

Submission form

Please provide your contact details below.

Name:	Nancy Watters
If this submission is made on behalf of an organisation, please name that organisation here:	Wellington Women Lawyers Association
Please provide a brief description of the organisation if applicable:	
Address/email:	nancy.watters@tpk.govt.nz
Interest in this topic (eg, user of fertility services, health professional, member of the public):	Professional women with an interest in issues affecting women

Please note that all correspondence may be requested by any member of the public under the Official Information Act 1982 (the Act). If there is any part of your correspondence that you consider should be properly withheld under the legislation of the Act, please make this clear in your submission, noting the reasons why you would like the information to be withheld.

If information from your submission is requested under the Act, the Ministry of Health (the Ministry) will release your submission to the person who requested it. However, if you are an individual, rather than an organisation, the Ministry will remove your personal details from the submission if you check the following box.

I do not give permission for my personal details to be released to persons under the Official Information Act 1982.

All submissions will be acknowledged by ACART, and a summary of submissions will be sent to those who request a copy. The summary will include the names of all those who made a submission. In the case of individuals who withhold permission to release personal details, the name of the organisation will be given if supplied.

Do you wish to receive a copy of the summary of submissions?

Yes No

Questions about the proposed guidelines

Question 1: Categories of applicants

ACART is proposing (see page 8) that applications to ECART for extending storage must be made by a clinic or a researcher.

Do you agree that clinics and researchers should be responsible for making applications to ECART for extending the storage of gametes and embryos? Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 2: Storage history of gametes and embryos

ACART is proposing (see page 9) that ECART must be provided with information about the storage history of gametes and embryos, including:

- the length of time that gametes have already been stored, both in New Zealand and overseas
- the length of time that embryos have already been stored, including:
 - time stored in both New Zealand and overseas
 - time during which gametes used to create the embryos have already been stored
 - any previously approved extension to the storage period.

Do you think the proposal covers everything ECART needs to know about the storage history of gametes and embryos? Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 3: Reasons ECART may approve extending the storage of gametes and embryos

ACART is proposing (see page 10) that ECART must determine that extending the storage period is for one of the following reasons:

- fertility preservation where individuals have stored gametes prior to medical treatment that may affect their fertility
- ongoing fertility treatment with procedures that are neither prohibited nor precluded at the time of the application to ECART for extending the storage period
- ongoing or future research using gametes or non-viable embryos.

Do you agree with the proposed reasons for when ECART may approve extending the storage of gametes and embryos beyond 10 years, or beyond an approved extended storage period? Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 4: Informed consent requirements

ACART is proposing (see page 12) that all parties should give informed consent to extending the storage of gametes and embryos. ECART therefore needs to determine that:

- parents or guardians gave consent on behalf of children younger than 16 years
- individuals who have stored gametes for their own use gave consent
- individuals who have donated gametes gave consent
- for embryos, both of the individuals who provided the gametes used to create the embryos, including any gamete donors, gave consent
- individuals who have donated gametes and embryos gave consent:
 - when giving the original consent to store and use the donated gametes or embryos, or
 - when an application for extending storage was made
- where an individual has died after storage of his or her gametes or of embryos created from the gametes, there is written evidence that the individual gave informed consent to both extending the storage period and the specific subsequent use of the gametes or an embryo created from the gametes.

Do you agree that:

- parents or guardians must give consent to extending storage on behalf of children younger than 16 years?
- individuals who have stored gametes for their own use must give consent to extending storage?
- individuals who have donated gametes must give consent to extending storage?
- both of the individuals who provided gametes used to create embryos, including any gamete donors, must give consent?
- gamete and embryo donors must consent to extending storage, either as part of their original consent to donate or later when an application for extending storage is made?
- where an individual has died after storage of his or her gametes, or of embryos created from his or her gametes, there must be written evidence that the individual gave informed consent to both extending storage and the specific future use?

Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 5: Length of extended storage period

ACART is proposing (see page 16) that when approving an application to extend the storage of gametes or embryos beyond 10 years, or beyond an approved extended storage period, ECART must set an extended storage period that is:

- no later than the 35th birthday of an individual younger than 25 years with stored gametes where a clinician declares that medical treatment is likely to cause or have caused a significant impairment to the fertility of the individual
- a maximum of five years for gametes stored on behalf of individuals 25 years and older where a clinician declares that medical treatment is likely to cause or have caused a significant impairment to the fertility of the individual
- a maximum of five years for gametes and embryos to be used in ongoing fertility treatment
- a maximum of 10 years for gametes and non-viable embryos donated for research.

Do you agree with the proposed maximum periods for extending the storage of gametes and embryos of:

- no later than the 35th birthday in the case of people up to the age of 25 years who have medical treatment which will significantly impair their fertility?
- up to five years in other cases of fertility preservation following medical treatment?
- up to five years for ongoing fertility treatment?
- up to 10 years in cases where gametes and non-viable embryos have been donated for research?

Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 6: Issues of particular interest to Māori

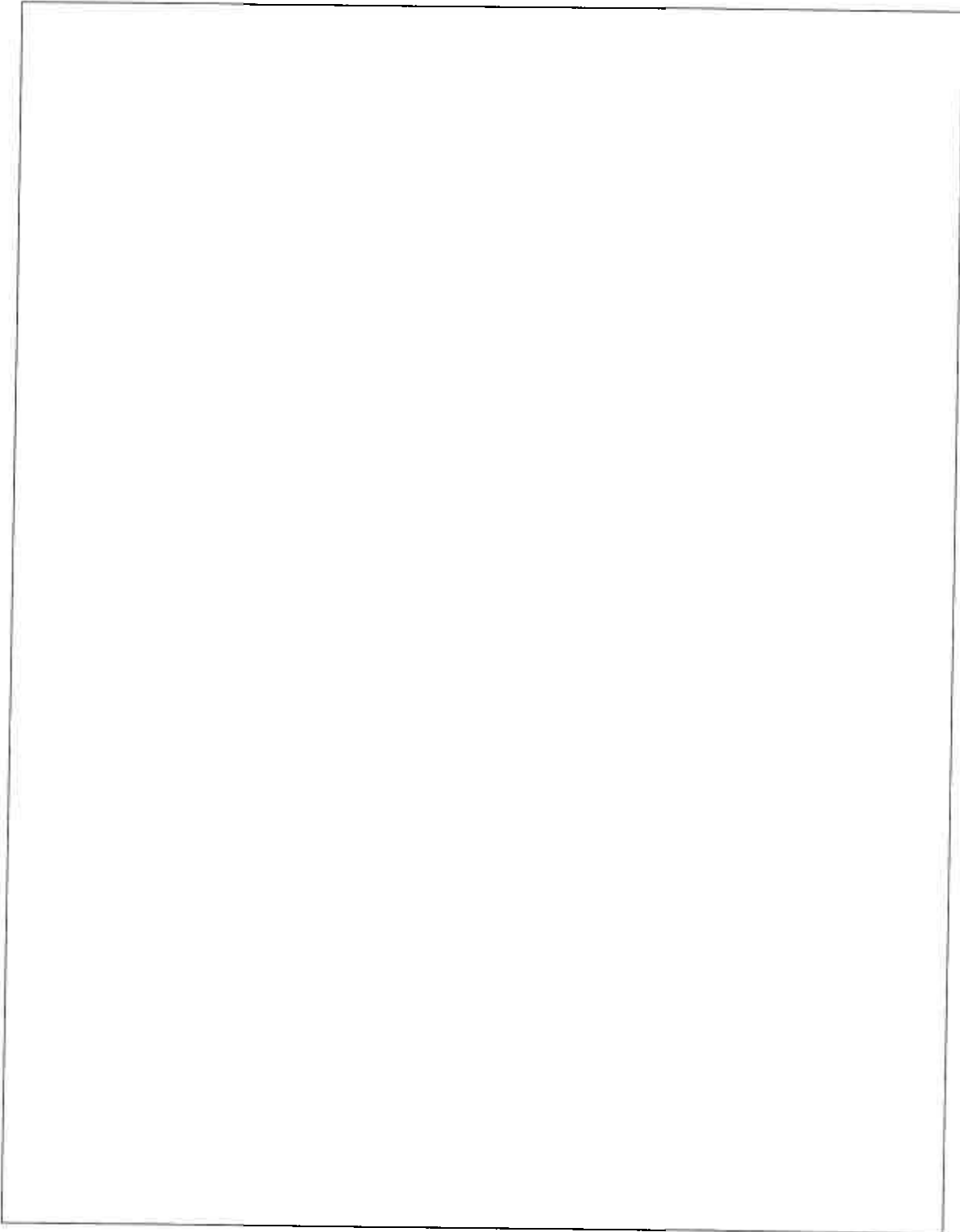
- (a) Who should be part of making decisions about an application to ECART to extend the storage of gametes and embryos?
- (b) What mechanisms should be put in place to manaaki (protect) the process by which whānau discuss and mediate the issues associated with extended storage?
- (c) Are there specific cultural issues or implications whānau should be prompted to consider?
- (d) Are there other Māori issues and perspectives that should inform the guidelines?

Please give reasons for your views.

Wellington Women Lawyers Association supports the submission made by Dr Jennifer Moore, Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago

Question 7: Any other comments

Do you have any other comments or suggestions about either the proposed guidelines or the associated discussion?



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Please provide your contact details below.

Name:	Dr Jennifer Moore
If this submission is made on behalf of an organisation, please name that organisation here:	Centre for Health Law and Policy in Emerging Technologies, Faculty of Law, University of Otago
Please provide a brief description of the organisation if applicable:	
Address/email:	jennifer.moore@otago.ac.nz
Interest in this topic (eg, user of fertility services, health professional, member of the public):	Public health and health law academics with content expertise in reproductive health.

Please note that all correspondence may be requested by any member of the public under the Official Information Act 1982 (the Act). If there is any part of your correspondence that you consider should be properly withheld under the legislation of the Act, please make this clear in your submission, noting the reasons why you would like the information to be withheld.

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Do you wish to receive a copy of the summary of submissions?

Yes

No

Questions about the proposed guidelines

Question 1: Categories of applicants

ACART is proposing (see page 8) that applications to ECART for extending storage must be made by a clinic or a researcher.

Do you agree that clinics and researchers should be responsible for making applications to ECART for extending the storage of gametes and embryos? Please give reasons for your views.

Individuals should also be able to make applications to ECART for extending the storage of gametes and embryos.

We realise that clinics are experienced in making applications to ECART on behalf of clients and we agree that clinics should be able to make applications. However, we do not believe that individuals should be precluded from making applications. Individuals should be able to *choose* whether they would like the clinic to submit an application on their behalf, or whether they would like to submit an application themselves. Research suggests that some individuals prefer to be involved in reproductive health processes and decision making including submission of applications.

Cost is not the only issue. Choice and participation are equally important. In Victoria, Australia, patients can complete and submit applications for extended storage of gametes and embryos.

The clinics' experience in submitting applications to ECART is outweighed by the benefits of enabling individuals'/patients' choice and ability to participate in reproductive health decision making.

Question 2: Storage history of gametes and embryos

ACART is proposing (see page 9) that ECART must be provided with information about the storage history of gametes and embryos, including:

- the length of time that gametes have already been stored, both in New Zealand and overseas
- the length of time that embryos have already been stored, including:
 - time stored in both New Zealand and overseas
 - time during which gametes used to create the embryos have already been stored
- any previously approved extension to the storage period.

Do you think the proposal covers everything ECART needs to know about the storage history of gametes and embryos? Please give reasons for your views.

Yes.

Question 3: Reasons ECART may approve extending the storage of gametes and embryos

ACART is proposing (see page 10) that ECART must determine that extending the storage period is for one of the following reasons:

- fertility preservation where individuals have stored gametes prior to medical treatment that may affect their fertility
- ongoing fertility treatment with procedures that are neither prohibited nor precluded at the time of the application to ECART for extending the storage period
- ongoing or future research using gametes or non-viable embryos.

Do you agree with the proposed reasons for when ECART may approve extending the storage of gametes and embryos beyond 10 years, or beyond an approved extended storage period? Please give reasons for your views.

The proposed reasons are too narrow.

People who wish to extend storage of gametes for future potential use, *unrelated* to medical reasons, should be able to choose to do so.

Question 4: Informed consent requirements

ACART is proposing (see page 12) that all parties should give informed consent to extending the storage of gametes and embryos. ECART therefore needs to determine that:

- parents or guardians gave consent on behalf of children younger than 16 years
- individuals who have stored gametes for their own use gave consent
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- where an individual has died after storage of his or her gametes or of embryos created from the gametes, there is written evidence that the individual gave informed consent to both extending the storage period and the specific subsequent use of the gametes or an embryo created from the gametes.

Do you agree that:

- parents or guardians must give consent to extending storage on behalf of children younger than 16 years?
- individuals who have stored gametes for their own use must give consent to extending storage?
- individuals who have donated gametes must give consent to extending storage?
- both of the individuals who provided gametes used to create embryos, including any gamete donors, must give consent?
- gamete and embryo donors must consent to extending storage, either as part of their original consent to donate or later when an application for extending storage is made?
- where an individual has died after storage of his or her gametes, or of embryos created from his or her gametes, there must be written evidence that the individual gave informed consent to both extending storage and the specific future use?

Please give reasons for your views.

The "proposed guidelines" do not need to be prescriptive about the need for written informed consent for the posthumous use of gametes and embryos.

There should not be a mandatory ("must") prescriptive requirement for "written evidence" of informed consent for the posthumous use of gametes and embryos. The Code of Rights does not require evidence of written consent in such circumstances and The Code applies to live people. Therefore, the Code of Rights has arguably been wrongly interpreted. Furthermore, what constitutes "written evidence"?

There should not be a mandatory requirement for parents and guardians to give consent to extending storage on behalf of children younger than 16 years. Such mandatory requirements may be a breach of the *Gillick* competent child.

Ethics Committees need to be able to fulfil their function of making decisions about situations such as the posthumous use of gametes and embryos. Where an individual has died after storage of his/her gametes or embryos, and there is no written evidence of consent to extending storage, Ethics Committees have a role to play in making decisions about such situations and they should be permitted to apply discretion and make decisions on a case-by-case basis.

Question 5: Length of extended storage period

ACART is proposing (see page 16) that when approving an application to extend the storage of gametes or embryos beyond 10 years, or beyond an approved extended storage period, ECART must set an extended storage period that is:

- no later than the 35th birthday of an individual younger than 25 years with stored gametes where a clinician declares that medical treatment is likely to cause or have caused a significant impairment to the fertility of the individual

- a maximum of five years for gametes stored on behalf of individuals 25 years and older where a clinician declares that medical treatment is likely to cause or have caused a significant impairment to the fertility of the individual
- a maximum of five years for gametes and embryos to be used in ongoing fertility treatment
- a maximum of 10 years for gametes and non-viable embryos donated for research.

Do you agree with the proposed maximum periods for extending the storage of gametes and embryos of:

- no later than the 35th birthday in the case of people up to the age of 25 years who have medical treatment which will significantly impair their fertility?
- up to five years in other cases of fertility preservation following medical treatment?
- up to five years for ongoing fertility treatment?
- up to 10 years in cases where gametes and non-viable embryos have been donated for research?

Please give reasons for your views.

An arbitrary maximum of the 35th birthday should not be imposed in the case of people up to the age of 25 years who have medical treatment which will significantly impair their fertility.

We realise that ACART's rationale for this proposal is to put patients "in a similar position to their peers...by providing them access to their gametes during their main reproductive years" (p.16 proposed guidelines).

However, individuals should be able to access gametes after their 35th birthdays should they wish to. As outlined in Question 1, research suggests that individuals prefer to be able to make choices about their reproductive health. The University of Otago's *Human Genome Research Project* illustrated the importance of reproductive liberty. *The Convention on the Elimination of all Forms of Discrimination Against Women* affirms women's right to reproductive choice.

Given the evidence, individuals who have stored their gametes and embryos due to medical treatment should be permitted and enabled to make decisions about extended storage.

Question 6: Issues of particular interest to Māori

- Who should be part of making decisions about an application to ECART to extend the storage of gametes and embryos?
- What mechanisms should be put in place to manaaki (protect) the process by which whānau discuss and mediate the issues associated with extended storage?
- Are there specific cultural issues or implications whānau should be prompted to consider?
- Are there other Māori issues and perspectives that should inform the guidelines?

Please give reasons for your views.

(a) The decisions about an application to ECART to extend the storage of gametes and embryos should be made by whanau, if the individual and whanau desire this approach.

These beliefs support and reinforce our submissions in Questions 1, 4 and 5. Guidelines should permit and enable individuals (and their families) to make reproductive health decisions. When guidelines are prescriptive and mandatory, individuals and whanau are discouraged (or prevented) from participating in important reproductive health decisions.

Many Maori believe that gametes and embryos belong to the whanau. However, not all Maori will necessarily hold such beliefs. Again, the key issue is choice.

(d) Tikanga should inform all stages from the choice to engage in fertility treatment, completion and return of biological material to the family. Maori typically conceptualise reproduction as whakapapa, rather than gametes and embryos and this view should inform ACART's guidelines.

Question 7: Any other comments

Do you have any other comments or suggestions about either the proposed guidelines or the associated discussion?

