



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

Held on 14 December 2018, at the Sudima Hotel, Christchurch.

Present

Kathleen Logan (Acting Chair)
Colin Gavaghan (by video-conference)(Deputy Chair)
Jonathan Darby
Sue McKenzie
John McMillan
Karen Reader
Barry Smith
Sarah Wakeman

Non-members present

Mary Birdsall, ECART
Martin Kennedy, ACART Secretariat

Welcome

- 1.1 The Chair welcomed the Committee members and Mary Birdsall from ECART.

Opening discussion — interim donation and surrogacy guidelines

- 1.2 Those present discussed whether ACART should publish interim guidelines for donations and surrogacy. In earlier meetings members had agreed not to do so as the committee would need to commit a not insignificant amount of time to produce them and they would be applicable to very few fertility treatment cases.
- 1.3 Members reconsidered this position in light of learning that ECART has recently had applications that could have been considered, and potentially approved, if the amended guidelines were in place.
- 1.4 Members agreed that, although it would be extra work to publish interim guidelines, it would be worth publishing them to enable ECART to consider more cases. They also noted that it would be useful to publish interim guidelines as there could be a significant delay before the fully amended guidelines would be available. Such a delay would be due to the standard process that must be followed after ACART advises the Minister about the planned new guidelines. That process would involve the Ministry of Health advising the Minister about ACART's recommendations, followed by changes to the HART Order, if the Minister and Cabinet agree. The publication of the final amended guidelines would happen once Cabinet agreed.
- 1.5 Members agreed interim guidelines would be warranted and to consult ECART about the idea. Members also asked the Secretariat to draft the guidelines and present them to ACART at its meeting in February 2019.
- 1.6 Members also noted that this change in plan will mean that some changes will be needed to the second consultation document to explain the amended process.

Actions

- *Secretariat to draft interim guidelines.*
- *Chair of ACART to write to Chair of ECART to explain the proposed new plan.*
- *ACART to consider the interim guidelines at the meeting in February 2019.*
- *Secretariat to amend the second consultation document to explain the new plan.*

2. Apologies

- 2.1 Nil.

3. Approval of the agenda

- 3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

- 4.1 Karen Reader asked for one item to be removed from her declarations. Sue McKenzie asked for one item to be added and two items to be removed from hers.

Action

- *Secretariat to amend the items as requested.*

5. Minutes of ACART's meeting of 19 October 2018

- 5.1 The minutes were approved.

Action

- *Secretariat to place the October 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 three items.

Cryopreserved ovarian tissue

- 7.2 The Secretariat advised those present that it had not received an update on the status of the project since the previous update several weeks ago.

Cryopreserved testicular tissue

- 7.3 The Secretariat advised those present that this item has not yet been progressed.

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 has been drafted.

ANZARD report for 2015

- 7.5 The ANZARD report for the 2015 calendar year was published online on 6 December 2018.

Actions stemming from the informed consent advice

- 7.6 The Chair asked whether there were any outstanding actions that had arisen from ACART's 2016 advice to the Minister on informed consent. The Secretariat advised that the publication of useful links on the Ministry of Health website was the only item it was aware of but that it would check and report back to the committee.

Action

- *Secretariat to check for actions from ACART's advice on informed consent and report back to members.*

8. Membership updates

- 8.1 The Chair advised those present that Analosa Veukiso-Ulugia (the preferred candidate to replace Catherine Poutasi) has been appointed.

9. Posthumous reproduction

- 9.1 Members noted the summary of submissions and that the working group would meet on Monday (the 17th December).
- 9.2 There was a discussion about the progress to date and the submissions, and the importance of consent. If posthumous reproduction is to be allowed, to any extent, it is essential that consent forms be clear about what can be consented to and by whom. There are numerous scenarios to consider when drafting consent forms, including people who have gametes or reproductive tissue stored as minors, during treatment for cancer, with a view to restoring fertility at a later date.
- 9.3 Members noted that, depending on what the new guidelines state, there could be inadvertent discrimination and it is important that any new guidelines do not create such discrimination. Members agreed it would be useful to set out the range of scenarios and the different legal implications that might arise in each scenario.
- 9.4 Members also noted that ACART's initial line of questioning, about taking gametes or tissues from a person who is unable to consent and whose death is imminent, may just make the project more complicated than necessary. 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).
- 9.5 There was discussion about a range of topics the working group will need to consider, including when and how a person's consent might be over-riden, who specifically is the beneficiary of posthumous reproduction and what exactly is the benefit, would compensation become a matter to deal with, and what implications might there be for inheritance rights. These matters all need careful thought from a legal perspective as well as an ethical one.

10. Donation guidelines review

- 10.1 The Chair summarised the status of the project and the actions ACART were being asked to take.
- 10.2 Members worked through the revised draft guidelines and agreed to most of the text and requested some changes. The Chair suggested that two specific provisions in the counselling requirements for all procedures should be moved into the general requirements and members agreed. She also suggested that the word 'above' be added to the second to last provision for embryo donation to be clear that the provision refers to the notes section preceding the provision.
- 10.3 There was a discussion about the types of family gamete donation cases that would be required to go to ECART. The guidelines, in the draft consultation document, do not state that the cases that would need to be submitted are those that are not prohibited and not established procedures. Members agreed to reinstate the 'notes' from the earlier version of the guidelines — these notes explain the types of family gamete donations that are established procedures and therefore not subject to ECART consideration. The Secretariat will add narrative, at paragraph 96 of the consultation document, to explain which cases must be submitted to ECART.

- 10.4 Members discussed the matter of ACART no longer proposing that *all* family gamete donations should be subject to ECART consideration. This is a significant policy change and, although it is explained in the narrative, there should be a question for submitters asking if they agree with this new proposal. Members agreed to add a sentence, at para 96, stating that ACART is now asking submitters what they think about ACART's new proposal and to add the question. The working group will consider the wording of the question before publication.
- 10.5 There was also a discussion about police vetting, in particular how and why it is done. Members noted that such vetting is standard practice and agreed that the process does not need to be explained in the consultation document but it would be helpful to briefly summarise how and why it is done in supplementary information that will be added to the ACART website.
- 10.6 There was a brief discussion about the residency provision in the surrogacy part of the draft guideline. The Chair confirmed that the intention of the provision is to ensure the child is not subjected to statelessness (if born in some places overseas), and that ECART will be able to assess whether all parties know where the child will be born and raised, so that communication between the parties can be maintained.

Actions

- *Secretariat to make the changes requested.*

11. Report on ECART's November meeting

- 11.1 Members noted the report and that two cases had been deferred while further information was sought.
- 11.2 There was also a discussion about the extent to which ECART can contribute to the development of ACART's advice and guidelines. Members agreed that, while ECART input is important, the committees must maintain their independence from one another and that ECART must not be afforded undue favour. ACART must be able to demonstrate its clear and independent decision making process.

12. Correspondence and Enquiries

- 12.1 Members noted the correspondence.

13. Governance — Chair's Report

- 13.1 Members noted the report.

14. Secretariat report to ACART

- 14.1 Members noted the report. See below for item 15 about an enquiry about PGD and item 16 about the *Births, Deaths, Marriages and Relationships Registration Bill*.

15. ACART comment on the use of PGD

- 15.1 Members noted that the committee had received an enquiry about the development of clinical guidelines for the use of PGD in New Zealand. The Genetic Health

Service provides guidance on the use of genetic testing and there is unlikely to be a need for ACART to be involved. The Ministry of Health has advised the enquirer that the guidance is available, and no further action is needed at this point.

16. The Births, Deaths, Marriages and Relationships Registration Bill

- 16.1 Members noted that this bill will soon be due for its second reading in parliament. The bill would probably not have been an opportunity for ACART to raise the matter of annotating birth certificates, to ensure donor conceived offspring can learn their genetic history.
- 16.2 However, the Chair proposed an alternative means of raising awareness about donor conception, which would be to have information (a prompt box) added to the birth certificate web-page of the Department of Internal Affairs, stating that the HART Register exists and that anybody can request information about their birth and whether egg and/or sperm donors were involved in their conception.
- 16.3 Members noted that adding such information would be consistent with information, on the web-site of the Department of Internal Affairs, about adoption. Members reiterated the importance of knowing one's genetic history and that this knowledge is important for tracing whakapapa.
- 16.4 The Chair agreed to draw this matter to the attention of the Minister of Health, if time permits, when she meets him early in 2019.

Action

- *Chair to raise with the Minister options that increase information to people seeking birth information, such as adding text to the birth certificates web-page to inform people there might be information about donor conception on the HART Register, or annotating birth certificates as per the Law Commission recommendations from 2005.*

17. ACART members in attendance at upcoming ECART meetings

- 17.1 Attendees for the upcoming ECART meetings are to be confirmed.

Action

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

18. Conclusion of meeting

- 18.1 The next ACART meeting is scheduled for Friday, 15 February 2019 in Wellington. Members should contact Moana for travel arrangements.

Action

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

- 18.2 The meeting closed at 12.30 pm.