



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

Held on 18 October 2019, at the Wellington Airport Conference Centre.

Present

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

Non-members present

Angela Ballentyne, ECART member
Kirsten Forrest, ECART Secretariat
Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat

1. Welcome

- 1.1 The Chair welcomed the Committee members and guests. The ECART member in attendance, Dr Angela Ballantyne, joined the meeting at 10 am and Drs Karen Reader and Colin Gavaghan joined the meeting at 9.30 am.

1.a Opening discussion

- 1.2 Dr Reader reported on the conference of the Fertility Society of Australasia that she had recently attended. She provided members a detailed written report on a wide range of matters including that the Australian National Health and Medical Research Council is looking into mitochondrial replacement therapy.

2. Apologies

- 2.1 Dr Sarah Wakeman.

3. Approval of the agenda

- 3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

- 4.1 No declarations.

5. Minutes of ACART's meeting of August 2019

- 5.1 The minutes were approved.

Action

- *Secretariat to place the August 2019 minutes on ACART's website.*

6. Actions arising from the August meeting

- 6.1 Members noted the status of the actions.

7. Work programme status

- 7.1 Members noted the status of the programme and that item 10 of today's agenda was to discuss the programme and the work that could be prioritised (see that item for more details). The Secretariat explained the process being used to advise Hon Jenny Salesa about ACART's work programme and to obtain her response.
- 7.2 The matter of recording the ethnicity of people using assisted reproduction came up and members 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. Members discussed options for having this data included in the New Zealand specific ANZARD report. Members were also curious about the amount of funding the government/district health boards provide each year to assisted reproduction and asked the secretariat to look into this and report back to the committee. The data would be useful for assessing the equity of access to publically funded fertility treatment.

Actions

- *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.*
- *Secretariat to find out and report back to the committee on how much money the government or district health boards allocate to assisted reproduction per annum.*

8. Membership updates

- 8.1 Members noted the paper and that appointments are unlikely to be made in 2019. The Chair explained that the newly-elected DHB appointments are a priority for the government.

9. Posthumous reproduction

- 9.1 Members considered the most recent iteration of the draft guidelines and consultation document after the documents underwent expert review by Professor Nicola Peart, and discussed the remaining policy matters.

Provisions for retrieval will be included

- 9.2 Members agreed to include provisions for the retrieval of gametes or tissue from a deceased person and that the consultation document should explain this proposal. Including such provisions is a reversal on ACART's earlier proposed position. Members noted that the number of cases would likely be very small and that in some cases it might not be possible to obtain authority from a High Court or ECART to retrieve the gametes or tissue. Despite this, the provisions should be included because ACART needs to ensure it covers all the regulatory matters that need to be addressed.

Action

- *Secretariat to amend the consultation document to include provisions for retrieval.*

Evidence of consent to retrieval can be provided after the retrieval

- 9.3 Members agreed that the evidence of consent to retrieval, by the deceased, can be provided *after* the retrieval and that the consultation document should explain this proposal. Members agreed that the consultation document would need to be very clear that evidence of consent would need to be provided for the use to then be considered by ECART. Members agreed the consultation document should explain the following.

- Consent to retrieval can be written or oral.
- There are risks involved in allowing retrieval to be done on the basis that the evidence of consent will be provided after the retrieval. The risks include interference with a corpse and actions being taken that go against the wishes of the deceased.
- In most cases ECART is unlikely to be able to consider short notice requests for

retrieval. However, where a person is terminally ill and the parties have advance notice of an impending death, ECART might be able to authorise that the retrieval of the gametes/tissue be done when the person dies.

- Members noted that if an application was made for retrieval using the ECART pathway, consideration for use could not be made at the same time as consideration for retrieval.
- By allowing people to provide evidence of consent after retrieval, ACART is effectively setting a lower bar to retrieval than it is to use.

Action

- *Secretariat to amend the consultation document to explain when evidence of consent to retrieval can be provided.*

All posthumous reproduction cases must go to ECART

- 9.4 After considerable discussion, members agreed that all uses involving posthumous reproduction must go to ECART. The reasons for this are that these cases will always involve ethical complexity, and the offspring must be protected from the risks associated with posthumous reproduction (e.g. they will never have the opportunity to know at least one of their genetic parents). Similarly, the wishes of the deceased need to be honoured and these wishes can be considered by requiring all cases to be considered to ECART.

Action

- *Secretariat to amend the consultation document to explain that all cases of posthumous reproduction must be submitted to ECART.*

Age of consent to retrieval and use

- 9.5 There was a considerable discussion about the age at which a person should be able to consent to the collection and/or use of his/her gametes or reproductive tissue. At present, if a minor has stored gametes or tissue (for example, during chemotherapy) before turning sixteen that material cannot then be used when they reach maturity. This is an unusual feature of the HART Act that members wish to address.
- 9.6 Members agreed that, to be consistent with other regulatory requirements for reproduction, the age at which a person should be able to consent to the use of his/her gametes/tissue should be 16, but they acknowledged that from some perspectives this is quite young. Members asked the Secretariat to find out the minimum age at which people can currently donate gametes or reproductive tissue, and also agreed that the consultation document should seek the public's input on this matter.

Action

- *Secretariat to find out the minimum age at which people can currently donate gametes or reproductive tissue.*

Extending the storage of gametes or tissue

- 9.7 Members discussed 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 this. Members noted the importance of the person storing the material specifying who could use the material, by what time and in what manner.

Action

- *Secretariat to amend the consultation document to explain the status of extending storage.*

Provide a lay reader summary

- 9.8 Members discussed the format of the document, noting that it is not “user friendly.” They agreed that a two-page summary, using simple language, should be included early in the document.

Action

- *Secretariat to write a simple two-page summary of the matters being consulted on and include this in the document.*

Reference to biological sex and to gender

- 9.9 Members noted the difference in meaning between “biological sex” and “gender” and that for the purposes of aiding clinical considerations, and consistency with the HART Act the words male and female were being used in the biological way. They agreed to insert a sentence explaining this and acknowledging that some people’s gender identity will not match their biological sex.

Action

- *Secretariat to insert text acknowledging that some people’s gender identity will not match their biological sex.*

Cultural considerations

- 9.10 Members noted that the section on cultural considerations might need to be refined and asked the Secretariat to seek input from the Māori policy unit at the Ministry of Health.

Action

- *Secretariat to seek input, on the cultural section, from the Māori policy group at the Ministry of Health.*

Structure of the consultation document

- 9.11 Members agreed to change the order of some of the sections, including moving the example of the *Re: Lee* case to earlier in the document and to merging and re-ordering some of the paragraphs in the sections about consent.

Action

- *Secretariat to amend the order and structure of the sections on consent and the Re Lee case.*

10. Agree ACART's priority work

- 10.1 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.
- 10.2 Members noted that ACART normally agrees its programme of work with the Minister of Health and scoping possible projects needs to be done to advise the Minister about possible work. In the case of human reproductive research, genetic modification and mitochondrial replacement, that scoping could itself be a substantial piece of work.
- 10.3 Members decided that amending the guidelines for extending the storage of gametes and embryos should be one priority and that scoping possible work on human reproductive research, genetic modification and mitochondrial replacement should be the other. This is not to say that several other matters are not important, including advice that the HART Order should be amended so that the use of frozen testicular tissue could become an established procedure. The option of carrying out more of a horizon scanning function was also noted.

11. Review of the Fertility Services Standard

- 11.1 Members noted the status of the review.

12. Member reports on papers / research

- 12.1 Karen Reader reported on her attendance at the conference of the Australasian Fertility Society (see the opening comments).

13. Minutes from and report on ECART's meeting of 4 July 2019

- 13.1 Several factors in the cases considered were of interest, in particular (i) advanced paternal age, (ii) intergeneration effects and (iii) whangai arrangements. Members noted these matters are often not simple. It is important that the parties involved have a good understanding of any risks.

14. Correspondence and Enquiries

- 15.1 Members noted the correspondence which included a copy of ACART's final advice to the Minister about the proposed changes to the donation and surrogacy guidelines.

15. Governance — Chair's Report

- 15.1 Members noted the report.

16. Secretariat report to ACART

16.1 Members noted the report.

17. ACART members at upcoming ECART meetings

17.1 Calum will attend the ECART meeting in Wellington on 7 November.

Action

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

18. Conclusion of meeting and next meeting dates

18.1 The upcoming meetings are as follows.

- Friday, 13 December 2019. Wellington.
- Thursday, 13 February 2020. Wellington.
- Thursday, 2 April 2020. Wellington.

Actions

- *Members to liaise with Moana for travel arrangements.*
- *Advise members the start and end times and location when arranging travel.*

18.2 The meeting closed at 2.30 pm.