ACART Consultation on Informed Consent.
Submission by Women's Health Action Trust.

Feedback form

Please provide your contact details below.

Name:	George Parker
If this feedback is on behalf of an organisation, please name the organisation:	Women's Health Action Trust
Please provide a brief description of the organisation if applicable:	Women's Health Consumer and Policy – Not-For-Profit
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.

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

We will acknowledge all feedback.

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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 [+] No [ ]

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

Yes [+] No [ ]

Please give reasons for your views.

Women's Health Action strongly supports more transparency about the information requirements to ensure informed consent as specified in the Fertility Services Standard. We have been frustrated about our (and consumers' in general) inability to access the standard, including where there have been consultations about the content of the standard. We **strongly** support the fertility services standard being available for viewing and download on the MoH and ACART websites with the sections relating to information requitements for informed consent highlighted and easily accessible.

We would also like to see all relevant legislation relating to ART made available to consumers in a sumarised and plain language format – potentially in a format like a consumer booklet. This would help ensure consistency in information sharing nationally.

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 [+] No [ ]

(b) Do you have any other comments?

Yes [+] No [ ]

We **strongly** support requirements for consent to be in writing given the complexity of the decisions being made. We would also like to see writen consent forms produced as carbon copies so all parties who give their consent to proceedures retain a copy of the consent form which clearly outlines what they have consented to, for their future reference, should uncertainties or disputes arise.

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 [+] No [ ]

(b) Do you have any other comments?

Yes [ ] No [+]

Please give reasons for your views.

We **strongly** support a requirement that gamete and embryo donors give their informed consent to the use of their gametes/embryos for training purposes, along with any other uses other than that for which they have been donated eg. research. We agree that this is consistent with the informed consent requirements of the Code of Health and Disability Services Consumer Rights.

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 [+] No [ ]

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

Yes [+] No [ ]

(c) Do you have any other comments?

Yes [ ] No [ ]

Please give reasons for your views.

Women's Health Action agrees that donors should be able to place conditions on the use of their gametes/embryos to an extent, however we believe this should be balanced against the ehtical principles of non-discrimination and equal opportunity. We support the Victoria-Australia model of a limit to the conditions that donors may place to the number of women who may use the donor's gametes or embryos, and the kinds of proceedures in which the gametes (or embryos) may be used. We do not agree that a gamete or embryo donor should be able to set limitations on the characterisitics of the person who may receive the gamete- for example on the basis of relationship status, sexuality, religion or ethnicity.

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 [ ]

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

Yes [+] No [ ]

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

Yes [ ] No [ ]

Please give reasons for your views.

We support donors having access to on-going information on the use of their gametes should they opt to have access to such information. Given this is likely to be a minority of donors we would suggest an alternative option of clinics informing donors that this information will be recorded and made available and that donors may contact the clinic at any point in the future to access this information should they wish to do so. This would help prevent a potential privacy issue of clinics sending out private information about the use of donors' gametes and embryos to no-longer current addresses or in the situation where the donor has moved on, had a change of life circumstances, or no longer wish to be informed about the use of their gametes/embryos.

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 [+] No [ ]

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

Yes [ ] No [ ]

Please give reasons for your views.

We agree with ACARTs reasoning and conclusion on this matter.

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 [+] 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 [+] No [ ]

Please give reasons for your views.

We agree with ACARTs reasoning and conclusion on this matter.

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 [+] 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 [+] No [ ]

Please give reasons for your views.

We agree with ACARTs reasoning and conclusion on this matter and consider the cooling off period a pragmatic solution to a complex situation. However we agree that ultimately the gamete donor should be able to withdraw or vary consent up until the point of no return.

Question 9: Form of requirements for informed consent

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

Yes [+] No [ ]

(b) Do you have any other comments?

Yes [+] No [ ]

Please give reasons for your views.

We agree with ACARTs reasoning and conclusions. We advocate for *meaningful* informed choice and consent and believe that this will be best supported in the complex arena of reproductive technologies by clear regulations outlining informed consent requirements and processes.

Question 10: Comments or suggestions

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

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

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