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

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Held in-person and online on 19 October 2023.

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

Lana Stockman. ECART.

Nic Aagaard. Manager, Ethics (morning).

Elsie Coleman. ACART Secretariat.

Chloe Croskery. ACART Secretariat.

Martin Kennedy. ACART Secretariat.

1. Welcome and Karakia

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

2. Opening comments

2.1 The Chair advised those present that three new members had recently been appointed and were all present today.

2.2 The member with expertise in reproductive research gave opening comments about research involving blastoids. The member noted that the HART Act does not currently regulate artificial embryos and that this will be important to address in the future.

3. Apologies

3.1 Shannon Hanrahan and Edmond Fehoko.

4. Approval of the agenda

4.1 Members approved the agenda. The Chair added one piece of correspondence about section 12 of the HART Act to the agenda.

Actions

- *Secretariat to add the October 2023 agenda to the ACART website.*

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 legal expertise) and Minu Punchihewa (representing the Children and Young People's Commission / Mana Mokopuna).

5.2 All present introduced themselves.

5.3 The Chair gave a presentation about ACART's functions and work programme.

6. Declarations of Interests

6.1 Members agreed to send any conflicts of interest to the Secretariat to be added to the register.

7. Minutes of ACART's meeting of August 2023

7.1 Members approved the minutes subject to some additions to the extending storage section.

Action

- *Secretariat to add two points to the extending storage section in the August 2023 minutes and send to members to approve.*

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

8. Actions arising from ACART's August 2023 meeting

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

9. Status of ACART's work programme

9.1 Members noted the report.

9.2 Members discussed the cultural competency of counselling staff at fertility clinics. Members noted that while ACART cannot influence how fertility clinics do this aspect of their work, they may wish to provide supplementary advice on cultural competency as a guide. Members agreed that this advice would need to identify Māori and Pacific approaches.

9.3 The Manager of the Ethics team suggested that the National Ethical Advisory Committee (NEAC) prioritisation framework could be a helpful guide for how to prioritise ACART's work programme.

Actions

- *Secretariat to prepare a transition plan for publishing the posthumous guidelines.*
- *Secretariat to publish the amended guidelines at the date to be stated in the transition plan.*
- *Secretariat to send the NEAC prioritisation framework as a guide to prioritise ACART's work programme.*
- *Secretariat to prepare the 2022/23 annual report.*
- *Secretariat to collate information, including the principles of the HART Act, that is relevant for producing commentary on cultural competency.*

10. Meeting dates for 2024

10.1 Members approved the 2024 meeting dates up until June 2024.

11. Report on ECART's recent meetings

11.1 Members noted the most recent ECART meeting on August 31st. The minutes were attached to this (October) agenda for ACART.

11.2 ECART's discussion about the mental health of surrogates was noted, as well as several cases. Members noted that one of the cases was deferred on the basis of the surrogate's BMI being above 40. In ACART's previous meeting, members had discussed whether the Chair would discuss BMI with the Chair of ECART to consider whether ACART should investigate the matter further. Members agreed that there was no need to investigate the matter of BMI further. The member with expertise in reproductive technology shared a recent study about birth outcomes and BMI.

12. Correspondence

12.1 Members discussed the correspondence from an individual wishing to donate embryos without the consent of their ex-partner. The Manager of Ethics noted that the Ministry of Health has responded to this piece of correspondence. The manager of the ethics team will check with the Ministry of Health whether ACART can see the letter. Following the meeting, ACART received this response.

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. This item was raised in ACART's previous meeting and the Chair advised members that since then he has sent a letter from ACART to ECART stating that the intention is that the rule applies regardless of which countries the parties are in.

12.3 Members noted the letter from ECART to ACART about the hard cut-off at 10 years and agreed to discuss this further during their extended storage item.

12.4 The Chair updated members on additional correspondence regarding an individual who had gametes collected as a minor and wishes to donate those gametes as an adult, which Section 12 of that HART Act does not appear to allow. Members agreed to write to ECART after viewing internal advice and agree that this section needs to be clarified.

Actions

- *Secretariat to provide members with the Ministry of Health response regarding embryo donation.*
- *Secretariat to send internal advice to ACART about section 12 of the HART Act.*
- *Secretariat to draft a letter to ECART about Section 12 of the HART Act.*

13. Extending storage

Meeting with Patient Review Panel

13.1 The Chair updated members on a recent meeting with the Chair and Associate of the Patient Review Panel about the extended storage legislation in Australia. The Chair explained that the Patient Review Panel considers applications for assisted reproductive procedures and extended storage of gametes and embryos in Victoria, Australia.

13.2 The Australian Reproductive Treatment Act allows applications to be considered after their expiry date in exceptional circumstances. The Chair noted that approximately 10% of applications received by the Patient Review Panel are made after the expiry date and most commonly these are made only days to weeks after the expiry date.

13.3 The Chair explained that the panel was relatively flexible about the meaning of exceptional circumstances, including situations such as administrative errors (e.g.

change of address). The Patient Review Panel considered the discretion as a helpful safeguard as the consequence of not approving these applications is the destruction of gametes and embryos.

Options for the 'hard cut-off' at 10 years

13.4 Members discussed whether they should recommend a change to the hard cut-off at 10 years in section 10 of the HART Act. The Committee noted the impacts of this section on people, particularly young people, who apply soon after the expiry date, such as losing the chance to have a biologically related child.

13.5 Given the significant implications of the current legislation, members agreed to write to the minister recommending a change to section 10 of the HART Act to allow ECART discretion to consider applications received after the applicable storage period. This would also involve ACART writing guidelines to ECART on what would constitute 'special circumstances' where applications submitted after the expiry date could be considered and approved. Some examples could be administrative error and importing gametes from overseas that had been lawfully stored for more than 10 years.

13.6 Members noted that issues with extended storge impact many people. Therefore, it should be at the top of ACART's priorities to recommend a change to this legislation.

Consulting

13.7 The Committee discussed whether the recommended change to the HART Act would be significant enough to consult with the public on. Members agreed that the change was not of significant interest to the public based on the criteria in the statute and agreed to write to the Minister without first consulting. The Committee also recognised that there was support around changing the 10-year cut-off in the first consultation on extended storage guidelines.

Other options

13.8 Members discussed whether there were any options for late applications to be considered for people who have currently applied after the expiry date under the current legislation. Members discussed the possibility of applicants reapplying with new information after their application was declined. Members asked that the current ECART decision letters be amended to state that applications had been declined rather than stating that they could not be considered. Members also asked that a statement be included in the letters to say that decisions on applications can be reviewed.

Storage period for fertility preservation

13.9 Members discussed whether there should be a distinction between the initial storage periods for fertility preservation vs fertility use. In Victoria, Australia, children and individuals deemed at risk of becoming prematurely infertile are granted an

initial storage time of 20 years for fertility preservation.

13.10 Members discussed how this would allow young people to apply at a later date when they would be more likely to be considering the use of their gametes. The member representing the Children and Young People's Commission / Mana Mokopuna noted that from the perspective of young people, fertility would often not be front and centre of their minds at a young age so making this change would remove the need to reapply when it is less of a consideration in their lives.

13.11 The Committee discussed various options such as allowing 20 years for fertility preservation and keeping 10 years for use or allowing 20 years for the initial storage period for all gametes and 10 years for embryos. Members also discussed changing the storage period of embryos to begin when the embryo is created, rather than when the gametes used to create the embryo were first stored.

13.12 The Committee agreed that they should recommend a change to the initial storage period for gametes stored for fertility preservation but did not decide on what the change (the new period) should be. The Committee agreed to decide this at the next meeting and that the priority should first be a change to the hard cut-off at 10 years.

Actions

- *Secretariat to draft advice to the Minister recommending a change to the hard cut-off at 10 years.*
- *ACART to discuss with ECART updating the ECART decision letters for applications submitted beyond their expiry date.*

14. Human reproductive research: draft guidelines

Changes to the draft guidelines

14.1 Members discussed the early draft guidelines document which included examples from the Australian NHMRC guidelines, the ACART reproductive research consultation document, and the 2017 draft guidelines.

14.2 Members suggested changes to the draft guidelines, including removing repetitions when provisions apply to all procedures and removing sections that will go in the application form rather than as set requirements. Members also agreed to changing the requirements in section C 'the needs, values, and beliefs of Māori should be considered and treated with respect'. Members discussed collective consent and whether this would be appropriate to include in the guidelines. It was decided that this information may be better suited to patient information sheets.

14.3 Members discussed the inclusion of a section on conscientious objection in the early draft guidelines. Members agreed that the guidelines' purpose is to identify what is allowable and non-allowable, and the process for applying. The guidelines will not compel researchers to undertake these types of research. The Secretariat

agreed to remove this section from the draft guidelines.

Non-clinical provisions

14.3 The committee discussed whether the creation of embryos for research should be enabled. Members agreed that the creation of embryos incidentally from gamete research could be enabled and possibly in other specific circumstances when there is no other way to research that question. The committee agreed to ask for expert advice on embryo creation provisions to ensure they are not missing anything and to ask for the public's feedback in the second consultation.

14.4 Members agreed to contact experts such as an expert embryologist and potentially members of the NHMRC in Australia once they have drafted the guidelines and to regularly engage with experts to ensure that the guidelines include what they need to.

14.5 The committee discussed thresholds for different types of non-clinical research. Members agreed to include requirements for clones and embryonic stem cells in the guidelines for non-clinical research and to leave hybrid embryos, synthetic embryos, and genetic editing out of these guidelines. Members agreed that looking at the regulation of clones and embryonic stem cells in other jurisdictions would be helpful and to seek expert advice in these areas. Members noted that ACART should advise the Minister that synthetic embryos are not currently regulated by the HART Act and that this needs to be updated.

14.6 Members agreed to seek expert advice on definitions. The member with expertise in reproductive research suggested that the definition and title of the guidelines 'human reproductive research' should be renamed to 'use of human gametes and embryos in research' as the original title could have negative connotations in the public.

Process of reviewing a research application

14.7 The committee discussed the options for reviewing research applications. Currently, the standard operating procedures for the HDECs do not allow them to consider reproductive research. ACART could request a change to the standard operating procedures to allow the HDECs to consider reproductive research applications in addition to ECART. Another option could be that HDEC members could be co-opted into ECART to consider research applications. Members agreed that deciding on the research process would not be a priority at this point and that the guidelines would be the first priority.

Working group

14.8 Members agreed to organise a working group to write draft guidelines outside of meetings. The committee confirmed that the working group would include the Chair, the member with expertise in human reproductive research, the member with expertise in assisted reproductive procedures, and the member with expertise in ethics. The working group would be a full day in addition to half a day of preparation

and would take place towards end of the year or start of 2024.

Consultation document

14.9 The committee agreed that the consultation document should only include brief background information and could refer people to the first consultation document for more detail. Members discussed the structure of the document, suggesting that the draft guidelines could form the main structure with questions referring to each section of the guidelines. Members suggested numbering the sections of the draft guidelines to allow them to be easily referenced in the questions.

14.10 The Committee discussed Māori Data Sovereignty issues in the consultation document and agreed to update these in the guidelines and in the second consultation document. The Deputy Chair/member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective, and the member with legal expertise and whakapapa Māori agreed to undertake this work.

Engagement plan

14.10 Members discussed consulting the Bioethics centre and giving a lecture to bioethics students, as well as consulting Fertility New Zealand via a webinar presentation. In addition, the member with expertise in reproductive technology suggested organising a group of researchers to have an online meet to consult on the guidelines.

Actions

- *Secretariat to amend the draft guidelines document with the suggested changes.*
- *Secretariat to add groups to the general engagement plan.*
- *Secretariat to research other jurisdictions guidelines e.g., UK and Australia.*
- *Secretariat to organise dates for a working group on the guidelines including contacting the Ethics Manager to allocate budget for this.*

15. Scope tentative work on the use of GE in assisted reproduction

15.1 Members discussed whether to do scoping work on the use of genetic editing (GE) in fertility treatment and research. This would be with a view to be able to provide advice on this topic if needed.

15.2 Members agreed to advise the Minister that ACART would like this scoping work to be part of its official work programme.

15.3 Scoping would involve researching the current legislation on genetic editing in fertility treatment and research in New Zealand. Scoping would also involve researching international legislation to assess how feasible genetic editing is and what the benefits and consequences are. Members noted that there have been three international symposiums on this topic that could be included in a literature

search.

15.4 The Committee agreed that surveying public attitudes would not be needed at this point and that first some researching would need to be done. Members agreed that this work is not a priority to complete before the end of the year.

15.5 Members agreed some of the content to be included in a cover paper for ACART to consider at the beginning of next year, including what activities might be possible using genetic editing and research from other jurisdictions. The Chair noted that it will be important that this paper includes Māori perspectives on the use of GE.

Actions

- *Secretariat to investigate GE in fertility treatment and research in New Zealand and in other jurisdictions, as well as investigating the relevance of other laws.*

16. Literature for ACART's ethical framework and Te Tiriti

16.1 Members discussed the literature review on Māori worldviews about reproductive technologies provided by the Deputy Chair/member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective.

16.2 Members agreed that this should be progressed further by the Deputy Chair, the lay member with legal expertise, and the member with the ability to articulate community perspectives. Members also asked whether a Māori female with expertise in tikanga could be commissioned/contracted to assist with this work. Ultimately, this work will be used to update ACART's ethical framework.

16.3 The lay member with legal expertise noted that the Māori Law Society may be interested in commenting on this work.

17. Chair's report

17.1 Members noted the written report.

18. Members' reports

18.1 The Chair thanked the member with expertise in human reproductive research for circulating two papers on BMI and research.

18.2 The Chair commented on the correspondence about a query regarding embryo donation and consent. The Chair noted that he would like to see the Ministry's response to the recent query.

19. Secretariat report

19.1 Members noted the report.

20. Work between meetings

20.1 Members confirmed next steps for the projects and publications.

20.2 Members agreed to a working group for human reproductive research with the Chair, the member with expertise in reproductive technology, the member with expertise in assisted reproductive procedures, and the member with expertise in Ethics in late 2023 or early 2024.

20.2 Members agreed to a half-day working group for two members to work on ACART's ethical framework and Te Tiriti considerations.

20.3 Members agreed for two members to work on updating the Māori Data Sovereignty section of the consultation document.

20.3 Members noted who will attend the next ECART meetings.

21. Update on appointments

21.1 No update.

The meeting closed at 3:00 pm.