



Minutes of the Eighty-second Meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 13 December 2019, at the Wellington Airport Conference Centre.

Present

Kathleen Logan (Chair)
Calum Barrett
Jonathan Darby
Sue McKenzie
Karen Reader
Analosa Veukiso-Ulugia
Sarah Wakeman

Non-members present

Iris Reuvecamp, ECART chair
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. The ECART member in attendance at this meeting was Iris Reuecamp. Six items were added to the agenda. These were:

- priority work and matters to discuss with the Associate Minister
- the need for police vetting of recipients of embryo donation
- the process for releasing the new Donation and Surrogacy Guidelines
- Tamati Coffey's proposed Surrogacy Bill in the Parliamentary Ballot
- training and sector days in 2020
- progress on the regulation of the import and export of gametes and embryos.

1.a Opening discussion

- 1.2 Calum Barrett took members through his thoughts on a posthumous use situation where a surviving partner applies to use their deceased partner's frozen gametes without being specifically named on the consent form when it was stored.
- 1.3 Members discussed how situations like this relate to the proposed revised Guidelines for posthumous reproduction, and the need for them to not needlessly restrict people from using the gametes in cases where it is clear that there was consent of another kind to its use.
- 1.4 Members discussed how specific a person's consent must be, and agreed they would discuss the specificity of consent more fully when the meeting moved on to the consultation document for the review of the guidelines for posthumous reproduction.

2. Apologies

- 2.1 Colin Gavaghan (Deputy Chair).

3. Approval of the agenda

- 3.1 Members approved the agenda.

Action

- *Secretariat to place the December 2019 agenda on ACART's website.*

4. Declarations of Interests

- 4.1 No declarations.

5. Minutes of ACART's meeting of October 2019

- 5.1 The minutes were approved.

Action

- *Secretariat to place the October 2019 minutes on ACART's website, and share with ECART.*

6. Actions arising from the October meeting

- 6.1 Members noted the status of the actions.

7. Work programme status

Implementation of the guidelines for donations and surrogacy

- 7.1 Members noted the status of the programme and that their advice regarding the Surrogacy and Donations Guidelines has been sent to the Minister. The Secretariat explained that the Ministry of Health is preparing parallel advice to Hon Jenny Salesa about ACART's revised Guidelines. Hon Salesa will be able to respond to ACART once she has considered the Ministry's advice. Iris noted that while ECART has been waiting for these Guidelines to be published, individuals and clinics have been in touch with ECART about families' wishes to start their treatment to have families. The Secretariat explained the steps that will be taken to ensure the implementation of the guidelines goes smoothly.

Ethnicity and equitable access to treatment

- 7.2 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). Members asked the Secretariat to formally request ethnicity data from the Ministry of Health, and for each clinic.
- 7.4 Members asked who provides funding for the ANZARD — specifically, the New Zealand publications. The Secretariat advised that while privately funded clinics provide the information to the University of New South Wales (who run the database) the analysis and the publication of this information in the New Zealand specific ANZARD report is funded by the Ministry of Health. Members questioned whether as part of this contract, ethnicity data could feature in future reports.

Genetic editing in healthcare

- 7.5 The Secretariat advised members that the Ministry of Health is initiating work to look into if, and how, the use of genetic modification in the health sector could be regulated. ACART has been invited to take part in the initial scoping work and the Chair advised members that she intends to take part if her other work commitments allow it.

Actions

- *Secretariat to draft a letter from the Chair to the private clinics asking if they would be willing to provide ACART ethnicity data.*
- *Secretariat to find out and report back to the committee on the ethnicity breakdown of cycles funded by the Ministry of Health per annum.*

8. Membership updates

- 8.1 Members noted that there are still no new reappointments by Cabinet to fill the vacant positions on ACART. The Chair explained that DHB appointments have been a priority for the government in the second half of 2019 and this has meant that committee memberships were not able to be considered.

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 for social rather than medical reasons is increasing.
- 9.2 Members went through outstanding matters in the draft consultation document and directed the Secretariat to make changes. Members also made some minor changes to the foreword to ensure it is clear to submitters that posthumous use is not always preceded by posthumous retrieval.

Actions

- *Secretariat to ensure that the document is mainly talking about use, and that retrieval is sometimes a step in the process of use.*
- *Secretariat to add the term 'fertility service provider' to the glossary.*
- *Secretariat to include in the foreword that ACART wants to ensure that the principles of the treaty and the HART Act are upheld in the final guidelines.*
- *Secretariat to ensure the final document is clear where it talks about use and it talks about retrieval.*

Use by specified individuals

- 9.3 Members discussed specific use and whether there is a need for the deceased to have specified an individual by name. Members discussed the policy intention behind why they would want to require a named individual, and noted that ideally people would be as clear as possible about their intentions for the use of their gametes, and understand and agree to their gametes being used after they've died. What is being consented to ultimately, is the creation of a child posthumously, or to research using their gametes. Members thought that asking people to specify a name could be problematic for their wishes and for ECART's consideration as many people store gametes for their siblings without putting a name.

- 9.4 ACART's policy intention is that the use needs to be for someone's own use, not "clinic donor" use (i.e. to an unspecified person) or where they intend to parent the resulting child if they are using a gamete from a deceased person.
- 9.5 ACART believes it important that the recipient be known to the now deceased before death to protect the resulting child and its sense of relationship with its deceased genetic parent. The Committee noted that these revised guidelines aim to protect the deceased from their gametes being used in a way that they hadn't anticipated, but members also do not want them to be too restrictive.

Provisions for retrieval by ECART

- 9.6 Members discussed the likelihood of ECART approving the posthumous retrieval of gametes or tissue, and directed the Secretariat to look into whether posthumous retrieval does in fact fall under the definition of an ARP in the Act. If it does not, posthumous retrieval will not be addressed in the guidelines. ACART needs to determine whether the High Court is the only authority with jurisdiction over this.
- 9.7 ACART takes the position that all posthumous retrieval and use should not be EP's. Members noted that if legal advice concludes that the posthumous retrieval of gametes is not an ARP then the consultation document must be clear that ACART will recommend that the Order be amended to include retrieval of gametes as an ARP. A sentence would be added that "any posthumous retrieval and use is not an EP"

Action

- *Secretariat to look into whether posthumous retrieval is an ARP or an EP, or neither.*

Storage periods and time frames for posthumous reproduction

- 9.8 Members discussed the draft provision that refers to time frames for posthumous use of gametes or reproductive tissue and decided to remove references to the need for an individual to specify a time frame in their consent. All agreed that there is no need for the revised guidelines to be so specific because maximum time frames of 10 years are already in the HART Act, and individuals freezing gametes or tissue before death have the option to consider if they would like to stipulate a different, shorter, time frame.

Extending the storage of gametes or tissue

- 9.9 Members talked about if and when people should be able to extend the storage of gametes or reproductive tissue they already have in storage. They noted that the date from which a period of storage is set will be the date on which the material was first retrieved and stored, not the date of the extension of the storage. After some consideration, members noted that there is already a guideline for extending storage and that that guideline would apply. Members agreed that no new provisions are needed and that the consultation document would need to explain the rationale for this — that the storage period in the Act is sufficient.

Stand-down period

- 9.10 Members noted that any stand down period is arbitrary, so decided to state in the guidelines that counsellors should ensure applicants consider their need for a grieving period. The narrative in the consultation document should be shortened to only address this point.

Action

- *Secretariat to amend the consultation document to explain the status of extending storage.*
- *Secretariat to add a question to ask submitters if the counselling provision in draft guidelines is adequate.*
- *Secretariat to remove the sections about storage and extending storage and to include a paragraph that notes that the current guidelines adequately address storage matters.*

Title of the guidelines

- 9.11 Members agreed a suitable title would be “Guidelines for the posthumous use of gametes and reproductive tissue and of stored embryos”

10. Monitoring: member reports

- 10.1 Members had no updates on this occasion.

11. Minutes from and report on ECART’s meeting of 4 July 2019

- 11.1 Members noted the report and discussed a case regarding the use of sperm after death by the individual’s wife. Several factors in the case were of interest, in particular (i) the status of the consent given to use of the sperm, (ii) what kinds of oral consents are acceptable, and (iii) the relevance of support from family and friends for the posthumous use of the stored sperm by the man’s wife to create a child. Members noted these matters are often not simple and considered how the proposed new guidelines would apply in such a case.

12. Correspondence and Enquiries

- 12.1 Members noted the correspondence.

13. Governance — Chair’s Report

- 13.1 Members noted the report.

14. Secretariat report

- 14.1 Members noted the report.

Extra item. Priority work and discussion points for meeting with Associate Minister

- a. Members noted that the committee and Secretariat would have the capacity to work on new topics, or focus more on existing topics, now that the guidelines and advice for donations and surrogacy are almost complete.

- b. The Secretariat advised members that the Associate Minister has agreed to ACART undertaking two new projects. These are (a) amending the guidelines for extending the storage of gametes and embryos and (b) clarifying the status of testicular tissue so that the use of frozen testicular tissue could become an established procedure. Members agreed to scope these projects at the meeting in February 2020.
- c. Members discussed possible talking points for the Chair's upcoming meeting with Hon Jenny Salesa and noted that:
 - the Chair should inform the Minister that some preliminary scoping work on the issues and solutions around gene editing has started
 - the importance of the inclusion of ART in the gene editing discussion and the fact that the genetic modification of embryos is prohibited by the HART Act
 - note that there is a pressing need to enact the donation guidelines due to the risk of unintentional discrimination against some individuals
 - note that there are individuals with frozen ovarian tissue who wish to use their tissue to start a family but are unable to do so until Cabinet considers the change.
- d. The Chair agreed to write to Associate Minister Salesa immediately so that she is ready for the meeting early in 2020.

Extra item. Police vetting

- a. In August 2019, the Ministry was advised by Fertility Associates that the New Zealand Police intend to cease undertaking police vetting for recipients of embryo donations, due to resource issues, the absence of legislative requirements to carry out the vetting, and vetting recipients of donated embryos not meeting the Police Vetting criteria.
- b. The Secretariat has been in contact with Police to find out what information is obtained in the vetting process to see if there is another way that this information might be obtained. The Police Vetting Service assesses all information held on a person, including (but not limited to) charges, warnings, convictions, and other information. When embryo recipients sign the consent form to be Police vetted they are giving consent to release any information that Police consider to be relevant.
- c. A criminal record check from the Ministry of Justice is the most similar service to Police Vetting, but they will only provide conviction history information.
- d. Members noted that the ACART guidelines for embryo donation are legally binding to ECART. The policy intent behind the provision requiring recipients of embryo donation to be vetted is so donors can be satisfied that the recipients don't have any relevant convictions and charges against them. If the Police drop the service (10 to 20 vets per year) this will mean that people cannot complete an ECART application to start a family.

Action

- *Secretariat to draft a formal letter to Police vetting services on behalf of ACART, noting these concerns and asking them to reinstate the service.*

Extra item. Proposed surrogacy bill

- a. Members noted that responsibility for the proposed Surrogacy Bill, in the Parliamentary ballot, has been transferred to Hon Tamati Coffey (from Hon Louisa Wall) and that ACART needs to be ready to respond in the event that the Bill is drawn from the ballot, considered by Parliament and goes to Select Committee.

Action

- *Secretariat to draft a response to the draft Bill.*

Extra item. Training and sector day

- a. The Chair advised members that in the first half of 2020 a training day was proposed for the new ACART and ECART members. Details will be arranged once the new members have been confirmed. In the second half of 2020 a combined training day for any other new members would be held in combination with a “sector day” similar to that held in 2017. Again, details will need to be confirmed.

Extra item. Regulation of the import and export of gametes and embryos

- a. The Chair noted that ACART's recommendations to regulate the import and export of gametes and embryos had not been carried out. Members agreed ACART should write to the Ministry of Health to enquire about progress on those regulations.

Action

- *Write to the Ministry of Health to enquire about progress on those regulations.*

15. ACART members at upcoming ECART meetings

- 15.1 Kathleen will attend the ECART meeting in Wellington on 27 February 2020.
- 15.2 All ECART meeting dates have been confirmed for next year and members expressed their interests in attending. These are:
 - 30 April 2019, Calum Barrett.
 - 25 June 2019, Sarah Wakeman.
 - 3 September 2019, Analosa Veukiso-Ulugia.
 - 29 October 2019, TBC.
 - 17 December 2019, TBC.

Action

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

16. Conclusion of meeting and next meeting dates

- 16.1 The upcoming ACART meetings are as follows.
 - Thursday, 13 February 2020. Wellington.
 - Thursday, 2 April 2020. Wellington.
 - Thursday, 11 June 2020. Wellington.

- Thursday, 13 August 2020. 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*
- *Advise members the start and end times and location when arranging travel.*

16.2 The meeting closed at 3pm.