



Minutes of the Seventieth Meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 8 December 2017, at the Wellington Airport Conference Centre

Present

Gillian Ferguson (Chair)
Mike Legge (Deputy Chair)
Jonathan Darby
Colin Gavaghan
Kathleen Logan
Sue McKenzie
John McMillan
Karen Reader
Sarah Wakeman

Non-members present

Philippa Bascand, Ministry of Health (from 9.55 am to 1.00 pm)
Martin Kennedy, ACART Secretariat
Carolyn Mason, ECART
Hayley Robertson, ACART Secretariat

1. Welcome

1.1 The Chair welcomed the Committee members, making particular mention of new member Dr Karen Reader who was attending her first ACART meeting.

1.2 Karen introduced herself, noting that she is a research fellow at Otago University. She commented on her current research which includes ovarian cancer, prostate cancer, and oocyte quality.

1.a Opening comments

1.3 Colin Gavaghan spoke about a range of matters he had been considering. In particular, he is interested in ACART's remit and the committee's positioning in the regulatory setting. He is particularly interested in the burden of justification when people are being regulated. Colin is interested in when and how ACART consults the public, and how the public's views can be meaningfully taken into account. The fact only small numbers of people respond to ACART consultations means that the responses cannot be taken as representative of social preferences. Nevertheless, those who do submit to consultations can provide new and useful ideas for ACART to consider.

1.4 There was a brief discussion following Colin's comments, about public participation in consultations and the idea that assisted reproduction could be widely accepted by the public now.

2. Apologies

2.1 Catherine Poutasi, Barry Smith.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

- *Place the December 2017 agenda on ACART's website.*

4. Declarations of Interests

4.1 These had previously been circulated. There were no amendments.

5. Minutes of ACART's meeting of 27 October 2017

5.1 The minutes were approved with no amendments.

Action

- *Place the October 2017 minutes on ACART's website.*
- *Secretariat to ask the University of New South Wales about adding PGS data to the next ANZARD report, as soon as possible.*

6. Actions arising from the previous minutes

6.1 Members noted the status of actions.

- *ACART to publish the Briefing to the Incoming Minister on ACART's website.*

7. Work programme

7.1 Members noted the status of actions arising from the August 2017 meeting.

The use of cryopreserved ovarian tissue to become an established procedure

7.2 There was a discussion about the progress on the amendments to the HART Order to allow the use of cryopreserved ovarian tissue to become as established procedure. There was a question about whether the legal status of the storage of the tissue would need to be addressed before the Order was approved. Sarah stated that the storage would be addressed under the current storage guidelines as clinics do not store tissue for more than 10 years.

Amend the Fertility Services Standard first?

7.3 Shortly after the discussion in paragraphs 7.1 and 7.2, Philippa Bascand joined the meeting and she spoke about the same topic.

7.4 Philippa noted that two matters had slowed down the progress of the work with the Parliamentary Council Office (PCO) to have the HART Order amended. The first matter is the new government's 100 day plan which has resulted in a substantial increase in urgent work for the PCO and so a delay in dealing with the HART Order.

7.5 The second matter Philippa noted was that the Ministry is considering whether the *Fertility Services Standard* needs to be amended to account for the introduction of the new procedure. There was a discussion about whether or not the Standard needs to be changed and who would be responsible for any work to make such changes.

7.6 ACART's position was that no such change is needed. The Secretariat will provide information for the Chair to write to the Ministry of Health explaining why the Standard does not need to be amended. The distinction between the storage and the use of the tissue needs to be explained.

7.7 Gillian noted that while ACART has an ongoing interest in the status of its recommendations, responsibility for implementation of recommendations is a matter for the Ministry of Health.

Action

- *To assist ACART in considering this matter further, the Secretariat is to ask the Ministry of Health to provide ACART any documents or e-mails explaining why the Ministry thinks the Standard should be amended and what process the Ministry proposed for making those amendments.*
- *The Secretariat will provide the information from the Ministry, and any supplementary information, for the Chair to write to the Ministry of Health outlining ACART's position on the matters relating to the Standard.*
- *The Secretariat to explain to ACART the next steps in progressing the Order and if ACART can do anything to make the process quicker.*
- *The Ministry of Health to provide an update for ACART's February 2018 meeting on the progress of the HART Order.*

8. Donations review

- 8.1 The Secretariat gave a general overview of the submissions, explaining that they fell clearly into two categories. The first category is the proposals that can be adopted as they are or with only minor changes. The second category is the proposals for which the Secretariat recommends ACART do further work. Gillian noted the point made by Colin in his opening comments that ACART had not received enough submission to be able to say that the public had a particular view on any of the proposals.

The biological link policy

- 8.2 Gillian noted that the submissions confirmed the clear divide between those favouring such a policy and those opposing it. Members agreed that ACART needs to clarify its rationale for proposing the removal of the mandatory biological link as it was not clear enough in the consultation document. ACART asked the Secretariat to collate the evidence from the working group discussions that had been used as the basis for the consultation document. A comparison with other jurisdictions would be useful.
- 8.3 Members observed that the consultation primarily elicited people's thoughts about procedures rather than the outcomes of those procedures. Having said this, the point about the consultation not measuring the thoughts of all of society is still relevant.
- 8.4 There was a discussion about the basis of the positions ACART takes — for example if those positions are based on morals, ethics, rights or some other basis. Gillian suggested that starting with the NZ Bill of Rights Act, which seeks to avoid discrimination, and using evidence of the outcomes for the people affected by the provisions would be an appropriate approach.

Justification to use a procedure

- 8.5 Members discussed if the provision is needed and how a threshold could be set. Members again agreed to revisit the literature to ensure there is a strong evidence base for ACART's position, and also to reconsider the intention and wording of the provision. ACART needs to clarify what the risks are that the provisions purport to address.
- 8.6 It would help to give a non-exhaustive list of examples for each risk e.g. "financial gain" refers to intending parents saving money by using a procedure regardless of the implications for the wellbeing of the offspring and other parties and the option of using a less risky procedure. Financial gain does not mean that the intending parents will gain financially by virtue of having a child.
- 8.6 ACART will go back through the applications that ECART declined or deferred to see the basis on which ECART made its decisions as this will help inform ACART's understanding of risks that are being managed.
- 8.7 There was a discussion about whether a provision could be adopted in which people could use a procedure in which they would have no biological link to a child but that in such cases a threshold would be set and certain criteria would need to be met to manage risks. The committee will consider this further once the original evidence and rationale have been revisited.

Consent

- 8.8 Gillian commented that there are no questions about the policy or principle that ACART has proposed. However, there is a need for ACART to clarify exactly when

consent must be obtained under certain circumstances. It was apparent from the submissions that not everybody understood when consent might need to be obtained again from participants if embryo donation is allowed.

Legal advice

- 8.9 There was a brief discussion about the value of participants obtaining legal advice early in their involvement in fertility treatment. When legal advice is needed, or beneficial, it should not be treated as an after-thought. While there would be merit in ACART or the Ministry providing a brief overview of the types of matters people should consider seeking legal advice on it is not ACART's role to provide detailed legal opinions or advice.

Family donations to be subject to ECART

- 8.10 Members noted that many respondents did not favour the proposal that all family gamete donations should be subject to ECART review. The discussion addressed why some family donations would be different to others and the risk of coercion. Sarah observed that counselling identifies matters of concern.
- 8.11 Members agreed that intergenerational risks need to be managed and that making donations that would result in intergenerational relationships subject to the guidelines would be the ideal way to manage those risks. Members agreed to review the ECART decisions to learn the bases on which family donation cases had been declined or deferred.

Embryo donation

- 8.12 Gillian observed that the submitters who objected to the proposals that would allow embryo donations primarily did so on the basis that the resulting relationships would be too complex. The work to clarify the rationale for allowing, or not, the removal of the biological link will provide the information needed to clarify ACART's position on embryo donations. The Secretariat will create a table setting out the various donation scenarios that could arise.

All clinic surrogacies to be subject to ECART approval

- 8.13 Gillian commented on the concerns raised by some submitters — these concerns were largely that there would be delays and extra costs in treatment. However, she considered that the proposal was still sound and should proceed, given the risks it is intended to address. ACART should provide more details about why it has made the proposal so that the rationale is clear and understood. The additional information should include evidence.

Surrogates should complete their own families first

- 8.14 Members discussed ECART's suggested change of wording. The discussion noted that there are clinical reasons for this provision — carrying a child has an element of risk and it would be unwise for a woman to risk not being able to have children for herself if having them first for another person made her infertile. However, it was also noted that so long as a woman is aware of the risks, she is entitled to make her own decisions as an autonomous individual. Members noted that the wording of the provision precluded the possibility of women acting as surrogates for other people when they already know that they do not wish to have families of their own. That is, such a scenario is not provided for in the proposed provision.

- 8.15 Sarah proposed that consideration be given to requiring a surrogate to have already gestated a child, on the basis that she would be aware of any health difficulties she might have and be aware of the emotional and physical aspects of giving birth. The matter of coercion was raised again, and how it can take different forms, and how there are nuances between feelings of duty versus compulsion. It was noted that possible coercion would not in itself be a reason for referring a case to ECART.
- 8.16 Members agreed to consider these matters further.

Next steps

- 8.17 Gillian suggested that the working group and any interested members should meet the day before the next ACART meeting to go back through the articles, evidence, rationale and wording of the provisions that need further work. Members agreed. The Secretariat will also collate any new papers that have been published since those that were used by the working group when developing the consultation document.

Action

- *The Secretariat to go through the applications that ECART declined or deferred to see the basis on which ECART made its decisions.*
- *The Secretariat to collate the evidence from the working group discussions that had been used as the basis for the proposals to remove the mandatory biological link.*
- *The Secretariat to collate the evidence from the working group discussions that had been used as the basis for the proposed provision for the justification to use a procedure.*
- *The Secretariat to draft a non-exhaustive list of examples of financial gain and social gain.*
- *The Secretariat to review the ECART decisions to learn the bases on which family donation cases had been declined or deferred.*
- *The Secretariat will create a table setting out the various donation scenarios that could arise.*
- *The Secretariat to collate the evidence from the working group discussions that had been used as the basis for the proposed provision that all clinic based surrogacies be subject to the guidelines.*
- *The Secretariat to collate evidence about how other jurisdictions manage surrogacy.*
- *The working group and any interested members should meet the day before the next ACART meeting.*

9. Posthumous reproduction

- 9.1 Gillian and the Secretariat gave the committee an update about of their attendance at the posthumous high court hearing in Auckland on 31 October 2017. The committee is awaiting Justice Heath's decision to finalise ACART's consultation document. Justice Heath's decision is expected before Christmas. The committee noted the need for flexibility in the project plan to allow for amending the document once the judgement is made.

- 9.2 The secretariat was able to provide ACART with anonymised copies of the legal documents for the court case.
- 9.3 The New Zealand Ethics Committee (NZEC) has been in touch with the ACART secretariat, regarding ACART's application for ethics advice, regarding consulting with school children with an age appropriate version of the consultation document. The committee thanked Kathleen Logan for her efforts in progressing the work. Following some minor amendments, it will be considered by the NZEC prior to the end of the year. Barry Smith is on the board of the NZEC so has declared a conflict of interests and will take no part in the evaluation of the work with school children.
- 9.4 The Secretariat provided the committee with a test consultation document and courier bags to test drive the consultation document with a small number of people before it is finalised and released publicly. The committee suggested that when the full document is released for consultation, it would be useful and good timing for members who have access to university students to obtain that group's views on the consultation document.
- 9.5 A member noted that it would be useful to amend the consultation document so that ACART can obtain demographic information about the cohorts of people who respond so that we know we are hearing from a range of people and can reflect any comparisons in the initial analysis.

Action

- *The Secretariat to advise the committee of Justice Heath's decision on the posthumous case when it is available.*
- *The Secretariat to organise a teleconference with Kathleen Logan and the NZEC to discuss ACART's application.*

10. Human Reproductive Research: briefing to the new Minister

- 10.1 Members discussed the draft briefing to the new Minister about the need to revise the guidelines on Human Reproductive Research. Some minor amendments were suggested.
- 10.2 Later in the meeting, members discussed whether the HART Act needs to be reviewed for a possible change to the provisions about the extension of the storage of gametes and embryos. The discussion is recorded under item 18, below, but an action is recorded here as ACART agreed it should send a single letter (briefing) to the Minister about ACART's work programme. One item in the letter would be about a change in the scope of the review of guidelines for human reproductive research and another item would be ACART providing advice about a possible review of the provisions in the Act for extending the storage of gametes and embryos.
- 10.3 Also, in item 13, below, members discussed ACART's work programme and that the policy projects are not ranked, they will all be progressed as resources allow. The letter should also note this.

Action

- *The Secretariat to amend the HRR components of the briefing, as requested.*
- *The Secretariat to add a section on seeking the Minister's agreement that ACART should advise him on a possible review of the provisions in the HART Act on extending the storage of gametes and embryos.*
- *The Secretariat to circulate the amended version to all members.*
- *Members to comment by mid-December.*

11. ACART's Monitoring Process

- 11.1 The Secretariat summarised the options for keeping up to date with developments and sharing findings amongst members. The Secretariat will ask the Ministry of Health library to carry out literature searches using the list of key words.
- 11.2 Members suggested the list of topics to monitor should also include 'donor conceived,' 'third party reproduction' and 'uterine transplants' and that embryos should be specifically 'human embryos.' Members agreed that providing written summaries of articles would not be needed but that members should give spoken summaries at ACART meetings in addition to sharing the original articles.

Actions

- *The Secretariat to amend the list of key words.*
- *The Secretariat to send the list of key words to the Ministry of Health library asking them to monitor the literature.*
- *The Secretariat to receive confirmation of all members' key areas for independent monitoring.*

12. Report on ECART's August meeting

- 12.1 Members noted the report. Gillian asked about the status of the annual summary of the ECART applications and the Secretariat advised it was in progress.

Actions

- *The Secretariat to produce and circulate the annual summary of ECART cases as soon as it is available.*

13. ACART's Priorities

- 13.1 Mike Legge moved that the discussion begin this item with an "in committee" session and Sue McKenzie seconded the proposal. Once the in committee session was finished Mike Legge moved that it end and Jonathan Darby seconded it. The in committee session lasted from 1.45 to 2.10 pm.
- 13.2 Once the Secretariat and Carolyn Mason re-joined the meeting members noted the recommendations and suggested that, rather than ranking the relative importance

of the policy projects, all the projects should be listed on the programme and be addressed as resources permitted. Having said this, it will be important to progress projects as quickly as possible if they affect a lot of people or for other reasons such as addressing risks. Maintaining momentum on projects that are underway is important.

- 13.3 Members noted that the project to revise the donation guidelines will likely carry on until at least August or September 2018 and that the first stage of the project on the posthumous use of gametes would likely continue until at least June 2018.
- 13.4 Mike commented that it would be timely to consider a revision of the HART Act as it is now 13 years old, is not subject to periodic review and there are several shortcomings in the Act. While ACART cannot amend the Act it can advise the Minister on the benefits of doing so. Mike commented that the principles of the Act do not need to be reconsidered.
- 13.5 ACART would be interested to know if the Ministry of Health thinks a review of the Act is advisable. ACART asked the Secretariat to ask the Ministry if the Ministry has any information about a possible review that it could share with ACART.

Actions

- *The Secretariat to ask the Ministry if the Ministry has any information about a possible review that it could share with ACART.*
- *ACART members to e-mail the Secretariat any ideas about aspects of the Act that could be reviewed.*

14. Correspondence and Enquiries

- 14.1 Members noted the correspondence. Hayley advised the members that the Ministry of Health was writing to the fertility clinics about compensation of gamete donors, and that this correspondence would be included in next meeting's agenda pack

Action

- *The Secretariat to circulate the letter to the chair and deputy chair for their information.*

15.a Governance — Chair's Report

- 15.1 The Committee noted the report. Gillian added that she had had a very useful meeting with Fertility New Zealand when she attended their annual general meeting and executive meeting on 18 November. Although FNZ does not have large numbers of people attending events they do have a lot of activity in their online community. It would be worthwhile ACART considering using the internet more for its activities when it wishes to reach interested parties.

16. Secretariat report to ACART

16.1 The Committee noted the report. There was a brief discussion about conferences in 2018. The FSA conference is in Melbourne in September. The University of Canterbury will host a symposium on what is considered to be a family, and Sue and Sarah can probably attend. Karen and/or Sarah might be able to attend the ESHRE with independent funding from the University of Otago and Fertility Associates respectively.

17. Consultation methods

17.1 Gillian explained that ACART had had a limited response to its public meetings on the review of the donation guidelines and she questioned whether it was an appropriate use of resources. There was a discussion about options for eliciting responses and about ACART's consultation obligations under the Act.

17.2 Suggestions for improving engagement included adding certain groups to the contact list including medical students, and using smaller, more targeted meetings. Meetings could be run more like hearings or focus groups with people invited to discuss the topic under consideration.

Actions

- *The Secretariat to go through the submissions from the last three ACART consultations and add any submitters to the contact list who are not yet on it.*

18. Suitability of the regulations for the cryopreservation of gametes and embryos

18.1 Mike introduced the item, observing that the requirement that clinics seek ECART approval to extend the storage of gametes and embryos is no longer warranted. There are several merits to removing the requirement, including reducing the administrative burden, the emotional and financial burden on participants, and the work for ECART and the clinics. ACART has closely followed the outcomes of the use of stored gametes and embryos and observed there are no long term concerns reported from the subsequent use of these gametes and embryos.

18.2 Gillian stated that ACART will write to ECART advising them that ACART would like to add the matter to the ACART work programme. The letter to ECART would ask them to state their interest in the work so that ACART can relay this position to the Minister when ACART asks the Minister to add the project to the ACART work programme.

18.3 The letter to the Minister would note that changes to the current approach would require amendments to the HART Act, which would need to be progressed by the Ministry of Justice. The Ministry of Health could have a role in amending the act but the extent of that involvement would need to be agreed by the Ministers involved.

- 18.4 There was a discussion about keeping ACART's communications with the Minister efficient and members noted that ACART is already writing to him about the project on human reproductive research. Members agreed to address both topics in the one letter. (See also item 10 above.) Members also agreed that the letter should briefly note ACART's position, discussed in item 13, that the projects are not ranked, they will all be progressed as resources allow.

Actions

- *The Secretariat to draft a letter from Gillian to ECART asking ECART's opinion about a possible review of the requirements in the HART Act that ECART must approve extensions to the storage of gametes and embryos.*
- *Gillian to approve the letter and the Secretariat to send it to ECART. [On receiving ECART's comments the Secretariat to amend the letter to the Minister about ACART's work programme (See item 10 above).]*

19. Gamete Shortage

- 19.1 Hayley summarised the purpose of this item, recapping that ACART had advised the Minister, in 2015, on the import and export of gametes and embryos and a range of associated matters. Subsequently, the Minister had asked the Ministry to explore options for addressing the gamete shortage. With the restructure of the Ministry of Health and the move of the ACART secretariat in to the new ethics group it is now possible that the policy work could fall to the Secretariat staff in their new capacity as members of the ethics group.
- 19.2 Gillian suggested that work on increasing donation rates is most appropriately progressed by the Ministry as part of its policy development work, rather than by ACART given this work did not appear to require the resources of a specialist advisory committee. She suggested that ACART take no further action at this time, but continue to receive updates on the matter through the Secretariat.

20. Agree ACART members in attendance at ECART meetings in 2018

- 20.1 Members agreed this item can be addressed out of session.

Actions

- *The Secretariat to e-mail the list of ECART meeting dates and locations for 2018 to all members.*
- *Members to email the Secretariat about their availability.*

Extra item I — Budget 2017/18

- Philippa advised ACART that the transfer of the ACART budget from the Strategy and Policy business unit to the Protection, Regulation and Assurance business unit was continuing and that the dollar amounts were yet to be confirmed.
- Gillian noted that ACART has not been provided with monthly reports on the committee's expenditure.

Extra item II — Ministerial delegations

- Gillian advised members that the Ministerial portfolios had been assigned and Minister Clark will be responsible for assisted reproduction.

21. Conclusion of meeting

22.1 The next ACART meeting is scheduled for 9 February 2018 and will be held at the “Front and Centre” conference facility in Wellington.

22.2 The meeting closed at 3.00 pm.