Feedback form

Please provide your contact details below.

Name:	Nigel McKerras
If this feedback is on behalf of an organisation, please name the organisation:	Fertility New Zealand
Please provide a brief description of the organisation if applicable:	Consumer support and advocacy
Address/email:	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	Consumer

We will place all feedback on ACART's website, except where we are asked that feedback be withheld in full or part for reasons of confidentiality. We will remove contact information from all feedback.

☐ I **request** that my feedback be withheld in full or part from publication on ACART's website. (If you wish a part to be withheld, please clearly indicate which part.)

Please note that all feedback may be requested by any member of the public under the Official Information Act 1982 (the Act). If there is any part of your feedback that you consider should be properly withheld under the Act, please make this clear in your feedback, noting the reasons.

If information from your feedback is requested under the Act, the Ministry of Health (the Ministry) will release your feedback to the person who requested it. The Ministry will remove your name and/or contact details from the feedback if you check one or both of the following boxes. Where feedback is on behalf of an organisation, the Ministry will not remove the name of the organisation.

☐ **I do not** give permission for my name to be released to any person under the Official Information Act 1982.

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We will acknowledge all feedback.

Questions for response

Question 1: Access to information that must be disclosed to patients and donors prior to consent

(a) Do you agree there is a need for better access to the information that must be disclosed to patients and donors prior to consent?

Yes [X] No [ ]

(b) Is there other information that should be given to patients and donors as part of the informed consent process?

Yes [ ] No [X]

Please give reasons for your views.

(a) fNZ supports consumers and the public having access to regulations and guidelines about informed consent for ART. We note that the Fertility Standards NZS8181 is a copyrighted document. We would welcome the Ministry of Health making it freely available.

(b) fNZ would welcome the Ministry of Health providing a plain language summary of the consent provisions of the HART Act 20014, the Code of the Health and Disability Services Consumers' Rights Regulation 1996 and the Fertility Standards.

Question 2: Form of consent

(a) Do you agree that consent to all assisted reproductive processes, where consent is required, must be in writing?

Yes [X] No [ ]

(b) Do you have any other comments?

Yes [X] No [ ]

(a) fNZ agrees that consent for ART shold be in writing, as is already required by the Fertility Standards workbook section 1.7.2 (a).

(b) Verbal consent should be allowed so that a person can withdraw from an ART procedure at short notice

Question 3: Donor consent to use gametes or embryos for training purposes

(a) Do you agree that the consent of gamete and embryo donors should be obtained if their gametes, or embryos created from their gametes, may be used for training purposes?

Yes [X] No [X]

(b) Do you have any other comments?

Yes [X] No [ ]

Please give reasons for your views.

(a) fNZ agrees that consent should be obtained from people for their gametes and/or non-viable embryos be used for training purposes.

fNZ does not think gamete donors should have to give separete consent for embryos created using their gametes to be used in training. A donor's permission is not required to use an embryo or to discard an embryo, so it should not be needed for an embryo to be used in training. A gamete donor's rights stop once sperm is added to an egg, as agreed in Question 6.

Question 4: Placing conditions on donor consent

(a) Do you agree that donors should continue to be able to place conditions on their consent?

Yes [X] No [ ]

(b) If so, should there be any limits on the conditions placed?

Yes [X] No [ ]

(c) Do you have any other comments?

Yes [X] No [ ]

Please give reasons for your views.

(a) fNZ agrees that donors should be able to set conditions on the use of their sperm, eggs or embryos, and that these conditions should be recorded in their consent form.

(b) The conditions should be reasonable and practical.

(c) Donors should be discouraged from changing conditions after they have donated, because often people reserve sperm to try for a subsequent pregnancy. It would be difficult for a recipient to have donor sperm withdrawn when they met the donor's original conditions but not the donor's new conditions.

Question 5: Ongoing information for donors on the use of their gametes

(a) Do you agree that gamete donors should be given the option of receiving ongoing information on the use of their gametes for the following situations:

(i) if the gamete is about to be used?

Yes [ ] No [X]

(ii) on the outcome(s) of the donation?

Yes [X] No [ ]

(b) Is there any other information that you think should be offered to gamete donors after consent has been given?

Yes [X] No [ ]

Please give reasons for your views.

(a) fNZ does not think that donors have the right to require the clinic to tell them when their gamete (or embryo) is about to be used. The privacy of recipients durin treatment should be an important consideration.

(b) Donors should be able to ask for information from the clinic at any time about the use of their donated material that preserves the confidentiality and privacy of recipients, including the number of children born and their gender.

(c) The clinic should provide information to donors when it relates to the wellbeing of children, such as birth of a child with a condition that might have been inherited from the donor.

Question 6: Withdrawal or variation of consent by donors

(a) Do you agree that gamete donors should be able to withdraw or vary consent to the use of their gametes up to the point of fertilisation?

Yes [X] No [ ]

(b) If not, when do you consider the 'point of no return' should be?

Yes [ ] No [X]

Please give reasons for your views.

fNZ agrees that a sperm or egg donor should be able to withdraw or vary consent up to the point of fertilisation, and that an embryo donor should be able to withdraw consent up to the point of embryo transfer.

Question 7: Consent of a partner, family or whānau to donation or use of donor gametes

(a) Do you agree that the consent of **partners** to the donation or use of a donor's gametes should not be required?

Yes [X] No [ ]

(b) Do you agree that the consent of **family or whānau** to the donation or use of a donor's gametes should not be required?

Yes [X] No [ ]

Please give reasons for your views.

(a) fNZ agrees that a donor has autonomy over the use of his or her gametes and should not require other people's consent. However, partners should be offered information and counselling about the implications of their partner's donation.

Question 8: Couple disputes about the future use of embryos

(a) Do you agree that where one party in a couple disputes the future use of embryos that have been created for them, there should be a 'cooling-off' period of 12 months – and if not, why not?

Yes | X | No |

(b) Do you agree that, if the couple cannot agree about the use of the embryos within that period, the embryos should be disposed of – and if not, why not?

Yes | X | No |

Please give reasons for your views.

(b) In general, we agree that if a couple cannot agree about the use of an embryo, the embryo should be disposed of. However, there is an important exception. If a couple creates an embryo using donor sperm, then the woman should be able to use that embryo even if her partner disagrees. The reasoning follows. Suppose the general pinciple applies in all cases, then this embryo would be discarded. The woman could then have a new cycle of IVF treatment using the same sperm donor to create an embryo with the same genetic composition as the embryo which was discarded. It is illogical, expensive, and wasteful of a potential human life to require an embryo to be discarded only to create a replacement embryo from the same gametes.

Question 9: Form of requirements for informed consent

(a) Do you agree that requirements for informed consent should be set out in regulations?

Yes | X | No |

(b) Do you have any other comments?

Yes | | No | X |

Please give reasons for your views.

Regulations can help ensure all necessary issues are covered when obtaining consent. They should focus on principles, rather than being proscriptive about detail.

Question 10: Comments or suggestions

(a) Do you have any general comments or suggestions about the requirements for informed consent?

No

(b) Do you have any other comments or suggestions about the issues discussed in this consultation document?

No