Minutes of the one hundred and ninth meeting of the Advisory Committee on Assisted Reproductive Technology

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Held online on 23 August 2024.

Present

Calum Barrett (Chair)

Neuton Lambert

Amanda Lees

Karen Reader

Catherine Ryan

Karaitiana Taiuru

Sarah Wakeman

Debbie Wilson

Non-members present

Kirsten Forrest. ECART Secretariat (part of meeting).

Martin Kennedy. ACART Secretariat.

Meg Larkin. Regulatory Policy team, Ministry of Health (part of meeting).

Richard Ngatai. ECART.

Saskia Patton. Manager, Ethics team, Ministry of Health.

Rebecca van Pelt. Regulatory Policy team, Ministry of Health (part of meeting).

1. Welcome and karakia

1.1 The Chair opened the meeting at 9.00 a.m. and welcomed the ECART observer.

2. Opening comments

2.1 The member with expertise in human reproductive research spoke about her attendance at the recent conference of the European Society of Human Reproduction and Embryology (ESHRE). She commented on numerous topics that had been discussed, including:

- that in some cases clinicians use new techniques before their efficacy has been fully proven
- innovations to improve the outcomes of fertility treatments
- the value of PGT-A
- the need for more long-term studies into children born from ART, and
- how to regulate and/or educate consumers about new ART treatments.

2.2 Members briefly discussed the use of "add-ons" by clinics, noting that although some add-ons are useful, some others have limited therapeutic value.

3. Apologies

3.1 Edmond Fehoko, Seth Fraser, Minu Punchihewa.

4. Approval of the agenda

4.1 Members approved the agenda, noting that two analysts, from the Ministry of Health, would join the discussions about (a) the surrogacy bill and (b) the forthcoming changes to the Human Assisted Reproductive Technology Order.

Action

- *Secretariat to add the August 2024 agenda to the ACART website.*

5. Declarations of Interests

5.1 The declarations were accepted.

5.2 One member provided a new declaration (by email, during the meeting).

Action

- *Secretariat to add the new declaration to the declarations register.*

6. Minutes of ACART's meeting of May 2024

6.1 Members approved the minutes with one amendment.

Actions

- *Secretariat to make the amendment.*
- *Secretariat to publish the May 2024 minutes on the ACART website.*

7. Actions arising from ACART's May 2024 meeting

7.1 Members noted the status of the actions arising from the May 2024 meeting. The Chair advised those present that, for one action, rather than writing a formal letter from ACART to ECART he had instead discussed the matter with the Chair of ECART. Members agreed that a formal letter was not needed.

8. Status of ACART's work programme

8.1 Members noted the report.

8.2 The manager of the Ethics team at the Ministry of Health (MoH) told members that, due to the cost cutting and restructuring at the Ministry, the analysts in the Ethics team will work more broadly across the various committees.

9. Appointments and new Chair

9.1 The Chair explained that work continues on the appointment of a new Chair and to appoint or reappoint several members.

9.2 The Chair proposed a process for identifying a member as the preferred new Chair. ACART's preference would then be sent to the Minister. Members agreed the process and will nominate and vote for their preferred Chair in the next week.

9.3 The Chair also updated members on the status of the membership, in particular noting that three of the current members could be reappointed, and three new members will need to be appointed. The Secretariat is working with the Appointments team at the Ministry of Health to submit the recommendations to the Minister of Health.

9.4 There was a discussion about the role of the Deputy Chair — the incumbent said he was happy to stay in the role if members agree but equally happy to step aside if members would like a different member to take the role. Members supported the incumbent to continue in his role.

Actions

- *Members to submit nominations to the Secretariat by 30 August.*
- *Secretariat to advise all members who the nominees are.*
- *Members to send confidential emails, to the ACART mailbox, stating their preferred candidate for Chair.*
- *Secretariat to tally the votes then advise members and the Appointments team who the members' preferred new Chair is.*

10. Report on ECART's recent meetings

10.1 Members noted that the minutes were from two full ECART meetings and one smaller, out of cycle, meeting.

10.2 There was a discussion about the role of ECART in influencing people's reproductive autonomy. The Chair observed that, when an intervention is needed to

enable reproduction, there is a higher ethical standard to be met and people's reproductive autonomy is affected because the regulations affect that autonomy.

10.3 Members discussed a family donation case and noted that the decision had relied on the "best or only" provision in the guidelines. There was also a discussion about a case involving a neurological disorder in an existing child and the parents' wish to use another family member as a gamete donor. The application was declined as there was a lack of information about whether this would reduce the risk of another similarly affected child".

11. Correspondence

11.1 The Chair explained the three items of correspondence.

11.2 The first item was ACART's letter to Minister Costello about the HART Act — it had been sent to the Minister several weeks ago but the final version of the letter had not yet been sent to members. The second item was the ACART letter to the University of New South Wales about the data submission process for ANZARD. The third letter was a copy of the recent ECART letter to Fertility Associates about the process for patients to apply to extend the storage of their reproductive material.

12. Human reproductive research

12.1 The Chair introduced this item, suggesting that members agree ACART's positions on the fourteen specific matters presented in the cover paper, several of which are policy matters. He suggested that rather than going through each item in the draft guidelines in detail, that those matters be worked on by the Secretariat and some members between meetings.

12.2 The Chair also noted the progress on the draft guidelines and consultation document and that the standards issued by the National Ethics Advisory Committee (NEAC) already cover several of the matters that ACART's draft guidelines address. To avoid duplication, and possible contradiction, where NEAC's standards already address a matter that ACART wishes to regulate, in its guidelines, ACART can refer researchers to the NEAC standards.

12.3 The member with expertise in human reproductive research observed that researchers can already use blastoids as they are not defined as embryos under the HART Act. She said that the consultation document should not say that ACART will not "enable" the activity in its guidelines.

STATEMENT ABOUT THE STATUS OF THE EMBRYO

12.4 Members agreed to keep the statement about the status of the embryo in the guidelines. The reason for this statement is to ensure that researchers understand that the human embryo has a unique moral status. Members asked the Secretariat to add a paragraph to the consultation document about how this moral status is relevant to research. One point to cover is that using embryo research to advance

science to help in health care has a moral significance.

SCOPE AND BOUNDARIES

12.5 Members discussed the scope and boundaries of the activities that would be covered by the guidelines. There was a discussion about when research “uses” reproductive material.

12.6 This discussion moved into questions about training and if and how training could be covered by ACART’s guidelines. (Discussed again later, below, at paragraph 12.13.)

12.7 Members agreed there was no need to specify in the guidelines that clinical research will be practitioner based — this fact will be self-evident to most interested parties.

LIMITING GAMETE NUMBERS

12.8 Members agreed to the text (in the cover paper) for limiting the number of gametes used in research.

CONSELLING WILL BE REQUIRED

12.9 In the provisions for counselling in non-clinical research, members agreed the provision should be that participants *must have had* counselling — at present, the wording is that parties should have been *offered* counselling.

STORAGE AND BIOBANKING

12.10 Members discussed how storage could be managed, noting in particular that biobanking options need to be explored and confirmed. Members agreed to consult the public on options. Specific matters to address include whether people should be able to recover stored material from dedicated biobanks and then use that material in clinical treatment.

CREATION OF EMBRYOS IN RESEARCH

12.11 There was a discussion about if and when researchers could be permitted to create human embryos for use in research. This conversation addressed the matter of human embryos being created for use in non-clinical research and subsequently disposed of.

12.12 Members agreed to ask the public for comments on the possible situations in which human embryos could be created. Members suggested using the text about this matter from the first round of consultation.

TRAINING

12.13 The conversation returned to training. Members agreed the consultation document should explain what the training activities might include. The discussion concluded

with the suggestion that ACART seek a legal opinion on whether ACART can or should issue guidelines that address training.

DISPOSAL OF MATERIAL WHEN THE RESEARCH IS FINISHED

12.14 Members agreed that every research application must include a statement about how the reproductive material will be managed when the research ends.

RESEARCH USING HUMAN EMBRYONIC STEM CELLS

12.15 The member with expertise in human reproductive research will provide a summary about research using human embryonic stem cells. That material will be incorporated into the consultation document.

Action

- *Secretariat to add a paragraph to the consultation document about how this moral status is relevant to research.*
- *Secretariat to confirm the wording, in the guidelines, that counselling is a requirement, not optional.*
- *Secretariat to amend the statement in the consultation document about "enabling" the use of blastoids.*
- *Secretariat to add a question about attitudes towards biobanking and storage.*
- *Secretariat to use the text from the first consultation to ask about attitudes towards the creation of embryos for non-clinical research.*
- *Secretariat to seek a legal opinion on whether ACART can or should issue guidelines that address training.*
- *Secretariat to add a statement to the consultation document that every research application must include a statement about how the reproductive material will be managed when the research ends*
- *Member with expertise in human reproductive research to provide a summary about research using human embryonic stem cells.*
- *Secretariat to incorporate the stem cell information into the consultation document.*

13. Initial storage period of reproductive material

13.1 The Chair introduced this item, suggesting that members agree ACART's positions on the main questions. In particular, he said it would be helpful to decide on the duration of initial storage and extensions of storage.

13.2 There was a brief discussion about biobanking and members agreed to explore that topic more fully in the item on human reproductive research.

13.3 The Chair observed the advantages of the current policy, being that the rule is very simple and does not discriminate. Storage is for 10 years regardless of the circumstances. The disadvantages of this policy are that some people who wish to

import reproductive material find that they have had their material stored for longer than is allowed in New Zealand and therefore ECART cannot consider their applications. The single rule also doesn't always account for an individual's specific circumstances i.e. children storing reproductive material for fertility preservation purposes. Another matter that could be addressed is that the HART Act does not state whether there are limits on the duration of extensions of storage.

13.4 The member with expertise in ethics observed that the current system disadvantages young people. She also observed that if the duration of storage for minors was 20 years, that people who store material at 19 will be comparatively disadvantaged compared to those who store material when they are just a year or so younger.

13.5 Members then discussed the "hard cut off" at 10 years. There was also a brief discussion about the difference between fertility preservation, general gamete storage, and embryo storage.

13.6 Members agreed that ACART's positions are as follows.

i. The beginning of the storage period for embryos should be from when the embryos are formed; the period should not be the current one, beginning when the gametes, used to make the embryos, were first stored.
ii. Fertility preservation is distinct from use. The storage period for gametes or tissue should be 20 years for people aged under 16 and for people who may be subject to premature infertility.
iii. The HART Act should state that the maximum allowable extension of storage should be stated as 10 years (whether gametes, tissue or embryos).

Actions

- *Secretariat to include these positions in ACART and ECART's submission on the surrogacy bill.*

14. New guidelines for posthumous reproduction

14.1 The Chair introduced this item, noting that ACART recently published revised guidelines for posthumous reproduction and that further revisions will be possible once the HART Order has been amended.

14.2 A member of the Regulatory Policy team at the Ministry of Health explained that Cabinet has agreed that the Order should be amended and that the Ministry of Health is now liaising with the Parliamentary Council Office on the wording of the Order. Once the final wording of the Order has been accepted, by the Cabinet Legislation Committee, the Order will be gazetted and come into force 28 days later.

14.3 Members agreed to update the supplementary advice for posthumous reproduction to more clearly explain what is meant by "suitable evidence of consent."

14.4 Members agreed to publish the advice about posthumous reproduction, that had

originally been sent to the Minister of Health, to recommend changes to the HART Order.

Actions

- *Secretariat to update the supplementary advice*
- *Secretariat to publish the advice.*

15. The surrogacy bill

15.1 A member of the Regulatory Policy team at the Ministry of Health explained the process that will be used to progress the bill which is currently at select committee. The Ministry staff member advised ACART that submissions are due by 18 September 2024. She said that the departmental report is scheduled to be submitted to the select committee by December 2024 with a view to returning the bill to the house by March 2025. The bill would most likely then be paused while work was done to decide how the operational changes would be funded.

15.2 The Chair asked if and how changes could be made to the bill to take into account ACART's preferences for the provisions for storing reproductive material. The Ministry staff member said that such changes would need to be agreed by Cabinet and the connection of those changes to the bill would need to be explained.

15.3 The Chair advised members that he had asked the Chair of ECART about making a joint, ACART and ECART, submission. The Chair of ECART has agreed. The ACART member with expertise in law told those present that she and the Chair of ECART are also working on a separate academic submission.

15.4 Members agreed to work through the summary of the bill that had been provided by the member with legal expertise. The agreed points would then be drafted into a submission, which will be circulated to members and ECART for approval, then submitted to the select committee.

Matters raised by the legal expert

CHANGE TO RULE ON DONATING GAMETES FROM MINORS

15.5 Members noted that, currently, no person may use a gamete that has been obtained from an individual who is under 16 years. The new provision says that a person commits an offence if they use a gamete obtained from an individual when the individual is, or was, under 16 years *but* it is a defence if the defendant proves that the gamete was used with the consent of the individual, after the individual turned 16 years, for a lawful purpose. Members agreed to comment favourably on this change.

PROVISIONS FOR STORING REPRODUCTIVE MATERIAL

15.6 Members briefly addressed this matter, but noted a separate item in today's agenda on this matter, and agreed to cover it more fully then.

NEW OBLIGATIONS ON CLINICS

15.7 The member with legal expertise commented on the amount of data that clinics would need to collect and submit for surrogacies. She suggested the amount of data might be burdensome for clinics. The member with expertise in assisted reproductive technology observed that although the amount of data would be significant the clinics already collect and submit a lot of this information.

15.8 A brief discussion concluded with ACART agreeing not to submit on this topic and noting that the clinics will submit on it.

NON-CLINIC SURROGACIES AND INFORMATION COLLECTION

15.9 Members discussed if and how data would be collected in cases where people have surrogacies but do not use clinics. They also discussed how the non-clinic cases would work in practice, and the difficulties people would face in having to organise their own legal reports and medical and counselling reports.

15.10 There was a discussion about why the bill presents surrogacy as a distinct activity, that is, separate from assisted reproductive technologies. The member with expertise in legal matters observed that by stating that surrogacy is not an ARP it might then mean that all of the established procedures associated with the surrogacy will no longer be established procedures. Members also noted that by making the assessment, of the social arrangement of surrogacy, subject to ECART the role is being transferred from the courts to ECART.

15.11 Members agreed that the submission should comment on this matter and that the intention and application of the provision need to be clearer.

PARTNERS ARE NOT PARENTS

15.12 Similarly, there was a brief discussion about whether the partner of the surrogate is a parent of the child. In particular, this question applies in the cases, although not common, of male partners of surrogates providing the sperm. In those cases, the male is the genetic parent, but it is unclear whether he would be recorded as such. Members agreed this was an academic point and wouldn't submit on it.

ENFORCABILITY AND COSTS

15.13 Members noted that, although surrogacy arrangements will not be enforceable, there will be an enforceability provision to ensure surrogates can recoup costs. Members discussed the matter of ECART's remit being expanded to include assessing applications for surrogacy to ensure the commissioning parents can and will pay the costs. Members noted that ECART does not have a member category dedicated to legal expertise and that such expertise would be needed.

15.14 Members agreed to submit on this matter, and to state that there are challenges with the proposal that need to be addressed.

ADVERTISING

15.15 After a brief discussion, members decided ACART will not submit on this matter.

NEW ROLES FOR ACART AND ECART

15.16 Members observed that ACART would need to issue new guidelines and that there could be a tension between precluding commercial gain while also ensuring the best interests of the child.

15.17 Members agreed to submit on this matter and noted that the committee will need to consult on new or amended guidelines once the bill becomes law.

MORE WORK FOR ECART

15.18 There was a wide-ranging discussion about the increased work for ECART and that ECART is already at capacity.

15.19 The operational details, for how direct applications (i.e. applications from intending parents and surrogates directly to ECART, not via a clinic) would be managed were touched on. A member suggested the submission draw attention to the difficulties that would arise with direct applications to ECART.

REVIEW PANEL

15.20 Members noted the proposal that a review panel be established for surrogacy cases that ECART declines. Members agreed to submit on this proposal and suggest that the review function be for *all* ECART decisions. Members discussed the pros and cons of different ways of establishing such a panel.

15.21 Later, the discussion returned to the matter of the review panel, with members agreeing that if such a panel is formed it would need a range of different skills and to be more than three people as stated in the bill.

ECART MEMBERSHIP

15.22 Members noted that the HART Act does not currently state how ECART must be comprised, whereas it does set out the membership categories for ACART. Members agreed the submission should recommend that the membership categories for ECART should be stated in the act. The proposal in the Bill would codify some roles but others would be set out in ECART's Terms of Reference — this approach is inconsistent.

15.23 Members noted that the people with expertise in children's interests could be from a variety of places, although one of them will have to be from the Office of the Children's Commissioner.

PARENTAGE

15.24 Members decided ACART will not submit on this matter.

RESOURCING OF ECART

15.25 The member with expertise in legal matters observed that the Law Commission report had commented on the need for the adequate resourcing of ECART. The member suggested that ACART emphasise this point in a submission to the select committee.

MATAURANGA MĀORI

15.26 Members agreed to endorse the provision that committee members have knowledge of Matauranga Māori. The ECART observer commented that having such knowledge can be helpful but also that it can take time for people to learn and there is a limited number of people with deep knowledge of this topic.

Action

- *Draft the joint submission using the points agreed above.*
- *Liaise with the ECART committee about the submission.*

16. Chairs report

16.1 The Chair advised members that he had been unable to attend the meeting with Minister Costello and the Chair of ECART as he had been unwell.

16.2 He had attended a meeting with Fertility New Zealand and commented on the extent to which people understood the law and guidelines for the storage of reproductive material.

17. Member reports

17.1 No reports were presented.

18. Secretariat report

18.1 Members noted the report.

18.2 The member with expertise in assisted reproductive technology told members she would attend the American Society for Reproductive Medicine (ASRM) conference in Denver later this year.

19. Work between meetings

19.1 The Chair noted the various actions that had been agreed to in this meeting.

20. Update on appointments

20.1 The Secretariat noted that this item had been covered earlier in the day, in item 9, Appointments and new Chair.

21. Attendance at ECART

21.1 The member to attend ECART on 24 October is yet to be confirmed.

21.2 The member with expertise in human reproductive research observed that ECART has been seeing more cases of single women attempting to have babies with donated eggs and sperm. The member with expertise in assisted reproductive technology added that there is also an increase in older women attempting to become pregnant. There was a brief discussion about the risks associated with older women having children and possible risks to the long-term outcomes for

children born to older mothers and with donated gametes.

The meeting closed at 3.45 p.m.