

Feedback form

Please provide your contact details below.

Name:	Ailsa Stewart, Convener- Health Standing Committee
If this feedback is on behalf of an organisation, please name the organisation:	National Council of Women New Zealand
Please provide a brief description of the organisation if applicable:	<p>The National Council of Women of New Zealand Te Kaunihera Wahine o Aotearoa (NCWNZ) is an umbrella group representing 288 organisations affiliated at either the national level or to one of our 20 branches. In addition to our organisation's membership, about 260 women are individual members of branches. NCWNZ's function is to represent and promote the interests of New Zealand women through research, discussion and action</p> <p>NCWNZ welcomes the opportunity to participate in this consultation process. Our submission has been prepared by the NCWNZ Health Standing Committee. We have sought comment from members of the Health Corresponding Committee and from individual branch members</p>
Address/email:	Ailsa.stewart@xtra.co.nz , office@ncwnz.org.nz
Interest in this topic (e.g. user of fertility services, health professional, researcher, member of public):	

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:

Questions for response

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 ☐ Y No ☐

Please give reasons for your views.

The assessment of known risks and benefits to health associated with the use of cryopreserved ovarian tissue to restore ovarian function seems to have been developed on research based evidence. The assessment is comprehensive and issues around monitoring the application have been identified. We believe monitoring must be consistent to detect any increases in relapses as this may be an indicator of changes in methodology/technique.

- (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 ☐ Y

If yes, please list below.

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 ☒ Y No ☐

Please give reasons for your views.

We believe this appears to be an appropriate level of risk. The risk assessment associated with the use of cryopreserved ovarian tissue and with the restoration of this tissue is relevantly similar to IVF in relationship to favourable outcomes. However, in Leukaemia patients it would not be unrealistic to increase "Concerns with transplanting tissue excised at the time of the disease" to "C" (possible). If it is proposed that the Danish model is followed and therefore no transplant of cryopreserved ovarian tissue in leukaemia patients, then the current assessment of "D" (unlikely) stands.

- (b) Please note any other comments below.

This assessment looks reasonable given the effect of data uncertainties at this early stage.

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 ☒ Y No ☐

Please give reasons for your views.

We consider ACART has identified relevant areas to monitor. It is well documented as shown in this paper, particularly in relation to the difficulty in collecting data on pregnancy rates.

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

Yes ☒ Y No ☐

Please give reasons for your views.

We believe it is most important that monitoring for misuse (e.g. transfer of tissue to other women) must also be carefully monitored. We consider the risks around the eventual disposal of stored tissue needs to be carefully considered and carefully monitored.

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 ☒ Y No ☐

Please give reasons for your views.

We believe ACART has identified all the ethical issues relevant to the use of cryopreserved ovarian tissue to restore ovarian function as comprehensively listed in the document. However, while the values and beliefs of Maori have been recognised, it is essential that other major ethnic/religious values and beliefs also be considered – e.g. Muslim, Asian and Pacific women.

- (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 ☒ Y No ☐

Please give reasons for your views.

As stated above in part (a).

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 ☒ Y No ☐

Please give reasons for your views.

Yes we support the use of cryopreserved ovarian tissue to restore ovarian function as an established procedure so long as monitoring is in place and rigorously applied. This should make it easier for women requiring this procedure to be able to access it in a timely manner rather than requiring approval on a case-by-case basis. The executive summary lists the rationale for this use very clearly, including advances in the procedure, acceptable risk ratio, especially for women who have undergone cancer treatment. It is also advantageous to women to be able to undertake this procedure in New Zealand, rather than having to travel abroad for the transplantation, especially travelling, following the procedure.

- (b) Please note any other comments below.

Permission obtained from women for the use of the said tissue for research purposes should be an established procedure. Permission must also be obtained, as an established procedure, for the destruction of the tissue should the woman have no further requirement for the tissue. This decision should be solely that of the woman concerned. This should be undertaken to clarify any future misunderstandings and to ensure it is consistent with international best practice and is monitored for the continuance of such.

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 ☒ Y No ☐

Please give reasons for your views.

Yes we do agree with ACART's position that the scope for the use of cryopreserved ovarian tissue to restore ovarian function be limited to the women from whom the tissue was excised for her own treatment. Having said that, we are very aware of the use of tissue transplantation to donors other than the owner of the tissue. For example with organ donation – both from the living and from brain dead. Breast milk banking is now gaining in popularity, having been considered risky historically. In the future, there may be the possibility of cryopreservation for other than the woman from whom the tissue was excised, but until established in New Zealand, we would recommend that this procedure be restricted to the woman from whom the tissue was excised.

Question 7

Refer to section 6.

Do you have any further comments to share with ACART?

It is important that an international database be established with clear criteria for the data collected, to enable consistent reporting. Problems have arisen in other fields where there has been misrepresentation and rendered the information collected spurious.

Good quality information needs to be available to the women/ girls accessing this procedure and also for the clinicians / specialists involved so that informed decisions can be made by all parties.

We would like to commend ACART on the thoroughness of the dissemination of this document and the comprehensive list of questions to be considered, to ensure that they have secured viewpoints from all interested sectors of the community.

Thank you for the opportunity to comment.