Minutes of the Seventy Seventh Meeting of the Advisory Committee on Assisted Reproductive Technology

---

Held on 15 February 2019, at the Front and Centre, Wellington.

Present

Kathleen Logan (Acting Chair)

Colin Gavaghan (by video-conference) (Deputy Chair)

Jonathan Darby

Sue McKenzie

John McMillan

Karen Reader

Sarah Wakeman

Analosa Veukiso-Ulugia

Non-members present

Tristan Katz, ACART Secretariat

Martin Kennedy, ACART Secretariat

Hayley Robertson, ACART Secretariat

1. Welcome

1.1 The Chair welcomed the Committee members and welcomed Analosa (ACART's new general lay member who also has Pacific perspectives) to her first Committee meeting.

1.a Opening discussion — requirements for consultation processes

1.2 Colin opened the meeting with a discussion about some of the requirements to consult, and noted the Committee's legal requirements in carrying out public consultation. He noted some applicable principles: that a consultation must allow sufficient time, the public must be adequately informed to consider the consultation, and that a consultations purpose is "not to tell or present, or agree", but rather seek the public's feedback. The Committee noted the tension between being comprehensive and accurate, versus making the material in a consultation clear enough for a lay person to understand.

1.3 ACART was interested to hear that in previous case law, a court found that all viewpoints on a consultation must be weighted equally, and it is not for Committees to make special allowances for people who have more interest in the outcome.

1.4 Members discussed what it means to have views represented in a consultation. They agreed that while ACART's consultations usually won't be representative of the whole population the submissions will provide a "saturation" of ideas, ie: when many of the same comments are heard ACART will know it has identified all of the relevant factors. Members agreed that sometimes this can be achieved in consultations with a small amount of responses but that care must be taken when drawing conclusions from small samples.

1.5 Colin advised that he will be giving this topic some more thought and will report back on ideas about the following.

- How can we publicise the consultation properly and ensure we fulfil our role properly?
- What weight should we give to results?
- What can ACART do better?

1.6 The next opening comments for April will be heard from Sue McKenzie.

2. Apologies

2.1 Barry Smith.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No declarations.

5. Minutes of ACART's meeting of 14 December 2018

5.1 The minutes were approved.

Action

- *Secretariat to place the December 2018 minutes on ACART's website.*

6. Actions arising from the previous minutes

6.1 Members noted the status of actions.

7. Work programme

7.1 Members noted the status of the programme and discussed the following items:

Cryopreserved ovarian tissue

7.2 The Secretariat advised those present that Minister Clark has been advised about this matter and that he intends to approach his colleagues about it.

Cryopreserved testicular tissue

7.3 The Secretariat advised those present that they have written to Health Legal on ACART's behalf to seek clarification about the status of the use of cryopreserved testicular tissue.

Action

- *Secretariat to work with Sarah Wakeman to clarify the scope of ACART's original enquiry.*

ACART Annual Report

7.4 ACART's 2017/18 Annual Report is completed and due to be tabled in the House. The 2018/19 report is being drafted.

Action

- *Secretariat to follow up with the Minister's office to get this tabled.*

ANZARD report for 2016

7.5 The ANZARD report for the 2015 calendar year was published online on 6 December 2018. The Secretariat has made contact with the University of New South Wales to contract the next one.

ACART's monitoring function

7.6 Members had a discussion about their monitoring function and noted they were concerned to be told that the budget did not allow for a member of ACART to travel to attend ECART's February meeting.

8. Membership updates

8.1 Due diligence interviews for the consumer position have been undertaken and a paper will be prepared by the Ministry of Health to send to the Minister with ACART and the Ministry's preferred candidates.

Action

- *Secretariat to email the Ministry on behalf of ACART that they would like to see a system of notifying candidates who were not successful.*
- *Secretariat to check with the Health Legal team about which of ACART's members have statutory roles and report back to the committee.*

9. Posthumous reproduction

High level principles of the Act must be adhered to

9.1 The Committee started by acknowledging the principles from the HART Act that should be taken into consideration when reviewing the guidelines on Posthumous Reproduction. These are:

- The health and wellbeing of any children created is an important consideration. Posthumous reproduction necessarily involves creating a child who has a deceased parent. Whether or not that is a risk to the wellbeing of any child created seems likely to depend upon a complex set of facts surrounding the family environment. The level of support is relevant to the wellbeing of any child created.
- The health and wellbeing of women.
- Informed choice and consent: if the deceased was given the opportunity to consent to the use of their gametes following their death but did not choose to consent to this, it is reasonable to presume that this is inconsistent with the priority the HART Act gives to consent (see s4(d)) i.e. that no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent.
- Openness about the origins for the use of all donated gametes: in the case of using gametes or embryos of deceased persons, openness becomes even more critical for protecting the health and wellbeing of any children created.

9.2 Members noted the summary of submissions and discussed the working group's discussion and recommendations from their meeting on 17 December 2018.

9.3 The Secretariat has collated all of the submissions received and confirmed with submitters if their submissions may be published online. Members agreed that the raw submissions can be published online.

9.4 Submissions from the consultation with young people will not be published online. Names and emails have been redacted and submissions are stored on ACART's secure filing system for future reference. A summary of these submissions will be published online.

9.5 Members agreed that the decisions made in this meeting would form the initial policy positions for the draft guidelines for posthumous reproduction. The Secretariat will begin drafting guidelines before the April ACART meeting. Once the draft guidelines have been finalised by the Committee, these will also go through public consultation. The following paragraphs set out the Committee's agreed positions.

9.6 Members noted that posthumous retrieval with a person's prior written consent was a high bar, and agreed that posthumous retrieval without written consent is ethically acceptable in some circumstances (for example, where there is evidence of oral consent) Members directed the Secretariat to investigate what changes to the law would be needed to allow retrieval without consent.

9.7 A clear pathway for use is essential if there is a pathway for retrieval, and there are benefits in providing different provisions in clearly separate stages for retrieval and use.

9.8 Members agreed to not extend policy to permit retrieval from those who are comatose or permanently lack the capacity to consent, on the grounds that it is considered too legally problematic. In practice, if a person's death is imminent and the presiding clinician knows that gametes or tissues are to be recovered he or she could do so shortly after the person dies (in the event that ACART agrees that such a procedure should be allowed).

9.9 Members agreed that the best decision-making body for applications of posthumous reproduction is ECART. Members also discussed whether all cases of posthumous reproduction should have ethical approval from ECART, discussing whether cases where it is the partner who will be using the gametes, or where there was prior written consent could be exempt from needing ECART approval.

9.10 Members agreed that minors should be protected from having their gametes retrieved posthumously and that this should be specifically written into any revised guidelines.

9.11 It was also agreed that where a minor stores gametes for their own fertility preservation, the gametes/tissue should be disposed of in the event of their death unless they have re-consented when they are mature to storage and any specific use. Members noted that the law is not consistent in New Zealand about the age of minors' rights and the Secretariat will do further work on this. It was also agreed that processes for informed consent for retrieval from minors should be strengthened.

9.12 Members agreed that material retrieved and used posthumously should only be able to be used by the partner of the deceased. There was a discussion about what is meant by 'partner' and an agreement to use the de facto definition. Members also agreed that only one's partner can authorise retrieval.

9.13 Members agreed that the present difference between the posthumous retrieval and use of sperm, eggs and embryos should be made consistent in law. Guidelines around the collection of eggs and sperm should be the same. Guidelines around the use of eggs and sperm should be the same, while recognising there would need to be a surrogate or new female partner (and therefore ECART approval) for the use of eggs.

Actions

- *Secretariat to organise editing and formatting to publish the redacted raw submissions and the summary of submissions from the stage one consultation online on ACART's web page.*
- *Secretariat to investigate what changes to the law would be needed to allow retrieval without consent.*
- *Secretariat to begin drafting guidelines for the April meeting.*

10. Review of the donation guidelines: discuss the draft interim guidelines and note the second consultation

10.1 The Secretariat asked members to consider the draft guidelines and request changes as needed. These guidelines will be published in the near future while the 'final' guidelines will be released once the Minister has been advised about the need to amend the HART Order and Cabinet has agreed to do so. The process for the final guidelines could take two years. Also, members agreed to discuss whether re-donation

and on-donation could be included in the guidelines without first needing to have the HART Order amended.

10.2 The Secretariat also advised members that ACART's consultation document for the second round of consultation had been published on 14 February 2019 and that stakeholders had been informed.

Family gamete donations

10.3 Members noted that, in the final guidelines (i.e. once the HART Order has been amended), the list of prohibited family gamete donations would be extended. Members agreed that, for the guidelines that will be published in the near future, the existing list of prohibited family gamete donations will be used.

Action

- *Secretariat to amend the provisions for family gamete donations.*

Re-donation and on-donation

10.4 Members discussed the provisions for re-donation and on-donation and decided the provisions could be included in the guidelines that will be published in the near future. In practice, clinics will typically send all embryo donation cases to ECART as it is important for such cases to have a high level of ethical consideration. Members requested several minor changes to this section and asked for definitions to be added to the provisions for embryo donation and use.

Action

- *Secretariat to amend the provisions for re-donation and on-donation and add definitions.*

10.5 There was a discussion about the way in which embryo donation is provided for in the HART Act and Order and how gamete donation is taken into account in cases of embryo donation. Members agreed they can issue the guidelines as proposed but also agreed to ask colleagues about other interpretations of the HART Act and what constitutes a procedure that must be subject to guidelines. The Deputy Chair offered to talk to his colleagues about this matter. Related to this matter, the Deputy Chair suggested that Nicola Peart, at Otago University, could be invited to the ACART meeting in April to discuss the HART Act and Order and where improvements could be made.

Action

- *Deputy Chair to invite Nicola Peart to ACART's April meeting.*

Surrogacy

10.6 Members noted that the provisions for surrogacy are suitable and need to be different to the provisions for embryo donation because surrogates gestate children that they do not intend to keep and that, in many cases, they use their own eggs. Members asked for a) a minor change to the wording of one of the surrogacy provisions and b) to add a note suggested by the Chair but to remove the words "non-binding" from that note.

Action

- *Secretariat to amend the provisions for surrogacy.*

Consent

10.7 On discussing the consent provisions members asked for minor format changes and asked that definitions be added for a) recipient, b) donor and c) original intending parent. These definitions should be preceded by the phrase "for the purpose of these guidelines."

Action

- *Secretariat to add definitions (same as for re-donation and on-donation).*

10.8 There was a discussion about the circumstances under which gamete donors need to have their consent updated in the event that people who have gametes and embryos stored wish to extend that storage. Members agreed to investigate this matter further and to revisit ACART's earlier investigation of how the provisions in the HART Act for extending storage might be amended or removed. The Secretariat will investigate and report back to the committee.

Action

- *Secretariat to summarise the work to date on the provisions in the HART Act for extending storage and report back to the committee.*

Confirm the guidelines and advise the Minister

10.9 Members agreed that the Secretariat should make the changes to the guidelines discussed today and write a briefing to Minister Clark explaining why the guidelines were being released, how they had been developed and what the next steps in the project would be. The working group would consider the guidelines and draft briefing and seek comments from ECART and Health Legal on the guidelines.

Actions

- *Secretariat to finalise the guidelines and send to the working group.*
- *Once agreed by the working group the Secretariat is to send the guidelines to Health Legal and ECART for opinions.*
- *Secretariat to write the briefing to Minister Clark explaining the guidelines.*

11. Members' reports on research

11.1 No items were reported.

12. Report on ECART's December meeting

12.1 Members noted the report.

12.2 Three applications were declined and three applications were deferred:

- one application for surrogacy was declined under principle (a) of the HART Act that the health and wellbeing of resulting children is an important consideration.

- one application for the creation of embryos from donated eggs and donated sperm was declined under section 3(a)(ii) of the Guidelines on the Creation of embryos, for reproductive purposes, from donated eggs in conjunction with donated sperm.
- one application for the creation of embryos from donated eggs and donated sperm was declined as the Committee was unable to reach a consensus.

12.a Role of ECART attendee

12.a.1 Members noted the importance of abiding by the agreed roles of the members of ACART and ECART when they attend one another's committee meetings. If the visiting member wishes to speak about a particular policy he or she should have approval from the presiding chair. Having approval from the chair minimises the risk of undue influence from the other committee.

12.a.2 It was also noted that where a visiting member is requested to speak to a topic or answer a question, the chair should have advised them in advance, giving adequate time for them to have consulted their committee members.

13. Correspondence and Enquiries

13.1 Members noted the correspondence, which was a query about children born via home insemination and noted that these inseminations are not subject to regulations.

14. Governance — Chair's Report

14.1 Members noted the report.

15. Secretariat report to ACART

15.1 Members noted the report.

Extra item 1

- Judge Andrew Becroft, Children's Commissioner, joined the meeting at 12 noon and commented on the importance of the work ACART does to ensure the wellbeing of children is taken into account when ART policy is developed.

Extra item 2

- The Director-General of Health, Dr Ashley Bloomfield, was scheduled to attend but had to reschedule and now plans to meet ACART in June.

16. ACART members in attendance at upcoming ECART meetings

16.1 Approval for funds for an ACART member to travel to attend ECART's next meeting, on 28 February 2019, had been declined by the Ministry. A member of the Secretariat is attending (as an observer only) and will report back to ACART. Attendees for the upcoming ECART meetings are to be confirmed.

Action

- *Secretariat contact all members asking for volunteers to attend the upcoming ECART meetings.*

17. Conclusion of meeting

17.1 The next ACART meeting is scheduled for Friday, 12 April 2019 in Dunedin. Members should contact Moana for travel arrangements.

Actions

- *Members liaise with Moana for travel arrangements.*
- *Advise members the start and end times and location when arranging travel.*
- *Secretariat to invite Nicola Peart to the next meeting in Dunedin and work with Colin to put together some questions for Nicola.*

17.2 The meeting closed at 3.15pm.