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

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Held on 14 June 2019, at the Wellington Airport Conference Centre.

Present

Kathleen Logan (Chair)
Calum Barrett
Jonathan Darby
Colin Gavaghan (Deputy Chair)
Sue McKenzie
Karen Reader
Sarah Wakeman

Non-members present

Jude Charlton, ECART
Hayley Robertson, ACART Secretariat
Martin Kennedy, ACART Secretariat
Linda McIver, Louisa Walls's office (10.30am to 11am)
Ashley Bloomfield, Director General of Health (11am to 11.45am)

1. Welcome

1.1 The Chair welcomed the Committee members.

1.a Opening discussion

1.2 Calum Barrett gave the opening comments, introducing himself as the newest consumer member of ACART. Calum discussed his background in Policy and Health Law, with an interest in assisted reproductive technology and Pre implantation Genetic Diagnosis, and noted the importance of openness with any children resulting from assisted reproductive technologies.

1.3 Calum then gave members a brief overview of his Master's thesis which examined an assisted reproductive technology called Mitochondrial Replacement Therapy (MRT), often referred to colloquially as 'three parent babies'. There are not yet Guidelines for MRT in New Zealand. MRT use is rare internationally, and complex technology is required, so it may not be provided in New Zealand. If it were to be considered by ACART to develop guidelines, the HART Act may first need to be amended to clarify that it is not prohibited along with genetic modification of embryos.

2. Apologies

2.1 Analosa Veukiso-Ulugia.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

- *Secretariat to place the June 2019 agenda on ACART's website.*

4. Declarations of Interests

4.1 No declarations. Sue McKenzie requested updates to her declarations.

Action

- *Amend the declarations as requested.*

5. Minutes of ACART's meeting of 12 April 2019

5.1 The minutes were approved subject to a clarification about RTAC. Fertility clinics are audited each year and in practice comply with the RTAC Code even though they are not formally required to do so.

Action

- *Secretariat to place the 12 April 2019 minutes on ACART's website.*

6. Actions arising from the April meeting

6.1 Members noted the status of the actions.

7. Work programme status

7.1 Members noted the status of the programme.

Fertility Services Standards review — scoping group meeting

7.2 The Chair noted that the Ministry of Health hosted a scoping day on Tuesday, 16 April, to discuss the review of the Fertility Services Standard. The scoping day helped to refine the plans for the review which is currently early in development.

7.3 The Chair and a member of the Secretariat attended the scoping day and contributed to the discussion about the broader issues that could be addressed.

Action

- *Secretariat to advise ACART of the consultation document and facilitate a response when it is released by the Ministry of Health.*

8. Membership updates

8.1 Members noted the paper.

9. Proposed draft surrogacy bill

9.1 Linda McIver from Hon Louisa Wall's Office attended ACART to discuss the draft surrogacy bill being produced by Ms Wall. Ms McIver advised that this is not yet in the ballot, but the intention is that it will go into the ballot.

9.2 Members asked Ms McIver several questions about the bill to understand the purpose of some provisions and how they would work in practice. Ms McIver explained the main provisions and proposed mechanisms in the draft bill.

10. Donation and surrogacy guidelines: discuss the draft guidelines and draft advice to the Minister

10.1 The Secretariat introduced the paper, noting that there were two main matters for attention. The first was to assess the guidelines, as they had been amended as requested at the last meeting. The second matter was to assess the draft advice to the Minister which had been substantially progressed since the April 2019 meeting.

The guidelines

10.2 Members worked through the guidelines, noting the changes and comments/questions from the Secretariat, and agreed to several changes.

10.3 Members discussed the definitions of 'donor' and 'recipient' that had been added to the guidelines and also how to make the guidelines gender neutral. Members asked the Secretariat to progress this out of session and the working group will consider the definitions when they meet on 4 July 2019. The discussion about the definition of 'recipient' covered whether the recipient has to be the person who will gestate the child, or whether it can be the person whose partner will gestate it.

10.4 A submitter had suggested changing the word "authority" to something more like "responsibility for" — the submitter had said that ideas such as ownership or authority could lead to embryos being treated as property and commodified. Members considered this and decided the working group should make a final decision.

10.5 There was a discussion about the new provision for 'retrospective' consenting when a procedure is proposed that had not been possible at the time of the original donation. Members decided the wording of the provisions is suitable. They also noted the

importance of donors in future being fully informed about the possibilities of re-donation and on-donation of embryos.

Draft advice to the Minister

10.6 Members noted the section "Matters ACART has Taken Into Account" could be condensed. They also agreed that for the narrative to be as inclusive as possible they would minimise the extent to which subsections of the population are referred to.

10.7 Members agreed that in the section explaining the first change (the removal of the mandatory biological link) a definition should be presented first in order to aid the reader.

10.8 Members agreed to send particular changes to the Secretariat who will use those to prepare material for the working group.

Actions

- *Secretariat to amend the guidelines as discussed.*
- *Secretariat to amend the definitions of donor and recipient.*
- *Members to send particular changes to the Secretariat.*
- *Secretariat to prepare material for the working group.*
- *Working group to consider the definitions, guidelines as a whole and the advice.*

11. Posthumous reproduction

11.1 The Chair introduced the meeting paper on the review of the guidelines for posthumous reproduction. She noted that the purpose of the discussion for the meeting is to make some key policy decisions about the following categories, to then be included in the draft consultation document that the working group will consider. The working group will meet in Dunedin on 9 July 2019 to consider the draft stage two consultation document for the first time.

Evidence of consent

11.2 Members agreed at the April meeting that all procedures of posthumous retrieval should only be performed with the consent of relevant parties, so the consent of the deceased holds significant weight in whether their gametes can be used after their death. Members have agreed to propose in the draft guidelines that posthumous use where there was posthumous retrieval without prior written consent, is only permitted if the surviving partner can prove evidence of consent.

11.3 Members then discussed what exactly is meant by evidence of consent and noted how important it is to define this in the consultation document, and for subsequent guidance to ECART in approving applications for use (where material was retrieved posthumously). It was noted that for other assisted reproductive procedures, ECART relies on official documents to prove consent. Members referred back to previous discussions about consent to assisted reproductive procedures, noting that written consent to use is the gold standard but that other kinds of verbal evidence, for example, a conversation with a nurse at the end of life that someone would like their gametes to be used by their partner after their death might be acceptable too.

11.4 Members discussed that without an exhaustive list, this evidence of consent could be something like evidence in someone's will that they would consent to the retrieval of their gametes for use after their death. It was agreed that the list of examples of

consent did not need to be exhaustive and when ACART consults it should make it clear that the list on which they are consulting is not intended to be exhaustive. This is an important point to seek public feedback on when the stage two consultation is released.

11.5 It was also agreed to propose in the draft guidelines that in the event that evidence of consent is not considered sufficient, ECART may not approve the procedure. Members noted that people would still have the option to take their case for use to the High Court.

11.6 Members proposed to keep the consultation document narrow and specific, for the reason that this is consistent with the Principles of the HART Act, in particular principle 4(d) that (d) *no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent.*

Best or only opportunity

11.7 In many circumstances, obtaining gametes from one's deceased partner is not the surviving partner's only opportunity, but might be 'better' than using a donor gamete. Members discussed the possible addition of the following provision into the draft guidelines — that "the procedure is the best or only opportunity for intending parents to have a child".

11.8 Members advised that it would not be appropriate to include this provision in these draft guidelines, given that the proposed guidelines for evidence of consent will be narrow enough that in almost all applications for use it will be the person's best opportunity to have a child.

A proposed new title for the Guidelines

11.9 Members agreed that the heading or name of the guidelines is a useful way to seek feedback on the draft guidelines for the stage two consultations, and also clarify what they propose, which is the conditions where posthumous reproduction is thought by the Committee to be ethically acceptable (i.e. not going against the wishes of the deceased; consistent with HART principles and HDC).

11.10 Members agreed to shorten the title and propose that they are named for stage two consultation as: "*Guidelines for the use of gametes and reproductive tissue from a deceased person".*

A stand down period

11.11 Members discussed a possible stand down period of time for grieving to take place before an application for use is taken to ECART. In the stage one public consultation, many young people said a year, and the idea was reiterated in some submissions.

11.12 Members agreed the provision in the current posthumous guidelines (2000) that leave the stand down period open for clinics to decide upon may be adequate. Also, ECART could direct a time-period to elapse before material could be used, to allow for grieving, if appropriate.

2.2) If the option selected in the consent form leads to a request for insemination by the partner of the deceased, then clinics/services must provide appropriate implications counselling which would include, for example, the advisability of a suitable time lapse before making use of the sperm, to allow for considered decision making.

11.13 There is currently no reference to a 'stand down period' in any ACART guidelines. Clinics generally manage this well, with a stand down period to ensure appropriate counselling takes place and there is sufficient time to apply for ethical approval to ECART.

Re-consent for minors

11.14 The Secretariat invited members to discuss and justify the age of re-consent, and decided on age 18.

Authorisation of retrieval

11.15 Members discussed the role of courts, for example the *Re. Lee* case, in which the court has determined it has the authority to authorise the collection of gametes/tissue. There was a discussion about what legal mechanism might be used, or recommended for introduction, to specify which authority should approve the collection of gametes/tissue. Because of the *Re Lee* pathway, members decided that the most appropriate approving authority to authorise the retrieval of gametes is proposed to be a Judge, via a court order. The rationale for this is about the urgency to which gametes need to be retrieved after death, so the judge's ruling would then give a court mandate for a physician to undertake the retrieval of gametes or tissue for storage. Once the gametes or reproductive tissue have been collected and stored the intending parent and clinic could arrange an application to ECART

11.16 Members noted that a court 'order' would not require a person (such as a medical professional or pathologist) to collect the tissue, rather it would permit (or authorise) the legality of the collection.

11.17 Members also noted that it is not the purpose of the draft guidelines to issue instructions to the courts. Rather, the draft guidelines may be a guide to the approving authority whether to allow retrieval or not, based on whether the person has consented and that there is a pathway available for the material to be used. Members agreed to seek the specific feedback on this pathway as part of the stage two consultation, most likely from the office of the Chief Justice.

When should posthumous use be subject to ethics review?

11.18 In the stage one consultation document, ACART proposed four main options of ethical review:

a) to require ethics review for all posthumous use of gametes and embryos

b) to never require ethics review

c) to require ethics review only in certain situations, such as if the gametes or embryos are to be used by a third party

d) to exempt certain uses from ethics review, such as if the gametes or embryos are to be used by the person's partner to create a full sibling for existing children.

11.19 Currently, ECART approval is required for all posthumous use of gametes, other than the use of stored sperm where there is consent to the specific use. There may be other situations in which ethics review should not be required. Members were asked to discuss and agree on a consensus of when ethics review is needed for posthumous use.

11.20 Members agreed to propose in the draft guidelines that ECART approval is not needed for situations where someone has stored gametes or tissue while they were alive and consented to its specific use, unless the procedure for use falls under other ECART guidelines such as the need for a surrogate. In most cases, the use of stored eggs by the surviving male partner would require a new female partner or a surrogate which would require ECART approval. Members recognise that this suggestion may require changes to the HART Order.

11.21 For situations where material is retrieved posthumously, members agreed to propose that these are assisted reproductive procedures where all applications for use require ECART review because of the ethical complexity in their retrieval and use.

Approval for posthumous retrieval and/or use must be made by the person's partner

11.22 Members agreed that the person requesting the retrieval of the gametes or tissue would need to be the deceased person's partner if they had one, because that is how children would have come about anyway had the person lived.

11.23 The Secretariat was asked to include the policy decisions into the draft consultation document for the working group to consider in July.

Actions

- *Secretariat to set out options for the working group to consider in July*
- *Secretariat to include policy decisions in the consultation document*
- *Working group to report back to ACART in August*

12. Monitoring: member reports

12.1 The Deputy Chair advised members he has been contacted by Television New Zealand about the extent to which some men make private sperm donations. TVNZ will interview the Deputy Chair about the practice and he intends to emphasise the need for people to be aware of the risks associated with private sperm donations.

13. Report on ECART's May meeting

13.1 Members noted the report.

14. Correspondence and Enquiries

14.1 Members noted the correspondence.

15.a Governance — Chair's Report

15.1 Members noted the report.

15.b. Member reports on papers / research

15.2 Members had no reports to share today.

16. Secretariat report to ACART

16.1 Members noted the report.

Extra item: visit from Ashley Bloomfield, Director General of Health

- Members did a round of introductions and welcomed Dr Bloomfield to the meeting. Ashley noted the ethics team now has a high level of support and he is pleased with the team and management support to the Committees.
- Dr Bloomfield talked about his first year in the job as Director General of Health and his initial priorities of stabilising the Ministry, making sure the right people are in the jobs, and strengthening relationships with the sector. He also noted his priorities for health, including but not limited to — equity, vulnerable populations, mental health and addiction.
- Members referred to a few key pieces of work where ACART has completed their recommendations, and queried the length of time it is taking for the policy work to be completed from the Ministry of Health side. Members noted that a review of the guidelines for human reproductive research is one project whereby since 2006 multiple Ministers have rejected the proposal to review the guidelines in full. ACART noted that this means that there are restrictions for clinics in New Zealand for the more robust use of randomised controlled trials for clinical quality assurance in established procedures.
- Dr Bloomfield assured the Committee that he would discuss particular items with the Minister of Health.

17. ACART members at upcoming ECART meetings

Action

- *Secretariat to contact all members to confirm attendance at the upcoming ECART meetings.*

18. Conclusion of meeting

18.1 The next ACART meeting is scheduled for Friday, 9th August and will be held at the Wellington Airport Conference Centre. Members should contact Moana for travel arrangements.

Actions

- *Members liaise with Moana for travel arrangements.*
- *Advise members the start and end times and location when arranging travel.*

18.2 The meeting closed at 3.30 pm.