

7 September 2015

ACART Secretariat
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Charities # CC11104

Dear ACART Secretariat

Family Planning feedback on informed consent and assisted reproductive technology

Family Planning appreciates the opportunity to provide feedback on Informed Consent and Assisted Reproductive Technology: Proposed advice to the Minister of Health. As an organisation that provides sexual and reproductive health services, informed consent is a key part of our services, both in a clinical setting and in relation to health promotion.

We agree with the recommendations put forward by the Committee. The only additional point we would make is that all reproductive health decisions should enable informed consent. This is not currently the case. In 2015, abortion remains in the Crimes Act (1961) and requires two certifying consultants to sign off on the procedure. This circumscribes the woman's right to bodily autonomy by making two medical professionals the ultimate arbitrators of that decision. We draw your attention to this because Family Planning believes that discussions about informed consent must acknowledge the current limitations with regard to our abortion laws and strive to address this inequality.

Our more detailed comments are attached below in the feedback form provided.

Thank you for the opportunity to comment. Please contact me if you wish to discuss further.

Yours sincerely



Jackie Edmond
Chief Executive

Feedback form

Please provide your contact details below.

Name:	Jackie Edmond
If this feedback is on behalf of an organisation, please name the organisation:	Family Planning New Zealand
Please provide a brief description of the organisation if applicable:	Family Planning provides sexual and reproductive health services across New Zealand.
Address/email:	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	

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.

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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.

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

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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.

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.

The consultation document points out that the Fertility Services Standard (the Standard) is not easily accessible. Family Planning agrees that the issues described in the document need some reflection and discussion with relevant people, particularly the consumer. It is important that there is easy access to the Standard to allow adequate time to study the content and reflect upon it.

Family Planning does not have any specific advice on the information that should be given to patients or donors.

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 ☐

There may be occasions when written consent is not applicable, e.g. where the patient has a physical disability or is illiterate. If there is an exceptional circumstance, the written form should be used as a guide to what needs to be covered and it should be noted on the form why it has not been signed.

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.

Family Planning believes it is important that the donor is aware of all the purposes for which their donated gametes and/or embryo may be used.

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.

Donors should be able to place conditions on their consent but only to the extent that these are within the current legal limits or guidelines. The examples given seem appropriate.

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 ☐

Please give reasons for your views.

Family Planning agrees with the principles of transparency and fairness, requiring the provision of information to the donor. Such principles are similar to the ones used in open adoption.

We agree with the point that this will put more obligations on a fertility service and also agree that it should be the donor's responsibility to keep the service up to date with contact details.

Additionally, Family Planning would make the following points:

- i) We are assuming that the donor is informed of the general details of who the proposed recipient/s are: same-sex couples; the same couple that previously used the donor's gametes/ embryo; or a different couple.
- ii) We do not believe there is a need to indicate what procedure is to be done.
- iii) We would like to see clarification on what is meant by outcome: is it just that a pregnancy has been established? Or would it require more detail, like a child has been born or even the sex of the child?

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 ☐

Please give reasons for your views.

Gamete donors should be able to withdraw or vary consent up to fertilisation (or insemination).

In the case of the use of an ensuing embryo which has been in storage, we suggest that the donor should be able to withdraw or vary consent up until embryo transfer as per paragraph 112 and as in 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.

Like tubal ligation and vasectomy, it is preferable to have a partner's consent but it should not be required. The involvement of partners and relevant family/whanau in the decision-making process should be encouraged.

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 that an embryo created to be used by two specific people should only be transferred with the current consent of both people. In the absence of agreement within a year, the best solution would be disposal.

Question 9: Form of requirements for informed consent

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

Yes

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No

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Please give reasons for your views.

It is much easier to standardise processes if regulations are available to provide guidance and set out good practice.