



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

Held on 6 April 2018, at the Dunedin Airport Conference Centre, Dunedin

Present

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

Non-members present

Paul Copland, ECART
Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat

1. Welcome

- 1.1 The Chair welcomed the Committee members and Paul Copland from ECART.
- 1.2 The Chair also regrettably noted the recent death of Jo Fitzpatrick, who was a member of ECART, and advised members she had passed her condolences to that committee.

1.a Opening comments

- 1.3 Kathleen spoke about outcomes for children and the need to be clear about, and act for, the best interest of the child. The Office of the Children's Commissioner has a comprehensive one page guideline on how to consider the best interests of a child. Kathleen noted there is a 'cross Ministry' group at the Ministry of Health that considers children's health and wellbeing.
- 1.4 Barry noted that the need for resources for the aging population is drawing resources away from children. John has information about the best interests of children that he will share with members.

Action

- *Share information about the best interests of children with members.*

2. Apologies

- 2.1 Sue McKenzie.

3. Approval of the agenda

- 3.1 Members approved the agenda. Two additional items were added: one was to farewell Mike Legge and the other was related to item 15 on genetic editing.

Action

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

4. Declarations of Interests

- 4.1 These had previously been circulated. No amendments were requested.

5. Minutes of ACART's meeting of 9 February 2018

- 5.1 The minutes were approved with minor amendments.

Actions

- *Amend the minutes as requested.*
- *Place the February 2018 minutes on ACART's website.*

6. Actions arising from the previous minutes

- 6.1 Members noted the status of actions and discussed matters arising.
- 6.2 Paul Copland noted that the case involving HLA tissue typing that had come to ECART had been completed.
- 6.3 Barry advised that the Royal Society had been very impressed with the quality of ACART's submission on the society's document on genetic editing.

- 6.4 Members agreed the Secretariat should follow up with the Department of Internal Affairs to ensure that ACART's contacts there are the most suitable people in that department to respond to ACART consultations. Related to that point, members agreed that when ACART consults reminders should be sent to parties whose input is likely to be needed.

Action

- *Follow up with the Department of Internal Affairs to ensure that ACART's contacts there are the most suitable people in that department to respond to ACART consultations*

7. Work programme

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

Cryopreserved ovarian tissue

- 7.2 If the Ministry of Health considers whether to publically fund the use of cryopreserved ovarian tissue it will need accurate estimates of the number of cases likely to occur. ACART should check the most recent literature on the procedure and advise the Ministry about the estimated numbers.

Action

- *Check the most recent literature on the use of cryopreserved ovarian tissue and advise the Ministry about the estimated numbers.*

Meet the Minister of Health

- 7.3 The Chair will meet the Minister of Health on 2 May to discuss ACART's functions and work programme. Members agreed what ACART's priority should be if the discussion turns to the new work the committee could move on to once it has finished the review of the donation guidelines.

IFFS report

- 7.4 John Peek (at Fertility Associates) is now providing data to the International Federation of Fertility Societies and the next report that will include New Zealand data will be published in 2019. Sarah will be ACART's primary contact with John once Mike has left ACART.

8. Membership

- 8.1 The Secretariat updated members on progress to find a replacement for Catherine Poutasi and to have Kathleen Logan's membership renewed.
- 8.2 Members voted for a new Deputy Chair to take over from Mike. Mike's membership ends on 19 April 2018. Kathleen Logan was elected and her position as Deputy Chair commences on 20 April 2018.

9. Posthumous reproduction

- 9.1 The Secretariat summarised the outcomes from the last working group meeting, held in March, to all members.

- 9.2 Members were asked in the meeting to review and discuss the near final consultation document for part one of the consultation.
- 9.3 Members made minor changes to the consultation document during the meeting, and agreed to email the Secretariat with tracked changed comments for the Secretariat to collate. The Secretariat will work with the Chair on the foreword for the stage one consultation document.
- 9.4 Members agreed the working group to approve the consultation document following these changes out of session, subject to any substantial comments received internally from Health Legal, the Manager of the Ethics group and ECART.

Public consultation plan

- 9.5 The finalised consultation document will be sent to ACART's list of submitters as well as a number of targeted individuals and groups that have been identified as having a particular interest in this consultation. It will be available on Survey Monkey and the Ministry of Health and ACART's web pages.
- 9.6 The Secretariat will work with the Ministry's communications team to look into the best way to socialise the consultation with the public for a wide reach.
- 9.7 Members were informed that the Secretariat will be supporting the Office of the Children's Commissioner to consult young people on the document, as part of some schools' curriculums. There may be a need for focus groups as part of this consultation.

Actions

- *Secretariat to receive feedback and update the consultation document following feedback from ECART, the Manager of Ethics in the Ministry's PRA Business Unit, and Health Legal.*
- *Secretariat to work with the Chair on the foreword for the document.*
- *Secretariat to complete internal processes such as briefing the Minister and organise formatting and publication with the Ministry of Health.*
- *The Office of the Children's Commissioner to circulate through schools an age appropriate version of the questionnaire to be used by young people to gauge their views on posthumous reproduction.*

10. Donation guidelines review

- 10.1 The Secretariat summarised the matters for discussion then explained the discussion it had had with the Ministry for Children about international surrogacy.
- 10.2 The Ministry for Children had commented on possible effects of removing the mandatory biological link, stating that doing so could have a bearing on the ability of offspring to identify their genetic parents in international surrogacy cases. The Ministry for Children is going to explain its ideas to ACART in writing. That Ministry had also commented on stateless children but acknowledged that this would not be affected by the proposed removal of the mandatory biological link.
- 10.3 The Secretariat gave its opinion that it does not appear that any new or exacerbated risk would result from removing the mandatory biological link in the ways that the Ministry of Children has commented on. Once the Secretariat has received the

written advice from the Ministry for Children it will share it with ACART and recommend next steps.

Action

- *Secretariat to obtain advice from the Ministry for Children.*
- *Secretariat to pass the advice to ACART.*

Finishing families, and being pregnant before being surrogates

- 10.4 Members discussed a) whether women should have finished their own families before being surrogates and b) the importance of having experienced pregnancy and giving birth before acting as a surrogate. Members considered the tension between individual autonomy and paternalism.

Should surrogates complete their own families first?

- 10.5 Members discussed the strength of the proposed provision for surrogates to have finished their own families first. That is, whether the provision should say a woman *must* have finished her own family first or whether the provision should strongly *recommend* that she should have.
- 10.6 Members noted that internationally there is a preference for finishing a family before acting as a surrogate but that it is not a requirement. Barry observed that a requirement that a woman must have finished her family before acting as a surrogate is not actually enforceable or measurable — a woman might have another child for herself after being a surrogate.
- 10.7 Members agreed that the provision should sit in the *initial* provisions for clinic assisted surrogacy and state: “*ECART must be satisfied that . . . the risks associated with a surrogacy for the adult parties and any resulting children are justified in the proposal. The risks are . . . risks to the health and wellbeing of the intending surrogate . . . including . . . the risks to the future reproductive capacity of the surrogate.*”

Should surrogates have experienced pregnancy and childbirth?

- 10.8 Members discussed whether a person can give fully informed consent to an action which they have not experienced before. Members agreed that the risks to the surrogate of not being able to have her own children (after being a surrogate) need to be acknowledged and accounted for. They agreed that the risks are significant enough that the provision needs to state that there is a strong preference that a woman have experienced a pregnancy before acting as a surrogate.
- 10.9 Members agreed the provision should sit in the counselling section for clinic assisted surrogacies and state: “*ECART must be satisfied that, where relevant, the risks to the surrogate of not having previously experienced pregnancy or childbirth have been considered by the intending surrogate.*”

Action

- *Secretariat to amend the surrogacy provisions as requested.*

Family gamete donations that should be subject to ECART approval

- 10.10 Members noted the new information, provided by the Secretariat, about the regulation of family gamete donations, in particular the list of prohibited family gamete donations in the United Kingdom. They also noted that the family gamete donations that are currently prohibited in New Zealand are prohibited in the guideline and not in the HART Act. Members asked the Secretariat to check the Fertility Services Audit Workbook to see if the prohibited donations are referred to in that document.
- 10.11 There was a discussion about whether revised guidelines should be expanded to include a greater range of close relatives between whom donations would be prohibited. Members agreed to adopt the UK list of prohibited relationships. Corresponding advice from ACART to the Minister will need to explain why the expanded provision is recommended. The provision would be based on “genetic relatedness.”
- 10.12 Members noted that the 2011 UK review of family donations concluded that the risks were appropriately managed by clinics. A member raised the issue of whether ACART had considered recommending that all family donations be established procedures, in the course of developing its preliminary position on family gamete donations. There was a discussion about the risks being managed and when cases should be referred to ECART. The Euro-centric notion of family was noted, as was the point that for some people and/or cultures intra-family donations might be preferable to donations by non-family members.
- 10.13 Members noted that the counselling process is mandatory for people using donations and will usually address the matters that need careful consideration. The referral of cases to ECART will only be needed in a small number of cases. Members agreed to add a provision to the family gamete donation section of the guideline that states: “*Cases with additional complexities can be referred to ECART.*” Members also agreed to recommend that the Order be amended to remove the list of relationships that automatically require ECART approval for a donation.
- 10.14 Members noted that any advice to the Minister of Health would need to clearly state which donations were prohibited, which would be subject to ECART approval and which would be established procedures. The advice would need to make recommendations about changes to the HART Order.

Action

- *Check the Fertility Services Audit Workbook to see if the prohibited donations are referred to in that document.*
- *Add a provision to the family gamete donation section of the guideline that states: “Cases with additional complexities can be referred to ECART.”*

Consent points

- 10.15 The Secretariat summarised why this matter was being reconsidered, noting that it was apparent from the submissions that the points at which consent would be needed were not entirely clear under the proposed new guidelines. This was particularly the case for the donation and re-donation of embryos.
- 10.16 The Secretariat stated that a useful approach to ensuring all parties understand if and when consent must be obtained (or possibly re-obtained) is to state the types of situations in which consent must be obtained. For example, if a person’s gametes are

used to create an embryo he or she must consent to an embryo being formed from those gametes, or if a person/couple donates an embryo they must consent to that donation.

- 10.17 The Secretariat also noted that with the proposed allowing of the re-donation of embryos a question arises about whether the original *gamete* donors would need to give consent again. If so, this would be a departure from the current position whereby gamete donors have no say in the use of an embryo once their gametes have been used to create the embryo. Members asked to check the details about ECART's submission and whether it had addressed the timing of consenting.
- 10.18 Members discussed the phrase "specific use," noting that it can be unhelpful. A member suggested that a more useful provision would state that donors should be required to *describe* the type of use to which they consented. A suggested provision was "A person must describe the use of the gametes they agree to."
- 10.19 Members asked the Secretariat to remove "specific use" from the provision. They also asked the Secretariat to check ECART's submission on this point and whether ECART had a particular question about the timing of consent.
- 10.20 Members noted that the proposed provisions 14, 15 and 16 of the consent provisions need to be amended to account for re-donations.

Actions

- *Remove "specific use" from the provision.*
- *Check whether ECART had a particular question about the timing of consent.*
- *Amend provisions 14, 15 and 16 of the consent provisions to account for re-donations.*
- *Secretariat to liaise with Colin to ensure consent provisions are suitable once amended.*

All clinic surrogacies to be subject to ECART approval

- 10.21 Members noted that they simply need to agree the list of reasons that ACART will provide to ensure the public understand why ACART has taken this position.
- 10.22 Members agreed that ACART should be clear that if clinic assisted surrogacies were not subject to ECART approval the management of those surrogacies would lie entirely with the clinics.

Actions

- *Secretariat to provide members a list of reasons for all clinic assisted surrogacies being subject to ECART approval*
- *Members to comment on the list.*

11. Report on ECART's February meeting

- 11.1 Members noted the report. They noted that all twelve applications for the extension of storage of gametes and embryos had been approved.
- 11.2 Paul Copland explained that the reason a surrogacy application had been declined was that the surrogate had several health conditions that would have put her and any offspring at risk.

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 she would attend the Fertility New Zealand meeting on Saturday 7 April and will give them an update on ACART's work.

13.3 Gillian explained she will also meet Philippa Bascand (Ministry of Health) on Tuesday 10 April and Mike will join the meeting by teleconference. The discussion will likely cover matters including how ACART and the Ministry of Health can cooperate on work, as well as capacity, budget and resourcing.

14. Secretariat report to ACART

14.1 The Committee noted the report.

15. Update on reproduction and genetic editing

15.1 Mike gave an update on the most recent and notable developments in reproduction and he spoke about news in the media about attempts to clone monkeys. Mike noted that of the many attempts 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.

15.2 Mike also spoke about developing treatment for "Fragile X" and about DNA sequencing and how it might be used to predict phenotypes. The development of artificial gametes is another matter for ACART to monitor and potentially advise on.

15.3 Mike updated members on genetic editing and advances in the technology. He noted that the elimination of genetic diseases would be a major reason for improving and using the technology.

Extra item — Karen's comments on embryo research

15.4 Karen advised members that she was aware of researchers in New Zealand who are interested in research using embryos. She noted that research using viable embryos is not permitted under the current guidelines. If the research guidelines are amended to allow research using viable embryos New Zealand would be able to take part in a greater range of research.

Extra item — farewell for Mike Legge

- Gillian thanked Mike for his service to the committee over the last six years, in particular noting his expertise and the extra time he spent on committee work of his own volition. Several other members also expressed their gratitude and Alison Douglass (former member and Chair of ACART) joined the meeting for the farewell to Mike.

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

16.1 Members noted the upcoming meetings. Attendees have been agreed.

17. Conclusion of meeting

17.1 The next ACART meeting is scheduled for Friday, 8 June 2018 and will be held at the “Front and Centre” Conference Centre in Wellington. Members should contact Moana for travel arrangements.

17.2 The meeting closed at 4.30 pm.