly.*

Extra item: presentation by John Peek

- The Chair welcomed Dr John Peek. Dr Peek was one of the first embryologists in Aotearoa New Zealand and played a key role in establishing assisted human reproduction here.
- Dr Peek gave a presentation on assisted reproduction, including its history and politics, the technology, the regulatory setting, how services are provided and funded, and opportunities for improvements.
- Dr Peek spoke about the importance of recognising the role of assisted reproductive and different people's preferences, how resources can be allocated, and the need for all people involved to be resilient. Dr Peek commented on the recent reports that have looked into how different groups of people have different experiences when using, or seeking, fertility treatment.
- There was a brief discussion about the ANZARD report and options for Aoteroa New Zealand to present data that is useful for clinics, consumers, and potentially the government. Dr Peek commented on the high cost of establishing a new method of reporting. He said that clinics might be reluctant to establish extra processes for extracting and submitting data, especially as the relevant data is already submitted and used to create the ANZARD report.

11. Human reproductive research

11.1 The Chair introduced this item, noting that the consultation document is progressing well and that there were only a few policy questions to confirm. He recommended that the bulk of the content be set out and that any trimming could then be done.

REFERENCES TO THE NEAC STANDARDS

11.2 Members discussed how the guidelines refer to the NEAC Standards. Members agreed an explanation should be added to paragraph 51 of the consultation document that researchers will need to meet the requirements of the NEAC Standards and of the ACART guidelines.

11.3 There was a discussion about whether participants needed to be counselled in non-clinical research and a member said that counselling in non-clinical research would be needed only if egg harvesting was involved. The draft guidelines have a provision to this effect.

ELABORATE ON “ADEQUATE CONSIDERATION OF THE SPECIAL STATUS OF EMBRYOS”

11.4 Members discussed the provision that researchers must demonstrate adequate consideration of the special status of embryos. Members noted several matters with the provision including:

- how would consideration be demonstrated?
- what is the “high standard” to be achieved?
- how can respect be demonstrated and what does it actually mean in the case of embryo research?

11.5 Members agreed to remove the word “adequate” from the provision. They also agreed to use text from the NEAC Standards to clarify what ACART means.

CONFIRM THAT WOMEN WHO HAVE EGGS HARVESTED FOR NON-CLINICAL USE COULD SUBSEQUENTLY DONATE THEM FOR CLINICAL USE

11.6 The Secretariat explained that the word “only” at the end of the heading could lead people to think that the provision means the harvested eggs could not subsequently be donated. Members decided that the word “only” should be removed.

AGREE THE QUESTION, TO ASK SUBMITTERS, ABOUT WHETHER TO ENABLE THE CREATION OF HUMAN EMBRYOS FOR NON-CLINICAL RESEARCH

11.7 Members agreed that although this question and the two that follow are related to one another there is enough difference for them to be presented as separate items.

11.8 In the case of enabling human embryos to be created solely for non-clinical research, members agreed the question should be “Should ACART enable the creation of human embryos for non-clinical research?” Members also agreed that a supplementary question should ask “If ACART enables the activity, what should the limits be?”

AGREE THE QUESTION, TO ASK SUBMITTERS, ABOUT WHETHER TO ENABLE THE CREATION OF CLONED EMBRYOS FOR NON-CLINICAL RESEARCH

11.9 As with the preceding activity, members agreed the question should be “Should ACART enable the creation of *cloned* human embryos for non-clinical research?”

11.10 Members agreed that ACART should seek support from a professional science communicator to ensure that cloning is clearly explained and that any concerns about unrealistic science-fiction type scenarios are addressed.

11.11 Members also agreed that the consultation document should be clear that financial benefits are secondary to the therapeutic and reproductive improvements.

DECIDE WHETHER TO REMOVE / SHORTEN THE NARRATIVE ABOUT HUMAN EMBRYONIC STEM CELLS

11.12 The discussion about stem cells concluded that the text can remain largely as it is. A member noted that the stem cells might not come from surplus embryos as they

could come from embryos that were created solely for non-clinical research if ACART enables this activity. This point is in the consultation document but needs to be clearer.

SHORTEN THE INTRODUCTION TO THE NON-CLINICAL SECTION?

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

TRAINING, AND ADVICE

11.14 The Secretariat advised members that an opinion from Health Legal had been sought and once the opinion has been provided, ACART can consider the matter further. The discussion noted that there is some uncertainty about if and how people are regulated in training to work with human reproductive material.

11.15 Members confirmed the conclusion of the previous meeting, that it is likely that ACART could recommend to the Minister 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.

11.16 Members agreed that a suitable question about regulating training, for the consultation document, would be "Do you think training on the use of human reproductive tissue should be an established procedure or more tightly regulated?"

11.17 An action was agreed, for the Secretariat to investigate whether RTAC (the Reproductive Technology Accreditation Committee) has guidance on training, such as how to use an ICSI machine.

THE QUESTIONS

11.18 Members agreed that the questions are largely fit for purpose and can be confirmed at the next meeting. The questions must be specific and that there should also be an opportunity for submitters to make general comments.

THE ENGAGEMENT PLAN

11.19 The Secretariat explained that the draft engagement plan, and the separate draft plan for Māori specific consultation, were attached for members' information. Members agreed to consider these in more detail at ACART's next meeting.

Actions

- *Secretariat to remove the word "adequate" from the provision.*
- *Secretariat to use text from the NEAC Standards to clarify what ACART means.*
- *Secretariat to remove the word "only" from the heading about egg harvesting.*
- *Secretariat to add a supplementary question for enabling embryos to be created solely for non-clinical research: "If ACART enables the activity, what should the limits be?"*
- *Secretariat to confirm the question for clones: "Should ACART enable the*

creation of cloned human embryos for non-clinical research?"

- *Secretariat to get support from a professional science communicator to explain cloning.*
- *Secretariat to ensure that the consultation document is clear that financial benefits are secondary to the therapeutic and reproductive improvements.*
- *Secretariat to make the consultation document clearer about the possible sources of human embryonic stem cells.*
- *Secretariat to investigate whether RTAC has guidance on training, such as how to use an ICSI machine.*
- *Secretariat to add text to paragraph 51 of the consultation document that researchers will need to meet the requirements of the NEAC Standards and of the ACART guidelines.*
- *Secretariat to update the draft engagement plans.*
- *Members to consider the draft engagement plans at ACART's next meeting.*

12. Advice to the Minister about storage

12.1 The Chair noted that the draft advice to the Minister, about recommendations for three changes to the HART Act, had already been agreed by members and that now, subject to minor changes, could be sent to the Minister. The Chair will send his amendments to the Secretariat.

12.2 The members with expertise in assisted reproduction and in human reproductive research also suggested changes to make the advice clearer.

Actions

- *Chair to send his amendments to the Secretariat.*

13. Acknowledgement of four members' terms ending

13.1 Members acknowledged the end of the terms of four members and that new members and the new Chair are likely to be announced in the near future. Members expressed their gratitude to one another and noted that they will keep up to date with ACART's work, in particular through consultations.

14. Chair's report

14.1 The Chair advised members that he had been keeping up to date with the appointments and liaising with the Secretariat about the various pieces of project work.

15. Member reports

16.1 No reports were presented.

16. Secretariat report

16.1 Members noted the report.

16.2 The Secretariat advised members that the proposed new members and reappointments had been submitted to Cabinet and a decision was likely in the near future.

17. Work between meetings

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

18. Update on appointments

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

19. Attendance at ECART

19.1 The members to attend ECART in 2025 are to be confirmed. The Secretariat will send members the ECART dates as soon as they are available.

Actions

- *Secretariat to send members the ECART dates as soon as they are available.*
- *Members to volunteer for ECART meetings in 2025.*

The meeting closed at 2.40 p.m.