

8 November 2017



Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Gillian Ferguson
Chair
Advisory Committee on Assisted Reproductive Technology (ACART)
PO Box 5013
WELLINGTON

Dear Ms Ferguson

Proposed Donation Guidelines: for family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy

Congratulations on your appointment as Chair of the Advisory Committee on Assisted Reproductive Technology.

Thank you for the opportunity to comment on the Advisory Committee on Assisted Reproductive Technology's (ACART) consultation document on ACART's proposed advice to the Minister of Health, *Proposed Donation Guidelines: for family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy* (the consultation document).

As you are no doubt aware, as Health and Disability Commissioner, I am charged with promoting and protecting the rights of health and disability services consumers, as set out in the Code of Health and Disability Services Consumers' Rights (the Code). One of my functions under the Health and Disability Commissioner Act 1994 is to make public statements in relation to any matter affecting the rights of health or disability services consumers.

The consultation document asks fourteen questions in respect of the use of the donation of gametes and requests feedback on those questions. I have focused my response on aspects of the document relating to the Code of Health and Disability Services Consumers' Rights (the Code) and informed consent.

Informed Consent

I note that throughout the document, 'consent' and 'informed consent' are interchanged. It is important to note that for the purposes of the Code, consent must always be informed, and I recommend the word 'informed' is inserted immediately before the word 'consent' wherever it is used.

To acknowledge that the right to be fully informed and to give informed consent are fundamental rights set out in the Code; I suggest that consideration is given to rewording the first sentence of paragraph 42 as follows:

“The Code applies to any person receiving, and any provider (either an individual or an organisation) providing, health services and/or disability support services in New Zealand.”

I also recommend rewording the first sentence of paragraph 43 to read:

“While the Code does not specifically address aspects of assisted reproductive technology, any regulations or guidelines must be consistent with it, and all providers must adhere to it, as fertility services fall under the definition of ‘health services’ in the Health and Disability Commissioner Act 1994 (the Act).”

I note an error in the first bullet point of paragraph 43 where ‘accord’ should read ‘accordance’.

Discrimination

In paragraph 84, you state that ECART must be satisfied that any application that does not include a genetic or gestational link is justified. This term ‘justification’ implies that the consideration is related to discrimination under the New Zealand Bill of Rights Act 1900. If the ACART policy will no longer require a genetic or gestational link, then there will be no need to consider justification in relation to that requirement in the policy as there is no longer any discrimination. ECART will rather need to consider whether the lack of a genetic or gestational link will impact on the other requirements in the guidelines.

Paragraph 106 states that you have not been able to identify any scenarios where individuals or couples would seek to use the procedure without a medical reason. Clarification around what is considered a ‘medical reason’ would be beneficial.

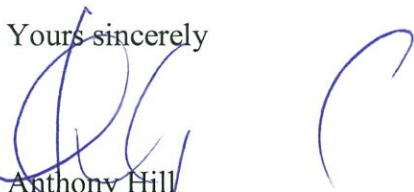
I recommend rewording the two bullet points in paragraph 113 to read as follows:

- donors would need to give informed consent for specific uses at the time of donation, after receiving counselling about the implications of the donation; or
- where informed consent is not given for a specific use at the time of donation, a clinic would need to contact the donor(s) to obtain informed consent to use an embryo created from their gamete in the specific planned procedure.

Conclusion

I trust that you find these comments of assistance. Please do not hesitate to contact Senior Legal Advisor, Jen Feltham on (04) 494 7925 or by email at jen.feltham@hdc.org.nz if you have any questions about this submission.

Yours sincerely



Anthony Hill
Health and Disability Commissioner