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

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Held on 10 August 2018, at the Dunedin Airport Conference Centre, Dunedin.

Present

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

Non-members present

Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat
Jeanne Snelling, Otago University (until 1.30pm)
Paul Copland, ECART

1. Welcome

1.1 The Chair welcomed the Committee members and Paul Copland from ECART, and noted that Dr Jeannie Snelling would be coming for a short presentation on PGD.

1.2 Gillian noted that she had resigned as Chair, with effect from 23 August, due to time and travel commitments from a new role.

1.a Opening comments

1.3 Jonathan took members through opening comments as ACART's member with a disability perspective. He noted that one of the provisions in the United Nations Convention on the Rights of Persons with Disabilities relates to sexual and reproductive health. The New Zealand Disability Strategy 2016 to 2026 also requires that persons with disability hold the positive right to reproduce and to not encounter barriers when accessing sexual and reproductive health services.

1.4 Members discussed the significance of these documents, given the history of paternalism and sterilisation of persons with disability, and how the disability community is expanding to include non-physical disabilities also. It was a reminder that information to all consumers needs to be accessible and appropriately communicated depending on the individual's needs.

2. Apologies

2.1 Sue McKenzie.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 Barry Smith asked for one item to be added to his declarations: he is now a member of the Perioperative Mortality Review Committee.

Action

- *Add the item requested.*

5. Minutes of ACART's meeting of 8 June 2018

5.1 The minutes were approved.

Action

- *Place the June 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.

7. Work programme

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

Cryopreserved ovarian tissue

7.2 ACART is concerned at the lack of progress for this item by the Ministry, given that the original correspondence indicated the HART Order would be amended by December 2017.

Action

- *ACART to include the risks around this work not being completed in the letter to the Director General of Health. (See paragraph 8.4 below.)*

Cryopreserved testicular tissue

7.3 In September 2015 the then ACART Chair wrote to the Ministry, noting that the status of frozen testicular tissue is unclear. In February 2018 members were advised that no action had been taken, and that this work — along with a list of outstanding policy work — is now to be undertaken by the Ministry staff in the Secretariat that supports ACART.

ACART Annual Report 2016/17

7.4 The 2016/17 Annual Report has been completed. The Secretariat has facilitated the next steps to notify the Minister of Health and have the Annual Report tabled in the House. Once that has happened, the Annual Report may be published on ACART's website.

7.5 The Secretariat has also completed the 2017/18 Annual Report, and is awaiting approval of the Chair's foreword before it is tabled in the House also.

Action

- *Secretariat to publish the 2016/17 Annual Report on ACART's website once it is tabled in the house.*

8. Planning ACART's work programme and the Ministry's related ART work

8.1 This paper asks the Committee to discuss and decide how to manage the depleting Secretariat support from the Ministry, and how to liaise with the Ministry of Health about the outstanding policy work that was transferred from the Ministry's policy staff to the ACART Secretariat during the Ministry's 2017 restructure.

8.2 The Committee noted that the ACART Secretariat is operating at approximately 0.7 full time equivalent for ACART. This has meant that the Chair and Deputy Chair have needed to pick up a lot of work to get it finished. The Committee is finding it very challenging to complete the work the Minister has agreed ACART should do in a timely manner.

8.3 The Chair noted that the Committee needed to receive direction about the work on Human Reproductive Research from the Minister before a meaningful conversation can be held about priorities.

8.4 Members decided that the Chair should write a formal letter to the Director General of Health about resourcing issues, indicating:

- ACART's concerns that the Secretariat FTE has diminished from 2.5 to 0.7 FTE
- the difficulties ACART has in fulfilling their functions
- the difficulties ACART has in delivering the work programme that has been agreed with the Minister

- that ACART faces a reputational risk
- they would like dedicated resource — perhaps a contractor — to enable the Committee to have certainty about a minimum level of policy support, when undertaking work planning.

Action

- *Write a formal letter to the Director General of Health.*

9. Membership updates

9.1 Members and the secretariat noted that:

- candidates to replace Catherine Poutasi have been short listed and interviews are about to be held
- Kathleen Logan's reappointment has been confirmed
- members are happy for Kathleen to be the acting Chair now that Gillian Ferguson is leaving ACART. Kathleen will confirm that her employer is comfortable with this arrangement
- a new Chair will need to be recommended to the Minister of Health
- Colin is happy to provide extra support until the new members are in place.

10. Posthumous reproduction

Public consultation

10.1 The Secretariat gave members an update the status of the stage one consultation document on Posthumous Reproduction. The consultation document was finalised in June and public consultation began on 3 July 2018. Submissions will be open for eight weeks, and will close on 3 September 2018. The Secretariat advised that at the time of the meeting on 10 August 2018, 16 submissions had been received.

10.2 The Secretariat is organising meetings with fertility clinics and interested groups to be attended by a member of the working group and a member of the Secretariat during the consultation period. Meetings have been organised with Repromed, Fertility Plus and Fertility Associates. Genea Oxford Fertility do not wish to meet.

Consultation with students

10.3 The Committee previously agreed that it would be useful to canvas the views of young people regarding posthumous reproduction by running targeted consultation questions with them. Children and young people make up a quarter of the population and it is the Committee's view that children's voices should be heard on matters that affect them.

10.4 The Centre for Science and Citizenship was commissioned by ACART to run a session with young people on 15 June 2018 and attended by a member of ACART and a member of the Secretariat. Four schools, consisting of young people aged 15 to 18 (around 120 students) attended the session in Auckland at Maclean's College. These students had an existing relationship with the Centre for Science and Citizenship, and had been attending sessions regarding beginning and end of life issues. The day was informative and engaging, and students were very thoughtful about the issues around posthumous reproduction. At the end of the day, students

could opt to fill out a version of our survey to tell us what they think. Kathleen Logan has collated the high level themes which will feed into the wider stage one consultation feedback.

Action

- *The Secretariat to present ACART with a submissions analysis following the end of the consultation period, and organise a working group meeting to consider next steps.*

11. Donation guidelines review

11.1 The Secretariat summarised the paper and the actions ACART were being asked to take.

11.2 Members worked through the revised draft guidelines and agreed to most of the text and requested some changes.

Action

- *Make the changes requested.*

Consent provisions

11.3 The Chair explained that not all parties who read the consultation version of the guidelines had interpreted the consent provisions in the same way. Consequently, those provisions had been clarified and explanatory text provided. Members agreed that this explanatory text should be shared with the sector when the guidelines are published.

Action

- *Prepare the explanatory text to share with the sector.*

The biological link and statelessness

11.4 Members discussed the proposal to rescind the mandatory biological link and what the risk might be that children could be stateless. Members agreed that the removal of the mandatory biological link could in fact reduce the risk of statelessness because, while the guidelines do not apply to international surrogacy, the Minister of Immigration may approve immigration cases involving offspring with no biological link to the intending parents.

11.5 Also, the removal of the mandatory biological link could reduce the number of intending parents seeking fertility treatment overseas. Having made these points members noted that a “residency” provision should be reinstated but the wording should be amended so that residency would be a consideration for ECART to take into account rather than a requirement.

11.5 Members agreed to send a formal response to the Ministry of Children, thanking them for their submission and explaining ACART’s decision.

Action

- *Write to the Ministry of Children, thanking them for their submission and explaining ACART's decision.*
- *Reinstate a residency provision to the guidelines.*

Family gamete donations

11.6 The Chair recalled that ACART had suggested that a) the HART Order be amended to state that all first order family gamete donations be prohibited and b) that four specific scenarios involving family gamete donations become subject to ECART approval.

11.7 The Chair then advised members that the Ministry of Health had responded to ACART's request for advice on if and how those types of donations could be subject to ECART approval. She informed members that the Ministry had responded saying that any restrictions would need a clear justification and that if no such justification could be made that ACART might consider alternative methods of regulation. One option would be to rely more on a clinical approach, such as is done in the United Kingdom. Another option could be to consider adding provisions to another regulatory mechanism such as the Code of Health and Disability Services Consumers' Rights or the Fertility Services Standard. The Secretariat observed that the FSS is about to be reviewed and drew attention to the other item in today's agenda about that review.

11.8 Members discussed this matter at length, noting that ACART believes there are good reasons to regulate certain donations. Members agreed that ACART needs to create a document setting out a clear case for the proposed provisions. Members also agreed to ask the Ministry of Health for further advice on options for regulating family gamete donations.

Action

- *Create a document setting out a clear case for the proposed provisions.*
- *Ask the Ministry of Health for further advice on options for regulating family gamete donations.*

Interim guidelines

11.9 Members discussed the provisions that could and could not be included in interim guidelines, and how many people might be affected by interim guidelines. They noted that to be worthwhile interim guidelines would need to affect more than just a handful of cases.

11.10 Members noted that an alternative process to produce the final guidelines might be preferred, whereby ACART finishes the analysis of regulatory options at its next meeting and then:

a) discusses these options with the public in a re-consultation document (discussed further below)
b) decides what the new guidelines should state and
c) decides what advice should be provided to the Minister before issuing the new guidelines, bearing in mind that ACART might recommend regulatory changes in that advice.

Consult again

11.11 Members discussed the option of consulting again, in particular on the provisions for family gamete donations and the consent provisions and agreed that a second round of consultation should be done.

Action

- *Complete the second consultation document (for consideration at the October meeting).*

Other points

11.12 Members discussed "coercion" again, noting that the wording was not quite right and that it is important to be clear about the terminology. Members agreed the phrase that should be used will be "there are concerns that there might be undue influence."

11.13 Members noted it is difficult to settle on a definition of "intergenerational." They noted that the four draft provisions for family gamete donations that would make cases subject to ECART consideration could be reworked to distil more specific concepts that could be included in a new provision that could include concerns such as intergenerational matters.

11.14 Members asked the Secretariat to compile a list of concerns that could be related to, or part of, intergenerational and use that to create a new provision — the underlying concerns need to be explored. They also agreed that at least half of ACART's October meeting should be spent on this project and that the Ministry of Health legal staff should be invited to take part.

Action

- *Compile a list of concerns that could be related to, or part of, intergenerational and use that to create a new provision.*
- *Invite the Ministry of Health legal staff to ACART's October meeting.*

12. ACART's monitoring process: member reports

12.1 Karen noted a recent study by ESHRE that finds there is no clinically significant difference in live birth outcomes from embryos that have undergone PGS, and embryos that have not. There is however, a reduction in miscarriage for embryos that have undergone PGS.

13. Report on ECART's June meeting

13.1 Members noted the report.

13.2 Paul Copland, the ECART member in attendance, discussed an application for embryo donation for reproductive purposes that had been declined by ECART at their previous meeting on 12 June 2018. Paul noted that ECART had a very long and varied discussion about this application. The reasons it was declined, were the committee believed the risks to the resulting child of carrying a fatal gene is high

(50%) and a mitigating strategy of testing the embryos using PDG is available to the recipient couple. ECART is willing to reconsider the application if the couple can give more information and ACART understands the applicants will be attending the next ECART meeting.

13.3 Members noted that the fact that the Human Assisted Reproductive Technology Act does not say the interests of the child are paramount makes it difficult to make decisions resting solely on the wellbeing and rights of the child as a justification.

14. ANZARD Report

14.1 The New Zealand specific 2015 ANZARD report was received in June 2018 and included in this agenda pack for members' information.

14.2 This item was deferred to ACART's next meeting in October when the Secretariat will attach a draft foreword from the Chair, and an information summary sheet of the report for member's consideration.

15. Correspondence and Enquiries

15.1 Members noted the correspondence.

15.2 ACART received correspondence from ECART that a study about Human Reproductive Research was declined by ECART under s 18(2)(b) of the Human Assisted Reproductive Technology Act. ACART noted that this application was very similar to a research application in 2014. Members agreed that ACART should advise the Minister about this recent application when it next seeks his agreement to the work programme.

Action

- *Advise the Minister about this recent application when next advising him about ACART's work programme.*

16. Governance — Chair's Report

16.1 Members noted the report.

17. Secretariat report to ACART

17.1 Members noted the report.

18. Review of the Fertility Services Standards, opportunity to comment

18.1 The Secretariat advised members that ACART has an opportunity to take part in the review of the Fertility Services Standard. The review will comprehensive, taking two years, and be led by the Ministry of Business, Innovation and Employment and supported by the Ministry of Health. The Health and Disability Services Standards will also be reviewed.

18.2 Members noted this is a good opportunity to ensure that fertility services are managed properly. They noted that ACART has already discussed options such as adopting, or borrowing from, the Code of Practice used by the British Human

Fertilisation and Embryology Authority and also the Australian Reproductive Technology Accreditation Committee.

18.3 Members agreed the Secretariat should speak to the Ministry of Health about how ACART can take part.

Action

- *Speak to the Ministry of Health about taking part in the review of the standards*

Extra item: presentation by Jeanne Snelling — Judging Genes and Choosing Children

- Jeanne took ACART through her research into the challenging and rapidly developing field of genetic technologies and Preimplantation Genetic Diagnosis (PGD). The evidence shows that there is no more risk to the embryo when undergoing PGD than with other procedures such as IVF or ICSI.
- PGD allows prospective parents to test for a number of conditions at a time, and the developing technology of Preimplantation Genetic Screening enables comprehensive screening of all chromosomes.
- Currently, the cost is high but the technology has become cheaper and is being adopted by clinics in New Zealand. Jeanne noted that screening is likely to be widely adopted in the future.
- The United Kingdom is leading at the forefront of genomics and PGD, and the National Health and Medical Research Guidelines in Australia give guidance about clinically significant incidental genetic findings.
- Members discussed access to screening technology and equity issues. With the recently declined ECART application in mind and Jonathan's opening comments about equality and the expanding definition of disability, members noted the HFEA guidance that if there is a known genetic disorder in an embryo, then ethical approval is needed before implanting.

Extra item: farewell for Gillian Ferguson

- Members thanked Gillian for her dedication to ACART and her professionalism and Gillian thanked members and wished them well.

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

19.1 Attendees had previously been agreed. Kathleen Logan will be the ACART member in attendance at ECART's next meeting on 23 August in Wellington.

20. Conclusion of meeting

20.1 The next ACART meeting is scheduled for Friday, 19 October 2018 and will be held at the "Front and Centre" event centre in Wellington. Members should contact Moana for travel arrangements.

Action

- *Advise members the start and end times and location when arranging travel.*

20.2 The meeting closed at 3.30 pm.