



## **Minutes of the Eighty-third Meeting of the Advisory Committee on Assisted Reproductive Technology**

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Held on 13 February 2020, at the Wellington Airport Conference Centre.

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### **Present**

Kathleen Logan (Chair)  
Calum Barrett  
Jonathan Darby (via teleconference)  
Colin Gavaghan (Deputy Chair) (via teleconference)  
Sue McKenzie  
Karen Reader  
Analosa Veukiso-Ulugia  
Sarah Wakeman

### **Non-members present**

Martin Kennedy, ACART Secretariat  
Hayley Robertson, ACART Secretariat

## **1. Welcome**

1.1 The Chair opened the meeting at 8.40 am and welcomed the Committee members and guests. There was no ECART member in attendance at this meeting.

### **1.a Opening discussion**

1.2 Members are concerned that, during busy travel times, ACART's budget sometimes does not stretch to flying in members who live in the regions and thought there was a risk that representation is sometimes only from members who live in major cities.

#### ***Actions***

- *Members to contact the Secretariat about any opening comments for the April meeting.*

## **2. Apologies**

2.1 None.

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

3.1 Members approved the agenda.

#### ***Action***

- *Secretariat to place the February 2020 agenda on ACART's website.*

## **4. Declarations of Interests**

4.1 No declarations.

## **5. Minutes of ACART's meeting of December 2019**

5.1 The minutes were approved with minor amendments and additions. There was a discussion about the difference between the terms 'donor' and 'deceased' and making sure that the words are not confused in the posthumous reproduction consultation document.

#### ***Action***

- *Secretariat to place the December 2019 minutes on ACART's website, and share with ECART.*
- *Secretariat to check through the minutes and draft guidelines to ensure that the word donor isn't used when the word deceased would be more appropriate.*

## **6. Actions arising from the December meeting**

6.1 Members noted the status of the actions.

## **7. Work programme status**

7.1 Members noted the status of the work programme and the plan for the implementation of the revised Donations Guidelines to be put in place once the Associate Minister has responded. The Secretariat advised members that changes will be communicated well in advance to fertility clinics so their forms can be

amended. The Secretariat has written up a comprehensive plan for the implementation.

#### *Ethnicity and equitable access to treatment*

- 7.2 Members had a discussion about the raw data received from the Ministry of Health about ethnicity and equitable access to ART treatment. At ACART's October 2019 meeting the matter of recording the ethnicity of people using assisted reproduction had come up and members had asked the Secretariat to find out and report back to the committee on what ethnicity data is collected for publicly funded treatment and whether ACART could have access to that data. The Secretariat reported back that the ANZARD does not report on ethnicity data and members discussed options for obtaining this data by other means. Members noted that although ACART is not required to advise the Minister on the equity of access to fertility services it can comment on the matter if it wishes to.
- 7.3 The Secretariat noted that the Ministry of Health records ethnicity data, but only for the treatments that the district health boards provide, which make up approximately 20% of treatment in New Zealand. The rest is privately funded, and clinics must provide data to ANZARD under the Fertility Services Standard (1.8.2). At the October 2019 meeting members had asked the Secretariat to formally request ethnicity data from the Ministry of Health, and for each clinic.
- 7.4 The Secretariat circulated a page of raw numbers, provided by the Ministry of Health, of ART treatment and members again discussed the benefits of the ANZARD reporting on ethnicity data could feature in future reports.

#### **Actions**

- *Secretariat to circulate the Ministry of Health's working excel spreadsheet of funded ART treatment to all members.*
- *Sarah to have a discussion with John Peek at Fertility Associates about writing to ANZARD about ethnicity data.*

#### **8. Membership updates**

- 8.1 Members noted that there are still no new reappointments by Cabinet to fill the vacant positions on ACART. It was noted that several members terms expired in April 2019. Members also expressed concern about not having an ethics member on ACART and noted that appointments are still moving slowly.

#### **Action**

- *Secretariat to check if there are any updates from the appointments team.*

#### **9. Posthumous reproduction**

- 9.1 Members considered the most recent iteration of the draft guidelines and consultation document and discussed the remaining policy matters. Members noted the origins of the project and the reasoning that clinics and the public would benefit from updated and clearer regulatory guidance on posthumous use, given that the number of people freezing their gametes long term is increasing.

- 9.2 Members went through outstanding matters in the draft consultation document and directed the Secretariat to make several grammatical changes. Members also requested that the narrative of the document make it clear that ECART is not required to meet under urgency to expedite cases of posthumous retrieval. Members also discussed Justice Heath's judgement that the Court's interpretation of the HART Order is that urgent retrieval should be done through the process of a High Court Order.
- 9.3 Members discussed whether the consultation document should explain that, in cases of posthumous gamete retrieval, consent to use can be proved after the retrieval has been done but decided there was no need to do so. Posthumous retrieval would almost always be approved by a High Court which can choose to authorise posthumous retrieval with an order that evidence of consent be provided at any time the court determines. If and when approval for *use* is subsequently sought from ECART, ECART will assess the consent to posthumous use. Consequently there is no need to explain that in these cases consent to posthumous use can be evidenced after retrieval.
- 9.4 Members directed the Secretariat to ensure that the consultation document explicitly notes that posthumous retrieval and use of sperm from a deceased man are currently Assisted Reproductive Procedures.
- 9.5 It was also noted that since the survey question proposes that all posthumous use should be subject to ethical review, this change would capture clinic donors also.

#### *The best interests of children*

- 9.6 Members discussed the importance of posthumously conceived children being informed about their conception. Members thought this communication was important but noted that it cannot be mandated, and people can only be encouraged to be transparent with their children about their birth story and their whakapapa/genetic history.

#### *Public consultation through Citizenspace*

- 9.7 The Ministry has an online consultation tool ("Citizenspace") which allows data to be extracted in several different ways. Members asked if it would be possible to have the commentary beside a survey question and directed the Secretariat to investigate how we can amend the consultation tool so that submitters aren't flicking back through pages to remember the commentary when they come to answer the survey question.

#### **Actions**

- *Secretariat to ensure the final document is clear where it talks about donor and where it talks about the deceased, as the deceased is not a gamete donor.*
- *Secretariat to make amendments from this meeting and send the document for editing prior to the April meeting.*
- *Secretariat to investigate how Citizenspace could be used in a more user-friendly way for submitters.*

**10. New project - Scope the project to have the use of cryopreserved testicular tissue declared an Established Procedure**

- 10.1 The Associate Minister of Health has agreed that ACART should commence work to have the use of cryopreserved testicular tissue declared an established procedure.
- 10.2 The use of cryopreserved testicular tissue (CTT) is not explicitly stated as an established procedure in the HART Order. Fertility clinics routinely use the tissue on the understanding that CTT comes within the definition of testicular tissue. At present, some parties have different understandings of the legal status of the use of the tissue. There is no practical reason for the use of the tissue not to be an EP.
- 10.3 While there is no practical problem with this situation, it would (to remove the risk of misunderstanding) be prudent to have the HART Order amended to state that the use of CTT is an established procedure.
- 10.4 The secretariat circulated to members the 2014 commissioned report about the safety and efficacy of using cryopreserved ovarian tissue and testicular tissue. Members discussed how long the project would take.
- 10.5 Members agreed that the working group for this project will comprise of Karen, Sarah, Colin, Kathleen and Sue.

**Action**

- *Secretariat prepare a first draft consultation document for the working group to consider in June 2020.*

**11. Scope the project to amend the guidelines for extending the storage of gametes and embryos**

- 11.1 The Associate Minister of Health has agreed that ACART should commence work to review the guidelines for extending the storage of gametes and embryos.
- 11.2 The proposed amendment would mean that gamete donors would not need to be consulted for storage extensions for embryos. At present, the guidelines for extending the storage of gametes and embryos have a provision that reads:
- 5) when considering an application to extend the storage period of gametes or embryos beyond the initial 10-year storage limit or beyond an approved extended storage period, ECART must take the following matters into account:
- a) whether all gamete providers (including donors) have given informed consent, including where an embryo has been created from the gametes.
- 11.3 Members also discussed the current provision that storage is limited to 10 years plus renewals. Members thought it would be a good idea to review the literature to understand why the storage period is currently 10 years then discuss whether it should be longer or even removed. There are good arguments for having limitations on storage but also for not, and members noted that the 10 year storage period is arbitrary given the longevity of fertility years.
- 11.4 Members discussed how long the project might take and noted that a review of the storage period would require a change to the HART Act and that any legislative

changes would need the government to agree and lead the work. Consequently, members agreed to keep the scope of the project to removing the requirement that gamete donors be consulted when people seek extensions to the storage of embryos created from those gametes.

- 11.5 Members agreed that the working group for this project will comprise of Analosa, Colin, Kathleen, Jonathan and Calum.

**Action**

- *Secretariat prepare a first draft consultation document for the working group to consider in June 2020.*

**12. Monitoring: member reports**

- 12.1 Members had no updates on this occasion.

**13. Minutes from and report on ECART's meeting of 7 November 2019**

- 13.1 Members noted the report and discussed a case regarding the use of sperm after death by the individual's wife and a case where the intending mothers age was much higher than the average child bearing age.

**14. Correspondence and Enquiries**

- 14.1 Members noted the correspondence and discussed the letter that the Chair had sent to the New Zealand Police, asking them to reinstate the service and outlining the reasons why they should not cease to undertake police vetting for recipients of embryo donations.

**15. Governance — Chair's Report**

- 15.1 Members noted the report.

**16. Secretariat report**

- 16.1 Members noted the report.

**17. Regulatory response to genetic editing in health**

- 17.1 Members noted that the Ministry of Health is initiating work on this topic and that Dr Logan will attend the meetings.

**18. ACART members at upcoming ECART meetings**

- 18.1 Kathleen will attend the next ECART meeting in Wellington on 27 February 2020.

- 18.2 All ECART meeting dates have been confirmed for next year and members expressed their interests in attending. These are:

- 27 February, Kathleen Logan.
- 30 April, Calum Barrett.
- 25 June, Sarah Wakeman.
- 3 September, Analosa Veukiso-Ulugia.
- 29 October, TBC.

- 17 December, TBC.

**Action**

- *Secretariat to contact all members to confirm attendance at the upcoming ECART meetings.*

**19. Conclusion of meeting and next meeting dates**

19.1 The upcoming ACART meetings are as follows and begin at 8.30am.

- Thursday, 2 April 2020. Wellington.
- Thursday, 11 June 2020. Via zoom.
- Thursday, 13 August 2020. to be confirmed – may be held in Dunedin instead of Wellington.
- Thursday, 15 October 2020. Wellington.
- Thursday, 10 December 2020. Wellington.

**Actions**

- *Members to liaise with Moana for travel arrangements*
- *Secretariat to advise ECART of the upcoming meeting dates.*

19.2 The meeting closed at 2.30pm.