

## **Minutes of the Ninetieth Meeting of the Advisory Committee on Assisted Reproductive Technology**

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Held on 15 April 2021, online and at the Office of the Children's Commissioner, Wellington.

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### **Present**

Kathleen Logan (Chair)  
Calum Barrett (Deputy Chair)  
Rosemary de Luca  
Seth Fraser  
Catherine Ryan  
Karaitiana Taiuru (morning session)  
Analosa Veukiso-Ulugia  
Sarah Wakeman

### **Apologies**

Colin Gavaghan  
Karen Reader

### **Non-members present**

Paul Copland, ECART Member  
Martin Kennedy, ACART Secretariat  
Hayley Robertson, ACART Secretariat  
Nic Aagaard, Manager, Ethics (morning session)

## **1. Welcome**

- 1.1 The Chair opened the meeting at 9.00 am and noted the apologies from Colin Gavaghan and Karen Reader. The Chair also noted that Karaitiana Taiuru would be available for only part of the meeting.
- 1.2 The ECART member in attendance was Paul Copland.
- 1.3 The meeting was held primarily online, and the Deputy Chair and Secretariat joined the Chair at her office in Wellington.
- 1.4 Members discussed the website that the meeting papers are hosted on and whether it is suitable. Most users have had some difficulties with the site and the “app” version is no longer supported by the vendor.
- 1.5 The member with expertise in ethics gave the opening comments. She explained how fertility treatment in New Zealand had been managed in the absence of legislation up to the development of the HART Act, including the precursors to ACART such as regional ethics committees and the National Ethics Committee on Assisted Human Reproduction.

## **2. Apologies**

- 2.1 The apologies were accepted.

## **3. Approval of the agenda**

- 3.1 The agenda was approved.

### **Action**

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

## **4. Declarations of Interests**

- 4.1 No conflicts of interest were declared.

## **5. Minutes of ACART's meeting of February 2021**

- 5.1 The minutes were approved.
- 5.2 There was a discussion about progress by the Government to prepare for 2022 when donor conceived people turning 18 will be able to independently seek information about the sperm/egg donors whose gametes were used for their conception. The consumer member noted that Fertility New Zealand are particularly keen that preparations be made so that donor conceived people can seek and obtain this information.
- 5.3 Members discussed the minutes about ACART's governance options. The Chair explained she had not yet written to the Minister about these options as she wanted to first have the full committee discussion about it including the member with expertise in Māori matters. (See item 9 in these minutes for details about the discussion at this April meeting.) Nic Aagaard advised attendees that the Ministry of Health is supportive to work through a number of solutions for governance of the

committee, and is also working on related matters to achieve equity.

#### **Action**

- *Secretariat to add the minutes to the ACART website.*

### **6. Actions arising from ACART's February 2021 meeting**

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

### **7. Work programme status**

7.1 Members noted the status of items on the work programme.

### **8. Meeting dates for August, October and December**

8.1 Members agreed the meeting dates would be:

- Friday, 13 August
- Thursday, 21 October
- Friday, 10 December.

#### **Action**

- *Secretariat to make arrangements for the meetings.*

### **9. ACART's obligations, as a Crown entity, under Te Tiriti o Waitangi**

9.1 The Chair introduced this item, noting ACART's obligations under the Treaty of Waitangi/Te Tiriti as it is a Crown entity.

9.2 Members discussed the minutes on this matter from the February meeting, which stated that members would like an *additional* person with expertise in Māori matters to ensure the committee garners a broad range of views. Members also noted that the appointment of the Deputy Chair, in February, was (a) a pragmatic decision as a deputy was needed promptly to continue ACART's high workload out of session and (b) that the person in deputy's position can be changed if ACART adopts a co-governance arrangement.

9.3 The Chair observed that if ACART does wish to have co-governance by having the member with expertise in Māori matters by default in a Chairing role, such changes would probably need to be made to ACART's Terms of Reference and possibly also to the HART Act.

9.4 The member with expertise in Māori matters explained the concerns he had and recommended that the committee engage an expert who can explain the ongoing impacts of colonisation, contemporary Māori society and its approaches to matters such as health care and governance. Members supported this proposal and agreed to engaging an expert as suggested.

9.5 The Chair suggested the session be held as soon as is practicable and that the governance matters be addressed in 2021. Nic Aagaard agreed that a face to face meeting would be appropriate for this activity and funding could be sought for ACART's June 2021 meeting.

## **The use of BMI to assess patients**

- 9.6 The member with expertise in Māori matters raised the matter of BMI being used to assess people for publicly funded fertility treatment. He stated that a colleague had spoken to him about the use of BMI in assessing clinical access and that doing so might be considered racist. It is noted that the formula for BMI, and its use in scoring patients for eligibility for publicly funded treatment, do not account for what can be a healthy BMI in different body types in different ethnic groups. Members agreed this is a significant concern for Māori and Pacific communities who are disproportionately excluded from publicly funded treatment.
- 9.7 There was a discussion about if and how BMI could or should be used to assess people for treatment, the implications of not using it, or of adjusting the cut-off levels for treatment (based on any medical evidence of peoples of different ethnicities), and also the extent to which ACART can advise on clinical practice.
- 9.8 It was noted that the criteria for public funding is set by the Ministry of Health. ACART has no role in setting clinical access criteria nor public funding, so if ACART does look into the matter it can only raise the issue as a concern. The Chair agreed to seek an opinion from the Ministry of Health about whether ACART's remit extends to matters such as how clinical decisions are made.

### **Actions**

- *Secretariat to draft a letter from the Chair to the Ministry of Health about whether ACART's remit extends to matters such as how clinical decisions are made, such as potential systemic racism in use of BMI in health services.*
- *Secretariat to liaise with the Chair about the June agenda and seek approval for a venue and travel funds.*

## **10. ACART's consultation process**

- 10.1 There was a discussion about ACART's consultation process and members agreed they would like to see greater and more meaningful engagement with Māori. The member with expertise in Māori matters noted the importance of engaging with the right people and that building relationships with them is crucial. He noted that this could take some time and involve physically meeting the right people.
- 10.2 The member offered to prepare information for ACART members to help members when they approach Māori who might be interested in sharing their feedback for ACART's consultations. The Chair asked if there were protocols about how the first contact can be made and if a phone call was suitable. The member with expertise in Māori matters said that a phone call for the first contact would be acceptable.
- 10.3 The member with expertise in Māori matters also recommended that the Māori consultation options should not be explored further until ACART had had the session on cultural awareness and members agreed.
- 10.4 The Chair asked Nic Aagaard if funds would be available for ACART members to travel to establish relationships and Mr Aagaard said that there would be discussions about this next week at the Ministry of Health. He said that it would be helpful to have information from ACART about the proposed travel and the Chair said ACART could provide estimates.

## **Consult on the use of cryopreserved testicular tissue**

- 10.5 Members agreed that the consultation document should be amended to clearly state that cultural considerations have been taken into account and can be expanded on during the consultation. The importance to many Māori and Pasifika peoples, of the use of such tissue, needs to be stated in the consultation document.
- 10.6 Members discussed whether to proceed with the consultation on the use of cryopreserved testicular tissue and agreed it should go ahead given the tight scope of the matter and that interest in it is likely to come from a very limited range of stakeholders.
- 10.7 Given the committee's longer-term commitment to improving its cultural competency in its consultation processes, and the desire not to delay the process, it was agreed a limited consultation proceed without targeted Māori engagement for this project.

### **Actions**

- *Secretariat to amend the consultation document to state that the matter will be important to some Māori and Pacific people.*
- *Secretariat to prepare for the consultation process with Ministerial paper and Q&A etc. preceding engagement with clinics, and regular interested parties.*

## **11. Confirm the plan for the consultation on guidelines for extending storage**

- 11.1 The Chair summarised the progress to date and invited members to discuss the consultation plan bearing in mind the recent discussions about ACART's consultation processes and how to engage with Māori.
- 11.2 Members agreed to add text to the document to more clearly state that there may be cultural considerations to take into account.
- 11.3 Some grammatical and text changes were requested.
- 11.4 Given the above commitment to improving consultation processes in the longer-term, and the technical nature of the proposal being of interest to a limited number of people (particularly donors, recipients, donor-conceived, and those with gametes and embryos in storage), it was agreed a limited consultation proceed as above.

### **Actions**

- *Secretariat to update the draft consultation document as requested.*
- *Secretariat to prepare for the consultation process with Ministerial paper and Q&A etc. preceding engagement with clinics, and regular interested parties.*

## **12. Review of the guidelines for posthumous reproduction**

- 12.1 Members considered the first iteration of the advice to the Minister about these guidelines. Members worked through the proposed guidelines and the advice suggesting specific changes. In particular, they asked the secretariat to add text about ACART's obligations under Te Tiriti o Waitangi and to specify the sensitivity of posthumous reproduction for some ethnic groups while noting that there is no

pan perspective. A member had asked if a definition of “personal donor” should be added to the guidelines and members agreed it would be helpful.

- 12.2 The Chair asked members to go through the document out of session and send any “tracked changes” version of the document to the Secretariat to prepare for the June meetings working group.

### **Actions**

- *Secretariat to amend the guidelines as requested.*
- *Members to go through the document out of session and send any “tracked changes” version of the document to the Secretariat.*

## **13. Member reports on papers/research**

- 13.1 No items were presented on this occasion. The secretariat had recently circulated numerous journal articles.

## **14. Report on ECART’s December 2020 meeting**

- 14.1 Members noted the report.
- 14.2 There was a discussion about a surrogacy case in the April 2021 meeting where the use of a surrogate was considered the *best* opportunity for an intending parent(s) to have a child. In this case, the intending mother might have been able to have a child, without using a surrogate, but the chances were determined to be very low and with advanced maternal age, as well as other factors such as limited remaining embryos, surrogacy would give them the best chance at having a child.
- 14.3 The member with expertise in fertility treatment noted that the ECART public minutes leave out personal details to protect the privacy of patients but the details of each case are important — for example, sometimes a surrogate might not be the best option and in fact what is needed is a donor egg.

## **15. Correspondence**

- 15.1 The items were noted.

## **16. Chair’s report**

- 16.1 The Chair commented on the appointment process that is underway, and that arrangements for meetings with the Minister including joint meetings with the Chair of ECART were being considered.
- 16.2 Minister’s meeting: The Chair advised members that when she met the Minister of Health, she had asked about ACART’s work on the guidelines for human reproductive research. Following the meeting with the Minister, the Chair wrote to him giving more details about the project and asking for his written agreement to the proposed scope.
- 16.3 While awaiting the Minister’s response, the committee could consider what guidelines would need to include to be useful, and how the consultation document could be developed. Members discussed using an iterative method, in discussion

with the sector, to identify the essential elements of potential guidelines that would be used in the event that the Minister agrees to the scope of the guidelines.

- 16.4 Members noted the value of looking at regulation of human reproductive research in other jurisdictions, as well as previous consultations done in New Zealand on the topic. Some of the specific matters that the consultation might include could be: topics such as the 14-day development rule (in the HART Act) and whether it should be changed to 28 days to become consistent with new UK regulation; research on clones chimeras, and hybrids; if and how embryonic stem cell lines can be developed and used from New Zealand populations (particularly considering whakapapa and Māori data sovereignty), and mitochondrial replacement therapy.
- 16.5 Members discussed a range of points including the importance of consulting widely.

## **17. Secretariat report**

- 17.1 The Secretariat report was taken as read.

### **Cryopreserved ovarian tissue**

- 17.2 The Secretariat advised members that the Order in Council had been approved for the use of cryopreserved ovarian tissue to become an established procedure. A formal letter confirming this will be sent to the sector by the Minister of Health. The Secretariat will liaise with the Chair and the Minister's office to ensure communications are sent out.

### **ANZARD report options**

- 17.3 The Secretariat updated members on progress to obtain the ANZARD report from an alternate and cheaper provider. The member with expertise in fertility treatment advised members that clinics must submit data for their RTAC accreditation to the existing Australian provider anyway, and would be unlikely agree to prepare and submit the same data plus ethnicity information to an additional provider due to the work involved in preparing that data. Members discussed options and noted that they can obtain data on the ethnicity of patients from the Ministry of Health — members asked the Secretariat to take the next steps on this. Members noted that this data will likely only include publicly funded patients.

### **Actions**

- *Secretariat will liaise with the Chair and the Minister's office to ensure communications are sent out.*
- *Secretariat to liaise with the MoH staff on obtaining data about publicly funded fertility treatments and report back to ACART in June.*

## **18. Work between meetings**

- 18.1 Identified in the various action points.

## **19. Attendance at ECART meetings**

- 19.1 Attending member to be confirmed out of session.

**20. Next meeting – mid June TBC**

- 20.1 The Chair suggested that the face to face meeting for cultural training could be shared (same day) with workshops on ACART's policy projects, depending on the length of the training. The June meeting was scheduled as Friday 11 June, but it may need to be adjusted to accommodate the provider of cultural training, and to enable people's travel.

The meeting closed at 2.40 pm.