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

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Held on 12 April 2019, at the Dunedin Airport Conference Centre.

Present

Kathleen Logan (Acting Chair)

Colin Gavaghan (Deputy Chair)

Jonathan Darby

Sue McKenzie

John McMillan

Karen Reader

Non-members present

Paul Copland, ECART

Tristan Katz, ACART Secretariat

Martin Kennedy, ACART Secretariat

Professor Nicola Peart, Otago University (10.30 am to 1.15 pm)

1. Welcome

1.1 The Chair welcomed the Committee members.

1.a Opening discussion

1.2 Sue McKenzie gave the opening comments, noting the new ways in which people are forming families and how technological changes have enabled more people to have children. Sue commented on the need to be clear about how and why fertility treatment can be regulated and what risks the government is attempting to manage. Sue also noted the need for adequate support for the committee.

1.2 Members had a general discussion about when and why ECART should consider cases and noted that, as new technologies and procedures become possible, ACART will need to consider whether certain activities would need to be subject to ECART consideration.

2. Apologies

2.1 Analosa Veukiso-Ulugia, Sarah Wakeman.

3. Remembrance of Barry Smith

3.1 Members acknowledged former ACART member Barry Smith who died in February 2019. Former member Mike Legge had provided a written remembrance and members spoke about Barry. Barry's professionalism, knowledge and congeniality will be missed.

4. Approval of the agenda

4.1 Members approved the agenda.

Action

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

5. Declarations of Interests

5.1 No declarations.

6. Minutes of ACART's meeting of February 2019

6.1 The minutes were approved subject to amendments.

Actions

- *Secretariat to amend the minutes as requested.*
- *Secretariat to place the February 2019 minutes on ACART's website.*

7. Actions arising from the February meeting

7.1 Members noted the status of the actions.

8. Work programme status

8.1 Members noted the status of the programme.

9. Membership updates

9.1 Members noted the paper.

10. Posthumous reproduction

10.1 The Acting Chair introduced the paper on the review of the guidelines for posthumous reproduction. She noted that the working group had discussed the matters the guidelines would need to address and that some policy matters needed further consideration. The guidelines will need to be written bearing in mind the main steps that could be taken in any case of posthumous reproduction — collection (of gametes or tissue), storage and use.

10.2 Members discussed the wellbeing of children born from posthumous reproduction and the interests of the deceased donors. Concerns for the children were that posthumous reproduction may enable creation of offspring for ageing parents due to potential long storage times post-death, larger age-gaps between siblings, uncertainty over inheritance, unknown views of children about being born from someone who was already deceased at conception, and that such children would never have the chance to meet their parents. Members recognised many of these concerns are not exclusive to posthumous reproduction, the levels of risk to child wellbeing depend on many variables, and such risks *per se* may not be grounds to prohibit the practice.

10.3 Members noted that all procedures should only be performed with the consent of relevant parties, so consent of the deceased holds significant weight in whether their gametes can be used in posthumous reproduction.

10.4 For the collection of gametes or reproductive tissue the first question to answer, in cases where the person is deceased and whose gametes or tissue are being collected, is who can authorise the collection of the gametes or tissue. The most likely person would be a judge but ACART will consider this further before making a recommendation.

10.5 The Acting Chair noted that a court 'order' would not *require* a person (such as a doctor or coroner) to collect the tissue, rather it would *permit* (or authorise) the person to collect it.

10.6 Members discussed the basis on which a judge could grant permission for gametes/tissue to be collected. They noted that there needed to be a clear pathway for the gametes/tissue to be lawfully stored and then for an application to be made to ECART to use the gametes/tissue. Members discussed if and how the person who will use the gametes/tissue would be able to prove that he or she had the consent of the person from whom the gametes/tissue would be collected.

10.7 Members agreed that the requestor would need to subsequently prove to ECART that he or she had the consent of the person from whom the gametes/tissue had been retrieved.

10.8 The possibility that a person might wish to export gametes or tissue also came up and ACART will consider this further when necessary.

10.9 It was noted that ACART has no authority to issue instructions to the courts. Rather, the focus of the guidelines would be on the matters ECART must consider when a case is brought to it by a clinic. Members discussed the extent to which ACART might go to ensure that the medical community and the judiciary are aware of the options people could have for collection of gametes or tissue. These communities would need to be aware of the pathways available for people to collect, store and use

gametes and embryos so that they would know their legal basis for issuing court orders and collecting gametes/tissue.

10.10 There was a discussion about what legal mechanism might be used, or recommended for introduction, to give some specific party the authority to approve the collection of gametes/tissue.

10.11 A discussion about consent ensued and it was noted that when a person consents to the storage of gametes at a fertility clinic that person is often not thinking about their possible death and how his/her gametes could be used posthumously. Members agreed to refer back to the definition of consent the committee had agreed on some months before this meeting.

10.12 There was a discussion about the regulatory setting, in particular what is allowed under the HART Act and HART Order and why the use of eggs and sperm are regulated so differently. Historically, the procedures that could be done were quite different for sperm and eggs, hence the different status of these under the HART Act and Order.

10.13 Members also discussed different interpretations of the HART Act and Order, and 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.

10.14 The secretariat was asked to summarise the discussion and set out options for the working group to consider. The working group would assess the options and report back to ACART in due course for the full committee to consider and decide on a course of action.

Actions

- *Secretariat to set out options for the working group to consider*
- *Working group to consider the options*
- *Working group to report back to ACART*

Issuing guidelines

10.15 Professor Peart, from Otago University, commented on how certain procedures are, or are not, accounted for in the HART Act and Order and whether they can be regulated by the guidelines. In particular she spoke about how embryo donations are subject to ACART's guidelines. Professor Peart and the Deputy Chair agreed that the donation of embryos can be regulated by the guidelines and they noted other parties who share this view.

10.16 Professor Peart noted that the Order should explicitly state that embryo donation is not an established procedure and recommended that ACART recommend this to the Minister of Health.

10.17 These observations are particularly pertinent to the next item on today's agenda.

11. Donation and surrogacy guidelines: discuss the second consultation, draft guidelines and draft advice to the Minister

11.1 The Secretariat introduced the paper, noting that two minor changes to the guidelines were presented for consideration. The Secretariat briefly summarised the status of the draft advice to the Minister and then drew members' attention to the submissions

to the second round of consultation. In particular, members were asked to work through the matters raised in the submissions that warranted further consideration.

Submissions

11.2 Members agreed that a provision should be added to take into account the possible retrospective effects of the guidelines. The provision will apply as follows: if people have gametes or embryos in storage now (and up until the new guidelines are issued) a provision should be introduced that states that if a procedure is sought that they have not previously consented to they will now need to consent. The provision should include gamete donors even where embryos have now been formed, because the gamete donors will not have consented to the newly allowed use of the embryo.

11.3 Members decided not to elaborate, on the provision that addresses the "on-donation" of embryos, to give ECART a specific basis on which to decline such cases if needed. ACART had discussed this in the past and agreed that ECART has and needs the discretion to consider each case on its attributes. Similarly, ACART decided it should not be mandatory for people donating embryos to obtain legal advice. The reasons for this are that the embryo donor will have no legal rights or obligations with respect to the embryo once it has been used, and also that the counselling process advises people that they can seek legal advice if they wish to receive it.

11.4 There was a discussion about the suggestion that the list of family members who fall within the "established procedures" definition be extended to include in-laws and step relationships. Members decided no change was needed, as such relations already fall within the definition of "established procedures".

11.5 A submitter had suggested that the consent provisions for surrogacy needed to be elaborated on. Members decided to add a new provision, to the general requirements that apply to all procedures, stating that "all relevant parties consent to the procedure."

11.6 A submitter had suggested that the provisions for surrogacy needed to be clearer about how the parties were being counselled and if it was only jointly. Members agreed to amend provision 4 or the provisions for clinic assisted surrogacy to state that all affected parties must have received joint and individual counselling.

11.7 Members decided **not** to change some provisions suggested by submitters. These provisions will continue to mean that:
i) counsellors must be satisfied that parties understand the implications of procedures
ii) it is preferable (not mandatory) that women have had their own children before becoming surrogates
iii) it is preferable (not mandatory) to complete one's family before acting as a surrogate
iv) residency provisions "must" (rather than "should") take into account certain factors.

11.8 Similarly, members decided **not** to i) replace the word "residency" in the surrogacy provisions with an alternate word ii) always refer to consent as "informed consent" and iii) state that counselling should be made available to embryo donors after a child is born from the donation.

11.9 Members did agree to change the wording of some provisions to state that they apply to “specified” or “specific” procedures. The phrase in the draft guidelines for posthumous reproduction will be suitable for “specific procedures.”

11.10 Two submitters had suggested that ACART provide additional explanatory material, or possibly non-binding guidelines, in particular about how donation, re-donation and on-donation work. ACART had previously decided it would provide additional explanatory information, and so agreed with the submitters. Members also decided to consider whether any of the explanatory information or requirements might be added to the Fertility Services Standard.

11.11 A submitter had recommended that ACART do more work to ensure that offspring can learn about their genetic heritage. The importance of whakapapa in New Zealand and openness and transparency were discussed, as well as the difficulty in communicating genetic heritage.

11.12 A submitter had recommended the establishment of a confidential, national register of donors so clinics can see if donors have reached the 10 family limit. Members asked the Secretariat to look into this to determine whether it is viable. The Secretariat will need to discuss it with the Department of Internal Affairs to ascertain whether the HART Register would be suitable to host such a new register function, whether the new register might duplicate existing functions, and what factors need to be considered.

Actions

- *Secretariat to talk to the Department of Internal Affairs about establishing a confidential register of gamete donors for clinics to use.*
- *Secretariat report back to the working group.*

The draft advice

11.12 Members went through the draft advice, noted that several sections are still early in development, and requested some specific changes. Members will also send written comments to the Secretariat.

Actions

- *Secretariat to make the specific changes requested by members.*
- *Members to send the Secretariat written comments about the draft advice.*
- *Secretariat to continue drafting the advice and send the next version to all members.*

12. Fertility Services Standards: discuss possible changes

12.1 Members noted that the Ministry of Health will host a scoping day on Tuesday, 16 April, to discuss the review of the *Fertility Services Standard*. Members can suggest changes they believe would be useful. Also, the scoping day will help to refine the plans for the review which is currently early in development.

12.2 A discussion covered whether amended standards might be suitable for including material from ACART's *Ethical Framework* and/or *Risk Acceptability Framework*.

12.3 Members asked the Secretariat to investigate why the "RTAC Code of Practice" was not adopted in New Zealand. Knowing this could help inform the discussion about what should be in the standards.

Actions

- *Secretariat to investigate why the "RTAC Code of Practice" was not mandatory in New Zealand*
- *Secretariat to report back to ACART.*

13. Member reports on papers / research

13.1 Deferred to the June meeting.

14. Report on ECART's February meeting

14.1 Members noted the report.

15. Correspondence and Enquiries

15.1 Members noted the correspondence which was a letter from the Acting Chair to Hon Dr David Clark.

16. Governance — Chair's Report

16.1 Members noted the report.

17. Secretariat report to ACART

17.1 Members noted the report.

18. Mitochondrial replacement therapy

18.1 Deferred to the June meeting.

19. Proposed draft surrogacy bill

19.1 Members noted the report.

Extra item — interview with TVNZ

- 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.

20. ACART members at upcoming ECART meetings

Action

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

21. Conclusion of meeting

21.1 The next ACART meeting is scheduled for Friday, 14 June 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.*

21.2 The meeting closed at 4.10 pm.