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

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Held online on 2 May 2024.

Present

Calum Barrett (Chair)

Seth Fraser

Neuton Lambert

Amanda Lees

Minu Punchihewa

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Sarah Wakeman

Debbie Wilson

Non-members present

Elsie Coleman. ACART Secretariat.

Martin Kennedy. ACART Secretariat.

Richard Ngatai. ECART.

Saskia Patton. Manager, Ethics team, Ministry of Health

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 gave the opening comments, noting the main policy topic for the day is ACART's work on human reproductive research. He commented on the importance of definitions for embryos, synthetic embryos and blastoids and that the guidelines and consultation document were progressing nicely. The Chair acknowledged the useful comments from two researchers who work on human reproductive research.

2.2 A member said that New Zealand will need to regulate if and how artificial embryos can be made and used and that it is important for the government to maintain the trust of the public in how such activities are regulated.

2.3 The Chair suggested that ACART's consultation document for human reproductive research should comment on the difference between embryos that can develop into people and those that cannot. He noted that research is needed in order to confirm the different situations in which embryos and embryo models can and cannot develop.

3. Apologies

3.1 Edmond Fehoko.

4. Approval of the agenda

4.1 Members approved the agenda and noted the importance of agreeing ACART's priorities in order to be able to agree the programme with the minister.

4.2 The Chair recommended that members work through the detail of the draft guidelines for human reproductive research, in particular to discuss the comments that the independent researchers had provided. Members agreed.

Action

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

5. Declarations of Interests

5.1 The declarations were accepted.

6. Minutes of ACART's meeting of February 2024

6.1 Members approved the minutes with one amendment.

Actions

- *Secretariat to make the amendment.*
- *Secretariat to publish the February 2024 minutes on the ACART website.*

7. Actions arising from ACART's February 2024 meeting

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

7.2 A member said she would attend the conference of the European Society of Human Reproduction and Embryology in Europe in a few weeks. The Chair suggested she could give the opening comments at ACART, after the conference, and comment on any topics that would be useful for ACART.

8. Status of ACART's work programme

8.1 Members noted the report.

8.2 The Secretariat gave an oral update, noting that the Ministry of Health (MoH) is about to advise the Minister about ACART and that the guidelines and advice for posthumous reproduction are about to be published.

9. ACART's meeting dates for the second half of 2024

9.1 Members agreed to the dates. The dates are:

- 22 August
- 17 October
- 12 December
- The 27 June date had already been agreed.

10. Report on ECART's recent meetings

10.1 Members noted the most recent ECART meeting had been held on 11 April. Members also noted the minutes from the ECART meeting of 19 February 2024.

10.2 There was a discussion about the content of ECART's minutes and members agreed that it would be useful for ECART's minutes to record the main points of the discussions about the wellbeing of the offspring. Members agreed ACART should write to the Chair of ECART to suggest this change.

10.3 The Chair commented on a case in which people involved in a surrogacy arrangement had "crowd-funded" to help a surrogate with her expenses. The Chair noted that the law is not fit for purpose when it comes to regulating "valuable consideration" and if and how people can be paid for taking part in assisted reproduction and in surrogacy in particular.

10.4 Members discussed a case in which a surrogate had a heart condition and the case had been approved. Members noted that ECART's role has some overlap between the purely ethical matters the guidelines require it to consider and the matters that could be argued to be more clinical rather than ethical.

10.5 There was a discussion about the applications to extend the storage of reproductive material. ACART members suggested it would be useful to see more detail about each case. The Secretariat will contact ECART's Secretariat to ask about the practicality of sharing the information.

10.6 There was a discussion about how applications are made for extending storage. The member with expertise in assisted reproductive technology explained that their clinic has a full-time person to manage storage extensions and that the clinic does not charge the patients for the work they do when applying to extend the storage. She noted that the clinic charges for the storage.

Actions

- *Secretariat to draft a letter from ACART's Chair to the Chair of ECART.*
- *Secretariat will contact ECART's Secretariat to ask about the practicality of sharing the information for extending storage.*
- *Secretariat will contact ECART's Secretariat to ask about the publication of the minutes for the storage extension cases.*

11. ANZARD report

Possible change to the data submission process

11.1 The Chair first updated members on the possibility of clinics submitting data, to the University of New South Wales, twice a year for the ANZARD database. This would be a change from the current practice of submitting once a year. ACART had initially agreed to support the proposal and co-signed a letter, with the university, that would be sent to the fertility clinics in Aotearoa New Zealand with the endorsement of the Fertility Society of Australia and New Zealand. However, one of the clinics had raised concerns about the extra time it would take to collate and submit data twice a year — the extra time was much more substantial than ACART had previously understood. Consequently, the fertility society had declined to send the letter to the clinics. The Chair discussed with members whether the benefits of proposed reporting change justified the increase in compliance costs. Members agreed that ACART would revise its position in light of this extra information, and would explain the situation to the university.

The most recent ANZARD report

11.2 Members discussed the most recent ANZARD report and agreed to its publication once the foreword had been added.

11.3 Members discussed some of the findings in the report, in particular the rates of the use of assisted reproduction and how for many ethnic groups the rates are not proportionate to the group's proportion of the total population. It was noted that there could be many reasons for this non-proportionality, and that ACART does not have information about the reasons why some ethnic groups are under or over represented in the data.

11.4 The point was made that live-birth success rates in assisted reproduction are only very slowly increasing and that this slow improvement supports the case for allowing more research on human reproduction. Members agreed this point should be added to the consultation document for human reproductive research.

11.5 The member with expertise in human reproductive research noted that the report does not differentiate between the different types of preimplantation testing and that the techniques have different implications. She said that the data should be

presented with the distinction made.

11.6 The member with expertise in Māori customary values asked that, in future, the tables in the reports have a macron in the word “Māori” The Secretariat will ask the university to make this change.

Actions

- *Secretariat to draft a letter from ACART to New Zealand’s other fertility services providers.*
- *Secretariat to draft a letter from ACART to the University of New South Wales.*
- *Secretariat to draft the foreword for the recent ANZARD report.*
- *Chair to approve the foreword.*
- *Secretariat to arrange the publication of the report.*
- *Secretariat to add a statement to the consultation document for human reproductive research about the benefits of doing more research.*
- *Secretariat to ask the University of New South Wales to write “Māori” with a macron.*

12. Correspondence

12.1 The Chair told members that he had responded to stakeholders on three matters. The enquiries had been about (a) whether people taking part in posthumous reproduction would be required to get legal advice (b) how PGD is used in Aotearoa New Zealand and (c) why the guidelines for storage limits are as they are.

13. ACART request to the Ministry of Health for support

13.1 The Chair introduced this item, explaining that a letter has been drafted for ACART to send to the Ministry of Health explaining that ACART needs sufficient financial and secretariat support to carry out its functions. The Chair also commented on the slow pace of some of ACART’s work and that this slowness is sometimes exacerbated with the time it takes the Ministry of Health to provide parallel advice.

13.2 The manager of the Ethics team gave members more contextual information, explaining that, by July 2024, the Ethics team was likely to have fewer staff and possibly a smaller budget, due to the cost-cutting at the Ministry. If the reductions happen, ACART might not be able to carry out as many activities as it would like to. The manager said that it would therefore be useful for ACART to identify its priorities and to plan the activities it would like to do in the 2024/25 financial year.

13.3 Members discussed the statutory obligations the committee has and also the need to advise the government on emerging matters such as the use of genetic editing in human reproductive research. A member suggested that ACART’s letter emphasise the benefits of maintaining ACART’s funding, because having adequate funding and secretariat support will mean ACART can assess topics once, thoroughly, rather than addressing topics in a piece meal approach.

13.4 The Chair suggested the letter should state that ACART relies on the secretariat being subject matter experts and that this secretariat must be maintained. A

member also suggested that the letter state that the use of assisted reproduction is increasing and these increases further support the case for ensuring ACART is able to function effectively. Members agreed and the secretariat will amend the letter as suggested. Members agreed to consider the next version of the letter between meetings.

Action

- *Secretariat to amend the letter to the Ministry as requested.*
- *Members to consider the amended letter.*

14. ACART's priorities, work programme, and letter to the Minister

14.1 This item was introduced by the Chair who noted that it is related to the previous item due to ACART's financial and secretariat support having a direct bearing on ACART's ability to carry out its statutory functions and progress its work on advice and guidelines in addition to its monitoring and reporting functions.

14.2 The manager of the Ethics team suggested a staged process for advising the Minister. Members and the manager discussed a range of matters that ACART and the Ministry need to address and concluded the following approach would be used.

- The first stage would be for the Ministry to brief the Minister to (a) introduce ACART (b) inform the Minister that ACART is about to publish the guidelines for posthumous reproduction and (c) ask her to note that a subsequent briefing from the Ministry would explain ACART's work programme and that ACART would seek her agreement to the programme.
- A subsequent briefing from the Ministry to the Minister would recommend that she meet the Chair of ACART and that this meeting could help to reach an agreement on the programme.
- ACART will send its current letter to the Minister but without the work programme text — the current letter will say that the work programme will be explained in a subsequent letter from ACART.

Consultation for advice on initial storage periods

14.3 The discussion moved to ACART's plan to consult on whether the initial storage period of ten 10 years, for reproductive material, should be revised. The Chair explained that ACART's earlier consultation on storage (in 2022) had, indirectly, elicited comments about the period and that there was enough information to make a case to amend the initial storage period.

14.4 The Chair also noted that the manager of the Ethics committee preferred a reduced consultation because (a) the earlier consultation had already elicited comments, (b) ACART had enough information to recommend a change and if a change were to happen then the government would have to do a full consultation and (c) a narrow consultation would save staff time and ACART budget.

14.5 Members agreed a targeted consultation would be suitable and discussed how it should be done. The member with expertise in assisted reproductive technology

said that her clinic likes to receive a letter first, explaining the proposal and allowing them time to prepare a response. They might then choose whether they would also like to meet.

14.6 Members agreed a letter would be suitable and that it would include a summary of the key information in the consultation document. The full consultation document itself will no longer be needed. The letter can include options and proposals and will invite people to discuss the matter with ACART. Members discussed who the recipients should be and tentatively agreed on clinics, Fertility New Zealand, and Donor Conceived Aotearoa. A member suggested that an easy and cost-effective option would be to do an online survey of university students.

Actions

- *Secretariat to amend the letter to the Minister as requested.*
- *Secretariat to write a second letter to the Minister, focusing on the work programme.*
- *Secretariat to write ACART's letter to people who will be invited to comment on the initial storage period of reproductive material.*
- *Secretariat to write a summary document of the matters to consider for the initial storage period.*

15. Human reproductive research

15.1 The Chair opened this item, noting that the guidelines and consultation document were progressing well. He acknowledged the useful comments from two researchers who work on human reproductive research and suggested that today members go through the draft guidelines including the comments from the independent experts to agree on the policy and wording matters. Members agreed.

15.2 Members discussed options for ensuring that proposed research will be scientifically valid. Members noted that it is standard practice for such research to go through a peer review process. There was discussion about whether applications that have less risk or fewer ethical concerns could go through an "expedited" process. One member explained that any research using human tissue has to be considered by a Health and Disability Ethics Committee (HDEC) but the HDECs do not do the scientific peer review. Members agreed the consultation document could include a question about the idea of different levels of risk or ethical concern. Members agreed that, at provision "A.a" in the draft guidelines, a statement should be added about what sort of applications go to the HDECs.

15.3 The Chair suggested a flow diagram would be useful to show how applications would be assessed. Members agreed that the consultation document should ask submitters their thoughts on the process for evaluating applications. The secretariat will create a table and/or flow diagram showing possible process options.

15.4 Members agreed that the consultation document could state that ACART cannot issue guidelines that would enable the clinical use of artificial embryos, because such an activity is not regulated in the HART Act. Members agreed the document should invite people to comment on this.

15.5 Members noted that the provision on tikanga appeared incomplete. The member with expertise in Māori customary values said the provision could simply refer to the narrative about tikanga in the National Ethical Standards document that is published by the National Ethics Advisory Committee. The Secretariat will make the change in the draft guidelines.

15.6 Biobanking was the next item, with the discussion touching on storage limits being unique to reproductive material and whether there should be restrictions on stored reproductive material, that had been donated for research, being returned for clinical treatment. Members acknowledged that any provisions for biobanking will need to be consistent with the provisions that HDECs use — the HDECs use the biobanking guidelines that NEAC has published. Members agreed the consultation document should include a question about whether the guidelines should include separate provisions for biobanking, as distinct from other storage.

15.7 Members discussed informed consent and concluded that the consultation document should state that participants must have all the possible research activities explained to them. The Secretariat will add the text to the document.

15.8 There was discussion about the meaning of the provision that research must be done in an accredited facility. Members agreed to remove this provision. Members also noted that the document should state that gonadal tissue will contain sperm or eggs and that the research could be on either the tissue or the gametes. If the research is on the tissue only the application will not need to be submitted to ECART.

15.9 The headings for each sub-section, in the part of the document about non-clinical research, were considered and could be made clearer. The Secretariat will draft alternate headings.

15.10 Members discussed the moral status of the embryo and agreed that, early in the document, ACART needs to acknowledge that different people have different ideas about this matter. The document also needs to be clear that if some types of research are to happen the only way it can be done is by creating embryos and that some of these embryos might not be used clinically.

15.11 The final part of this item was to confirm that the draft guidelines and consultation should include a section on training. The provisions, and explanation in the consultation document, would need to be clear that the provisions are for researchers and clinicians needing to learn how to work with human reproductive material. The Committee noted that any eventual guidelines would either need to be titled appropriately to acknowledge that they covered both Human Reproductive Research and Training, or split into separate guidelines.

Actions

- *Secretariat to create a table and/or flow diagram showing possible process options.*
- *Secretariat to add a question to the consultation document asking people their thoughts about the possible process(es).*
- *Secretariat to add a question to the document about the idea of different levels of risk or ethical concern.*

- *Secretariat to amend the tikanga provision, to refer to the National Ethical Standards.*
- *Secretariat to add text to the consultation document to state that participants must have all the possible research activities explained to them.*
- *Secretariat to add text that gonadal tissue contains gametes and that research might be on the tissue or on the gametes in the tissue.*
- *Secretariat to draft alternate headings for the sub-sections in the part of the document about non-clinical research.*

16. ACART's Ethical framework and Te Tiriti

16.1 The Chair explained that this is a brief item for noting. The changes to the framework are close to final and the publication process is about to begin.

17. New guidelines for posthumous reproduction

17.1 The Chair explained that this is a brief item for noting. The Ministry of Health is about to advise the Minister about the publication of the guidelines and the publication process is about to begin.

17.2 The Secretariat advised members that the implementation is in progress and that the process for people to apply to ECART is being planned. If necessary, applications could be made using paper application forms rather than using the online forms which are being developed now.

18. Chair's report

18.1 The Chair noted that his report was standard. He advised members that he has yet to schedule a meeting with the Chair of the Gene Technology Advisory Committee.

19. Member reports

19.1 No reports were presented, but members noted the recent articles the Secretariat had sent. The Chair noted the increasing number of articles being published about embryo models.

20. Secretariat report

20.1 Members noted the report.

21. Work between meetings.

21.1 The Chair noted the various actions that had been agreed to in this meeting. Members are asked to consider two items between meetings (see items 13 and 14).

22. Update on appointments.

22.1 The Secretariat told members that the Ethics team had recently recommended, to the appointments team in the Ministry of Health, that advertising could begin for three members who need to be replaced and that work could be initiated to

reappoint four other members.

23. Attendance at ECART

22.1 Catherine Ryan is scheduled to attend ECART on 20 June.

22.2 The Secretariat will ask the ECART Secretariat for the dates of ECART's meetings for the rest of 2024.

Action

- *Secretariat will ask the ECART Secretariat for the dates of ECART's meetings for the rest of 2024.*

The meeting closed at 2:50 p.m.