Minutes of the Fifty-ninth Meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 12 February 2016 at the Wellington Airport Conference Centre, Wellington

Present

Alison Douglass (Chair)

Mike Legge (Deputy Chair)

Karen Buckingham

Jonathan Darby

Nikki Horne

Kathleen Logan

Barry Smith

Non-members present

Paul Copland (ECART)

Philippa Bascand (Manager, Ethics Committees, Ministry of Health; 8.45am to 1.30 pm)

Betty-Ann Kelly (ACART Secretariat)

Hayley Robertson (ACART Secretariat)

Martin Kennedy (ACART Secretariat)

Stella Li (ACART Secretariat)

Dev Oza (Manager, Business and Committee Services, Ministry of Health; 9.45am to 1.30pm)

Apologies

Sue McKenzie

1. Welcome

1.1 The Chair welcomed the Committee members and guests.

1.2 Kathleen Logan gave the opening comments. She talked about attending the Redefining Families Conference in January 2016.

1.3 She commented that the sense of belonging and the idea of relatedness is important to children; it can be argued that a biological link enhances a child's sense of connection. She noted that these notions underpin the biological link policy, and that ACART will need to look carefully at these when reviewing the policy.

1.4 Kathleen also talked about two different perspectives towards family formation discussed at the conference. On one hand people are of the view that there should be minimal restrictions or regulations in the way people form their families. On the other, we should be prepared to draw the line where there are pathways to family formation that are unnecessary and/or unethical.

2. Approval of the agenda

2.1 Members approved the agenda.

Action

- *Secretariat to place the February 2016 agenda on ACART's website.*

3. Declarations of Interests

3.1 There were no declarations of interests.

4. Minutes of ACART's meeting of 11 December 2015

4.1 The minutes were approved subject to minor changes.

Action

- *Secretariat to amend the December 2015 minutes and place on ACART's website.*

5. Actions arising from the previous minutes

5.1 Members noted the status of actions arising from the 11 December 2015 meeting.

6. Work programme — current status

6.1 Members noted the status of the items on the programme.

6.2 The Committee discussed progress towards a Ministerial decision about developing new human reproductive research guidelines. Members agreed to draft a preliminary scoping document that would set out ACART's views about the scope of human reproductive research, as a basis for deciding what would be in and out of scope in the potential guidelines. Members thought such a document may be useful for the Minister's consideration. Members agreed that it would be helpful to share ACARTs conclusions with the Ministry of Health, to ensure that the scope of any guidelines was consistent with the Ministry view.

Action

- *Secretariat to draft a preliminary scoping document, to include analysis of what would be in and out of scope in potential human reproductive research guidelines, with examples of types of research.*

7. Operations of the HART Act – Report on ECART decisions

7.1 Members noted that the decisions of ECART's September 2015 meeting will be discussed at the April 2016 meeting.

Guest – Philippa Bascand, Manager, Ethics Committees, Ministry of Health

7.2 Philippa provided the Committee with an update on the arrangements of the ECART Chair.

7.3 She commented on ECART's 2015 workload, noting the Committee had received a high number of applications. Furthermore, ECART had needed to consider a wide range of scenarios presented in applications when deciding what would be in the best interests of a potential child.

7.3 A review of ECART's Terms of Reference was on ECART's future work programme. Philippa also noted the possibility of developing a joint Memorandum of Understanding between ECART, ACART and the Ministry of Health.

7.4 The Chair noted that new ACART appointments were in progress. The training day later in the year for new ACART members could include the forthcoming new ECART member, depending on timing.

Actions

- *ACART to consider ECART's September 2015 meeting decisions at ACART's April 2016 meeting.*
- *Secretariat to organise a joint training day for new ACART and ECART members.*

8. Informed consent — consider the draft advice to the Minister

8.1 Members considered draft advice to the Minister about informed consent for human assisted reproduction which included the Working Group's recommendations.

8.2 Members agreed it would be useful to include the main themes from the consultation, in the summary of submissions document, in the body of the advice.

8.3 The Committee talked about the challenges related to informed consent in the context of assisted reproduction. The members agreed the advice needed to be clearer and more specific wording on these issues, including around the challenges presented from cultural and disability perspectives.

8.4 Members noted that some matters that are routine aspects of assisted reproduction appear to be outside the jurisdiction of the Code of Health and Disability Services Consumers' Rights (the Code). ACART had made a submission on the matter to the 2013 review of the Code.

8.5 For instance, gamete donors continue to have an interest in their gametes being used in accord with their consent, beyond the period that gametes are obtained and stored. Embryo donors do not use a health care procedure in order to donate, except for counselling before ECART considers an application, and similarly have an interest in a donated embryo being used in accord with their consent.

8.6 The Committee provided feedback on the draft recommendations regarding:

- access to information
- written consent
- consent for gametes and embryos to be used in training
- placing conditions on donations
- a cooling off period for disputes over embryos

Access to information

8.7 Members discussed what it means to improve access to information. Based on the consultation feedback, members noted that access to information about current clinical processes does not appear to be a problem. Nor is there a lack of information available. Members talked about the potential to improve access in terms of ensuring the information provided is understandable, communicated appropriately, and tailored to a consumer's or donor's circumstances.

8.8 Members also talked about the potential for improving access to information more generally, for example educating consumers and donors on what information or consents they can expect.

8.9 The Committee noted that clinics all had their own well-established consent forms, and agreed ACART would not recommend standardised consent forms. ACART does not have a role in auditing the current consent forms.

Written consent

8.10 ACART discussed the draft recommendation on written consent. Members noted that it is currently best practice for some procedures to require written consent. However the Committee acknowledged that in law, the form of consent provided may be written or oral.

Consent for gametes and embryos to be used in training

8.11 Members agreed that the recommendation must be clear on ACART's understanding of what 'training' is. Members agreed the advice should include a definition and examples of training.

Placing conditions on donations

8.12 The Committee considered that ACART did not have a role in prescribing what the conditions on donations should be, and that the type of conditions set should be donors' choice.

8.13 The Committee noted an embryo donation is similar to a personal gamete donation because the donors make choices about who receives the donated gamete or embryo. While this is not the case for clinic gamete donors, clinic gamete donors should also be able to make choices about the use of their

gametes. ACART noted that not allowing donors to place conditions could potentially decrease the pool of available gamete donors.

A cooling off period for disputes over embryos

8.14 The Committee discussed the potential recommendation of a cooling off period where there is a dispute regarding the future of an embryo. Members agreed the advice should include recommending that a dispute resolution process or other forum should be available to couples during this time.

8.15 The Committee noted that there may be implications for the time limitations on the storage of embryos (currently ten years), and what that would mean for any stored embryos if the cooling off period was not limited in duration and ran past the maximum storage time.

8.16 Members agreed to request information from the Human Fertilisation and Embryology Authority (HFEA) about the operation and outcomes of the cooling off period in the United Kingdom.

Actions

- *Secretariat to include the main themes from the consultation document, as per the summary of submissions, in the body of the advice.*
- *Barry Smith and Jonathan Darby to assist with wording in the section on challenges related to informed consent in the context of assisted reproduction.*
- *Secretariat to contact the Health and Disability Commission inviting feedback on the recommendations in the advice.*
- *Secretariat to draft an e-mail for the Chair to the HFEA asking for information about the operation of the UK cooling off period.*
- *Secretariat to make any amendments to the draft advice in accord with ACART's decisions.*
- *Secretariat to circulate a new draft to members.*
- *The Chair to decide if a further Working Group meeting was needed in March.*

9. Use of cryopreserved ovarian tissue

9.1 The Committee discussed the draft consultation document on the use of cryopreserved ovarian tissue. Members noted the need to be clear on the meaning of 'use' of cryopreserved ovarian tissue. Members noted that where there is a successful transplantation, there is successful restoration of ovarian function which would potentially enable a woman to have a baby. ACART agreed it is important to capture the broader uses of the transplanted tissue (eg, producing hormones and fertilisable eggs) beyond assisted reproduction.

9.2 The Committee noted its proposed advice is focused on the use of cryopreserved ovarian tissue. While the technical report includes information on both ovarian and testicular tissue, the Committee agreed to include the full technical report in its proposed advice, explaining that testicular tissue is not addressed in the proposed advice.

9.3 Members provided feedback and editorial comments on the document. The Committee agreed that the Secretariat should amend the document and for the Working Group to sign-off via email.

9.4 Members agreed that following Working Group sign-off the consultation preparation and process can proceed.

Action

- *Secretariat to amend the consultation document as discussed and email to the Working Group for final sign-off.*

10. Review of the donation guidelines

10.1 The Secretariat provided the Committee with an update on Secretariat work to date in 2016 on the project concerned with reviewing the three donation guidelines (family gamete donation, embryo donation, and donated eggs/donated sperm).

10.2 Working Group members agreed to meet in March 2016 to consider information and analysis provided, and to decide any recommendations to ACART about policy and next steps.

Action

- *Secretariat to organise a Working Group meeting in March 2016.*

11. Monitoring

11.1 The Committee agreed to defer this agenda item for discussion at ACART's April 2016 meeting.

Action

- *ACART to consider February's Monitoring paper at ACART's April 2016 meeting.*

12. Governance

13. Governance

Chair's report.

13.1 The Committee noted the report.

14. Correspondence

14.1 There was no correspondence.

15. Secretariat report to ACART

15.1 The Committee noted the report..

16. An ACART member to volunteer to be the "member in attendance" at the next ECART meeting

16.1 Sue McKenzie will attend the upcoming March ECART meeting.

17. Conclusion of meeting

17.1 The work likely between meetings includes work on:

- the advice to the Associate Minister on informed consent
- the consultation document on the use of cryopreserved ovarian tissue
- the review of the donation guidelines.

17.2 The next ACART meeting is scheduled for 8 April 2016 and will be held at the Wellington Airport Conference centre.

17.3 The meeting closed at 2.30pm.