



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

Held on 9 February 2018, at the “Front and Centre” Conference Centre, Wellington

Present

Gillian Ferguson (Chair)

Mike Legge (Deputy Chair)

Jonathan Darby

Colin Gavaghan

Kathleen Logan

Sue McKenzie

John McMillan

Karen Reader

Barry Smith

Sarah Wakeman

Non-members present

Martin Kennedy, ACART Secretariat

Iris Reuvecamp, Chair ECART

Hayley Robertson, ACART Secretariat

1. Welcome

1.1 The Chair welcomed the Committee members and Iris Reuvecamp from ECART.

1.a Opening comments

1.2 Karen Reader spoke about her research in reproductive biology, noting that some procedures used by clinics were developed in clinics rather than in a setting of purely scientific research. Karen commented on how embryos differ depending on how they were created and the need for more research to better understand the implications of those differences. She also raised the matter of whether consumers understand the limitations of the knowledge about embryo development. Karen observed that public understanding of fertility and how it declines could be improved.

1.3 Members then discussed fertility education and how ACART can obtain meaningful responses in its consultations if people's understanding is poor.

1.4 This discussion led to a request by ACART for an update from the Ministry of Health on progress on creating a web-page for consumers to find links to information about fertility treatment in New Zealand. The update should be provided to ACART for its April meeting.

Action

- *Request an update from the Ministry of Health on progress on creating a web-page for consumers to find links to information about fertility treatment in New Zealand.*

2. Apologies

2.1 Catherine Poutasi, Judge Andrew Becroft.

3. Approval of the agenda

3.1 Members approved the agenda. Three additional items were added: one discussed as part of Item 7 and the other two after Item 15.

Action

- *Place the February 2018 agenda on ACART's website.*

4. Declarations of Interests

4.1 These had previously been circulated. Two amendments were requested.

Action

- *Amend two of the declarations as requested.*

5. Minutes of ACART's meeting of 8 December 2017

5.1 The minutes were approved with minor amendments. Gillian asked that the draft minutes be amended to clarify that ACART has not been provided with monthly reports on the committee's expenditure.

Actions

- *Amend two of the statements.*
- *Place the December 2017 minutes on ACART's website.*

6. Actions arising from the previous minutes

- 6.1 Members noted the status of actions and discussed three matters arising.
- 6.2 Gillian thanked Iris for ECART's quick response to an enquiry ACART had made before Christmas.
- 6.3 Members discussed the availability of accessible documents. They noted that if ACART and the Ministry of Health do not provide accessible documents they are at risk of a complaint for not complying with obligations under the United Nations Convention on the Rights of Persons with Disabilities. Members asked the Secretariat to make enquiries at the Ministry of Health about who handles matters related to accessible documents and report the findings to ACART.

Action

- *Ask the Ministry of Health who handles matters related to accessible documents and report the findings to ACART.*
- 6.4 Karen enquired about ACART's monitoring functions and whether she should send material to the Secretariat. Hayley confirmed members can send material to the Secretariat and the Secretariat coordinates the distribution of that material to all members. Members agreed that the Secretariat should circulate the abstracts for journal articles that might be relevant. Members can then decide which articles they would like to read in full.

7. Work programme

- 7.1 Members noted the status of the programme and discussed three items.

Budget

- 7.2 Members noted that knowing how the budget is tracking would help to plan the work programme and the consultations in particular.

Ministry progress in response to ACART advice

- 7.3 Members asked that the standing item on the work programme include an update on how the Ministry of Health is progressing with its policy and/or operational work in response to ACART's advice. The current items are for ACART's advice on informed consent, and the import and export of embryos and gametes.

Action

- *Write to the Ministry of Health requesting an update on progress on these two topics.*

Extra item 1 — ACART's Briefing to the incoming Minister

- Gillian advised members on progress in submitting ACART's BIM and supplementary letter to Minister Clark and members discussed the next steps.
- Gillian reported that she and Mike had spoken to staff at the Ministry of Health (Philippa Bascand, Manager Ethics and Phil Knipe, Chief Legal Advisor) and been advised that a higher level version of the BIM and supplementary letter would be

useful as a preliminary briefing to the Minister. Members agreed to provide a brief introductory paper to the Minister, accompanied by a revised version of the BIM.

- Members noted that several administrative matters remain outstanding following the transfer of the Secretariat to the PRA Group, including the process for submitting material such as the BIM to the Minister's Office. Gillian advised members she has requested to meet the manager of the Ministry's Ethics team in mid-March to discuss these matters. Before the meeting ACART will write to the Ministry setting out the points it wishes to discuss.

Actions

- *The Secretariat is to amend the BIM and supplementary letter and draft a cover sheet within two weeks, and send to members*
- *The Secretariat is to draft a letter from ACART to the Ministry of Health about the matters it would like to discuss.*

8. Posthumous reproduction

8.1 Justice Heath's High Court decision on the posthumous use of sperm case was made public on 21 December 2017. Members received an anonymised judgment and summary of Justice Heath's decision. Members noted the following key findings.

- There are no statutory or regulatory provisions that deal explicitly with the ability for a partner to collect and use sperm from a deceased person/partner.
- The HART Act does not exclude the possibility that the ECART could grant permission for use of sperm from a deceased male (effectively this means that use of sperm from a dead person is an assisted reproductive procedure — noting that there are currently no guidelines for ECART to apply until ACART potentially issues new guidelines concerning Posthumous Reproduction).

8.2 Members confirmed the target release of the first consultation of Posthumous Reproduction for April 2018. Members agreed on a final working group date for 9 March 2018 to finalise the consultation document, which will include a summary of Justice Heath's decision.

8.3 The New Zealand Ethics Committee gave advice on the age appropriate version of the consultation document and some minor amendments were made. Members were informed that young people will be consulted on the document in the first school term, as part of some schools curriculum. There may be a need for focus groups as part of this consultation.

Action

- *Secretariat to update the consultation document and circulate to the working group by 26 February.*
- *Secretariat to organise a final working group meeting in Dunedin for 9 March 2018.*
- *Secretariat to draft a consultation plan for consideration at the March working group meeting.*

9. Donations review

- 9.1 Gillian reported on the successful working group meeting that had been held the day before the ACART meeting, noting that the group had confirmed its recommendations for the biological link policy and the policy about whether participants should have a justification to use a procedure.
- 9.2 Martin quickly summarised the type of material that had been presented and the process the working group suggested be used to agree the provisions. Members then discussed the review of the guidelines, going through each of the main topics that needed further consideration, taking particular note of the points raised in the working group.

The biological link policy

- 9.3 Gillian summarised the main points made in the working group meeting. These were that when deciding the provisions that the guidelines should contain:
- a. the removal of potential discrimination from the guidelines was an important consideration
 - b. consideration had to be given to whether there is any justification for retaining the biological link policy, given its potentially discriminatory effect
 - c. there is little evidence, either way, on the outcomes for offspring and adult participants of having no genetic and no biological link between intending parents and offspring
 - d. factors of particular importance for wellbeing are the quality of parenting and the early informing of offspring of their origins
 - e. it is the *combination* of no genetic and no biological link that ACART most needs to consider.
- 9.4 Members noted that quality of parenting and early disclosure to donor-conceived children are matters beyond regulatory control. In this context, members revisited the matter of birth certificates being amended to include a standard statement to show that there could be more information available. This would align with the HART Act to strengthen information about a person's whakapapa.
- 9.5 John drew attention to the distinction between health and wellbeing, noting that health is a more definite and measurable criterion, whereas wellbeing tends to emphasise a person's self-reported feelings.
- 9.6 Colin commented on 'lop-sided' parenting and that having a genetic link to a child does not necessarily mean parents will have a greater interest in a child and that it is not necessarily irrational for a couple to choose to have no genetic link to a child. Members discussed the different ways in which people can consider their interest in their child e.g. that they could have a very strong interest because they particularly want to raise the child even though it's not genetically or biologically related. Colin also commented on an idea ACART had covered in earlier meetings about the risks to a child's wellbeing if ACART makes a statement that society has a general preference for a genetic or biological link between a child and a parent.
- 9.7 Gillian suggested that, rather than stating that there is a preference for having a genetic or biological link, the guidelines should state that people should consider the importance and implications of having or not having a genetic or biological link to a child. Members agreed with this suggestion and that ACART should rescind the mandatory requirement that a child have either a genetic or biological link to at least one intending parent.

- 9.8 Gillian commented on a matter the Ministry of Health had recently raised, which was that the proposed changes to the donations guidelines might raise immigration matters which ACART had not yet addressed. Specifically, when a child is born overseas and the parents wish to bring it to New Zealand to live, they might have to prove that it is genetically related to at least one of them. However, the Minister might have some power of discretion in such cases. ACART needs to look into this matter and, if needed, provide further advice. Members noted that the Ministry of Health had, in the past, advised clinics about the requirements for exporting gametes and embryos. The Secretariat was asked to send the letter to Iris for her information.
- 9.9 The Secretariat was asked to check ACART's mailing list and confirm that the Department of Internal Affairs had been sent ACART's consultation document for this project.

Actions

- *Secretariat to amend the draft revised guideline as discussed by the working group and agreed by ACART.*
- *Secretariat to look into the matter of the immigration of children and determine whether ACART needs to provide further advice.*
- *Send the Ministry's letter about the export of gametes and embryos to Iris.*
- *Check ACART's mailing list and confirm that the Department of Internal Affairs had been sent ACART's consultation document.*

Justification to use a procedure

- 9.10 Gillian recapped the discussion from the previous days working group, noting that the current guidelines are inconsistent with one another in how they require a procedure to be justified. She also noted that the consultation document had not asked submitters whether they think that there should in fact be *any* requirement that a procedure be justified.
- 9.11 Members noted that with the proposed removal of the mandatory biological link there could be cases with extra complexity and that this could be a reason to retain a provision about a procedure needing to be justified. This led to consideration of the provision that a procedure be "the best or only opportunity" for intending parents to have children. Gillian observed that if there will no longer be a mandatory requirement for a biological link then it begs the question of whether there should be a provision requiring a procedure to be justified. Members considered that the limited availability of directly relevant evidence calls for a cautious approach.
- 9.12 Members noted that if there is no mandatory requirement for a biological link and also no requirement that a procedure be justified ECART will have minimal grounds on which to decline applications it believes are risky. Members agreed that a provision should be retained that "ECART must be satisfied that the procedure is the best opportunity for intending parents to have a child."

Actions

- *Secretariat to amend the draft revised guideline as discussed by the working group and agreed by ACART.*

Social or financial gain

- 9.13 Gillian noted that some submitters had asked for more information about this provision. She advised members that the working group had concluded that if the

biological link provision was rescinded it followed that the provision about social and financial gain would no longer apply. The working group had concluded that intending parents should be fully aware of the implications of using a procedure, in particular the implications for the offspring.

- 9.14 Members discussed a number of factors, several of which were closely related to the concept of whether a procedure was “justified.” They noted the difficult nature of defining need and how people’s preferences will not always perfectly match a medical or clinical definition of need. Members also revisited the point that ECART should have a clear basis on which to evaluate applications.
- 9.15 Members agreed that the provision that a procedure be “the best opportunity” for that individual/couple, effectively captures the intent and that the separate provision that the term “social or financial gain” is not needed. However, members considered that particular caution was required in relation to surrogacy arrangements, noting the particular risks and the limited evidence on the absence of a biological link. Members considered that retaining a requirement that the proposal is justified in light of the associated risks was appropriate.
- 9.16 Members agreed to see the next version of the proposed revised guidelines before deciding ACART’s final position on this particular provision.

Actions

- *Secretariat to amend the draft revised guideline as discussed by the working group and agreed by ACART.*
- *Members to consider the amended proposed guideline.*

Family donations to be subject to ECART

- 9.17 Gillian reflected that ACART had decided, at its previous full meeting, to have a provision that specified that family gamete donations should be subject to ECART review if the circumstances of that donation met criteria such as having certain risk factors.
- 9.18 Members discussed whether certain donations between family members might be more risky than others and why this might be.
- 9.19 Sarah noted that clinics do not think that all family gamete donations need to be considered by ECART. Iris advised that ECART also recommends against all family donations being subject to ECART’s approval. She observed that the definition of “family” is particularly important as the proposed change could result in large numbers of cases being referred to ECART, and many of these referrals might be unnecessary. Iris suggested that if donations involved certain risk factors then it would be appropriate for ECART to consider them.
- 9.20 Barry suggested it would be useful for ACART to have a record of the reasons for applications being deferred or declined. This information would be useful as the basis for deciding how provisions should be worded. Members agreed to write to ECART asking them to provide a summary of the criteria on which they defer or decline procedures that involve the donation of family gametes.
- 9.21 Members agreed that risk factors that could be stated in the provision would include coercion (such as whether financial dependency could be present), intergenerational effects, and whether the wellbeing of the offspring could be at risk.

Actions

- *Secretariat to amend the draft revised guideline as discussed by the working group and agreed by ACART.*
- *Secretariat to draft a letter from ACART to ECART asking ECART to provide a summary of the criteria on which they defer or decline procedures that involve the donation of family gametes. The letter should ask ECART if the guidelines have enough criteria on which ECART can base declines or deferrals.*

Surrogates should complete their own families first and have experienced a pregnancy

- 9.22 The discussion began with Gillian suggesting members consider whether a provision for surrogates completing their families first be a specific requirement or an “important consideration.” Sarah wanted to check if and how other jurisdictions regulate this matter before ACART settled on a provision. Sarah wanted to ensure New Zealand did not take a position that was notably different to other states. Iris said that ECART’s preference would be that the provision gives a strong indication but also gives ECART some discretion.
- 9.23 Members agreed it would be *preferable* for a surrogate to have completed her family, and that ideally she should have given birth to her own child before acting as a surrogate. Members agreed to confirm this provision at the next full meeting, once more information is available about how other jurisdictions manage surrogacy. The Secretariat was asked to provide the information.

Actions

- *Secretariat to provide members information about how other jurisdictions regulate this matter*
- *Members to consider the matter further at the next ACART meeting.*

Consent

- 9.24 Members noted that ACART needs to clarify when consent would need to be given, and by who, if the mandatory biological link is to be rescinded. The Secretariat was asked to provide information to enable members to assess this matter.

Actions

- *Secretariat to provide members information about consent points.*
- *Members to consider the matter further at the next ACART meeting.*

All clinic surrogacies to be subject to ECART approval

- 9.25 Members noted that ACART needs to clarify the rationale for its proposal that all clinic assisted surrogacies should require ECART approval. The Secretariat was asked to provide information to enable members to confirm this proposal.

Actions

- *Secretariat to provide members information about consent points.*
- *Members to consider the matter further at the next ACART meeting.*

Next steps

- 9.26 Gillian noted that ACART will need to re-consult the key stakeholders to fulfill ACART’s consultation obligations under the HART Act.

10. ACART's monitoring process: member reports

10.1 Members noted the new process is being used and material is being circulated. No member reports were submitted at the meeting.

11. Report on ECART's December meeting

11.1 Members noted the report.

11.2 Mike asked about a particular case that involved HLA tissue typing. Iris will ask the ECART Secretariat for details and send them to ACART.

Actions

- *Iris to ask the ECART Secretariat for details about the HLA tissue typing case and send them to ACART.*

12. Correspondence and Enquiries

12.1 Members noted the correspondence.

13.a Governance — Chair's Report

13.1 The Committee noted the report.

13.2 Gillian advised members that funds are available for two members to attend the symposium on parentage that the University of Canterbury will host in June. Kathleen has submitted an abstract for an item to present, and Gillian would like to go as an observer.

14. Secretariat report to ACART

14.1 The Committee noted the report.

14.2 There was a discussion about the FSA conference and the need to agree who could go and if they would give a presentation. Early bird registration is now open. Members agreed to discuss, by e-mail, their interest in going and whether they have a topic they would like to present. The Ministry of Health would need to approve the funds.

Actions

- *Members to discuss, by e-mail, their interest in going and whether they have a topic they would like to present.*
- *The Secretariat to ask the Ministry of Health about approval in principle for the funds.*

15. The Royal Society document about genetic editing

15.1 Members discussed the draft response Mike had written to the Royal Society about its discussion document on genetic editing. They agreed that while the document

addressed an important topic some text revision should be considered. Members discussed making some amendments to ACART's response and the amended letter will be circulated to all members for final comments before being sent to the Society.

- 15.2 Members also noted the Society is hosting open discussion events and that attending these could be useful. The Secretariat has the details of the events has circulated these to members.

Actions

- *Mike to amend the response to the society and send to the secretariat.*
- *The Secretariat to circulate the response to all members for final comments.*

Extra item 2 — an update on mitochondrial donation

- Mike gave an update on the most recent and notable developments in mitochondrial donation. Two women in the United Kingdom will have treatment this year to have a baby using an embryo that has been created using mitochondrial donation. The exact technique of the donation has yet to be confirmed.
- Mike also spoke about news in the media about attempts to clone monkeys and whether this could be a precursor to cloning humans. Mike noted that of the many attempts to clone monkeys there have only been two cloned live born monkeys from 63 surrogate pregnancies and the technique is still a long way from being proven or reliable.
- Mike also noted that this year makes the 40 year anniversary of the birth of Louise Brown, the first person born from IVF treatment. (New Zealand's first child born from IVF was in 1984.) Ideally ACART would prepare a statement that could be used to mark the occasion and/or to respond to enquiries about the technology. The Secretariat was asked to draft material for this purpose.

Action

- *The Secretariat to draft a statement about IVF and circulate to members for their comments.*

Extra item 3 — membership changes

Catherine Poutasi

- Members noted that Catherine Poutasi has resigned from ACART due to other commitments. There was a discussion about replacing Catherine and members agreed to seek a replacement with the same skills i.e. Pasifika and social sciences. The Secretariat was asked to prepare the advertisement for the replacement person.

Action

- *The Secretariat to prepare the advertisement for the replacement person*

A new Deputy Chair

- Gillian noted that Mike's term ends in April and that a new Deputy Chair will be needed. Members agreed they will choose a new Deputy Chair at the April meeting and to nominate candidates before the meeting.

Action

- *Members to nominate candidates before the April meeting.*

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

16.1 Members confirmed their availability and noted some date changes.

16.2 The details now are:

- February 22nd, Wellington, Sue
- April 26th, Auckland, Jonathan
- June 11th and 12th, Christchurch, Sarah (only for the 12th)
- August 23rd, Wellington, Kathleen
- October 18th, Auckland, Karen
- December 13th, Wellington, Gillian.

Action

- *The Secretariat to update ECART on the ACART attendees.*

17. Conclusion of meeting

17.1 The next ACART meeting is scheduled for 6 April 2018 and will be held at the Dunedin Airport Conference Centre. Members should contact Moana for travel arrangements.

Action

- *Members to contact Moana to make travel arrangements.*

17.2 The meeting closed at 3.00 pm.