

## Minutes of the one hundred and first meeting of the Advisory Committee on Assisted Reproductive Technology

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Held online on 2 March 2023.

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### **Present**

Calum Barrett (Chair)  
Edmond Fehoko (to 10:30am)  
Seth Fraser  
Shannon Te Ahu Hanrahan  
Kathleen Logan  
Karen Reader  
Catherine Ryan  
Karaitiana Taiuru  
Sarah Wakeman  
Debbie Wilson

### **Non-members present**

Pearl Baird. Administrator, Ethics, Ministry of Health.  
Elsie Coleman. ACART Secretariat.  
Chloe Croskery. ACART Secretariat.  
Martin Kennedy. ACART Secretariat.  
Richard Ngatai. 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 the ability to articulate the interests of children gave members a presentation on the role of the Children's Commission and the importance of including children's perspective. The rights of children in New Zealand are recognised within a few key principles including Te Tiriti o Waitangi and the UNDRH<sup>1</sup>, making up the Children's Convention.

1.3 The presentation detailed the psychological impacts that may occur when a child learns of their donor origins, and the risk of a child not being able to meet their biological parents. In te ao Māori, children are considered a taonga, and the mana that they hold must be recognised and respected. There is currently very limited research on children's perspectives, such as whether they prefer to be genetically related to their parents. Research is often centred around families and the parents' perspectives, or adults reflecting on their childhood.

1.4 The Chair of ACART queried whether ACART is aligned with these points of the rights of children and the member with the ability to articulate the interests of children said she believed ACART is.

## **2. Apologies**

2.1 Nil.

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

3.1 Members approved the agenda and agreed to add an item, from the representative of the Office of the Children's Commissioner, on membership.

### **Action**

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

## **4. Declarations of Interests**

4.1 The member with an expertise in Māori customary values noted that he is one of the directors of the Indigenous Genomics Institute.

## **5. Minutes of ACART's meeting of December 2022**

5.1 Members approved the minutes subject to changes suggested by the member with expertise in assisted reproduction.

### **Action**

- *Secretariat to publish the December minutes on the ACART website.*

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<sup>1</sup> Universal Declaration of Human Rights.

## **6. Actions arising from ACART's December 2022 meeting**

- 6.1 Members noted the status of the actions from the December 2022 meeting.
- 6.3 Members discussed the Therapeutic Products Bill and a member noted that some of the proposed provisions would have the effect of regulating some cultural practices.
- 6.4 The secretariat will check whether the Therapeutic Products Bill is likely to have any direct implications for ACART and whether ACART should make a submission to the consultation.

### **Action**

- *Check whether ACART should make a submission to the Therapeutic Products Bill consultation.*

## **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 finalising 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 Members discussed the length of time between ACART submitting advice to the Ministry of Health and the Ministry then sending its parallel advice to the Minister. Members noted the delays can have real consequences for people seeking fertility treatment. The discussion covered whether ACART could publish its revised guidelines for posthumous reproduction in the near future. The secretariat offered to ask the MoH for an update on the likely timing of advice to the Minister and report back to the committee.

### **Action**

- *Ask the MoH for an update on the likely timing of advice to the Minister.*

## **8. Report on ECART's recent meetings**

- 8.1 Members noted the report from ECART's meeting on 24 February. The member with the ability to articulate the interests of children attended this meeting.
- 8.2 Two ACART members had attended the ECART meeting held on 8 December. The members discussed an application from the December meeting which had previously been declined. Members agreed that the current system relies on trust of professionalism for all those involved in an application. Members discussed the significance of clinical intervention and the responsibility that ECART has to ensure safety for all those applying to the Committee.
- 8.3 ACART discussed the wider issues of cultural competency and communication within fertility and clinical setting. Members agreed to investigate this matter further and potentially draft advice for the sector on best practice. The work would begin with scoping.
- 8.4 There was a brief discussion about cases where doctors were not present and the

ECART member at this meeting informed ACART members that doctors had previously considered the case.

**Action**

- *Secretariat to liaise with the member with expertise in assisted reproduction about current practices in culturally appropriate counselling*
- *Chair and secretariat to liaise with the member with expertise in Māori customary values and practice for guidance on opening conversations with clinics.*

**9. ANZARD report for the year 2019**

9.1 Members approved the ANZARD report subject to minor grammatical and administrative changes as well as increased reporting on ethnicity data.

**Action**

- *Secretariat to contact supplier to request two changes. The changes are to a) check for typos and b) ask that future reports refer to people with more than one ethnicity as “multiple ethnicities” not “discordant ethnicities.”*
- *Secretariat to ask the supplier to specify which particular preimplantation genetic process is used.*
- *Secretariat to amend the foreword to state that this is the first time ethnicity data is being reported.*

**10. Annual report to the Minister for the 2020/21 financial year**

10.1 Members approved the report.

**Action**

- *Secretariat to arrange for the report to be submitted to the minister and subsequently published.*

**11. Correspondence**

11.1 The Committee discussed an enquiry from a member of the public about the success of their experience having an ovarian tissue transplant in Australia. They wished to share their story in the hope of legalising the procedure in New Zealand. The secretariat had informed the individual of the recent amendment to the HART Order which came into force on 17 May 2021, has made the use of cryopreserved ovarian tissue an established procedure.

11.2 The Committee member with expertise in assisted reproductive procedures noted that since the HART order change there have been two ovarian tissue transplants take place. Two centres in New Zealand (Auckland and Christchurch) are part of the Future Fertility Study which is taking place across Australia and New Zealand and offers fertility preservation to children and young people up to age 25 faced with a cancer diagnosis.

11.3 The Committee discussed uterine transplants currently being done overseas. It was noted that at present, this transplant is complicated. It comes at a high cost, will result in a high-risk pregnancy, and involves a hysterectomy post pregnancy.

## **12. Review of the guidelines for extending storage**

- 12.1 Members reviewed the draft advice to the minister for amending the guidelines and discussed the next steps for this project.
- 12.2 Prior to the meeting the Secretariat circulated the draft advice and the Chair and the member with the ability to articulate the interests of children added changes. This updated document will be circulated to all members for feedback. Subject to these changes, members agreed the draft advice may be published.
- 12.3 Members discussed whether, and to what extent, the age of donors should be a factor in storage applications. Members also discussed the significance of the age of intending parents when they seek fertility treatment. Members noted that the age of donors and intending parents (and the related matter of storage periods) could have consequences for the psychological wellbeing of the offspring.
- 12.4 Members decided that the age of both donors and intending parents, and any related storage periods, are relevant to extending storage due to the rights of, and benefits to, individuals to meet their genetic parents and the parents who would raise them.
- 12.5 The discussion addressed several factors including:
  - a) increasing difficulty in contacting donors as time progresses
  - b) the clinical practice of generally not using reproductive material from people aged over 45
  - c) the increased risks to a woman and a baby of gestating a baby once she is beyond a certain age
  - d) life expectancy is currently increasing
  - e) the benefits for clinics in having a regulation or guidance that clearly states why storage should not be extended and/or treatment should not be provided
  - f) providing an exception to the rule if the stored material is to be used for non-clinical research
  - g) the need to provide evidence of harms that ACRT wishes to avoid or mitigate
  - h) the need to manage this matter carefully as people's rights could be affected, depending on ACRT's conclusions.
- 12.6 Members discussed the importance of whakapapa and that must also be considered when considering regulations about age limits for donors.
- 12.7 Members discussed the possibility of recommending discretion to ECART when considering extension applications for storage for material with exceptional circumstances. The grounds for declining applications to extend storage was also discussed. ACART will need to investigate these concepts further before deciding if and how it can provide more detailed guidance to ECART.
- 12.8 Members agreed the Secretariat should find more information, about settings in which limitations can be applied to people's behaviour on the basis of age, and present the findings to ACART. Members could then consider if and how limitations might be appropriate for the storage of human gametes and embryos.

## **Actions**

- *Secretariat to circulate draft advice.*
- *Secretariat to format the advice and submit it to the minister.*

### **13. Consultation on guidelines for human reproductive research**

- 13.1 Members who had participated provided a summary of the recent talk given at Fertility New Zealand about this consultation.
- 13.2 The Chair noted that it would be beneficial to look at human reproductive research instruments and guidelines in other jurisdictions, and suggested that Canada, the United Kingdom, and Australia could be of particular interest to the Committee.
- 13.3 The Secretariat noted that, as the submission close date is close to the date of the April meeting, they may not be able to provide a complete summary and analysis of submissions.
- 13.4 Secretariat updated the Committee on the communications plan and the Committee discussed further avenues to reach out to the public and interest groups.

## **Actions**

- *Individual members to follow up with their agreed connections*
- *Secretariat to research human reproductive research instruments and guidelines in other jurisdictions*
- *Secretariat to contact Māori health at the Ministry of Health for a review*
- *Secretariat to contact universities to discuss interest in making a submission*
- *A member will contact a connection at the Centre for Science and Research about making a submission*
- *Secretariat to provide raw cut submissions to the Committee in April meeting*

### **14. Chair's report**

- 14.1 Members noted the written report.
- 14.2 The Chair noted an online panel they presented at with Fertility New Zealand. They noted that there was a range of questions at the end, with a general interest on consent. The Chair noted they were pleased with the connection made with the public.

### **15. Members' reports**

- 15.1 No items on this occasion.

### **16. Secretariat report**

- 16.1 Members noted the report.

### **17. Work between meetings**

- 17.1 Members agreed to hold a focus group with ECART and Māori stakeholder groups

### **Action**

- *Hold the focus group with ECART and Māori stakeholder groups*

## **18. Update on appointments**

18.1 The Secretariat provided an update on the status of appointing new Committee members with expertise in ethics and children's perspectives. The secretariat advised members that the Ministry of Health expects to advise the minister on appointments within the next few weeks.

18.2 Members noted the urgency in appointing these members.

### **Additional item**

- The member representing the Office of the Children's Commissioner advised ACART members that the OCC had new staff and that at least one was suitable to join ACART. As the ACART member from the OCC is not selected by Cabinet ACART can simply advise the appointments team at the MoH of the new person.
- Members agreed and asked the secretariat to arrange this.

### **Action**

- *Advise the appointments team at the MoH about the new representative from the OCC.*

## **19. Attendance at ECART**

19.1 Members confirmed their availability.

- 3 April 2023: Karaitiana Taiuru

The meeting closed at 1.00 pm.