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

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Held online on 29 February 2024

Present

Calum Barrett (Chair)
Edmond Fehoko
Seth Fraser
Neuton Lambert
Amanda Lees
Minu Punchihewa
Karen Reader
Catherine Ryan
Karaitiana Taiuru
Sarah Wakeman
Debbie Wilson

Non-members present

Jeanne Snelling. ECART.
Elsie Coleman. ACART Secretariat.
Martin Kennedy. ACART Secretariat.
Saskia Patton. Manager, Ethics, MoH.

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 member with expertise in legal matters informed members about a recent ruling, in a supreme court in a state in the USA, about wrongful death of stored human embryos. She explained that the ruling has created uncertainty amongst fertility clinics in the USA who are concerned about the implications of the ruling for their ability to store embryos and do IVF.

3. Apologies

3.1 Nil.

3.2 The Chair reminded members that Shannon Hanrahan had resigned from ACART due to other demands. The Chair acknowledged Shannon's valuable contribution and noted that ACART is likely to cross paths with him again as he is active in the health sector.

4. Approval of the agenda

4.1 Members approved the agenda. The Chair added an item about the proposal that clinics adjust the way in which the submit data to the ANZARD database.

Actions

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

5. Declarations of Interests

5.1 Members confirmed the declarations.

6. Minutes of ACART's meeting of December 2023

6.1 Members approved the minutes subject to one point of clarification and the addition of a missing word.

Action

- *Secretariat to amend the two items.*
- *Secretariat to publish the December 2023 minutes on the ACART website.*

7. Actions arising from ACART's December 2023 meeting

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

7.2 The Chair noted that ACART's website has some inconsistent formatting that needs

to be addressed.

Action

- *Secretariat to correct the inconsistent entries on ACART's website.*

8. Status of ACART's work programme

8.1 Members noted the report.

8.2 The Chair commented on a recent media enquiry which had prompted a discussion about the need for the (Associate) Minister to be informed about ACART's work programme. The Chair noted that the new Associate Minister also needs to be informed about ACART's advice, to previous ministers, about the recommended changes to both the HART Act and Order.

8.3 There was a brief discussion about ECART's interest in guidance on two matters. The first matter is on cultural competency at fertility clinics. The second is that ECART has received an enquiry from a clinic about what surrogacy costs can be reimbursed and that its response needs to be accurate (also discussed in the next item).

9. Report on ECART's recent meetings

9.1 Members noted the most recent ECART meeting on 19th February.

9.2 Members noted that one of the cases had involved a discussion about cultural matters and how the parties needed to address these for ECART to be satisfied that the arrangement would be ethical.

9.3 There was also discussion about the extent to which surrogates can be reimbursed and that ECART is finalising advice on this to respond to an enquiry.

10. Correspondence

10.1 Members discussed several items of correspondence including enquiries from media, the public and the sector.

10.2 The Chair advised members that a journalist had asked why the storage of reproductive material is limited to 10 years. The Chair advised members that he had responded and that the response would be sent to members for their information (the response had been sent after the ACART papers had been despatched). The article is scheduled to be published in "The Spinoff" on Monday 4 March 2024.

10.3 The Chair then informed members about a letter he had received from the Parliamentary Council Office. The letter asked ACART to ensure that ACART's guidelines are readily accessible to the public.

10.4 The next item was the enquiry from a fertility clinic about why ACART's guidelines for posthumous reproduction do not require the participants to obtain a legal report. A member reminded those present that the main reason (for not requiring a legal

report) was to make the guidelines for posthumous reproduction consistent with the donation and surrogacy guidelines which do not require people to obtain legal reports. Both sets of guidelines recommend that people obtain the reports but do not require it but the counselling that participants have will address the likely legal matters that could arise. Also, there can be considerable cost in fertility treatment and having a requirement to obtain a legal report would be an additional cost.

10.5 A student had asked ACART about the application of the PGD guidelines. The Secretariat had drafted a response and needed to obtain more information about two of the questions which were about detailed technical matters. The member with expertise in assisted reproductive technology offered to help with the response. The Secretariat will send the response to members once it is completed.

10.6 The next item was the clinic enquiry about whether clinics can apply to ECART, for extensions of storage, on behalf of their patients. The member with expertise in assisted reproductive technology advised that ideally the patients should apply themselves and that the clinics can help if necessary. She noted that she would liaise with the staff in her clinic about the process. The discussion noted a particular case in which an applicant was finding it difficult to apply.

10.7 Members discussed the enquiry about the extent to which surrogates can be reimbursed for expenses incurred. Members noted the need for any advice given by ACART or ECART to be accurate and that the HART Act specifies what is allowed. The member with expertise in legal matters noted that the surrogacy bill aims to address the matter of compensation for surrogates. There was some discussion about the use of support plans to help surrogates. There was also discussion about the intention of the HART Act which limits compensation in order to prevent coercion or inducement to act as surrogates.

Actions

- *Secretariat to provide members with the response to the journalist about the 10 year storage limit.*
- *Secretariat to send the PGD response to members once it is completed.*

11. New manager of the Ethics team

11.1 Saskia Patton, the new manager of the Ethics team at the Ministry of Health, joined the meeting. Saskia informed members about her background, then moved on to the current priorities of the Government and ministry and how the ministry can support ACART. She noted the Government requirement that the ministry cut costs by 6.5%. She said that the implications of cuts for ACART are not yet known and she would like to make a case for ACART's funding not to be cut, to ensure it can continue to carry out its functions. Saskia suggested that ACART consider options at its next meeting, providing clear reasons to support its case.

11.2 The Chair noted the pressures and that ACART's limited time per year already restricts its ability to produce advice and guidelines. He emphasised the need to

meet six times a year, even if that meant reducing other support.

11.3 There was a discussion about a range of reasons in favour of keeping ACART functioning, and the risks of not doing so were identified. The Secretariat will collate the reasons into the paper that ACART will consider at its next meeting.

11.4 The discussion also revisited the point that, in the near future, the Associate Minister needs to be informed about ACART's work programme.

Actions

- *Secretariat to collate the reasons for supporting ACART into a paper.*
- *ACART to consider the paper at its next meeting.*

12. ACART's ethical framework and Te Tiriti

12.1 Members discussed the proposed amended framework and there was general agreement to the new text, with requests for some changes. Members discussed data sovereignty and how this concept could or should be presented in the framework. A member noted the importance of genetic data for whakapapa.

12.2 Members discussed whether the framework could be revised to specify particular ethnic or cultural groups in addition to Māori. A member noted that the framework currently discusses the need for all people's ethnic or cultural affiliations to be considered when they are involved in fertility treatment of research. A member noted that the framework does not discuss disability rights and that this absence could be addressed.

12.3 There was a discussion about adding the content of the framework to ACART's document that summarises the range of matters ACART considers when it assesses any topic. Members noted that ACART mostly uses the framework to guide its work when it develops its rationale for guidelines or advice. Members decided to revisit the framework once the large projects on guidelines are closer to being finished.

12.4 Members agreed the document could be published with a note to readers that it is a "living document" that will be updated from time to time.

12.5 The Chair concluded the discussion, asking the Secretariat to accept the changes, amend the formatting, update the references, then begin the publication process.

Actions

- *Secretariat to accept the changes, with the further changes requested.*
- *Secretariat to amend the formatting.*
- *Secretariat to update the references.*
- *Secretariat to begin the publication process.*

13. Extending storage: advice to the minister and consultation document

Advice to the Minister

13.1 Members noted the updated advice to the Minister recommending amendments to sections 10A and 12 of the HART Act. The amendment to section 10A would allow ECART discretion to consider applications submitted after the 10-year expiry date if special circumstances are present. The amendment to section 12 would allow people who stored gametes as minors to donate their gametes when they are adults.

13.2 Members agreed to the following changes:

(a) Remove appendix 1 'Proposed special circumstances'. Members suggested instead adding a sentence to paragraph 12 stating that if the amendment to section 10A is made then ACART will consult with the Minister and the public about what the special circumstances could be.
(b) Amend paragraphs 5 and 11 about material stored offshore and the consequences of clinics storing material beyond the disposal period.
(c) Editing and formatting changes including numbering all paragraphs and making the distinction between the 6-month discretionary period and the 10-year limit clearer throughout the document.

13.3 Members agreed to approve the final letter in between meetings so that it can be sent to the Minister before the 2 May 2024 meeting.

Draft consultation document

13.4 Members noted the draft consultation document and agreed to the current structure. Members discussed reasons the 10-year period was initially established, noting that when the HART Act was written it was not known how long material could be stored for and remain usable. The committee agreed that this scientific rationale for an initial 10-year storage period no longer applies as it is now known that material can be stored for decades.

13.5 Members suggested including an explanation at the beginning of the document justifying why ACART is currently looking at the initial 10-year storage limit, including enabling people to access and use assisted reproductive technology in New Zealand. Members also agreed that it needs to be clear at the beginning of the document that applicants can apply for as many extensions to the initial 10-year period as needed.

13.6 The committee agreed to include principles from the ethical framework at the beginning of the document under 'matters ACART has considered', such as upholding autonomy, allowing people to make decisions, and upholding justice.

13.7 There was also discussion about whether to include options for longer embryo storage periods in the document. The 10-year initial storage period allows a check-in to ensure that both parties agree with the continued storage of embryos. This

would also allow a check-in with people in situations where the parties have separated or where one is now deceased. The committee acknowledged that people generally create and store embryos for use, while gametes may be stored for a range of reasons including fertility preservation. Members agreed to only recommend extending the initial storage period for gametes and to include a question at the end of the document where people could discuss whether they think longer storage periods should also apply for embryos.

13.8 Members agreed to recommend that the 10-year storage period resets when embryos are created (rather than beginning from when gametes were stored), which is consistent with the policy around consent and the view that embryos are a separate entity.

13.9 One member suggested that the consultation document include questions about an option for embryos donated to research/a biobank to be stored for an unlimited amount of time. Another member recommended changing the names used in the consultation document examples so people from a wider range of groups could identify with the examples.

Actions

- *Secretariat to make amendments to the letter to the Minister and send it to the Minister between meetings.*
- *Secretariat to update the consultation document with the changes suggested by the committee, including information at the start about the ethical framework and justifying why the work is being done.*

14. Human reproductive research: draft guidelines

14.1 Members noted the guidelines produced by the working group on 1st February 2024. The committee agreed to keep the provisions specific to the area of assisted reproductive technology and to refer to the National Ethical Guidelines on Health and Disability Research where needed. Members also agreed that the areas that needed particular focus were the creation of embryos for research, clones, and stem cell research.

14.2 There was discussion about potential provisions for the creation of embryos specifically to be used only in research, such as using similar provisions to the Singapore guidelines, including scientific merit and the potential for medical benefit. The Chair noted the importance of defining a high standard and only allowing the creation of embryos in set circumstances such as creating embryos with certain conditions.

14.3 The committee agreed to ask two fertility researchers for their feedback on the draft guidelines before consulting the wider public as well as asking for specific comments on the provisions for clones and stem cells.

14.4 Members discussed the likely process for the ethical review of research on gametes and embryos. The working group had suggested that the research applications

could go through a Health and Disability Committee (HDEC) to assess the scientific validity of the proposal, and could then be considered by the Ethics Committee on Assisted Reproductive Technology (ECART). Another suggestion was that ECART could review the research applications with a couple of HDEC members co-opted to meetings for research ethics expertise, as well as requiring independent peer review for scientific validity. The secretariat can advise further on the process and costs.

Actions

- *Secretariat to email the two fertility researchers to request feedback on the current guidelines. The Secretariat could ask to set up a meeting with the researchers also if needed.*
- *Secretariat to start drafting the consultation document from the supplementary guidance comments in the guidelines document.*

15. Guidelines for posthumous reproduction

15.1 The Secretariat advised members that it is liaising with the clinics and the Secretariat of the ECART committee to ensure they will be ready to use the amended guidelines when they are published. There are several operational matters to prepare before issuing the guidelines, such as ensuring application and consent forms are suitable. The Secretariat expects the work to be completed by May 2024.

15.2 The Secretariat also noted that the Ministry is preparing a briefing to Associate Minister Costello to advise her of ACART's forthcoming publication.

Actions

- *Secretariat to amend the glossary to use the definition of embryo that is in the HART Act.*
- *Secretariat to remove the "key words" section and add the words to the glossary.*

16. Chair's report

16.1 Members noted the written report. The Chair told members he had been to the recent Fertility New Zealand meeting.

17. Members' reports

17.1 The member with expertise in human reproductive research advised members she will attend the ESHRE conference soon. The possibility of partial financial support from the Ministry had been raised late in 2023 and the Secretariat will follow up on that.

Action

- *Secretariat to revisit the correspondence about partial funding.*

18. Secretariat report

18.1 Members noted the report.

19. Work between meetings

19.1 Members confirmed next steps for the projects and publications. The priorities are (a) the consultation document for the guidelines for extending storage and (b) the guidelines for human reproductive research.

20. Update on appointments

20.1 The Secretariat advised members that it is liaising with the Appointments team at the Ministry on the advertising plan.

21. Attendance at ECART meetings

21.1 Members confirmed attendance at the upcoming EACRT meetings. Neuton will attend on 11 April and Catherine on 20 June.

The meeting closed at 2:35 pm.