

**ACART Consultation on Informed Consent.
Submission by John France.**

Feedback form

Please provide your contact details below.

Name:	John France PhD, DSc, FAACB
If this feedback is on behalf of an organisation, please name the organisation:	
Please provide a brief description of the organisation if applicable:	
Address/email:	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	Health Professional (retired)

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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.

As noted in the Consultation Document, the Fertility Services Standard is not freely available. It would be of value if prospective users of fertility services could have access to the information provided in 'the Standard' before involvement with a fertility service. Making 'the Standard' freely available via the internet would enable this access. In the context of patient and donor legal rights, it should be a requirement of the fertility services provider to ensure patients and donors have understood the information provided in 'the Standard'. An informed choice and the giving of informed consent is dependent on full understanding of this information.

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 ☐

ACART Consultation on Informed Consent. Submission by John France.

With all procedures involving ethical considerations, issues or outcomes, informed consent by patients or donors must be obtained in writing. This has long been a requirement in the various fields of health care and research in New Zealand.

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.

The consent needs to be obtained in writing. The training procedures need to be explained to the donors and the fertility service provider must ensure the donors understand what is involved and why. The Consultation Document did not provide an outline of what the training involves. Perhaps it is included in 'the Standard'. If not it should be.

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.

**ACART Consultation on Informed Consent.
Submission by John France.**

I agree with the conclusion and ethical and policy arguments on this question given by ACART in the Consultation Document.

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.

Both situation (i) and (ii) are relevant if the donor is going to be able to provide informed consent and have trust in the infertility service provider appropriate use of the gametes donated. As well as being informed that the gamete(s) are about to be used the donor should be informed that this is in keeping with any conditions the donor may have placed on their use. The gamete donor who elects the option of receiving the information on use and outcome would have an obligation to inform the provider of any change in contact details.

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 ☐

ACART Consultation on Informed Consent. Submission by John France.

Please give reasons for your views.

I agree that gamete donors should be able to withdraw or vary consent to the use of their gametes. However, up to the point of fertilisation is a timing that is too late in the process. There is now a recipient involved and respect and consideration must be given to the emotional, social and financial implications associated with their involvement. A 'point of no return' is probably best when the donor is informed that their gamete(s) is about to be used (see my response to Question 5).

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.

- a) The good and sound relationship between spouses or partners involves among other requirements a strong trust in each other. The donation and use of the gametes of one spouse/partner without the knowledge and consent of the other surely would challenge this trust and the stability of the relationship.
- b) European society has a major individualistic component and while in some circumstances consent of family to a member's donation of gametes may be desirable, I don't think this consent can be imposed as a requirement. Maori culture on the otherhand is more communal and consent of whanau I think would be expected.

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?

**ACART Consultation on Informed Consent.
Submission by John France.**

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.

- a) It is important that the couple are given the opportunity and a process to work towards a positive resolution of the dispute and to avoid a total breakdown of their relationship (if this has not already occurred). A 'cooling-off' period of 12 months during which time their involvement with a skilled mediator seems appropriate. The mediator should also act as the advocate for the embryos.
- b) I believe human life must be respected and protected from its very beginning. Accordingly, I do not agree that the stored embryos should be disposed of if the dispute between the couple over their use is not resolved after the 'cooling-off' period. Who makes the decision to dispose of the embryos? It is highly likely one of the couple would object and not consent, otherwise why the dispute. The fertility service provider must play a neutral role. Would the disposal, therefore, be mandatory covered by regulations? **I propose that the existing 10 year storage limitation should apply.** If the couple's relationship ends in a break-up and they have existing children then custody of the children is decided in the Family Courts. Custody and responsibility for future use of their stored embryos should be included in this judicial decision.

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.

I agree with ACART's conclusions and reasoning on this Question given in the Consultation Document.

**ACART Consultation on Informed Consent.
Submission by John France.**

Question 10: Comments or suggestions

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

No further comments.

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

The only major ethical issue of contention in this consultation is with Question 8(b). I have proposed that the existing 10 year limitation on embryo storage should apply and that when there is a complete breakdown of the couple's relationship, the Family Court should decide on custody of the embryos to cover this period. Donation of the embryos is a option for consideration. If the couples relationship is ongoing, a future change in circumstances may result in agreement in use of the embryos. Disposal of the embryos during or following the 12 month's cooling-off period, I cannot agree with.

I wish to also comment on the use of the wording 'disposed of' in regard to embryos. While I have used this wording in my answers to Question 8, I did so as it was the wording used in the Document. We talk about disposal of rubbish, unwanted objects and suchlike but never of living human beings as the wording does not reflect respect for what is being disposed of. The human embryo is alive, is the beginning of the life of a individual person and therefore should be treated with dignity and respect. Afterall, we all began our life as embryos. The wording was not appropriate in its use in Question 8. 'Allowed to die' might have been more suitable.