Minutes

Meeting of ACART and ECART to discuss ACART's proposed revisions of the donation guidelines

Date	26 October 2017
Time	9.00 to 10 am
Location	Ministry of Health office, Wellington
Present	Gillian Ferguson, Mike Legge: ACART
	Iris Reuvecamp: ECART
	Kirsten Forrest: ECART Secretariat
	Martin Kennedy: ACART Secretariat (scribe)
	Philippa Bascand: manager of the ECART Secretariat

Discussion

1. Gillian summarised why ACART is doing this work, noting key points such as the complexity of the matters being addressed, the likely resource implications of the proposed changes, and the need for the guidelines to be easier to use.
2. Those present worked through the document in the order in which it was written.
3. On provision 19 of the proposed new guideline, Iris suggested the wording be amended to say "any legal reports show that the legal implications of the procedure(s) have been explained." Fertility services providers cannot be expected to ascertain whether participants have *understood* the implications of the procedures.
4. Iris commented on provision 21 of the proposed new guideline, asking whether the plan was that all health information would be shared with all parties. That is not the current practice. Iris said that ECART believes the information should be shared if it is significant. There are privacy and consent implications associated with people's health information.
5. Iris commented on the requirement, in provision 5 of the embryo donation section, that recipients have been vetted by police. This requirement has time and cost implications and there is no guidance on the types of records ECART is required to take in to account when considering applications.
6. Iris asked that existing children be added to provision 2 of the section on clinic assisted surrogacy.
7. ECART does not agree with provision 3 of the section on clinic assisted surrogacy that requires a surrogate to have completed her family before becoming a surrogate. ECART suggests that this be amended so that it reads "there has been discussion between the affected parties as to whether or not the surrogate has completed her family before becoming a surrogate for others".
8. Iris asked that certain text be cut from provisions 5 and 6 of the section on clinic assisted surrogacy, as follows.

5. ~~in the opinion of the counsellor~~ the wellbeing and welfare of the intending surrogate and any resulting offspring is safeguarded

6. all affected parties have considered~~, and in the opinion of the counsellor, have understood~~: (bullet points follow)

9. Iris asked that a provision be added to those in the section on clinic assisted surrogacy as follows: "8. Oranga Tamariki approval has been granted".

10. With reference to question 1 (page 23 of the consultation document), Iris said that ECART agrees with the proposal to rescind the biological link policy with the restriction that cases can be approved under the rationale that it is the best or only opportunity to have a child. However, she said that ECART would question the suggestion that people will usually prefer to have a genetic link to a child if they can. ECART has seen some cases recently of people choosing not to have a genetic link to a child even though this is possible. These cases have involved intending parents preferring to be equally unrelated to the child. Iris also noted that some people will prefer not to use their own gametes for religious reasons.

11. In response to question 2 (page 24 of the consultation document), ECART agrees that donor offspring should have access to information about the donors, although it considers it important that careful consideration is given to how this would be flagged on the birth certificate.

12. In response to question 3 (page 26 of the consultation document), ECART agrees with the proposal for a single donation guideline.

13. ECART agrees with the broad framing of the justification to use a procedure (question 4, page 28 of the consultation document).

14. ECART noted that the proposal to change the requirements to state that there must be a "justification to use a procedure" (paragraph 103 of the consultation document) would mean the application forms would need to be amended.

15. With reference to the heading "4.3 Consent by gamete donors" on page 28, Iris asked how the consent requirements will apply in the case of posthumous reproduction. Gillian said that ACART will address posthumous reproduction in the next few months when it review the guidelines for the posthumous use of sperm. Iris suggested that consideration be given to whether there was a need for separate posthumous reproduction guidelines, or whether these could be incorporated into these guidelines. Iris noted that recent posthumous reproduction cases had been considered under the current guidelines, not the posthumous reproduction guidelines (noting that these related only to use of sperm and were outdated).

16. There was a discussion about the interpretation of the phrase "specific procedure" (paragraph 109 of the consultation document) and that the HART Order used the phrase "specific use".

17. In response to question 5 (page 30 of the consultation document), there was a discussion about the timing of consent and whether clinics would need to go back to donors in any situations, such as the re-donation of embryos.

18. In response to question 6 (page 31 of the consultation document), ECART agrees that potential coercion should be taken into account (and notes that this is currently the case).

19. In response to question 7 (page 32 of the consultation document) ECART agrees with the proposal to continue the two-family limit for full genetic siblings.

20. For question 8, about participants obtaining legal advice, Iris suggested the wording be changed (see "legal advice requirements of the draft guidelines, page 4 of the consultation document):

    a. for provision 17, so that its states that "where an application does not include a surrogacy arrangement, parties have considered the legal aspects related to the procedure," and

    b. for provision 19, so that it states "any legal reports show that the legal implications of the procedures have been explained to the parties"

21. There was discussion about how it was important not to impose further unnecessary costs on parties, and that a suggestion that each party consider the option of seeking independent legal advice could mean that parties felt that they were required to seek legal advice. ECART also feels that it didn't really add anything to its consideration of the matter – for example, it is unlikely to make any difference to ECART's consideration of the application if legal advice hadn't been sought. Accordingly, ECART felt that an alternative might be to develop standard information sheets on the key legal aspects of ART which could be routinely provided to participants. ACART would consider whether this was something they would be involved in, or whether this was something the Ministry of Health could lead.

22. In relation to the proposals relating to the provisions applying to family gamete donation (page 34 onwards), Iris stated that ECART strongly disagrees with the proposal that all family gamete donations be referred to ECART. She said that the risks are not all the same for all family gamete donation cases. She noted that ECART would end up being deluged with applications which were completely unnecessary. She suggested that ACART consider carving out the factors that might cause concern and would require further ethical consideration by ECART. In particular, ECART considered that ECART approval should be sought for cases involving a) intergenerational donations/outcomes b) cases in which there could be concerns about coercion and c) concerns about the wellbeing of any potential children. Iris said that this would most appropriately be dealt with by amending the relevant provisions of the HART Order.

23. In response to question 10 (page 38), ECART considers that further thought should be given to the rights and interests of gamete donors and how they would be upheld; the rights and interests of intending parents; the complexity of consequent relationships; the well-being of the potential child(ren); and ongoing contact and access to information.

24. There was a discussion about allowing the re-donation of embryos (page 39, in response to question 11). Such a change would mean that relationships could be created that are even more complex than those that can currently be created. There would be implications for donors and consent.

25. There was a question about why the original intending parents would be the people to decide if they would re-donate: this question is particularly important for the first

recipient couple if they have had a child, because a re-donation could result in another family having a full genetic sibling to their child.

26. There was also a question about how “family” is defined and what would happen in cases where couples separated. Would the embryos be able to be used again by one of the parents, or would that parent’s new situation be categorised as a new family?
27. ECART considers that the guidelines need to take into account the potential for an interest in the fate of donated embryo(s) to come about not only as a result of being a gamete donor (biological parent), or intending parent for whom the embryos were created, but also the interests of any parent(s) of any children who are full genetic siblings of the remaining embryo(s). Depending on the age of any full genetic siblings they would also seem to have an interest that should be taken into account, at least in some scenarios.
28. ECART agrees with the proposal to clarify the status of embryo donation in the regulatory framework (paragraph 156 of the consultation document).
29. ECART agrees that all clinic assisted surrogacies should be subject to the guidelines (question 12, page 41 of the consultation document)
30. Iris said that John McMillan, who had attended the last ECART meeting, had suggested that perhaps ACART should consult with ECART before finalising the consultation document, so that it allowed for some unforeseen issues to be worked through. Iris said she would leave that suggestion with ACART for its’ further consideration.

End.