Minutes of the one hundredth meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 15 December 2022.

Present

Calum Barrett (Chair)

Seth Fraser

Shannon Te Ahu Hanrahan (online)

Kathleen Logan

Karen Reader

Catherine Ryan

Karaitiana Taiuru (online)

Sarah Wakeman

Debbie Wilson (to 11.45 a.m.)

Non-members present

Pearl Baird. Administrator, Ethics, Ministry of Health.

Liz Bohm. Principle Analyst, Ethics, Ministry of Health.

Elsie Coleman. ACART Secretariat.

Chloe Croskery. ACART Secretariat.

Martin Kennedy. ACART Secretariat.

Analosa Veukiso-Ulugia (to 2 p.m.; online). ECART.

1a. Welcome

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

1b. Opening comments

1.2 The member with expertise in assisted reproductive procedures gave members a summary of the conference of the Fertility Society of Australasia. The society has changed its name to the Fertility Society of Australia and New Zealand. One of the items of interest was uterine transplants and the various medical matters associated with this activity. The conference also had a session on posthumous reproduction, and the regulation of this activity varies from state to state in Australia. An item of particular interest to ACART was mitochondrial replacement therapy. This procedure is going to be trialled in Australia but data is yet to be produced.

2. Apologies

2.1 Edmond Fehoko.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of October 2022

5.1 Members approved the minutes.

Action

- *Secretariat to publish the October minutes.*

6. Actions arising from ACART's October 2022 meeting

6.1 Members noted the status of the actions from the October 2022 meeting. The member with expertise in assisted reproductive procedures advised members that she had spoken with the person who had enquired about the possible sex selection of embryos.

7. Status of ACART's work programme

7.1 Members noted the report.

7.2 The Secretariat advised members that the Ministry of Health is preparing parallel advice, to the minister, that will address ACART's advice about (a) the use of cryopreserved testicular tissue (b) the guidelines for posthumous reproduction and (c) the donation and surrogacy guidelines.

7.3 The Chair stated that the submissions about the guidelines for extending stored material have raised important matters that should be investigated further. This matter is discussed in more detail in item 10, below.

7.4 Members discussed options for ensuring meaningful engagement with Māori for the consultation about human reproductive research. This matter is discussed in more detail in item 11, below.

7.5 There was a brief discussion about ACART monitoring ECART. Members noted that, with the coming move to a computer based system for applications to ECART, it will soon be easier to carry out the monitoring.

8. Report on ECART's recent meetings

8.1 Members noted the oral report from ECART's meeting on 8 December. Two ACART members had attended, and one commented on if, and to what extent, ECART has discretion to consider applications submitted after the 10 year storage period had ended. This matter is related to one of the matters raised in the submissions about extending storage (see item 10, below) and ACART will look into the matter in 2023.

8.2 The ACART members who attended ECART also spoke about the situations in which ECART should decline an application and the extent to which ECART should be able to restrict people's behaviours. Members agreed it can be difficult to decide what level of risk is acceptable, especially in cases where the risk is not easily quantifiable.

9. Correspondence

9.1 The Chair had recently written to the Ministry of Health to enquire about progress on ACART's advice for (a) the use of cryopreserved testicular tissue (b) the guidelines for posthumous reproduction and (c) the donation and surrogacy guidelines.

10. Review of the guidelines for extending storage

10.1 The Chair introduced this item, advising members that the submissions should be adequate for ACART to confirm the recommendations it made in the first part of the consultation document. He said the submissions had also identified matters that ACART could consider in more detail. For each of the questions, members noted the importance of donors understanding their rights and authority (or absence of) over the materials they have donated.

10.2 For recommendation 1 (gamete donors should not be required to consent when recipients apply to extend the storage of an embryo), ACART confirmed the recommendation. Members noted the related matters submitters had raised about the duration of storage, the age of donors at the time the embryos would be used, and whether donors would be contactable. Members agreed that ACART will do more detailed work on these matters in 2023.

10.3 For recommendation 2 (gamete donors should consent when recipients apply to extend the storage of gametes), ACART confirmed the recommendation. Members

discussed the matter of donors not being contactable. They noted that, if the donors are not contactable, the guidelines enable ECART to extend the storage if the clinic demonstrates it made a reasonable attempt to contact the donors and that declining the extension would be unduly harsh on the recipients. This matter, of donors being contactable, was also raised in recommendations 1 and 3 and ACART settled on its current policy being suitable.

10.4 For recommendation 3 (embryo donors should consent when recipients apply to extend the storage of an embryo), ACART confirmed the recommendation. The matter of donors being contactable has already been covered in the first and second recommendations. The matters of the age of donors and duration of storage were noted and will be part of ACART's work in 2023.

10.5 For recommendation 4 (the researchers named in the ECART ethics approval should consent to extending the storage of reproductive material donated to research), ACART confirmed the recommendation. Members noted that ACART's work to produce new guidelines for human reproductive research could have a bearing on the guidelines for extending storage and the exact wording of the provisions for storing human reproductive materials. That work will be done over the next two to three years.

10.6 The fifth question in the consultation document was about time limits on storage. ACART concluded that the risks associated with delayed use of reproductive material should be investigated thoroughly. The risks include harm to the offspring if they cannot meet the donors, and intergenerational effects. Members noted that, while the HART Act can be changed only be parliament, ACART could make a recommendation about time limits on storage if it found the evidence made it sensible to do so. ACART will investigate this matter in detail in 2023.

10.7 Related to time limits on storage was the matter of the cut-off point at ten years and the law not allowing ECART to consider late applications. This rule has resulted in some people being unable to use, or extend the storage of, their reproductive materials. Another time-related matter was the period of storage for young people/children and the fact that it is highly likely they will need more than 10 years storage before they can consider using the material. ACART will investigate these matters in detail in 2023.

10.8 For question 6, that fertility clinics rather than ECART could be responsible for approving storage extension applications, ACART concluded that such a process is not recommended. Members noted that, legally, ACART issues its guidance to ECART, and in addition to that, it is important to have an independent ethical body that can consider cases involving complex ethical matters. It is also important that clinics not have a conflict of interest (in approving cases which they will benefit from financially).

10.9 Question 7 asked, under what circumstances should ECART decline an application for storage extension? Members agreed that the working group could investigate this in 2023 with a view to including useful explanatory material in the supplementary advice that ACART will publish to accompany the guidelines. Members noted the importance of liaising with clinics and interest groups to inform this work. The work will be an integral part of the investigation of age limits, storage

duration limits, and ACART should approach the Human Rights Commission about any potential age discrimination.

10.10 For question 8 (Should ECART be able to extend storage of materials intended for future unspecified research?), ACART confirmed that ECART should. The Chair observed that this is closely related to question 4 (about researchers consenting to extensions) and that the advice to the minister should note this point.

10.11 Question 9 had asked if submitters had any other comments. Submitters raised several matters. Some of the matters are those discussed above about (a) age of donors at the time their materials are used (b) the duration of storage (c) the cut off rule at 10 years. ACART will consider these matters in detail in 2023.

10.12 Members discussed the working group and the group is now comprised of:

- the Chair
- the member with the ability to articulate issues from a disability perspective
- the member with expertise in assisted reproductive procedures
- the member who is Māori and has expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective.

10.13 Members agreed the next steps (see the actions, below).

Actions

- *Secretariat to publish the raw submissions on the ACART website.*
- *Secretariat to arrange the working group for early 2023.*
- *Secretariat to draft the advice to the Minister.*
- *Confirm the revised guidelines.*
- *Investigate age limits, storage duration limits, the cut off rule at 10 years.*

11. Consultation on guidelines for human reproductive research

11.1 Members discussed the consultation plan, with a view to confirming the actions to get a broad engagement with the public. The general lay member with Māori heritage recommended that the Secretariat liaise with the Secretariat of the National Ethics Advisory Committee about its consultation methods.

11.2 Members discussed the methods for advertising the consultation and agreed that effort should be put into social media including renewing the Tweet as it does not come up easily in searches. Adding an item to LinkedIn is one option for broadening the advertising.

11.3 Members noted that the Therapeutic Products Bill has been tabled in Parliament and that ACART should check it to see if, how and to what extent it could have a bearing on ACART's work on human reproductive research.

11.4 The topic is a sensitive one and members agreed that they should liaise with the manager of the Ethics team to ensure risks are managed.

11.5 The discussion moved on to how the draft guidelines will be developed after this first round of consultation. Members agreed to investigate the way other countries

regulate human reproductive research and what their guidelines comprise.

Actions

- *Secretariat to liaise with the Secretariat of the National Ethics Advisory Committee about its consultation methods.*
- *Secretariat to prepare a presentation that members can use at consultation meetings and focus groups.*
- *Secretariat to work with the social media team at the Ministry of Health to promote the consultation.*
- *Secretariat to renew the Tweet*.
- *Secretariat to add details to the consultation plan.*
- *Secretariat to check the Therapeutic Products Bill to see if, how and to what extent it could have a bearing on ACART's work on human reproductive research.*
- *Secretariat to begin a discussion with the manager of the Ethics team to ensure risks are managed.*
- *Secretariat to investigate the way other countries regulate human reproductive research and what their guidelines comprise.*

12. Chair's report

12.1 Members noted the written report.

12.2 The Chair commented on recent articles about decreasing sperm counts in men and the possible causes and implications of this trend. It is possible that dropping sperm counts will lead to an increase in demand for fertility services.

13. Members' reports

13.1 The member with expertise in assisted reproductive procedures gave members a summary of the conference of the Fertility Society of Australasia.

14. Secretariat report

14.1 Members noted the report.

15. Work between meetings

15.1 Members agreed to:

- meetings in February and March 2023 for the consultation on human reproductive research
- a working group meeting to discuss the submissions to the consultation on the proposed changes to the guidelines for extending the storage of gametes and embryos.

15.2 The member with the ability to articulate the interests of children will attend ECART

early in 2023 and will give a presentation on children's wellbeing.

Action

- *The Secretariat and Chair will liaise with working group members to progress these items.*

16. Update on appointments

16.1 The Secretariat advised members that the Ministry of Health has submitted its recommended candidates to the Minister of Health.

17. Attendance at ECART

17.1 Members confirmed their availability.

- 24 February 2023: Kathleen Logan.

The meeting closed at 2.30 pm.