

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

Held on 30 June 2022, online.

Present

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

Non-members present

Zoe Benge. ACART Secretariat
Martin Kennedy. ACART Secretariat
Sadie Miles. ACART Secretariat
Iris Reuvecamp. ECART

1a. Welcome

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

1b. Opening comments

1.2 There was no formal opening commentary on this occasion.

2. Apologies

2.1 Rosemary De Luca, Edmond Fehoko.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of May 2022

5.1 Members approved the minutes subject to one change.

Action

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

6. Actions arising from ACART's May 2022 meeting

6.1 Members noted the status of the actions from the May 2022 meeting.

6.2 Members asked the Secretariat to confirm if and how members might be able to use the new file sharing system the Ministry of Health is setting up. If members have approved e-mail addresses they might be granted limited access to certain files. This system would be very useful for distributing meeting papers and reference material and to work together on documents that ACART is writing.

Action

- *Secretariat to confirm if and how members might be able to use the new file sharing system the Ministry of Health is setting up.*

7. Status of ACART's work programme

7.1 Members noted the report.

7.2 The Secretariat advised members that ACART's annual reports for the last two years have been tabled in parliament and can now be published on ACART's website.

7.3 The Secretariat advised members that the stakeholder engagement plan can be

amended to include the Māori specific material that was agreed between the Chair, Deputy Chair and the lay member with a community perspective who has Māori heritage.

Action

- *Secretariat to work with the Chair to amend the stakeholder engagement plan to include the Māori specific material.*

8. Report on ECART's recent meetings

8.1 Members noted the reports from ECART's meetings in February and April 2022. ECART had considered a range of matters including:

- how body mass index is used to determine clinical safety
- if and how ECART can place conditions on cases. If ECART thinks it necessary, they grant the approval providing the person agrees to being referred for specialist obstetric care during pregnancy
- how to consider surrogacy and donor cases where the offspring will have different genetic origins to the culture in which they will be raised
- the need for clear evidence of informed consent in cases of posthumous reproduction.

9. Correspondence

Advice about 'best or only opportunity'

9.1 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. The Chair had amended the advice, and explained that it would not be practical or helpful for ACART to issue an exhaustive list of criteria for such cases.

9.2 The advice spurred a discussion about if and how ECART might be able to take age into account when considering cases. At present, the presiding physician will consider whether a person's age will raise clinical risks. ACART's guidelines do not include any criterion about age. The discussion covered the possibility that there might be a case that age could be a criterion for assessing cases and would not be unjustified discrimination. No immediate action was suggested, but it was noted that this may be an area for further work in the future

9.3 The discussion also covered the matter of 'financial convenience' in cases of embryo donation and how this should be interpreted and applied. The discussion addressed the point that for some people using donated embryos will be the easiest, cheapest and quickest way to get treatment. A member noted that ACART should keep its policies under review so that it can assess the implications of those policies and, if necessary, amend them.

9.4 Members agreed the Secretariat and Chair should make the final changes to the document and issue it.

Enquiry about sex selection

9.5 Members discussed an enquiry, from a fertility services provider, about whether sex

selection of embryos might be allowed in a case where a family has children who have a rare condition that is predominantly but not exclusively seen in males.

9.6 Members discussed the wording of the HART Order and whether a situation such as this family's would be one in which sex selection would be allowed. The Chair noted the high threshold for sex selection, and that such an interpretation could set a precedent for allowing sex selection for other conditions that are also not sex-linked but rather that occur more in one sex than the other.

9.7 Members concluded that the Order would not intend for such cases to be allowed.

Action

- *Secretariat to draft a letter from the Chair to the fertility services provider stating that such an activity would not be permitted.*
- *Request an opinion from Health Legal first.*

10. Surrogacy: Law Commission Report and Surrogacy Bill

10.1 Members discussed the recently published report from the Law Commission about surrogacy, and the surrogacy bill that is currently at select committee. Members had a wide ranging discussion about the risks and benefits of the proposals and recommendations in each document and noted that the bill is open for submissions until 20 July 2022.

10.2 Members agreed that some of the proposals in the bill are not ideal and that ACART should make a submission. In particular, ACART wishes to comment on the risks of the proposal that the family court could, in some cases, transfer legal parenthood against the wishes of the birth mother.

10.3 Members noted that both the bill and the recommendations in the Law Commission report would make substantial changes to ECART's role and that some of the functions are not in keeping with ECART's current functions. Closely related to that is the fact that ACART would not have the legal authority to give ECART advice about some of those new functions.

10.4 More generally, members noted that the bill and Law Commission report should be considered together and that it was unclear how much the select committee was currently considering the Law Commission's report.

Action

- *Secretariat to draft a submission to the select committee and liaise with members to confirm the content.*

11. Consultation plan for the review of the guidelines for extending storage

11.1 The Secretariat informed members that the consultation document is now being formatted and that it should be published by Friday, 8 July.

11.2 The Secretariat recommended that members state their availability to attend meetings with stakeholders, and that preferably they would attend meetings in the cities or towns they live in, to minimise expenses. The dates of the meetings will be

set as the consultation period progresses. The Secretariat drew members attention to the FAQs so that members could have those FAQs handy at meetings with stakeholders.

- 11.3 A member suggested that the draft email to stakeholders should include the text from the media statement that ACART is consulting on this matter because of the anomaly in the current guidelines.

Actions

- *Secretariat to amend the email to stakeholders as requested.*
- *Secretariat to liaise with members about meeting dates as the consultation progresses.*

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

- 12.1 The Chair opened this item by commenting on the substantial work done on the consultation document since the last full ACART meeting and that the structure and content is coming together. He noted that some sections still need work.
- 12.2 The Chair suggested that today members focus on (a) whether the ethics and moral status of the embryo have been adequately addressed and (b) the essential questions that the document needs to present. The Chair said that, with these two items made clear, the narrative in the document would fall into place.
- 12.3 For the chapter on the status of the embryo members agreed to reinstate the text, from an earlier version of the document, about the ethical matters that are associated with human embryos. Members agreed that these points should be presented at the start of this chapter. The Chair advised members he would like ACART's ethics expert to review the chapter. The Chair also noted that the Australian guidelines on human reproductive research set out several criteria that must be adhered to and that ACART could refer to these when writing this chapter.
- 12.4 Members discussed where in the document the material should be presented about the benefits of research. Chapter five includes some narrative about this, as do each of the scenarios in Part II of the document. The discussion also addressed the fundamental question about if and how it would be acceptable to do research with human embryos. Members agreed a question on this point should be presented at the start of Part II. Also, members agreed that the document needs a clear explanation of what standard clinical research is.

- 12.5 The Chair suggested that each area of research be presented as:
- information about what the activity involves
 - what the benefits and risks of the activity are
 - the scenario, to help readers understand what would actually happen
 - then the questions, which would follow a standard pattern of:
 - should this activity be permitted?
 - if no, why not?
 - if yes, what limitations might be needed?
 - what are the possible risks and/or harms that need to be considered?
 - how can these be addressed?
 - are there ethical matters specific to the activity that you would like to comment on?
- 12.6 Members noted the substantial changes to the chapter on Te Ao Māori and human reproductive research. There was discussion about how questions about Te Ao Māori perspectives could be presented — members agreed to consider such questions in more depth out of session.
- 12.7 There was a discussion about genetic editing in human reproductive research, with members concluding that CRISPR technology needed to be presented and members noted that genetic editing would at this stage be limited to treatments for single gene disorders.
- 12.8 The Secretariat asked if members would like the document to include narrative about research using human gametes and members agreed that a scenario should be presented. The Secretariat also asked if the creation of human embryos from stem cells should be presented and members decided the example could be explained in the section on innovative non-clinical research and so would be captured in the questions for those activities.
- 12.9 Members agreed to carry out more drafting and to seek approval for funds to do this extra work. The work also includes adding narrative about the general benefits and risks of research and about training.

Actions

- *Secretariat to amend the consultation document as requested.*
- *Secretariat to reinstate the text, from an earlier version of the document, about the ethical matters that are associated with human embryos.*
- *Ethics expert to review the chapter.*
- *Secretariat to add narrative about the criteria, in the Australian guidelines on human reproductive research, that must be adhered to.*
- *Secretariat to add a question, at the start of Part II, about if and how it would be acceptable to do research with human embryos.*

- *Secretariat to add a clear explanation of what standard clinical research is.*
- *Members to send specific changes for items they have identified as needing changes.*
- *Present the chapters and questions in Part II as set out above in paragraph 12.5.*
- *Secretariat to liaise with the member with expertise in tikanga about the questions for Te Ao Māori perspectives.*
- *The member representing the Office of the Children’s Commissioner to add narrative about genetic editing and CRISPR.*
- *Secretariat to add narrative about research using human gametes.*
- *Secretariat to add narrative about research that creates human embryos from stem cells.*

13. Implementation plan for the guidelines for posthumous reproduction

- 13.1 The Chair noted that ACART had completed the guidelines and advice and they would be presented to the Minister of Health in the near future with parallel advice from the Ministry of Health. [See also the ‘extra item, toward the end of these minutes, about comments from ECART about these guidelines.]
- 13.2 The Chair suggested that members consider how to ensure the guidelines would be available for use as soon as they were published. Members agreed to draft a media statement, confirm the supplementary advice, and send a courtesy email to ECART.

Actions

- *Secretariat to send the Chair a draft media statement*
- *Chair to send the Secretariat comments on the media statement.*
- *Secretariat to send members the draft supplementary advice*
- *Members to discuss the supplementary advice.*
- *Secretariat to send the Chair a draft email to ECART.*
- *Chair to comment on the email to ECART.*

14. Chair’s report

- 14.1 Members noted the report. The Chair advised members he had recently met the Chair of the National Ethics Advisory Committee, John McMillan, and discussed opportunities for the committees to liaise with one another on matters of common interest.
- 14.2 The lay member with a community perspective and Māori heritage informed members that he was the Acting Chair for NEAC while the Chair was away for six months.

15. Members' reports

15.1 No items this meeting.

16. Secretariat report

16.1 Members noted the report. The Secretariat informed members that Sadie Miles, in the Ethics team at the Ministry of Health, is now helping support ACART.

16.2 The Secretariat also informed members that it has been preparing for the joint training day of ACART and ECART that will be held on 6 July 2022 in person in Wellington. Members who will present, agreed to send electronic versions of their presentations to the secretariat. The Secretariat will set up a 'Teams' meeting as a back-up for the day in case of travel disruptions.

Actions

- *Presenters to send electronic versions of presentations to the Secretariat.*
- *Secretariat to set up a Teams meeting.*

17. Work between meetings

17.1 Members will work on the draft consultation document for human reproductive research as discussed above in item 13.

Action

- *Members and Secretariat to carry out the various actions set out in these minutes.*

18. Update on appointments

18.1 The Secretariat updated members on appointments, advising them that the Ministry of Health was re-advertising for two positions.

18.2 Members briefly discussed the opportunities and the Chair recommended that members share the advertisements with anybody they believe could be interested in applying.

19. Training day

19.1 Members noted the agenda for the day and two actions were agreed, as recorded above in the Secretariat's report.

Extra item: guidelines for posthumous reproduction

- The ECART observer noted that ACART's guidelines and advice were completed some time ago and that there is a pressing need for these new guidelines to be published. The Secretariat advised those present that ACART's advice and guidelines would be presented to the Minister of Health in the near future once the parallel advice from the Ministry of Health is completed.

20. Attendance at ECART

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

- 5 August. Catherine
- 29 October. Debbie
- 16 December. TBC.

The meeting closed at 2.30 pm.