

Minutes of the ninety-second meeting of the Advisory Committee on Assisted Reproductive Technology

Held on 13 August 2021, online.

Present

Kathleen Logan (Chair)
Calum Barrett (Deputy Chair)
Rosemary De Luca
Seth Fraser
Karen Reader
Catherine Ryan
Karaitiana Taiuru (Apology for part of the morning.)
Analosa Veukiso-Ulugia
Sarah Wakeman

Non-members present

Mike Legge, ECART Member
Martin Kennedy, ACART Secretariat
Hayley Robertson, ACART Secretariat

1. Welcome

- 1.1 The Chair opened the meeting at 9.00am and welcomed the ECART member, Mike Legge.
- 1.2 Chair's opening comments. The Chair noted that some of ACART's current work is on contentious matters and is in the formative stages. ACART relies on all members' expertise and if someone is absent there may be a risk of matters not being addressed adequately. Robust discussion will ensure ACART can defend its decisions and explain its proposals to the sector and the Minister of Health. The Chair highlighted the need for respectful discussion.
- 1.3 The Chair advised those present that there is a very full agenda and work programme with four projects to consider plus a number of correspondence items to reply to.

2. Apologies

- 2.1 Nil.

3. Approval of the agenda

- 3.1 Members approved the agenda.

Action

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

4. Declarations of Interests

- 4.1 No conflicts of interest were declared.

5. Minutes of ACART's meeting of June 2021

- 5.1 Members approved the minutes subject to one change.

Action

Secretariat to make one amendment to the June minutes and publish on ACART's website.

6. Actions arising from ACART's June meeting

- 6.1 Members noted the status of the actions from the June meeting.

7. Status of ACART's work programme

- 7.1 Members noted the report.

8.a Correspondence: requirement for a biological link

- Members discussed the two enquiries: one about the importance of a biological link between intending parents and offspring and another about if and when gamete donors can give their consent to an activity.
- 8.1 ECART has requested supplementary advice, about the "biological link," (in particular, genetic links) to assist them with deciding whether to approve an application. It needs a clear basis on which to make its decisions and needs to be

consistent.

- 8.2 ACART had removed the mandatory biological link because it was unlikely to be justifiable, not because it was unimportant. ACART's position was, and still is, that a biological link is important, but the mandatory link was removed to remove the potentially discriminatory provisions. This removal enabled surrogacy with both donated eggs and donated sperm or donated embryos.
- 8.3 ACART needs to be clear that the link is important and needs to explain why it has this position. The primary reason in favour of having a biological link is that it is best for the resulting child. The Chair suggested citing evidence to support this position.
- 8.4 The discussion addressed the importance of counselling considering the absence of a biological link. Members noted that by the time an application gets to ECART couples have already had joint counselling (with the donors), giving all a chance to explore joint values. ACART thinks this is valuable and should remain a key part of the surrogacy process.
- 8.5 A member suggested a possible solution in cases where the intending parents are choosing not to have a genetic link even if they are able to have one, would be for ACART to ask that the intending parents present a clear and compelling case, having had counselling and discussing the potential impacts from a child's perspective of missing out on a genetic link with their parents.
- 8.6 In conclusion, ACART members confirmed their position that it is preferable to have a genetic link if possible but there could be reasons why embryo donation or the use of both donated eggs and donated sperm would be appropriate instead. If that's the case, these need to be clear for ECART.
- 8.7 Members agreed to focus on the definition of "best or only" opportunity to use a procedure.
- 8.8 Members discussed tikanga and the importance of cultural consultation and conversations with family, noting that birth is the primary concern from a tikanga perspective. Members discussed an example of a Ngai Tahu couple using a Pākeha embryo — the child would not be recognised as a member of the iwi. But different Māori tribes have different rules about tribal membership.
- 8.9 The importance of a religious perspective for some intending parents was also discussed, noting that some couples consider it more appropriate to use embryos that already exist rather than creating surplus from their own gametes.
- 8.10 ACART also acknowledged that applying to ECART is not the preferred situation for a lot of people as it involves a lot of time, effort and expense. There is also a shortage of donor eggs and sperm. ACART is aware of the pragmatic approach to using embryo donation because it is not only easier but also quicker and cheaper.
- 8.11 ACART decided the response to ECART should be that it is desirable to have the link if possible, citing evidence why. The response should also reiterate that using donor gametes should not be for financial gain or convenience i.e. where people use donated embryos without first trying to use their own gametes if possible, or using donated embryos instead of donated gametes only because it's cheaper and easier.

Actions

- Secretariat to draft supplementary advice for ACART to issue to ECART.
- Members to consider the advice out of session.

8.b Correspondence: timing of donor consent

- 8.12 Members discussed the policy that once an embryo has been created, there is no more opportunity for gamete donors to have a say in how the embryo is used because the embryo is a new entity.
- 8.13 Members noted the new ACART guidance about on-donation discusses who consents under what circumstances (in the supplementary advice to the sector). Members agreed that gamete donors need to know about the possibility of on-donation when they donate their gametes and that they cannot withdraw their consent or change their minds.
- 8.14 The discussion addressed whether gamete donors should be asked to consent to a **new** activity if that activity had not been discussed when the gametes were originally donated. Members agreed that this should be allowed: this process also has the advantage of ensuring that consent would be current.
- 8.15 The Chair suggested if a clinic wanted consent to be current as a matter of policy, they could suggest the donor stipulate that as a 'condition of donation' that they must be contacted for consent to embryo on-donation or other new use, eg research.

Actions

- Secretariat to draft replies to ECART.
- Chair to approve via email.

9. Report on ECART's April meeting

- 9.1 Members noted the report.
- 9.2 One decision had been deferred because of a life expectancy consideration. ACART members noted the impacts of the deferral on the application.
- 9.3 ACART members noted that ECART members had discussed the need for another medical expert on ECART and that this has been raised with the Ministry of Health. ECART members had also discussed the need for staggering the replacement of members to ensure continuity of expertise.
- 9.4 ECART members had also discussed the need for more frequent meetings. ACART members noted that the Law Commission's discussion document (about surrogacy) states that ECART needs more members, and that ECART should be better resourced to deal with increasing surrogacy cases.
- 9.5 ECART members had discussed rolling memberships, a surrogacy subcommittee, and the ability to consider matters between meetings. Such improvements would enable ECART to ensure the principles of the HART Act are met.

10. Governance arrangements

- 10.1 ACART recognises its requirement to honour Te Tiriti o Waitangi. Like any Crown entity, ACART is obliged to follow it and work in partnership with Māori. ACART had no Māori member for two years, relying on advice from external experts in Māori interests. ACART is now working to honour Te Tiriti and looking at its governance options. The options include a dedicated Māori chair, or deputy chair, or a co-chair.
- 10.2 The discussion addressed the benefits and challenges of co-chairing. Particular challenges include how to split the work and decision making.
- 10.3 The member with expertise in Māori interests noted that the “He puapua” report recommends Māori involvement in public (government) decision making. The report supports kaupapa Māori and meeting Te Tiriti obligations.
- 10.4. Members noted that a co-governance arrangement would ensure that the Māori membership role would not be a token role. Members further discussed if or why the arrangement would be a co-governance role? A deputy or chairing option might be adequate and pragmatic. They were interested to ensure that while Māori interests were met the governance was still workable.
- 10.5 The discussion covered other options including a flat governance structure and whether that would be plausible. A flat structure could have the advantage of sharing the work more evenly between members rather than relying so heavily on the chair and deputy. Some members liked this concept and considered the Chair/Deputy roles were more support roles for all members to participate in the work.
- 10.6 The member with expertise in Māori interests said that having a person with expertise in Māori interests in a governance role would ensure that ACART meets its treaty obligations, is seen to be working with Māori, and that the committee’s decisions actually help Māori in practical ways. He noted that having Māori heritage doesn’t necessarily mean the person will have an in-depth knowledge of Māori interests.
- 10.7 Several matters were raised including if and how ACART can take into account the interests of other ethnic groups, noting that doing so isn’t actually feasible with a maximum of 12 members. Membership diversity is heavily influenced by the legislated requirements of members, and the limited diversity of the applicants to those roles. Also, the appointments process did not appear very useful in attracting more diverse people than are currently on ethics committees.
- 10.8 A member also observed that the Chair is appointed by the Minister and the Minister might appoint somebody who is not yet a member. This point led to the matter of members needing experience with the committee to contribute meaningfully as the work is detailed, sometimes complex, and it can take time to become familiar with all of the context and history.
- 10.9 Members agreed that the secretariat draft a letter to the minister proposing a that a member with expertise in Māori interests always be assigned a role as either the chair or deputy. This letter would be clear that the Minister appoints the Chair and that any such arrangement will need to be formalised and the committee’s term of reference would need to be amended.

Actions

- Secretariat to draft a letter from the chair to the minister.
- Members to consider the letter out of session.
- Chair to approve via email.

11. Guidelines for extending storage

- 11.1 Members noted the proposed changes to the consultation document. Originally, ACART had agreed to a narrow scope, but ECART has suggested a broader scope. If ACART agrees, it will need to amend the document before it goes out for consultation.
- 11.2 The original purpose of the consultation was to get public input to the removal of one problematic provision so that clinics don't have to go back to gamete donors for consent to storage extension of embryos. Members noted that embryos are under the authority of the person who 'owns' the embryo.
- 11.3 Members agreed there is a benefit on extending the scope of this document. They discussed the addition of questions about several matters including the duration (period) of the storage extensions, the age of intending parents, the intended use of the embryos, whether a time limit should be set, and whether the current ten year limit is suitable or needed.
- 11.4 Members agreed that any new consent needs to be consistent with the original intent of the donation. Closely related to this, they noted that if an activity had not been an option at the time of the donation of the gametes, but was now being considered, then clinics should go back to the gamete donors for consent to the new activity.
- 11.5 The discussion addressed the fact that ECART does not make decisions based on any proposed **use** after the extension of the storage. However, from time to time ECART might consider whether the intending parent will be too old to be able to safely carry a pregnancy. More difficult cases are when, for example, a 70 year old man wants to extend storage for another 10 years. Under the Human Rights Act clinics can't have an age cut off, but they do have a medical cut off. For women aged over 50, one fertility services provider takes cases to their Medical Directors meeting due to the risks of medical events (e.g. stroke) from pregnancy.
- 11.6 Members noted the benefit of having a limit to storage because it prompts people to decide what to do with their stored gametes or embryos. A member commented that when considering such rules it is also helpful to ask why you would not allow the person to extend the storage: this question can prompt a new line of thinking about the ethical matters that need (or don't need) to be addressed.
- 11.7 There was a discussion about people storing gametes or embryos without a plan, but rather to keep their options open. Members agreed the consultation document should ask questions about whether ECART should consider people's reasons for storage and whether the proposed use should be a factor that ECART must consider. A member noted that some people use the storage option as a way of not having to make a decision: some people find it difficult to agree to dispose of stored material.

- 11.8 Intergenerational effects were discussed and members considered the ethical concerns of this. The discussion distinguished between the social and psychological effects of people being, for example, siblings but born 30, or 40 or 50 years apart, and the unrelated matter of whether consanguinity risks might rise due to siblings being born with large times between them. The discussion also covered the example of a person using a grandparent's embryo (where allowed). Members considered the complexity for the Māori/whakapapa narrative and how this could be accommodated in guidelines.
- 11.9 Members discussed if and how the guidelines might provide for uses that are not yet possible. For example, people wanting to store material for future stem cell therapy. Members discussed who would consent to the extension of that storage? There was an agreement that the ACART needs to confirm the legality of provisions for (a) uses, when it is the storage that is being extended and (b) uses that are not yet available.
- 11.10 Biobanking was discussed, focussing on the need to be clear about the definition, what the purpose of the banking is, and who would run the banks.
- 11.11 Members agreed they would email the secretariat any comments on the consultation document. Members asked that the secretariat separate out clinical and non-clinical research at the bottom of section 3. Members asked that narrative about disposal, and what it involves, be added to the document.
- 11.12 Members concluded that the point of no return for embryo research in laboratories is once the embryo is part of a research project. Members agreed the consultation should ask submitters about (a) the point of no return and (b) who consents to extensions of storage for bio-banked material.

Actions

- Secretariat to amend the document for consideration at ACART's next meeting.
- Secretariat to add narrative about disposal to the document.
- Secretariat to draft a request for legal advice to the Ministry of Health.
- Chair to approve the request for legal advice.

12. Guidelines for human reproductive research

- 12.1 Members discussed whether to create two separate guidelines, one for clinical research and the other for non-clinical research, because they are very different scenarios with clinical leading to a live baby while non-clinical will never lead to the birth of a baby.
- 12.2 The discussion addressed the ethical complexity of the two pathways and the need to be clear about which cases need to go to ECART. Members concluded that separate guidelines would not be necessary but agreed to have separate sections, for clinical and non-clinical research, in one guideline.
- 12.3 Members noted that some activities such as training do not sit neatly in either of these categories. Other activities might also not fit well, such as any research in which an embryo is used but is not strictly the subject of the research. For example, when testing culture media, the test is on the media but the embryo needs to be

used to test it. There is also a grey area when deciding whether some activities are clearly in 'fertility' or more in obstetrics. These matters will need to be addressed.

- 12.4 The preamble will present ACART's definition of research and refer to the principles of the HART Act, and ACART's ethical framework.
- 12.5 The discussion moved on to the "14 day rule" which is based on the day at which the "primitive streak" starts forming. Members did not decide whether ACART should consult on the 14 day rule. There was a discussion about the phrase in the 2021 ISSCR Guidelines for Stem Cell Research that research longer than 14 days can be approved if it is justified by the scientific objectives. This is one of a number of criteria recommended, but the ISSCR Guidelines document defers to national public consultations and domestic regulation.
- 12.6 Members confirmed a two stage consultation would be used. The first stage will explain the proposal to have guidelines for HRR and the rationale, including the principles to be used to determine guidelines, with descriptions of the kinds of research that could be done and why. It would ask people's preferences for and thoughts about the principles, and their perspectives on types of research. The second stage would present draft guidelines and advice to the minister. Members discussed whether draft guidelines should be presented in the first stage, as an indication of an early working draft, but decided to focus on what's possible, 'educate' people and ask what they think.
- 12.7 The consultation will state that the HART Act prohibits various activities and that ACART does not intend to question any of those prohibitions.
- 12.8 Members considered if and how the consultation might get broad public interest, noting that the document will need to be accessible and in lay speak. The document will need to be clear about the rationale for the proposals and to clearly discuss the benefits and risks.
- 12.9 Members noted that mātauranga Māori (Māori knowledge) about fertility research will include a large range of ideas and it would be useful to contact Māori researchers initially. A member noted Mason Durie's book, about the gift of children, would be a useful reference.
- 12.10 Suggestions were made that the document should present a range of cultural and religious perspectives. The ECART member observed that "humanised organs" (organs in non-human animals that have had human genes added to them) have not yet raised major cultural objections.
- 12.11 The secretariat will continue drafting the consultation document for the first stage of consultation.

13. Cryopreserved testicular tissue

- 13.1 The secretariat noted that the consultation period closes today and that it had collated the responses — a high level summary was provided to committee. Submitters had generally agreed with proposal but queried the possible experimental uses of the tissue (as transplant) and some matters arising from definitions.
- 13.2 Some clinics stated that never freeze tissue as it is — they retrieve sperm first, or

they modify the tissue so that it is easier to retrieve sperm after freezing the material. Either way, the tissue is not stored in its original state. The responses have made it apparent that ACART will need to consider how to proceed on the basis of this new information.

- 13.3 Also, some of the procedures that could be done with the tissue are not yet at a point where they could be “established procedures.” That is, for some uses of the material they would still need to be subject to guidelines. Also, the consultation has raised the matter, again, of what is meant by the term “use” in the HART Act?
- 13.4 The secretariat will produce a full summary of submissions, and the matters arising, for the committee to review. A working group could then meet to decide next steps. Members agreed to have a working group meeting in October, preferably face to face.

Actions

- Secretariat to produce a full summary of submissions for committee.
- Working group to consider in October.

14. Posthumous reproduction

- 14.1 Members noted that the working group had considered the draft guidelines and advice to the minister on 24 June.
- 14.2 Members went through the document addressing each of the points that had been marked for attention. They requested some amendments and will send any written comments to the secretariat out of session.
- 14.3 Members discussed again the matter of consent to retrieval after death if you don't have any material already stored.
- 14.4 Members agreed another working group will be needed to write the supplementary advice for the sector. The secretariat will make arrangements for that group and draft material.

Actions

- Members to email Hayley comments by Friday 20 August.
- Secretariat to draft supplementary advice.
- Secretariat to prepare for a working group.

Extra item: Law Commission consultation on surrogacy

- Nicola Lambie, from the Law Commission, gave an overview of the commission's consultation document and ACART confirmed it will make a submission.
- There was discussion about compensation for surrogates, in particular asking if and how it might be acceptable. The Law Commission's document presents what reimbursement might be appropriate, e.g. out of pocket expenses, and paid parental leave.
- There was a discussion about the nationality status of children in cases of New Zealanders having surrogates in other countries gestate a child for them. The

immigration status of such children is not guaranteed.

- Members discussed if and how a contract/document could be used to record the expectations and intentions of all the relevant parties. The commission's view is that the surrogacy would remain an unenforceable agreement — they do not want to create an expectation, or reality, of enforceability. The commission's legal advice would be explicit that surrogacies are not and will never be enforceable.
- Members agreed to have a working group to write ACART's response. Sarah, Kathleen, and Calum volunteered. They will meet in early September, subject to funding agreement, for meeting, by the Ministry of Health.
- All members agreed to consider the final by email.

Extra item: updating ACART's ethical framework

- A working group, of Rosemary, Karaitiana, and Catherine will consider this item. Claim for work between meetings, subject to funding agreement, for meeting, by the Ministry of Health.
- The discussion evolved to consider working groups for the ethical framework, the guidelines for human reproductive research, and for the review of the use of cryopreserved testicular tissue. Members suggested the working groups should be face to face, on the day of the October meeting. Suggestion to have it at the airport with break out rooms.

Actions

- Secretariat to seek agreement from the Ministry of Health for face to face meeting/working groups in October
- Secretariat to seek agreement for working group members to be paid for work between meetings.

15. Chair's report

15.1 Members noted the report.

16. Members' reports

16.1 No items this meeting.

17. Secretariat report

17.1 Members noted the report.

18. Work between meetings

18.1 Discussed with each project/policy item, above.

19. Attendance at ECART

- 29 October, Karaitiana.
- 9 December (recently confirmed new date), Catherine.

The meeting closed at 3:30 pm.