

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

Held on 5 May 2022, online.

Present

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

Non-members present

Zoe Benge. ACART Secretariat
Martin Kennedy. ACART Secretariat
Mirae Wilson. ACART Secretariat
Richard Ngatai. ECART

1a. Welcome

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

1b. Opening comments

1.2 The member with expertise in legal matters gave the opening comments. The member noted that the Law Commission's report on surrogacy in New Zealand will be published in the near future and that the entire way in which surrogacy is regulated is being reviewed.

1.3 The member also noted that a bill is now before Parliament to revise the regulation of surrogacy and that the select committee overseeing that review will probably consider the Law Commission's report when progressing the bill.

2. Apologies

2.1 Catherine Ryan, Edmond Fehoko.

2.2 Debbie Wilson left the meeting at 1.45 pm.

3. Approval of the agenda

3.1 The Chair suggested adding an item about the recruitment of members to ACART and a member suggested a quick discussion about upcoming conferences. Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of March 2022

5.1 Members approved the minutes subject to minor changes.

Action

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

6. Actions arising from ACART's March 2022 meeting

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

7. Status of ACART's work programme

7.1 Members noted the report.

7.2 The Chair advised members that the Minister of Health had recently approved ACART's new Terms of Reference. These terms will be published on ACART's website in the near future.

Action

- *Secretariat to complete the publication of the revised Terms of Reference.*

8. Report on ECART's recent meetings

8.1 Members noted the reports.

8.2 The matter of posthumous reproduction came up and members agreed that ACART should confirm its narrative to use in response to media and public queries that are likely to come up.

9. Correspondence

Invitation to the Ministry for Ethnic Communities

9.1 The Chair advised members that he had written to the Chief Executive of the Ministry for Ethnic Communities inviting him, or a delegate, to come to an ACART meeting. The letter explained that ACART is working to ensure it consults a wide range of people and that ACART wants to be sure it reaches a broad range of ethnic groups, especially those who might not have considered ACART's work in the past.

Letter to Starship about storing testicular tissue

9.2 The Chair explained that he had written to staff at Starship hospital in response to their enquiry about a protocol for storing testicular tissue from pre-pubertal boys. The letter stated that ACART believed that the use of the tissue would fall under the Human Tissue Act and supported the protocol in principle."

Advice about 'best or only opportunity'

9.3 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. Members covered a range of points and noted that ACART's advice needs to be practical so that ECART can decide on cases.

9.4 The matters of social gain and financial gain were investigated, and members noted that these are broad categories — a financial gain could be anything from saving a thousand dollars to several thousand dollars, or it could be that a woman can continue working and not need to take time off work. The 'need' of the intending parents to save that money could vary greatly from family to family.

9.5 Members noted the importance of the wellbeing of the child and the options of the intending parents to use their own sperm or eggs. They also noted that any criteria for deciding cases cannot be arbitrary but also that, because the details of cases can vary greatly, setting clear criteria needs to be done carefully.

- 9.6 Members agreed that ACART's advice to ECART should state that:
- (a) a genetic link is important
 - (b) where a genetic link is possible but not pursued, the counselling report must show that the intending parents have considered the implications of not having a genetic link to the child and how they will manage this as the child grows
 - (c) the best interests of the child must have been taken into account and especially any implications of the absence of a genetic link
 - (d) ECART can consider the wellbeing of the intending parents including the 'completion' of their family.

9.7 Members agreed to confirm the advice out of session.

Actions

- *Chair to work with the Secretariat to refine the advice.*

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

- 10.1 The Chair opened this item by thanking the working group. He asked whether all members agree that the first round of consultation should focus on gauging the public's thoughts about research with embryos, or if the consultation could make proposals. Members agreed that gauging the public's thoughts was the most appropriate objective for the first round of consultation.
- 10.2 The Chair suggested that, for each broad area of possible research, the purpose of it be presented with commentary about its benefits and then narrative about the ethical matters that are likely to be relevant. For each main research area, scenarios would be presented — members then agreed the scenarios should be presented before the benefits.
- 10.3 Members discussed how ideas about the status of the embryo should be presented. The member with expertise in ethics recommended including some of the material that had been in an earlier draft, in particular the text that addresses ethical matters such as if and when embryos have personhood. There was some discussion about a range of ethical questions associated with human embryos, including when they can feel pain, if they have consciousness, how long they have been gestating/developing for, what the type of research (eg clinical or non-clinical and innovative) is and what is the significance of 14 days of development.
- 10.4 Members discussed if and how human embryos might be respected and what this means in practice, especially when it comes to research. The discussion addressed what it is about human embryos that makes some people think they are special and how it is that other people don't share the same belief.
- 10.5 The discussion covered whether harm might be done. This point led to questions about when human embryos could be considered 'surplus.' Members noted the importance of particular words and that, in examples like this, perhaps 'surplus' might be better stated as something like 'not needed for fertility treatment' or a

similar phrase.

- 10.6 A member stated that Maui Hudson has, in the past, written about cultural perspectives on human embryos. Members agreed to consider that narrative, with a view to including relevant parts in the first consultation document.
- 10.7 The discussion returned to why human embryo research might be done and the Secretariat suggested that instead of ACART talking about the value of research it might refer to risks and benefits. A member noted that some people might be concerned that scientists could eventually do research that the public, or individuals, had not originally anticipated. The matter of specific consent came up as such consent is important in setting the parameters of research.
- 10.8 The matter of consent brought the conversation back to respect for human embryos and how cultural norms are important. Cultural norms brought the conversation onto how individual and group preferences could or should be accounted for.
- 10.9 Members agreed to work on the next version of the document with some of the specialist members responsible for particular chapters. Members agreed to seek approval from the Ministry of Health for budget to spend time on the chapters. Members also discussed the need for this consultation to reach a broad audience and that, due to the nature of the topic, enough time and resources should be allocated to ensure good engagement with the public.

Actions

- *Secretariat to amend the consultation document as requested.*
- *Include some of the material from an earlier draft, in particular about if and when embryos have personhood.*
- *Members to send specific changes for items they have identified as needing changes.*
- *Secretariat to amend specific items as requested.*

11. Supplementary advice to the Guidelines for Posthumous Reproduction

- 11.1 The Chair introduced the topic noting that the advice was now finished and was in the agenda pack for members' reference.
- 11.2 The Secretariat will send the advice to the Ministry of Health to include with ACART's full advice to the Minister of Health.

Action

- *Secretariat to send the supplementary advice to the Ministry of Health*

12. Consultation document for the review of the guidelines for extending storage

- 12.1 The Chair opened this item, noting that the focus of the discussion would be on the draft communications plan, as the consultation document was approved at ACART's last meeting on 3 March 2022.

- 12.2 Members requested a few final minor changes to the consultation document for the

Secretariat to action.

- 12.3 The Secretariat highlighted sections of the draft communications plan that required input from members. These sections related to the project ACART is currently undertaking to approve its consultation process to achieve greater engagement with Māori stakeholders, and clarification about the administrative processes that fertility clinics undertake with applicants for storage (and extension of storage) of material.
- 12.4 A member asked about the purpose of the 'Questions and answers' section of the communications plan as the content appeared to be directly answered through reading the consultation document. The Secretariat clarified that the purpose is to support members through the provision of prepared answers to questions that are likely to be asked by stakeholders.
- 12.5 The Chair confirmed that consultation will be for 12 weeks, not eight, as requested by Fertility New Zealand. Members agreed it is appropriate for the consultation to run for this length and agreed that consultation should begin as soon as possible.

Action

- *Secretariat to amend the consultation document as requested.*
- *Secretariat to add content and detail provided by members to the draft communications plan.*
- *Secretariat to progress the communications plan with the Communications team at the Ministry of Health and begin the consultation process as soon as possible.*

13. Relationships with Māori parties

- 13.1 The Chair introduced the item, advising that he and two members with expertise in Māori interests had met separately to discuss ACART's options and confirm details of the actions that ACART can take. The Chair observed that the National Ethics Advisory Committee is also reviewing its consultation methods and ACART can liaise with them to learn from one another.
- 13.2 Members noted that new technologies present opportunities to reach people who might not otherwise submit on ACART's work.

14. ACART's functions and processes

- 14.1 The Chair introduced this item, commenting that ACART has the opportunity to reflect on how it carries out its functions and whether any particular processes could

be improved. A range of matters can be considered including:

- whether face-to-face meetings might resume, at least some of the time
- the process for drafting papers
- how the agenda pack is distributed
- the use of working groups
- the use of supplementary advice
- whether to advise the Minister on any particular topics
- the role of the Secretariat.

14.2 Members asked whether Microsoft Teams would be a suitable way to circulate the agenda papers. The Secretariat will look into this and report back to the committee.

14.3 The matter of face-to-face meetings was raised and members agreed to ask the Ministry of Health about resuming such meetings after the training day in July. Members agreed there are significant advantages to meeting face-to-face as it is much easier to discuss complex ideas in person. It was noted that online meetings are preferable for members who do not live close to an airport and agreed that face-to-face meetings should only be used for the most important meetings.

14.4 Members discussed the process for formal communication between ACART and the Minister and the need to ensure the Minister's responses are shared with all members promptly. Similarly, all members should see draft communications from ACART to the Minister and other stakeholders and be able to comment before the items are sent.

14.5 Consultation processes were considered and the need to engage a wide range of audiences was noted. This point led to a discussion about how ACART is increasing its engagement with Māori, in particular how ACART is working to establish meaningful relationships rather than to approach Māori only when consulting.

14.6 Members agreed that the June meeting should be used to consider the improved consultation plan.

Actions

- *Secretariat to investigate if Microsoft Teams would be suitable for sharing the agenda papers.*
- *Report back to the committee.*
- *Add the revised consultation plan to the June agenda.*

15. Chair's report

15.1 Members noted the report.

16. Members' reports

16.1 No items this meeting.

17. Secretariat report

17.1 Members noted the report.

Extra item: appointments

- The representative of the Office of the Children's Commissioner advised members that a replacement member is being sought. The timing of the replacement is unknown.

18. Work between meetings

18.1 The Secretariat will send a "Doodle Poll" to all members to gauge options for a face-to-face meeting in August.

Action

- *Secretariat to send a "Doodle Poll" to all members to gauge options for a face-to-face meeting in August*

19. Update on appointments

19.1 The Secretariat updated members on appointments, advising them that the Ministry of Health was about to re-advertise for two positions.

20. Attendance at ECART

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

- 9 June. Sarah
- 5 August. Catherine
- 29 October. Debbie
- 16 December. Rosemary.

The meeting closed at 2.30 pm.