

# Feedback form

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Please provide your contact details below.

Name:	Lynda Williams and Jo Fitzpatrick
If this feedback is on behalf of an organisation, please name the organisation:	Auckland Women's Health Council
Please provide a brief description of the organisation if applicable:	Provides information and support for women and a consumer perspective on women's health issues.
Address/email:	<a href="mailto:awhc@womenshealthcouncil.org.nz">awhc@womenshealthcouncil.org.nz</a>
Interest in this topic (e.g. user of fertility services, health professional, researcher, member of public):	Women's health advocacy group

Please refer to page v for information about:

- Publication of feedback on ACART's website
- Official Information Act requests – possible release of you feedback
- Official Information Act requests – possible release of you name and contact details

We will acknowledge 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.)
- ☐ I **do not** give permission for my name to be published on ACART's website.
- ☐ I **do not** give permission for my contact details to be published on ACART's website.

If you consider that your feedback, or your name and contact details (if you are submitting on behalf of an organisation), should be withheld under the Act, please state the reasons here:

The Auckland Women's Health Council agrees to its submission being publicly disclosed.

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# Questions for response

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## Question 1

*Refer to sections 3 and 4.*

- (a) Do you agree with ACART's assessment of the known risks and benefits to health associated with the use of cryopreserved ovarian tissue to restore ovarian function?

Yes ☒ No ☐

Please give reasons for your views.

The identification of risks and benefits to health associated with the use of cryopreserved ovarian tissue has been thorough and wide ranging. This is appropriate given the newness of the procedure and its applications.

We agree with the risk assessment profile as outlined in the risk table on pages 71 and 72, and believe the actions outlined to monitor and mitigate them are appropriate and necessary.

- (b) Are there any risks and/or benefits associated with the use of cryopreserved ovarian tissue to restore ovarian function that ACART has not identified or assessed?

Yes ☐ No ☒

If yes, please list below.

We were reassured that ACART had identified potential risks for which no data is currently available. This gave us confidence that ACART horizon scanning had been thoughtful and thorough, and we trust that ACART will continue to monitor the situation and report on future developments as more evidence is published.

## Question 2

*Refer to section 4.*

- (a) Do you agree with ACART's conclusion that the risks associated with the use of cryopreserved ovarian tissue to restore ovarian function falls within a level that is acceptable in New Zealand?

Yes ☒ No ☐

Please give reasons for your views.

The risks have been well identified and the more serious of these have been subject to scrutiny and evaluation. We are therefore comfortable that they are within acceptable levels.

- (b) Please note any other comments below.

The AWHC emphasises the importance of women being provided with good information to enable them to give informed consent to the use of cryopreserved ovarian tissue. This means the risks must not be downplayed and the potential benefits oversold.

## Question 3

*Refer to section 4.*

- (a) Has ACART identified all the relevant areas to monitor the use of cryopreserved ovarian tissue to restore ovarian function?

Yes ☒ No ☐

Please give reasons for your views.

The AWHC supports the ongoing monitoring of the outcomes for children.

- (b) Are there any other areas ACART should monitor?

Yes ☒ No ☐

Please give reasons for your views.

It is unclear whether ACART will continue to monitor the situation where transplanting tissue is excised at the time of active disease. We believe this is an area which should continue to be monitored to inform future use.

We also strongly recommend a New Zealand database is established to assist with ongoing monitoring.

## Question 4

*Refer to section 5.*

- (a) Has ACART identified all the ethical issues relevant to the use of cryopreserved ovarian tissue to restore ovarian function?

Yes ☒ No ☐

Please give reasons for your views.

We are comfortable that all the ethical issues relating to the use of cryopreserved ovarian tissue by a woman using her own previously excised tissue have been canvassed.

- (b) Do you agree with ACART's ethical analysis that there are no significant ethical issues associated with the use of cryopreserved ovarian tissue to restore ovarian function?

Yes ☒ No ☐

Please give reasons for your views.

We agree there are no significant ethical issues associated with the use of cryopreserved ovarian tissue for women using their own tissue.

## Question 5

*Refer to section 6.*

- (a) Do you agree that the use of cryopreserved ovarian tissue to restore ovarian function should become an established procedure?

Yes ☒ No ☐

Please give reasons for your views.

The major current known risks and benefits have been identified and well canvassed. We believe that these can be adequately assessed for each individual woman by the woman and her clinician.

Given that the risks are primarily personal and clinical, we see no useful role for ethical oversight - which would add time and expense to the process for no clear benefit.

- (b) Please note any other comments below.

Given the above factors, and that the process is currently available overseas we believe that women who would like to use their own cryopreserved ovarian tissue should have the opportunity to do so in New Zealand.

## Question 6

*Refer to section 6.*

Do you agree with ACART's position that the scope for the use of cryopreserved ovarian tissue to restore ovarian function be limited to the woman from whom the tissue was excised, for her own treatment?

Yes ☒ No ☐

Please give reasons for your views.

The AWHC's endorsement of the use of cryopreserved ovarian tissue to restore ovarian function is predicated on the assumption that it is only for her own use. We believe extension of use beyond that opens up both clinical and ethical issues and risk which are not currently acceptable.

## Question 7

*Refer to section 6.*

Do you have any further comments to share with ACART?

The AWHC appreciates the opportunity to provide feedback on the issues reported in ACART's consultation document.

We request that we be kept informed about future developments concerning these issues.