Minutes of the ninety-fifth meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 3 March 2022, online.

Present

Calum Barrett (Chair)
Rosemary De Luca
Edmond Fehoko
Seth Fraser
Shannon Te Ahu Hanrahan
Kathleen Logan (Deputy Chair)
Karen Reader
Catherine Ryan
Karaitiana Taiuru
Sarah Wakeman
Debbie Wilson

Non-members present

Nic Aagaard. Manager, Ethics, Ministry of Health (present for introductions)
Martin Kennedy. ACART Secretariat
Mirae Wilson. ACART Secretariat
Iris Reuvecamp. ECART

1a. Welcome

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

1b. Opening comments

1.2 The member with expertise in assisted reproductive procedures spoke about the work being done by the 'Donor identity in Aotearoa New Zealand' project. The project, led by Professor Cindy Farquhar, is looking at the effect of the HART Act on gamete donors and recipients in terms of disclosure of donor identity.

2. Apologies

2.1 Nil.

2.2 Edmond Fehoko left the meeting at 2 p.m.

3. Approval of the agenda

3.1 The Chair suggested a change to the order of items and members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of December 2021

5.1 Members approved the minutes subject to minor changes.

Action

- *Secretariat to amend and publish the December minutes.*

6. Actions arising from ACART's December meeting

6.1 Members noted the status of the actions from the December meeting.

6.2 Members discussed the process ACART uses to draft its documents and whether this could be improved. The Chair commented on the importance of getting the policies right and acknowledged comments about the need for the details of the language to also be accurate.

6.3 Suggestions for improvements included referring to ECART's decisions to see the types of matters they deal with and making greater use of supplementary information.

6.4 There was general agreement that the guidelines need to be kept as up to date as possible. Section 35 of the HART Act directs ACRAT to ensure this is the case.

7. Status of ACART's work programme

7.1 Members noted the report.

8. Members introduce themselves

8.1 The Chair welcomed the new members and all present introduced themselves. The three new members are:

- Shannon Hanrahan, layperson with a community perspective
- Debbie Wilson, layperson with expertise in law
- Edmond Fehoko, layperson with expertise in Pasifika interests.

8.2 Nic Aagaard, Manager of the Ethics team at the Ministry of Health, introduced himself and explained his role and that of the Ethics team which includes the Secretariats for several committees. Nic commented on the current travel restrictions due to COVID and on the plans to have a full training day with all of ACART and ECART. The current plan is to hold the day in July. He also noted the "modernisation of ethics" (Ethics team processes at the Ministry of Health) work is underway and is a substantial programme.

9. Overview of ACART's functions and work

9.1 The Chair presented the general summary of ACART's role and the regulatory setting and how it interacts with ECART and the Minister of Health.

9.2 There was a short discussion about ACART's functions and how it works. A member suggested more attention be paid to the fact that New Zealand has a broad range of people with different ethical perspectives and religious or philosophical positions.

10. Elect a Deputy Chair

10.1 The Chair asked members to elect a new Deputy Chair. One person, Karaitiana Taiuru, had been nominated and was unanimously elected.

11. Correspondence

Letter to Minister Little about scope of consultation

11.1 The Chair advised members he had submitted a letter to Minister Little about the scope of the project to revise the guidelines for human reproductive research. The Secretariat advised members that the letter is with the Ministry of Health who are finalising parallel advice to submit with the letter.

11.2 Members discussed the process for deciding how to change the scope of projects and agreed to amend the letter to the Minister to emphasise that the change in scope would allow ACART to consult the public about two possible activities. These activities would be (1) human embryos could be produced as a result of research on (for example) gametes to investigate fertilisation and (2) human embryos could be created specifically to use in research. In both cases the embryos would not be used in fertility treatment, they would be disposed of.

Advice about 'best or only opportunity'

11.3 Members discussed the advice to ECART about the 'best or only opportunity' to have a child and the significance of a biological link between offspring and intending parents.

11.4 The Chair noted that there are effectively three options, being (1) that if there is no biological link the case cannot be approved (2) that there is no requirement for a biological link and (3) that generally people will choose to have a biological link but that there might be good reasons to allow some cases with no biological link if a compelling case is made.

11.5 Members agreed that option 3 was their preference. They discussed the reasons that might make cases, without a biological link, acceptable even if the intending parents could have such a link. Members agreed that the advice to ECART should give examples of the types of reasons that would not be acceptable. Members agreed that the Chair would work with the Secretariat to refine the advice to ECART. The ECART observer offered to send ACART suggestions.

Actions

- *Chair to work with the Secretariat to refine the advice to ECART.*
- *ECART observer to send ACART suggestions.*

12. Report on ECART's recent meeting

12.1 Members noted the report.

13. Relationships with Māori parties

13.1 The Chair introduced the item, asking what ACART could do differently to get more engagement with Māori and suggesting that ACART should focus on establishing genuine relationships. He noted that sending Māori parties questionnaires without a meaningful relationship with those parties is not good practice.

13.2 Members discussed strategies for engaging more with Māori and the Secretariat advised members it has approached colleagues in the Ministry of Health and is waiting for a response. Members noted there are substantial changes happening to the health sector and that many people may be too busy to allocate time to ACART and its consultations. The members noted that ACART's work is, generally, quite a special interest area that might not be of great interest to the broader population.

13.3 Members agreed that ACART's consultation material needs to be succinct and easy to understand. They agreed it would be helpful to prepare different materials for different audiences.

13.4 The Chair and two members with expertise in Māori interests agreed to meet separately to discuss ACART's options and confirm details of the actions that ACART can take. The member with close contacts in the Ōpōtiki area offered to contact colleagues there to gauge how they like to be consulted.

Actions

- *Chair and two members with expertise in Māori interests to discuss details of the actions that ACART can take.*
- *The member with close contacts in the Ōpōtiki area to contact colleagues there to gauge how they might like to liaise with ACART and to be consulted.*

14. Cryopreserved testicular tissue

14.1 The Chair introduced this item, noting that the draft CSTT advice is almost ready for submission to the Minister of Health and that there are just a few details to confirm.

14.2 It was noted that the collection of tissue is a surgical procedure that is not, and does not need to be, stated in the HART Order. Members agreed that the advice could state this.

14.3 Members discussed the development of technology to enable testicular tissue taken from pre-pubertal boys to be used to obtain sperm. The technology is still under development and trials will be done, possibly including in Aotearoa New Zealand. Members agreed that the advice, and the Order, do not need to refer to the use of testicular tissue taken from pre-pubertal boys.

14.4 Some members had minor wording changes which they will send to the Secretariat to make.

Actions

- *Some members to send specific wording changes to the Secretariat.*
- *Secretariat to make the final changes to the advice.*

15. Supplementary advice to the Guidelines for Posthumous Reproduction

15.1 The Chair introduced the topic asking if members thought the supplementary advice needed any additional information. A discussion ensued about the specificity of the term “specific use” and whether it was detailed enough. A member said ACART has left it reasonably open to give ECART the latitude to apply it in a way that would take into account the merits of individual cases.

15.2 Members discussed what specific uses would be likely to be unacceptable and agreed to amend the statement to more clearly state that the type of use must be specified by a person before they are deceased. Members agreed to present examples and to consider a revised version out of session.

Actions

- *Secretariat to amend the text about ‘specific use’ as discussed.*
- *Secretariat to add example of types of uses that would be acceptable and unacceptable.*
- *Members to consider the next version between ACART’s full meetings.*

16. Consultation document for the review of the Guidelines for Extending the Storage Period of Gametes and Embryos

16.1 The objective for this meeting was to confirm the consultation document, including the proposed revised guidelines, and to discuss the draft communications plan for consultation.

16.2 The Chair introduced this item and provided a verbal overview of the background of this project for the benefit of new members.

16.3 Part I of the document had previously been confirmed by the Committee. The Chair asked the Committee to confirm the questions being asked in Part II of the document. The Chair noted that the questions in Part II are intentionally broad.

16.4 Members confirmed the questions in Part II and noted with some minor errors and wording changes for the Secretariat to amend. Members also requested the removal of content, which referred to the United Kingdom's legal requirements for storage extensions.

16.5 The Chair also requested the addition of a final question (question nine) to ask, "Do you have any other comments on the extension of storage of gametes and embryos?"

16.6 Members noted that there will be complications for samples being stored for reproductive research. For example, if biobanks are used with tissue donated to research, there will be a continuous need to apply for storage extensions. It will also take a while to accumulate enough samples in order to undertake research.

16.7 A member queried how fertility clinics would be accountable and monitored if they were to manage storage extensions. ACART's member with expertise in reproductive procedures advised that monitoring would fall under accreditation to meet the New Zealand Fertility Services Standards.

16.8 The Chair advised that Fertility New Zealand requested a 12-week consultation period instead of eight weeks in order to have an in-depth discussion with their members. The Committee agreed to this. The Chair will discuss with the Secretariat to confirm a date for consultation to begin. The date will be before the next ACART meeting.

Actions

- *Secretariat to make final changes and additions to the consultation document.*
- *Secretariat to finalise the consultation document for publication.*
- *Secretariat to confirm the date for consultation to begin, with the Chair.*

17. Consultation document for the review of the Guidelines for Human Reproductive Research

17.1 The Chair opened this item by noting the document is now in two main sections, the first being the background or context and the second being the proposals and questions. He suggested this meeting do a high level review of the first section then

look more closely and the second section to ensure the questions and narrative were fit for purpose.

17.2 Members made several specific suggestions including to:

- make chapter 4 more succinct
- present the narrative about the legal status of the embryo earlier
- use plainer English as much as possible, but acknowledging that many of the concepts will not be conducive to much simplification
- create different materials for different audiences
- begin planning the consultation strategy sooner (that is, there is no need to wait until the document is finished)
- consider how to reach a wide audience, as the focus so far has been on general, Māori and Pacific and has not considered other ethnic groups or interest groups.

17.3 For the first chapter of the second section (the general requirements for research), members agreed that the questions could be removed, and the details put in a separate information document on ACART's website. The document on ACART's website could go in a 'resources' page, with other material such as ACART's supplementary information to the guidelines. The chapter about general research processes in this consultation document could then be a few summary paragraphs and could have one general question about whether submitters have any comments.

17.4 For chapter 8, with the questions about possible research, members agreed that the questions need to be open — that is they should not ask if submitters agree with a proposal but rather should simply ask what they think about a possible research activity.

17.5 There was a discussion about the proposals that could be clustered under a heading "non-clinical research." Such a heading could be useful as a means of assuring people that research that might be contentious would not lead to born people. For example, a genetically modified embryo might be enabled for non-clinical research, but it could not be used clinically (ie it could not be implanted into a human).

17.6 Members agreed to amend the scenarios and to add the 'day of transfer' as an example. Members agreed that they would send suggested changes to the Secretariat, the Secretariat would amend the document, then the working group would spend a half day finalising the document.

Actions

- *Secretariat to amend the consultation document as requested.*
- *Members to send specific changes for items they have identified as needing changes.*
- *Secretariat to amend specific items as requested.*
- *Secretariat to draft the consultation plan.*
- *Working group to spend a half day making any final amendments and to consider the consultation plan.*

18. Chair's report

18.1 Members noted the report. There are three conferences this year that are likely to be of interest. The member with expertise in reproductive research will attend the conference of the Society for Reproductive Biology in Dunedin later this year.

19. Members' reports

19.1 No items this meeting.

20. Secretariat report

20.1 Members noted the report.

21. Work between meetings

21.1 Discussed with each project/policy item, above. Members will send material to the Secretariat who will then update the documents.

22. Update on appointments

22.1 The Secretariat updated members on appointments, advising them that the Ministry of Health was about to advertise for three positions.

23. Attendance at ECART

23.1 Members agreed to the following attendances at ECART in 2022.

- 11 April. Karaitiana
- 3 June. Sarah
- 5 August. Catherine
- 29 October. Debbie
- 16 December. Rosemary.

The meeting closed at 3:10 pm.