

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation.	Fertility Associates
Please provide a brief description of the organisation (if applicable).	Fertility services provider
Address/email	Private Bag 28910 Remuera Auckland
Interest in this topic (e.g., user of fertility services, health professional, researcher, member of public)	Fertility services provider

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

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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:

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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 agree that all cases should be considered by ECART.

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?

No

Comments

As part of consent for IVF treatment, clinics ask the partners whether the surviving partner can use any resultant embryos. In the case of a man dying, his female partner could use the embryos without involving a third party. The same applies for a same sex female couple if one dies and the surviving partner wishes to have embryos transferred to herself.

We do not think this scenario needs ECART approval, since the participants have considered the issue, have made an informed decision, have recorded their decision on the consent form, and using the embryos does not involve any other party.

Where posthumous use of an embryo requires a third party, we think ECART review should be required.

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?

No

Comments

We think that the scenarios we have outlined in Question 3 should be established procedures that do not require ECART review.

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?

Yes

Comments

We agree; this is current practice based on NECHAR guidelines for sperm.

We understand that this applies to both donors recruited by patients and donors recruited by clinics.

In addition, for clarity, we suggest that this provision include embryos already created using the donor sperm or donor eggs but not yet used.

We suggest that these guidelines also include sperm or eggs from a personal donor who has consented to posthumous use but where there are no offspring in the recipient family at the time the donor dies (also see question 6).

B. Consent must be to a specific use

Question 5

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

No

Comments

With the exception of donor sperm covered in question 4, we agree that that the person who dies must have consented to use by a named person.

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

Although we agree that the deceased person must consent to a specific use, we suggest that the specified person should be the partner of the person who dies, and that the specified person should also be an intending parent.

This does not stop a person from arranging to become a personal donor before they die if they want to be able to leave their sperm or eggs to a brother or sister, for instance (see question 5). To do this, the person (ie. the intending donor) and the intending recipient(s) would complete the preparation that normally occurs before donation, such as compiling a full medical history, screening, counselling, and consent to donation.

If the specified person is not the partner, then the subsequent use after death would effectively be donation without preparation for donation.

The reason for our view is that we have had several cases where the parents of the deceased are interested in pursuing fertility treatment to create a grandchild using the deceased's gametes (along with a donor for the complementary gamete) with or without the need for a surrogate. It is not uncommon for young people to request to leave their gametes to their parents. It would be beneficial for the clinic and the person storing material to have clear boundaries on what is allowed.

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

We agree that there must be evidence of consent for posthumous use.

However, it is unlikely that there will be either written or oral consent by a person who suffers an unforeseen death, such as a fatal accident.

We suggest that ACART should outline what would be considered sufficient evidence of consent by a person who does not leave written consent. Fertility providers will have to decide whether to maintain storage of sperm or eggs collected after accidental death. It seems inappropriate to continue storage if there is no route to use.

C. The evidence of consent may be written or oral

Question 8

Do you agree that oral consent is acceptable?

Yes

Comments

We agree that consent can be oral, but what constitutes sufficient oral consent should be clearly outlined. As covered in discussion point 108 in the paper, not everything people say in conversation about their future wishes to have children counts as informed consent.

Question 9

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

Yes

Comments

We agree that there must be evidence of oral consent if there is no written consent. We suggest that oral consent should require a level of formality, such as an affidavit.

ACART should decide whether an affidavit from the person who is requesting use of the deceased's material is sufficient, or whether an independent witness is also required.

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?

Yes

Comments

Consent to posthumous use, where the gametes or tissue had not already been stored at the time of death, must imply consent to posthumous retrieval.

Consent to posthumous use in another context, such as in an IVF consent form on what to do with embryos if one partner dies, does not imply consent for posthumous retrieval. (ie. If a man consents to his partner using embryos created in their IVF cycle if he dies, this does not imply that the partner can ask for posthumous retrieval of sperm to make more embryos.)

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?

Yes

Comments

We agree – consent to retrieve implies consent to use whatever method of retrieval is most appropriate.

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

We agree that posthumous retrieval should require ECART or High Court approval.

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

A decision to allow retrieval must be made within a few hours at most to maximise the viability of sperm or eggs, so having two avenues, ECART or the High Court, is pragmatic.

We note that neither ECART or the High Court is likely to have evidence on hand in the case of accidental death to decide whether there is sufficient consent, written or oral, for subsequent use of the material retrieved. Therefore, we dispute discussion point 115, which states that the High Court is unlikely to authorise retrieval in circumstances where there is no prospect of future use

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

Since minors are not legally permitted to have sex to (to have children), it is consistent to prohibit posthumous retrieval from minors so that their gametes can be used to create children.

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 (see question 14).

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 – it is inconsistent to allow people to be able to use their gametes which have been stored in their body but not stored in a clinic (eg. from before cancer treatment).

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?

Yes

Comments

A stand down period can be psychologically helpful so that decisions are not made in a rush during a period of grief. However, ECART meetings are infrequent and preparation time consuming so in practice there will be a stand-down period.

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

It is adequate if a clinic can defer treatment if it thinks the person is not yet able to make a well-considered decision.

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

We consider that the retrieval of material should also be included in the title, because these guidelines also provide the framework for when who can authorise retrieval, not just use. It is also specifically included in the scope of the guidelines.

Even though the High Court is not bound by these guidelines, it is still stipulated that both the High Court and ECART can authorise retrieval.

Further feedback:

Specific use

Where the deceased has specified a person who may use their material, and there is the need for a surrogate, does the surrogate also need to be specified? While this seems impractical, the birth mother will be the legal parent until adoption by the intending parent. This issue needs to be considered with respect to pre-approval by Oranga Tamariki for adoption.

Information contained in the Births, Deaths and Marriages register

The HART Act requires clinics to provide Births, Death and Marriages identifying information on donors and intending parents who provided a gamete when a child is born. This ensures that a person has access to his or her genetic parentage.

This is not the case for a person conceived using posthumous gametes. We suggest that the HART Act's provision for donor gametes and embryos be extended to conception where one or both genetic parents had died before conception.

Counselling requirements

In the guidelines it mentions that counselling must cover the fact the resulting children may only have one or no living genetic parent. The guidelines need to recognise that some of these children will have been conceived using donors, who are living genetic parents.