Minutes of the ninety-fourth meeting of the Advisory Committee on Assisted Reproductive Technology

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Held on 10 December 2021, online.

Present

Calum Barrett (Acting Chair)

Kathleen Logan (Deputy Chair)

Rosemary De Luca

Seth Fraser

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Analosa Veukiso-Ulugia

Sarah Wakeman

Non-members present

Zoe Benge, ACART Secretariat

Martin Kennedy, ACART Secretariat

Mirae Wilson, ACART Secretariat

Paul Copland, ECART

Sadie Miles, Ethics team, Ministry of Health (Observer)

Robyn Minns, Ethics team, Ministry of Health (Observer)

1. Welcome

1.1 The Acting Chair opened the meeting at 9.00 am and gave the opening comments.

1.2 The Acting Chair noted that the opening comments item at the start of each meeting had dropped off the agenda over the last few months and that it would be good to re-establish it as a standard item.

1.3 He commented on the rise in surrogacy in numerous nations and noted that New Zealand's Law Commission is reviewing surrogacy in New Zealand. There was a discussion about the causes of increasing surrogacy and whether it could be due to more surrogates becoming available, or more demand for surrogates, or both.

2. Apologies

2.1 Nil.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of October 2021

5.1 Members approved the minutes subject to minor changes.

Action

- *Secretariat to amend and publish the October minutes.*

6. Actions arising from ACART's October meeting

6.1 Members noted the status of the actions from the October meeting.

7. Status of ACART's work programme

7.1 Members noted the report.

7.2 Members agreed the table should be split into three sections, the first being work currently underway, the second being 'business as usual' items, and the third being historical items that are presented simply for members' information.

7.3 A member commented about the drafting process for documents ACART is currently working on and suggested that the drafting process is reviewed and streamlined.

7.4 Members asked for an update on the supply of New Zealand data to the International Federation of Fertility Societies (IFFS).

Actions

- *Secretariat to split the document into three sections.*
- *Secretariat and ACART to review and streamline the drafting process.*
- *Secretariat to check the status of reporting to the IFFS and advise members of that status.*

8. Correspondence

8.1 The Acting Chair noted the two letters in the agenda pack, being (a) a letter of thanks from Associate Minister Henare to Dr Logan and (b) from ACART to Minister Little about governance options.

8.2 The Acting Chair updated members on the status of two matters that the ACART and ECART Chairs had discussed. The Chair of ECART had asked the Chair of ACART about if and when gamete donors might be able to change their consent once embryos had been formed from their gametes. The Acting Chair advised members that he had discussed the matter with the Chair of ECART and a letter was no longer needed as the matter had been resolved.

8.3 ECART's second query had been about the importance of offspring having a genetic link to intending parents. Members discussed the matter and agreed to write a formal statement about the genetic link, discuss it with stakeholders, then publish it on ACART's website as supplementary advice to the donation and surrogacy guidelines.

Actions

- *Secretariat to draft the statement about the importance of a genetic link.*
- *Members to consider at the full meeting in March 2022.*
- *ACART to consult stakeholders.*
- *ACART to publish the statement.*

9. Report on ECART's recent meeting

9.1 Members noted the report.

9.2 Members noted several cases in which stored gametes/embryos had been granted temporary extensions of storage. The Secretariat has the authority to make these temporary extensions while the patients and clinics address the storage.

9.3 Members noted that ACART will soon consult on the Guidelines for Extending the Storage Period of Gametes and Embryos and that the consultation will be an opportunity to address a range of questions associated with the storage of gametes and embryos.

10.A. Review ACART's ethical statement about human embryos

10.1 Members discussed the purpose of the statement and if and how it could be incorporated into ACART's consultation document about the Guidelines for Human

Reproductive Research.

10.2 A member of the working group said that the editing of the ethical statement, since the working group had drafted it, had changed the meaning. The Acting Chair acknowledged this and agreed the statement should be as the working group had drafted it.

10.3 Members noted that the working group had two tasks which needed to be kept distinct from one another. The first task was to draft an ethical statement about the status of the embryo. The second task was to update the current Ethical Framework document to better incorporate obligations under Te Tiriti o Waitangi.

10.4 Members agreed to continue to draft a statement about the status of the embryo and to consult on that statement. The final document would be published on ACART's website. The statement could also be included in the revised Ethical Framework when that document is revised.

10.5 The discussion returned to incorporating the statement about embryos into ACART's consultation document about the guidelines for human reproductive research. Members agreed the statement should be written in full first, then the relevant parts of it incorporated into the corresponding sections of the consultation document. A link to, or copy of, the full statement should be included in the consultation document.

10.6 The working group who write the statement will need a clear brief about exactly what they are being asked to produce. Members of the working group agreed they could continue the work on the statement between ACART's full meetings.

Actions

- *Secretariat to return the statement about the status of the embryo to its original draft form.*
- *Secretariat to draft a clear brief about exactly what the working group is being asked to produce.*
- *Working group to continue work on the statement of the status of the embryo.*
- *Secretariat to incorporate narrative from the statement, about the status of the embryo, into the consultation document for the guidelines for human reproductive research (once the statement is available).*

10.B. Review ACART's Ethical Framework

10.7 Members noted that the Ethical Framework contains material that is essentially context about ACART's role and not actually part of the framework that ACART applies when assessing policy matters. The Framework could be amended to clarify what is context and what is part of the analytical framework.

10.8 Members agreed to undertake the following, once the work on the Ethical Statement about Human Embryos had been completed:

- add commentary about Te Tiriti o Waitangi and te ao Māori
- elaborate on 'principle g' of the HART Act, which is to take into account the different ethical, spiritual, and cultural perspectives in New Zealand. The Minister for Ethnic Communities could be invited to speak to ACART

- change the title of the document, as the document is not an ethical framework
- consider how the framework accommodates risk assessment.

Actions

- *Working group to revise the analytical framework.*
- *Draft a letter to the Ministry for Ethnic Communities.*

11. Cryopreserved testicular tissue

11.1 The Committee discussed the draft CSTT paper and it was agreed that tracked changes versions of the document could be sent to the Secretariat for review outside of the meeting.

11.2 It was noted that the current definition of the proposed EP, “cryopreservation of spermatozoa including testicular tissue (CSTT) and associated cell preparations used to collect sperm” is overly complicated. It was suggested that the EP should be referred to as “cryopreservation of spermatozoa including testicular tissue”.

11.3 It was agreed that CSTT should be listed under sperm cryopreservation. The use of CSTT would then be covered under the current wording (“collection and preparation of sperm”) in the ISCI and IVF sections of the Order.

11.4 It was agreed that the specific amended wording for the HART Order does not need to be provided in the advice to the Minister. Rather, this would be decided later in collaboration with the Parliamentary Counsel Office.

11.5 It was agreed that transplantation should not be mentioned in the advice as an exclusion or prohibition. Rather, it should merely state that transplantation is an experimental procedure and not regulated for at the moment. As the use of CTT will be covered under ICSI and IVF, transplantation would not be included as a use, allowing tissue to be frozen from pre-pubertal boys, but not transplanted.

Actions

- *Members to send annotated copies of the draft advice to the Secretariat.*
- *Secretariat to revise the draft advice based on the annotations and discussion noted above.*

12. Supplementary advice to the Guidelines for Posthumous Reproduction

12.1 The discussion began with some members observing that some specific points in the advice to the Minister need amendments. Members also agreed that the advice to the Minister needs to state the importance of changing the HART Order as soon as possible so that the regulatory changes can take effect.

12.2 A member noted that the supplementary advice needs a clear statement, early on, distinguishing between established procedures and assisted reproductive procedures. In particular, the term ‘assisted reproductive procedures’ is used in the HART Act, HART Order, and guidelines to mean some particular activities and the term also has its general use, being a phrase for a wide range of activities in fertility treatment.

Actions

In the supplementary advice

- *Secretariat to amend the "key words" to explain how the terms established procedure and assisted reproductive procedure are used.*
- *Secretariat to amend some specific sentences.*
- *Members to consider the next version between ACART's full meetings.*

In the advice to the Minister

- *Secretariat to add narrative about the importance of amending the HART Order as soon as possible.*

13. Consultation document for the review of the Guidelines for Extending the Storage Period of Gametes and Embryos

13.1 The objective for this meeting was to agree on the questions that are asked in the consultation document and the related content.

13.2 The Acting Chair provided a brief history about the project and noted that it aims to bring the Guidelines for Extending the Storage Period of Gametes and Embryos into alignment with ACART's other policy positions. It was noted that ECART had also asked ACART to broaden its scope of consultation.

13.3 Members agreed to the questions and content in Part I of the document.

13.4 The majority of the discussion covered Part II of the document. Members noted that Part II provides an opportunity for ACART to ask broader questions about storage of gametes and embryos. While the outcomes of those questions might not be actioned immediately, they will be useful for ACART to understand.

13.5 A member highlighted that the extended storage period is currently required by law. It is important that ACART makes the application process simple, rather than create unnecessary barriers.

13.6 Members discussed the issue that there is no grace period for those who make an application after the 10-year period. This issue relates to the question about whether there should be a time limit for storage and/or storage extensions. Under this section, members agreed to include a discussion point for the possible scenario that people under 20-years-old could automatically have a 20-year storage period, and those over 20-years-old would have 10 years.

13.7 The Acting Chair requested inclusion of a question about whether fertility clinics should be required to have a 10-year time limit for storage and manage the storage periods themselves. Patients could apply directly to clinics for extension and clinics would have a list of criteria under the HART Act to consider. Members agreed to include this as a separate question in the document.

13.8 The ECART member in attendance noted that the matters that ECART considers when extending storage are reasons to **use** the gametes/embryos, not reasons to **store** them. There is an issue in terms of identifying the harms that ECART is trying to prevent when considering applications, plus the issues of age and quality of

material.

13.9 Members agreed to replace the question about intergenerational effects with a broader question, asking the circumstances in which ECART should not approve an application for storage extension. This section will detail the possible harms, including intergenerational effects and age. The issue of age discrimination will also be addressed. Members also agreed to include discussion about how the 10-year limit does mean that people who, for example, have embryos remaining from treatment do actually use or dispose of them. The law helps people to make decisions and prevent indefinite storage periods. The Acting Chair also requested reference to section 10D(2)(c) of the HART Act. This section provides grounds for ECART to remove/cancel approval.

13.10 Members agreed to retain the separate question about whether ECART should be able to extend storage of materials intended for future unspecified research. A member noted that ACART's guidelines overlap with each other. Noting ACART's current review of the Guidelines for Human Reproductive Research, if people donate material to research, the Guidelines for Extending Storage need to be clear about who is in charge of the materials donated to research.

13.11 A member asked how broad the consultation will be. The Secretariat advised that this will be a broad consultation, not limited to clinical stakeholders. ACART's usual list of stakeholders will be contacted. The Secretariat noted that the list is being extended to include suggestions from ACART's member with expertise in Māori interests. There will be a project to work on building ACART's relationship with the various Māori groups. Further detail will be provided at ACART's next meeting.

13.12 Members noted that the consultation document will be finalised for ACART's next meeting in March 2022. The Secretariat will also provide the consultation plan for discussion with the aim that public consultation will begin in March.

Actions

- *Secretariat to make final changes and additions to the consultation document.*
- *Secretariat to finalise the consultation document for the March 2022 meeting.*
- *Secretariat to provide the consultation plan for the March 2022 meeting.*

14. Consultation document for the review of the Guidelines for Human Reproductive Research

14.1 The Acting Chair opened this item by acknowledging the comments by some members that the document is long. He suggested that, rather than removing material, the document could be split into two main sections, the first being the context and the second being the proposals. There was general agreement to this proposal. Members also suggested that the web version of the document should include hyperlinks so that readers could quickly and easily move to other sections if interested in knowing more about a particular matter.

14.2 There was discussion about the consultation process, the need for adequate budget, and the work being done to improve ACART's engagement with Māori.

14.3 A member commented on the section that explains how sperm, eggs and embryos

are collected and/or created and/or stored. She observed that this section could be briefer.

14.4 Members discussed whether the consultation document should include narrative about the standard requirements of research applications. Members agreed that a short section could briefly state that any applications would need to comply with standard application processes. That is, applications would need to state the purpose of the research, the processes that would be used, the expected findings and anticipated benefits, how consent would be obtained, and who would be involved.

14.5 Several additional pieces of information were agreed for adding to the document, including narrative about the recently revised guidelines from the International Society for Stem Cell Research, New Zealand's Therapeutic Products Bill, and the different consent processes that would be needed for clinical and non-clinical research.

Actions

- *Secretariat to amend the consultation document for the March 2022 meeting.*
- *Secretariat to add narrative elaborating on 'principle g' of the HART Act, which is to take into account the different ethical, spiritual, and cultural perspectives in New Zealand.*
- *Members to send specific changes for items they have identified as needing changes.*
- *Secretariat to amend specific items as requested.*

15. Chair's report

15.1 Members noted the report.

16. Members' reports

16.1 No items this meeting.

17. Secretariat report

17.1 Members noted the report.

17.2 The Secretariat noted that there had recently been a conference of the Australasian Association of Bioethics and Health Law but that no members of ACART had attended.

17.3 The Secretariat explained that the Ministry of Health has started organising a training day for new members of ACART and ECART. The day is likely to be 14 February 2022, in person in Wellington. Members will be contacted about attending and, in some cases, speaking.

18. Work between meetings

18.1 Discussed with each project/policy item, above.

19. Update on appointments

19.1 The Secretariat updated members on appointments, advising them that the recommendations had been sent to Minister Henare and would be presented to Cabinet (APH) in due course.

20. Attendance at ECART

20.1 A member asked the Secretariat to circulate the dates of the upcoming ECART meetings.

Action

- *Obtain and circulate the dates of the ECART meetings for 2022.*

The meeting closed at 3:30 pm.