Minutes of the Eightieth Meeting of the Advisory Committee on Assisted Reproductive Technology

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Held on 9 August 2019, at the Wellington Airport Conference Centre.

Present

Kathleen Logan (Chair)
Calum Barrett
Jonathan Darby
Colin Gavaghan (Deputy Chair)
Sue McKenzie
Karen Reader
Analosa Veukiso-Ulugia (by phone)
Sarah Wakeman

Non-members present

Mark Joyce, Ethics team, Ministry of Health
Tristan Katz, ACART Secretariat
Martin Kennedy, ACART Secretariat
Iris Reuvecamp, ECART (until 1 pm)
Hayley Robertson, ACART Secretariat

1. Welcome

1.1 The Chair welcomed the Committee members.

1.a Opening discussion

1.2 The Chair spoke about the importance of ACART's role and members noted the increasing use of assisted reproduction as people are forming families later in life.

1.3 The Chair thanked members for their dedication in supporting decent regulation by working to close gaps in the law.

2. Apologies

2.1 Nil.

3. Approval of the agenda

3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

4.1 No declarations.

5. Minutes of ACART's meeting of June 2019

5.1 The minutes were approved.

Action

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

6. Actions arising from the June meeting

6.1 Members noted the status of the actions.

7. Work programme status

7.1 Members noted the status of the programme. Members also noted that item 12 of today's agenda was to discuss the programme and the work that could be prioritised now that the review of the guidelines for donations and surrogacy is almost complete.

8. Membership updates

8.1 Members noted the paper.

9. Meeting dates for 2020

9.1 Members discussed ACART's meeting dates for 2020. To save money, ACART could meet on days other than Mondays and Fridays, if possible, because flights are often more expensive on those days. The three members who have teaching commitments will probably not know their schedules until the end of 2019. Members agreed the following.

- Thursday, 13 February. Wellington.
- Thursday, 2 April. Wellington.
- The dates for the meetings after April will be confirmed in December 2019 or January 2020. Place holders are: 11 June, 13 August, 15 October and 10 December.

9.2 Members asked the Secretariat to confirm all travel and venue bookings now for October and December 2020.

Action

- *Confirm all travel and venue bookings now for October and December 2019.*

10. Posthumous reproduction

10.1 Members considered the second iteration of the draft guidelines and discussed several outstanding policy matters.

Structure of the draft guidelines

10.2 Members had a discussion about how to structure the draft guidelines to allow the Secretariat to advance the consultation document. At the June ACART meeting, members decided to limit the guidelines to posthumous 'use' rather than to include 'retrieval'. This is because the guidelines will be used only to inform ECART decisions about posthumous use. ECART will not authorise retrieval, and ACART's guidelines cannot direct a Judge, so ACART's guidelines will have no bearing on retrieval other than that the presiding judge will know that a pathway for use exists. The draft guidelines are now concerned with 'use' only.

10.3 Therefore, the draft guidelines have been written bearing in mind that they will act only as guidance to ECART to consider applications for use of posthumously retrieved material.

When should posthumous use be subject to ethics review?

10.4 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.

10.5 The working group on 9 July proposed option a) to the full committee. Members all agreed to publicly consult on the provision that ethical approval from ECART should be required for all posthumous use of gametes because of the ethical complexity in their use.

ACART's proposals for evidence of consent

10.6 Members had a discussion about what exactly is meant by consent and 'evidence of consent', what is being consented to and whose consent is valid. The working group noted that not everything that people say in conversation counts as consent.

10.7 Members accepted the working group's proposal that the deceased must have made an informed choice and given informed consent to the retrieval and use. The consent should specify that the gametes are to be used for posthumous reproduction and by whom they may be used. The working group also proposed that posthumous use, where there was posthumous retrieval without prior written consent, should only be permitted if the surviving partner can provide other evidence of consent. The surviving partner should not be allowed to proceed on the basis of a statement, with no evidence to support it, that the deceased had agreed to it. This evidence can be oral, but must be able to be proven for ECART to approve use.

10.8 Members noted that what is already being proposed in ACART's draft guidelines sets a more lenient standard than the UK, Canada and some Australian jurisdictions, in that ACART is not proposing to take a hard line on solely written consent.

10.9 Members agreed to consult the public on these proposals for the draft guidelines.

Does consent for use imply consent to posthumous retrieval?

10.10 Members noted that the working group had discussed whether consent to posthumous use implies consent to retrieval in cases where an individual hasn't stored gametes during their lifetime. Members agreed to include a section on this matter in the consultation document so that the public's feedback can be sought.

10.11 Members thought this is an issue related to posthumous retrieval, and that the key point is knowing that the person who had died had consented to use while alive — even if they did not previously have any gametes or reproductive tissue stored. Members noted that it seems logical that ECART could assume that consent to use after death is implicitly consent to retrieval, but that evidence of informed consent to retrieval requires some evidence that the now deceased understood what retrieval involves. However, they agreed not to take a position on the nature of evidence of informed consent to retrieval because that is a court decision.

Specific use

10.12 Members discussed the proposed definition of specific use and whether consent to use should include who exactly may use the gametes or tissue. Members noted that this might be important from a practical point of view as ECART often faces problems where someone has consented before death to someone being able to use, or decide the use of, their gametes or embryos, but not how or who will actually use them.

10.13 Members noted that there are circumstances where people are storing gametes or tissue to preserve fertility because they are going through an illness and will have other things on their mind. It is important from an ECART perspective however to note on the forms, "the extent of consent", and note how far it goes even if they are not able to name an intending parent.

10.14 Members agreed to consult and seek feedback on the parameters of specific use, whether it be the partner only, a family member, or also to leave the partner to do what they like with it. It was agreed that the rationale behind this is that the deceased must have shown that they have thought about what the potential uses of their gametes might be.

The role of family in decision making

10.15 Members discussed the role of the family in deciding whether posthumous reproduction will be allowed. It was noted that the Fertility Services Standard *"does not require consent from family or whānau members, however clinics must provide culturally relevant services, for example enabling Māori to have whānau, hapū and iwi involved in their care".*

10.16 Members discussed the concern that children born from posthumous reproduction might not have support from their extended family if perhaps the family did not agree to the posthumous conception. Members noted that the wellbeing of children is one of the key considerations of ECART in assessing applications.

10.17 Members agreed that the role of family members is important but should not supersede the wishes of the partner, or the deceased person themselves, and that the autonomy of the deceased and their partner in terms of their reproduction is paramount— as is the case in other guidelines.

10.18 It was thought that the proposed requirement for actual evidence of consent from the deceased for specific use is largely analogous to consent to gamete or embryo donation while alive — and other family members wouldn't get a veto in that case.

10.19 Members noted that family or concerned parties can always write to ECART if they believe they have evidence that the deceased might have changed their mind or had not actually consented to posthumous reproduction.

Provisions for Minors

10.20 Section 12 of the HART Act places restrictions on obtaining gametes from minors. The Act states that no person may obtain a gamete from an individual under 16 years of age, or use a gamete obtained from an individual under 16, unless they intend to preserve the gamete for the individual's use, or to bring about the birth of a child likely to be brought up by the individual from whom the gamete was obtained.

10.21 Members considered the issues around minors and how the previous proposed ages fit with Section 12 of the Act. Members agreed to seek feedback in the consultation on the following draft proposals for minors:

a) a 'minor' means an individual aged under 16 (as consistent with the HART Act)
b) gametes and reproductive tissue obtained from minors may only be used by the individual from whom the gamete was obtained
c) neither gametes nor reproductive tissue can be retrieved from deceased minors.

10.22 It is the case currently that b) gametes and reproductive tissue obtained from minors may only be used by the individual from whom the gamete was obtained. The working group also sought members' agreement on proposing in the guidelines a change to the HART Act at Section 12 (3) to allow material, retrieved from an individual aged under 16 for their fertility preservation, to be used according to their express wishes if they consent to a new use (e.g. donation) as an adult. For reasons unknown, the Act does not allow for this.

References to other guidelines

10.23 Members agreed to remove all references to other guidelines (e.g. when a procedure also involved a surrogacy) throughout the draft guidelines. But they noted that the guidelines do need to address somewhere what/if other guidelines apply, and decided to add a sentence to the preamble to note this approach.

10.24 The Secretariat will also ensure that the wording in the draft guidelines is consistent with other ACART guidelines.

Actions

- *Secretariat to update the consultation document, survey questions and draft guidelines, for members to consider at the next meeting.*

11. Donation and surrogacy guidelines: note the guidelines and advice for the Minister

11.1 Members noted that the policy work for, and writing of, the guidelines and advice was complete. The Secretariat had sent the advice (which includes the guidelines) for editing and formatting, to meet the publication requirements of the Ministry of Health, and would then submit it to the Associate Minister of Health later in August.

11.2 The Chair advised members that she would, in her letter of introduction to Associate Minister Salesa (who had recently become the minister responsible for ACART), offer to discuss the advice and guidelines with her when they meet. (See also item 12 below, about ACART's programme of work and priorities.)

Actions

- *Secretariat to submit the advice to the Associate Minister when it is returned from editing and formatting.*

12. Agree ACART's priority work

12.1 Members noted that the committee and Secretariat would have the capacity to work on new topics, or focus more on existing topics, now that the guidelines and advice for donations and surrogacy are almost complete. Members considered the need for and benefits of several projects and agreed that an important consideration when setting priorities was the extent to which the work would directly affect people involved in fertility treatment.

12.2 Members decided the following.

1) Guidelines for human reproductive research.

12.3 ACART could amend these guidelines but needs to confirm the scope to ensure it is worth committing the resources. ACART will ask the Minister to expand the scope of the HRR work that is already on its work programme, using at least two options other than 'non-viable embryos.' This project would require consulting the public. Members also discussed the possibility of hosting a forum on human reproductive research and will make a decision if and when the project proceeds.

2) The guidelines for extending the storage of embryos and gametes.

12.4 ACART will assess whether to amend these guidelines, to remove the requirement that gamete donors must be consulted on their donations when applications to extend storage are made, even when embryos have already been created from those gametes. This project would require consulting the public.

3) Advice to the minister on the various technological changes that are underway or have recently been introduced, as per s37 of the HART Act.

12.5 In particular, the technologies that can be used to edit genes may be worth advising on. The advice could cover mitochondrial replacement therapy, definitions of gene editing, and the efficacy and safety of the technologies. It could, possibly, also address any of: embryos from stem cells, the creation and use of embryonic stem cells, uterus implants, and artificial uteri. Several of these technologies are closely related to human reproductive research, so the two streams of work should be

considered simultaneously to ensure coherency in the work. This project could include public consultation.

4) ACART's working parameters.

12.6 Members discussed whether to assess ACART's working parameters, such as the ethical framework and the roles of ethics and morality in ACART's functions, and the definitions of discrimination and of consent. Members decided that this cannot be done properly without an Ethics Expert representative on the committee which is a current vacancy, but that there are aspects that could be worth doing as resources permit. It would be desirable to have the Māori representative vacancy filled beforehand too. This project could include public consultation.

5) Guidelines for cases where more than one guideline is relevant.

12.7 Members noted that ACART should assess whether it needs to make any changes to the guidelines that addresses cases where more than one guideline might be relevant. This project might require consultation with the public.

12.8 Each of these projects would need working groups.

12.9 The Chair advised members that she is writing to the new Associate Minister and will ask her to agree to add items to ACART's work programme and to amend those items that are already on it as needed (such as the limited review of the research guidelines).

Actions

- *Send the summary of the Canterbury University surrogacy survey to members.*

13. Member reports on papers / research

13.1 A paper about the regulation of embryo research, in Canada, had been provided by Karen Reader.

14. ACART's Annual Report

14.1 Members noted the draft report and that some details are yet to be finalised.

15. Correspondence and Enquiries

15.1 Members noted the correspondence which was a letter from Rob McHawk, at the Ministry of Health, advising ACART that Minister Clark had delegated responsibility for ACART to Associate Minister Jenny Salesa.

16. Governance — Chair's Report

16.1 Members noted the report.

17. Secretariat report to ACART

17.1 Members noted the report.

17.2 Members noted several forthcoming conferences including:

- the Society for Reproductive Biology, in August, in Sydney
- the FSA conference, in September, in Canberra
- the APNEC conference in October in Wellington
- the AABHL conference, in November, in Dunedin.

18. ACART members at upcoming ECART meetings

18.1 Analosa will attend the ECART meeting in Auckland in October.

Action

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

19. Conclusion of meeting

19.1 The next ACART meeting is scheduled for Friday, 18 October 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.*

19.2 The meeting closed at 3.00 pm.