

Feedback form

Please provide your contact details below.

Name	[redacted]
If this feedback is on behalf of an organisation, please name the organisation.	InterChurch Bioethics Council, New Zealand
Please provide a brief description of the organisation (if applicable).	The InterChurch Bioethics Council (ICBC) is an ecumenical, cross-cultural body elected and supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand (www.interchurchbioethics.org.nz). ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education.
Address/email	[redacted]
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Our science, ethics and medical fields of expertise include assisted reproductive technologies. ICBC aims to present information on the background science and technology application, with accompanying ethical exploration to allow informed discussion within our faith congregations and for the general public.

Are you:

☒ Male ☒ Female ☐ Other gender identity

Would you like to make a verbal submission in person or using electronic communications?

☐ Yes ☒ No

Which of the following age groups do you belong to?

☐ 13–19 years ☐ 20–24 years ☐ 25–34 years
☒ 35–44 years ☒ 45–54 years ☒ 55–64 years
☒ 65–74 years ☒ 75+ years

What is your ethnicity? (Tick all you identify with)

☒ NZ European ☒ Māori ☒ Pacific peoples
☐ Asian ☐ Other

Privacy

We may publish all submissions, or a summary of submissions on ACART's website. If you are submitting as an individual, we will automatically remove your personal details and any identifiable information. You can also choose to have your personal details withheld if your submission is requested under the Official Information Act 1982.

If you do not want your submission published, please tick this box:

☐ Do not publish this submission.

Your submission may be subject to requests made under the Official Information Act 1982. If you want your personal details removed from your submission, please tick this box:

☒ Remove my personal details from responses to Official Information Act 1982 requests.

If your submission contains commercially sensitive information that you do not wish to be released, please tick this box:

☐ This submission contains commercially sensitive information.

A. All posthumous use should be subject to ECART review

Question 1

Should ethical review by ECART be required for all posthumous uses of gametes or reproductive tissue, even if consent to specific use was given while the deceased person was alive?

Yes

Comments

We thank ACART for these Stage 2 Consultation guidelines for posthumous reproduction, and we would like to commend the Council on their careful consideration and address of the key concerns the ICBC had from Stage 1 consultation of the guidelines, namely:

- i) in keeping with the HART Act 2004, the rights, needs and protection of resultant children are paramount in these guidelines
- ii) full counselling and grief support must surround the partner, family and wider whānau during posthumous decisions
- iii) individual autonomy and rights are not most important here, since many people are involved both in the present and in the future
- iv) key questions important to Māori need to hold equal priority in guideline considerations.

In particular, the ICBC agrees with ACART's guidelines of:

- Requiring specific consent for a specific person to use reproductive material posthumously, with strong evidence of this consent being attained without coercion
- All posthumous use of reproductive material, including from donor, requires ethical consideration by ECART
- Reproduction for incapacitated people does not come into the same category, and therefore regulation, as post-humous reproduction
- Minors should not be involved in post-humous reproduction while still a minor or when their death occurs during that age period.

The ICBC would like to suggest the following changes to the draft 2 guidelines:

- Consent for posthumous use of gametes and reproductive material does not directly imply consent for any posthumous retrieval, as procedures for use and retrieval may not have the same acceptance for different people culturally and spiritually. Therefore, retrieval should require a separate ethical investigation and consent.
- Both posthumous use and retrieval should therefore be named in the title of these guidelines.

We agree that ethical review by ECART should be required for all posthumous use of gametes and reproductive tissue, including when consent for use by a specific person was given prior to a partner's death. ECART consideration would be a valuable safeguard, to check deceased person's consent without coercion, check if there are any new family circumstances eg health of the remaining parent, and check that ongoing counselling/legal/medical support for the family is available where needed. This would therefore ensure that all current circumstances into which a child would be born could be ethically evaluated.

Question 2

Should ethical review by ECART always be required for the posthumous use of **stored embryos**, even if consent to specific use was given while the deceased person was alive?

Yes

Comments

The posthumous use of stored embryos should be included in the ECART ethical review. As in question 1 for stored gametes and reproductive tissue, this is best practice to ensure all considerations have been made for the welfare of the resultant child, as well as checking deceased person's consent, and availability of counselling for partner and family.

Question 3

Do you agree that ACART should recommend a change to the HART Order 2005 to ensure all posthumous **use** is considered by ECART?

Yes

Comments

We agree this legislation change should be made to the HART Order 2005, as the best ethical safeguard for any posthumous reproduction requests (use and/or retrieval). Where ECART consideration is not available in the required time period for retrieval, a High Court judge could make the same ethical investigation, including full consideration of the deceased's consent of retrieval and use.

Question 4

Do you agree that the guidelines should allow for the posthumous use of clinic donor sperm or eggs, if there is already a child from the person who donated those gametes and the new child will be in the same family?

No

Comments

These guidelines should not allow automatic use of a deceased donor's gametes without full ethical consideration both for the resultant child, and to check consent from the donor. ECART consideration should be required for all requests of posthumous use of donor sperm or eggs, even when there is already a child in the family produced using the donor's gametes. In this way the full effects on a resultant child of having one biological parent already deceased can be weighed alongside the benefit to the child of having a full sibling.

B. Consent must be to a specific use

Question 5

Do you agree that the deceased person must have consented to a specific use?

Yes

Comments

We agree that the deceased person prior to their death, or foreseeable death, must have consented (written consent or with strong evidence of verbal consent) to allow their gametes, embryos or reproductive material to be used by a specific named person(s). ECART consideration of the evidence of consent would evaluate that coercion hasn't occurred, and that consent is authentic.

Question 6

Do you agree with ACART, that the definition of specific use should mean "consent to use by a specific person/s"?

Yes

Comments

We agree that specific use means consent to use for ART purposes by a specific person (eg. the partner of the deceased person), or a surrogate for that remaining partner if required.

Consent to use must be proven

Question 7

Do you agree that the intending parent(s) must provide evidence of consent to posthumous use in order to use gametes, reproductive tissue or stored embryos from a deceased person?

Yes

Comments

The partner of the deceased person should be the intending parent who provides evidence of consent – this ideally should be written evidence from the Fertility Clinic. Other evidence of verbal consent would need to be evaluated for authenticity and non-coercion. If there is consent for use for a person other than a partner, there should be thorough consideration of relationship effects on the resulting child(ren) by ECART.

C. The evidence of consent may be written or oral

Question 8

Do you agree that oral consent is acceptable?

Yes, with evidence

Comments

There would have to be convincing evidence of oral consent for this to be acceptable, decided on by ECART.

It would be best practice by fertility clinics that all stored gametes, embryos and reproductive materials have accompanying information including consent for specific use from the donors/parents, as well as any consent for posthumous retrieval.

Question 9

Do you agree that there must be evidence of oral consent for that consent to be acceptable?

Yes

Comments

Evidence of oral consent would be required for the consent to be recognised as being valid. Oral consent is weaker than written consent, therefore should be carefully evaluated for evidence.

D. In most cases, the deceased's consent to retrieval can be inferred from their consent to posthumous use

Question 10

Do you agree that consent to posthumous use of gametes or reproductive tissue can be taken to imply consent to posthumous retrieval of the gametes or tissue?

No

Comments

Consent for posthumous use of stored gametes and reproductive material does not necessarily mean that consent has been given for further posthumous retrieval of gametes or material. This is a different request to retrieve more gametes or reproductive material for which a different consent should be obtained, in keeping with the deceased person's cultural and spiritual beliefs. Both consents for posthumous retrieval and use could easily be collected by the fertility clinic at time of first storage.

In contrast, where there is no fertility clinic involvement prior to death (i.e. no

stored gametes or ART procedures having been carried out), a consent for posthumous use of gametes or material by a person before their death would often imply consent for retrieval. However, there would need to be evidence that the deceased person was informed of the retrieval process, and was culturally and spiritually consenting.

ECART consideration would be needed to assess evidence of the deceased's consent for retrieval, if that was informed consent, and if retrieval as well as use of gametes fitted well within the deceased person's culture and spirituality. The HART Act 2004 reference to no ART procedures being carried out without informed consent, and retaining the dignity of the person, along with present and future generations, needs to be upheld.

Question 11

Do you agree that there is no need to test whether the deceased person had a full understanding of the method of retrieval of the gametes or tissue?

No

Comments

Informed consent of posthumous retrieval should include the person being informed of methods of retrieval, or at least being asked if they would like that information before their consent decision.

E. ECART or the High Court will be able to authorise retrieval of gametes or reproductive tissue from a deceased person

Question 12

Do you agree that ACART should recommend a change to the HART Order 2005 so that it is clear that posthumous retrieval is never an established procedure?

Yes

Comments

Posthumous retrieval should not be an established procedure where there is no ethical evaluation before proceeding. The HART Order 2005 needs to clarify that.

For the few cases where someone suddenly dies while they are trying to conceive a child, with no gametes or reproductive material having been stored, or not enough stored material remaining, the opportunity of gamete or tissue retrieval posthumously might offer a compassionate medical technology to complete a family already anticipated.

For these few cases, posthumous retrieval should be available if considered ethically permissible by ECART (or if ECART is unable to meet in time, a High Court

judge who makes all the ethical considerations that ECART would make), but it should not be an established service widely available, and certainly not available without full ethical consideration.

Question 13

Do you agree that, subject to the change to the HART Order 2005, ECART could authorise posthumous retrieval? (Note: This would seldom or never actually happen because retrieval cases would usually be decided by the High Court.)

Yes

Comments

We agree that ECART, or the High Court in cases where retrieval time is short, are the bodies to authorise posthumous retrieval of gametes or reproductive material, as long as they both are making equivalent ethical investigations.

F. Prohibiting retrieval from deceased minors

Question 14

Do you agree that the retrieval of gametes and reproductive tissue from deceased minors, for reproduction, should be prohibited?

Yes

Comments

We agree that in no cases should retrieval of gametes or reproductive material from deceased minors be carried out.

Question 15

Do you agree that if a minor freezes gametes or reproductive tissue and dies before they can use those gametes or reproductive tissue (or can consent as an adult to another use), then the gametes or reproductive tissue are not able to be used by anyone else?

Yes

Comments

We agree that gametes or reproductive material from a minor stored while the minor is still alive cannot be used after the minor's death by anyone else.

G. One change to the HART Act to enable minors to choose the use of their own gametes/tissue after they reach the age of 16 years

Question 16

Do you agree that ACART should provide advice to the Minister to amend section 12 of the HART Act 2004 to enable people to choose the use of their own gametes/tissue after they reach the age of 16 years?

Yes

Comments

We agree that when a minor reaches adulthood, they should have the same conditions for their stored reproductive material as other adults.

However, the age of 16 may be too young for this decision, as a 16 year old is probably unlikely to be in a relationship currently anticipating parenthood, and is likely to be still at risk of undue influence by other family members for posthumous use of their stored reproductive material.

Therefore, a record of written evidence should be kept of the person's consent for use by a specified person, recorded when the person was in a relationship that anticipated having a child.

H. No requirement for a specific stand-down period

Question 17

Do you agree that there is no need for the guidelines to include a specific provision about a stand-down period?

No

Comments

Specific provision for a stand-down period would be a useful safeguard during a grieving process. However, if the stand-down period then puts the partner in a position of being too old to carry a child through pregnancy, then this stand-down period should be flexible, under the evaluation of ECART.

Question 18

Do you agree that the counselling provision (7.f), about allowing time for grieving, is adequate for ensuring people make a well-considered decision?

Yes

Comments

We agree with the provision for counselling and for the scope such counselling offers, including counselling throughout the grieving period, including after pregnancy.

I. The title of these guidelines

Question 19

Do you agree with the proposed title for the guidelines of *Guidelines for the Posthumous Use of Gametes, Reproductive Tissue and Stored Embryos*?

No

Comments

To show the full scope of these guidelines, we propose the title below to include separate guidelines for retrieval as well as for use:

Guidelines for Posthumous Reproduction: Retrieval and Use of Gametes and Reproductive Tissue, and Use of Stored Embryos