

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

Held on 15 October 2020, at The Brentwood Hotel, Kilbirnie, Wellington.

Present

Colin Gavaghan (Acting Chair)
Calum Barrett
Rosemary de Luca
Seth Fraser
Karen Reader
Catherine Ryan
Karaitiana Taiuru
Analosa Veukiso-Ulugia
Sarah Wakeman

Non-members present

Mania Maniapoto-Ngaia, ECART Member
Nic Aagaard, Acting Manager Ethics, Ministry of Health
Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat
Tristan Katz, ACART Secretariat
Joel Tyrie, ACART Secretariat

1. Welcome

1.1 The Acting Chair opened the meeting at 9.00am and welcomed the new Committee members appointed to ACART on 6 August 2020.

1.2 On this occasion, the ECART member in attendance was Mania Maniapoto-Ngaia.

2. Apologies

2.1 Kathleen Logan; Judge Andrew Becroft (Children's Commissioner).

3. Approval of the agenda

3.1 Members approved the agenda.

Action:

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

4. Declarations of Interests

4.1 No conflicts of interest were declared at this meeting.

5. Minutes of ACART's meeting of August 2020

5.1 The minutes were approved.

Action:

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

6. Actions arising from ACART's August meeting

6.1 Members noted the status of the actions from the August meeting, including those actions that were carried over to this meeting.

6.2 Members noted that public consultation for the new standards for fertility services is likely to begin this month.

6.4 Members were updated on the status of the consultation document on the use of cryopreserved testicular tissue. The secretariat advised members that they are finalising information from other Countries about if and how they regulate the use of the material. The consultation document will then be edited and formatted before public consultation begins.

6.5 Members were updated on the status of the collection of ethnicity data from fertility services in New Zealand.

7. New Members induction

7.1 The Acting Chair presented on the relevant legislation for assisted reproductive technologies and procedures in New Zealand and how they are interrelated. The principles of the HART Act were discussed, in addition to ACART's ethical framework and the history and context of that framework. ACART's current and future work programme, and the need for more meaningful consultation with Maori was discussed with new and existing members.

7.2 The Acting Chair explained prohibited activities, regulated activities and established procedures and that the term "assisted reproductive procedure" is used in two different ways in the HART Act. On some occasions, the different uses of the term

have created uncertainty.

- 7.3 The Secretariat briefly summarised the supplementary information that was sent to the fertility clinics and ECART when the new guidelines for donations and surrogacy were published. The information includes and explanation of how a party might be deemed to have an “interest in an embryo” depending on:

- a combination of having a genetic link
- having had the embryo created for one’s own use
- and whether a full genetic sibling, to a child in another family, would be born in the family now intending to have a child.

Actions:

- *ACART to discuss methods for future consultations and Secretariat to add information on the ACART website describing the standard consultation process followed.*
- *Secretariat to add the investigation of demographic information of ART consumers to ACART’s work programme.*

8. Work programme status

- 8.1 Members noted the status of items on the work programme, including the following.

- The donation and surrogacy guidelines have been completed, sent to the Associate Minister with advice, and published.
- The stage two guidelines on the posthumous use of sperm have been consulted on, and the submissions are being collated.
- The Human Reproductive Research guidelines are in need of review, which is pending agreement from the Associate Minister.
- The use of Cryopreserved Testicular Tissue will be reviewed to determine whether it should become an established procedure. Information on international regulation of the use of CTT is currently being investigated, following which the public will be consulted.
- The 2017 ANZARD report is being requested, and the Secretariat will discuss with the UNSW how to include ethnicity data in future reports.
- Approval of the changes to the use of cryopreserved ovarian tissue is with the Minister.

- 8.2 Possible future work was also discussed, including exploring options to improve consultation processes with existing resources, a possible review of the HART Act, the regulation of surrogacy in New Zealand, the adoption of a Code of Practice, providing advice to the Minister regarding emerging technologies and writing an overview of the regulatory setting.

9. 2021 meeting dates

- 9.1 Members agreed meeting dates for the first half of 2021, including:

- 18 February
- 15 April

- 10 June.
- 9.2 Members proposed that some future meetings be used as working groups; and requested these should occur in person.
- 9.3 Members proposed that some online-only meetings should take place on Fridays to account for members' teaching commitments.
- 10. Member reports on papers/research**
- 10.1 Members noted the report, including that no conferences were attended recently.
- 10.2 The Secretariat noted recent papers circulated on gene editing and mitochondrial replacement therapy.
- 10.3 Members proposed that a database of relevant ART literature be built for future use by ACART.
- 10.4 The Secretariat noted recent correspondence with ECART included communications from individuals who would usually receive fertility treatments overseas but are currently unable to travel due to the COVID-19 pandemic.
- 11. Report on ECART's June meeting**
- 11.1 Members noted the report.
- 12. Draft Annual Report for 2019/20**
- 12.1 Members noted the draft reported, including that that some member profiles were outdated. Members suggested some additions to the definition of "standard consultation process".

Actions:

- *Members to send the Secretariat their updated bios to amend the report and the ACART website.*
- *Secretariat to send circulate the draft Annual Report for members to suggest any changes.*

Projects

- 13. Submissions for the consultation on guidelines for posthumous reproductions, and next steps**
- 13.1 Members discussed the history and context of the consultation process for the benefit of new members, and noted that the stage two consultation period ended on 30 September 2020. The Secretariat advised members that a first draft of the submissions analysis had been undertaken and gave members a verbal update of main themes and policy proposals to revise.
- 13.2 The Secretariat advised new members that the stage two consultation was published on 15 July 2020, as a follow-up from a previous consultation on whether posthumous reproduction was ever ethically acceptable.
- 13.3 The Secretariat noted that a small number of submissions were still expected, however the high-level themes and submissions of note are as follows.
- Many thought that not all cases of posthumous use should require ECART

approval.

- If wishes of the deceased are written in a legal document, they should be upheld.
- The acceptable types of consent should be flexible, and not solely written.
- Opinions were divided on whether a deceased person under the age of 16 should be protected from having their gametes collected.
- Some cultural issues were raised, particularly the tension between individual versus collective rights in relation to continuation of an individual's genealogy.
- It was also suggested that there might not be a legal mechanism in the HART Act for ECART to approve the posthumous retrieval of gametes.

13.4 Members agreed to continue with the proposal that there should not necessarily be a mandatory stand-down period for the posthumous use of gametes for the reason that grief is not linear and the allowance for more flexibility should be upheld.

13.5 Members suggested that the secretariat prepare for consideration at the December meeting:

- consent requirements should be well defined and signalled to discuss what kinds of consents would be acceptable for posthumous retrieval and use
- tikanga regarding deceased persons should be considered further
- considerations for the dignity of deceased persons regarding retrieval should be added to the guidelines
- consent form in which someone can name who has permission to use their material should be developed, and considerations of free and informed consent and specifying conditions for use of materials should be made
- it should be decided whether ECART are able to authorise posthumous retrieval
- further discussion about which scenarios should be reviewed by ECART is required.

Actions

- *Secretariat to complete the summary of submissions for members to approve for publishing in December.*
- *Secretariat to seek agreement to a working group meeting in early December to refine policy proposals for the next iteration of the draft guidelines for all members to consider at the December meeting.*

14. Review the guidelines for extending the storage of gametes and embryos: confirm/approve the consultation document

14.1 Members discussed the history and context of this work for the benefit of new members, including the issues with the current guidelines and potential storage scenarios.

- 14.2 Members discussed whether donors should be asked to consent to the extension of storage for scenarios they had previously consented to. There was a discussion about whether the extension was being sought for donated gametes, or embryos made from donated gametes, or donated embryos. The Secretariat suggested setting the scenarios out in a clear, simple table, to assist newer members to analyse the relevant matters.
- 14.3 Members raised the need for a distinction in documents between the Treaty of Waitangi and Te Tiriti o Waitangi, noting that the documents are not congruent.

Actions:

- *Secretariat to remove the wording “gamete donors be asked to change their mind” — as this in fact refers to situations to which they have not turned their minds to.*
- *Members to review the document and provide further comments before the next meeting.*
- *Secretariat to consider writing questions about the different policy options in the consultation document.*
- *Secretariat to discuss the wording of the consultation document with the concerned Members between meetings.*

Standing items

15. Correspondence and enquiries: for noting

- 15.1 Members noted feedback from the sector regarding the large volume of ECART applications and queried the time between meetings to have the minutes approved.

Action:

- *Secretariat to pass this feedback on to ECART.*

16.a Chair's report

- 16.a.1 The Acting Chair reported on behalf of the Chair, on meetings they attended including ACART's August meeting, the pre-meet for the present meeting, meetings regarding ACART consultations, the implementation of ACART's new guidelines, and the new application forms being developed by ECART.
- 16.a.2 The Acting Chair reported that Police will be consulting with regards to their vetting practices as part of their review of the legislation for those practices.
- 16.a.3 The Acting Chair reported on the Chair's attendance of the Genetic Editing Advisory Group in February.
- 16.a.4 The Acting Chair noted the ongoing response to the COVID-19 pandemic and any updates to advice from the Ministry of Health.
- 16.a.5 The Acting Chair noted the work underway to confirm the membership of the ACART member with legal expertise and the member who works in the fertility sector.
- 16.a.6 The Acting Chair reported that the Chair had met with the Manager of Ethics at the Ministry of Health.

16.a.7 The Acting Chair reported on the emails and correspondence in regards to the publication of ACART's new guidelines for donations and surrogacy.

17. Secretariat report

17.1 Members noted the Secretariat report and thanked the Secretariat for the large volume of work undertaken between meetings.

18. Work between meetings

18.1 Members asked for the budget for a working group meeting to consider the feedback on posthumous reproduction to refine proposals to take to the full committee in the December meeting.

19. Attendance at ECART meetings

19.1 Karen Reader confirmed that she will attend the ECART meeting on 29 October 2020.

19.2 Calum Barrett confirmed that he will attend the ECART meeting on 17 December 2020.

The meeting closed at 3:00pm.