



## **Minutes of the Sixty-seventh Meeting of the Advisory Committee on Assisted Reproductive Technology**

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Held on 9 June 2017, at the Wellington Airport Conference Centre

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### **Present**

Alison Douglass (Chair)

Mike Legge (Deputy Chair)

Jonathan Darby

Gillian Ferguson

Sue McKenzie

John McMillan

Catherine Poutasi

Barry Smith

Sarah Wakeman

### **Non-members present**

Freddie Graham, ECART

Martin Kennedy, ACART Secretariat

Isabel Ross, ACART Secretariat

## 1. Welcome

1.1 The Chair welcomed the Committee members.

### 1.a Opening comments

1.2 Alison Douglass gave the opening comments, and as this was her final meeting with the committee she reflected on the past, present and future of assisted reproductive technology and on her time on ACART (and NECAHR) over a period of 20+ years.

1.3 She commented that the Interim National Committee established in 1993 (INECART) and NECAHR were originally entirely ethics focused, and operated in a 'legal vacuum'. Alison observed that there is now a greater legal focus of ART in the operation under the HART Act (for example, consideration of issues of discrimination). She noted it is interesting that surrogacy and posthumous use of sperm were issues of interest in the early days of NECAHR as these issues are currently very much matters of public interest. Developing ACART's ethical framework was an important part of ACART's functions so as to apply the principles in the HART Act.

1.4 Having noted these foci on ethics and the law, Alison encouraged ACART to be "bold, positive and brave" about its policy role. Going forward, the review of the Donation Guidelines and removal of the biological link policy is a significant policy shift. Alison also commented on the similar policy considerations of the Human Tissue Act and HART Act and how and if they could complement one another.

1.5 Alison thanked the Committee members and the secretariat for their hard work, dedication, and the interesting and intelligent discussions on ART.

## 2. Apologies

2.1 Kathleen Logan (Chair has sent flowers on behalf of the committee for a family bereavement).

## 3. Approval of the agenda

3.1 Members approved the agenda.

### Action

- *Place the June 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 7 April 2017

5.1 The minutes were approved with minor amendments.

### Action

- *Place the amended April 2017 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 actions arising from the April 2017 meeting.

### ***Briefing to the incoming Minister***

7.2 Members noted that ACART will need to draft a BIM over the next few weeks. The 2014 BIM provides a useful template. A draft could be considered by ACART in August and confirmed in October.

### **Action**

- *Secretariat to draft a skeleton BIM, with limited content, and circulate to members for initial comments.*

### **Budget**

7.3 Gillian Ferguson, as incoming Chair, led the committee through a discussion about ACART's budget and priorities for 2017/18. She reported on a meeting she, Mike and Alison had had the previous day with Gabrielle Baker, Manager Population Outcomes at the Ministry of Health, about the budget. Gillian noted that, in budget negotiations, it is important for ACART to have a clear idea about key deliverables and costs.

7.4 Members noted what it cost to run ACART in an 'average year', and that it would need an additional \$49,305 than in the 2016/17 financial year to run its three projects at 'full pace'. There will also be more significant public consultations in the next financial year. For the projects to progress, ACART will need to consult comprehensively so that all stakeholders can contribute and to minimise the risk of not addressing matters that could be relevant to the work. Consultation is likely to entail several regional meetings/hui for each project, with associated costs. ACART would need sufficient funds to carry out the consultation rounds — without the funds to consult ACART would make little progress on the projects.

7.5 Members noted that ACART would also need more secretariat support than it currently has in order to be able to run three projects in 2017/18.

### ***Donations review consultation***

7.6 The committee discussed the consultation process for the donations review and what it will look like. Members noted that this is likely to be one of the more major consultations that ACART has undertaken. It may include face-to-face sessions with parties including but not limited to clinics, consumers, the Ministry of Health, Health and Disability Commissioner, and ECART, and there will need to be a geographical spread. Members said they would also need to consider organising a hui to seek Māori input.

7.7 Members agreed to finalise the consultation document through email out of session, with a view to consulting in the August-October period.

7.8 The Secretariat will draft a consultation plan and circulate that to members for comment. The plan will then be considered at ACART's August meeting.

### **Actions**

- *Secretariat to draft and circulate consultation plan.*

### ***Posthumous reproduction consultation***

- 7.9 Members discussed the need for a two-stage consultation for posthumous reproduction, and whether the project could be completed with only one consultation. Members of the Working Group explained that their decision to undertake a two-stage consultation was in order to help it prepare a better guideline for the second stage of consultation. The first stage will focus on whether it should ever be permissible for gametes to be retrieved from a person who is deceased.

### ***Work programme priorities***

- 7.10 Members discussed the order of priority for the committee's current three projects. ACART concluded that it would prioritise the two major projects currently under way (the donation guidelines review and posthumous reproduction) and work on the third (human reproductive research) as time and resources permit. The committee noted it could progress this work faster with additional discretionary funding.
- 7.11 The incoming Chair will discuss the priorities with Associate Minister Dunne when she meets him on 23 June. The letter to the Minister, in advance of that meeting, will be amended to take these prioritisation decisions into account.

#### **Action**

- *Secretariat amend the letter to take these prioritisation decisions into account.*

### ***Monitoring ECART decisions***

- 7.12 Members noted the regular updates on ECART decisions need to continue and to do so ECART must provide its decisions in a timely manner.

#### **Action**

- *Secretariat to liaise with the ECART secretariat to request whether ECART decisions would be available for the next ACART meeting in August.*

## **8. Membership changes: for noting**

- 8.1 Members noted upcoming ACART membership changes. Alison Douglass's term expires on 22 June 2017. On 23 June 2017 Gillian Ferguson will become Chair and Colin Gavaghan will join the committee as the member with expertise in legal matters. The position for the member with expertise in human reproductive research (currently held by Mike Legge) is currently been advertised, as Mike's term ends in October 2017.

## **9. Review of the donation guidelines**

- 9.1 Members heard a report from the working group's May teleconference and commented on the draft guideline and consultation document. Betty-Ann Kelly has been contracted to help the Committee finalise the discussion document.
- 9.2 The Chair reported on a meeting she, Mike and Gillian had had with Health Legal the previous day. Health Legal has had a preliminary look at the guidelines with a view to considering whether any aspect could be seen as discriminatory and

subject to a legal challenge. These are areas that ACART should keep in mind and ensure its policy behind them is robust and sound.

9.3 The Committee went through the key proposals and rationales with a view to taking the document forward. Members requested various amendments to the guideline and discussion document. Points of note included the following.

- The rationale for provisions needs to be clear.
- The focus of the “one guideline” and the discussion document is on areas of policy change, not existing policies eg. counselling requirements, where there will be no changes.
- There was a discussion about the limits on the number of full genetic siblings and the number of offspring a gamete donor can have.
- The Fertility Services Standard is under review in 2017 and ACART will be able to submit on that review.
- There was discussion about the words ‘need’, ‘necessary’ and ‘fertility’. ACART agreed to remove any reference to fertility in the single guideline, and replace need and necessary in the single guideline so that the provision will read ‘the procedure is the best or only opportunity for the intending parent(s) to have a child’.
- ‘Re-donation’ needs to be included in the single guideline and the discussion as ACART is proposing to introduce an activity that is not currently allowed.
- There needs to be clarity in the document about when an embryo is being ‘donated’.
- On balance, the police vetting discussion need not be included as this is an existing policy.
- The document needs to seek public feedback on any cultural implications of the proposed removal of the biological link.

9.4 Members agreed to consider the latest version of the document and provide track changes to the Secretariat.

9.5 The committee noted there needs to be further discussion about the level of consultation necessary for this project.

### **Actions**

- *Jonathan to provide text about disability.*
- *Barry and Catherine to provide text for a question about cultural implications of the proposed removal of the biological link.*
- *Secretariat to write the glossary.*
- *Committee members to send track changes to the Secretariat so the Secretariat can amend the document.*

## **10. Human reproductive research**

10.1 The committee briefly discussed the status of ACART’s review of the guidelines on research on gametes and non-viable embryos. ACART will explore what future guidelines could look like. ACART is going to advise Associate Minister Dunne, in

its letter to him about its work programme (item 7.10 above) how it plans to run the project.

- 10.2 ACART considered a draft letter to the Ministry of Health regarding the Ministry's advice.

## **11. Review of the guidelines for posthumous reproduction**

- 11.1 The committee considered the current version of the discussion document.
- 11.2 Members noted that the front end of the document needs to explain why there are two consultation rounds. The introduction also needs to state that the scope of the document for consultation will go beyond the scope of the current guidelines and into areas of legal uncertainty, such as collection of gametes from deceased people.
- 11.3 Members discussed the two stages of consultation and instructed the Secretariat to pick out the substantial content from the document, and use it in a limited first consultation round. The document needs to be structured so the responses cover what ACART is looking for feedback on, and not extra content.
- 11.4 Members discussed the suggested questions for the feedback form and agreed it needs to be succinct. Members proposed using a Likert scale where possible, as this would reduce the number of questions asked and mean that feedback is also received on how strongly submitters feel about the questions.
- 11.5 Members noted that the Chair had written to the Chief Coroner and the Family Court Judge seeking meetings to discuss entities that could have the legal authority to approve the posthumous retrieval of gametes from recently deceased people. Both have responded positively.

### **Actions**

- *Amend the consultation document to:*
  - *explain why there are two rounds of consultation*
  - *state that the contents of the document are all beyond what the current law allows*
  - *make the questions into "Likert" questions.*

## **12. Parallel advice to Minister Dunne from the Ministry of Health**

- 12.1 The Chair outlined the draft letters, and the questions ACART is asking about the advice. She noted that ACART needs to ask about timeframes for the import/export advice, as the sector is asking questions about this.

### **Action**

- *Add a sentence to the letter, asking the Ministry to say when it expects to complete its work on the import and export of gametes and embryos.*

## **13. Correspondence and enquiries**

- 13.1 A draft ACART response to ECART about its enquiries, considered at ACART's April 2017 meeting, was presented for further discussion. Members noted there is a tension between giving too much advice and not giving enough advice.

### **Actions**

- *Finalise the response to ECART and Secretariat to send it.*

## **14. Governance**

### **14.a Chair's report**

- 14.1 The Committee noted the report.

### **14. b Members' reports**

- 14.2 Members noted Kathleen's report from the Rethinking Commercial Surrogacy Symposium hosted by Canterbury University School of Law.

## **15. Secretariat report to ACART**

- 15.1 The Committee noted the report.

## **16. ACART members in attendance at ECART meetings**

- 16.1 Not discussed. Attendees have already been identified for ECART's meeting in August.

## **17. Conclusion of meeting**

- 17.1 The next ACART meeting is scheduled for 11 August 2017 and will be held at the Wellington Airport Conference centre.
- 17.2 The meeting closed at 3.30 pm.