

Feedback form

Please provide your contact details below.

Name	
If this feedback is on behalf of an organisation, please name the organisation.	
Please provide a brief description of the organisation (if applicable).	
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Researcher/writer on issues related to adoption and assisted reproduction

Are you:

☐ Male ☐ Female ☐ Other gender identity

FEMALE [Boxes do not seem to be tickable!]

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

☐ Yes ☐ No

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

75 YEARS

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

☐ NZ European ☐ Māori ☐ Pacific peoples

☐ Asian ☐ Other

NZ EUROPEAN

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☐ Do not publish this submission.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:

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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

I agree with ACART's case for requiring all posthumous uses to have ethical review by ECART, and never to be considered established procedures. This is indeed an extremely complex procedure and should not be permitted to occur without ethical review.

The definition of "specific use" is problematic:

ACART proposes that when a person consents to the posthumous reproductive use of gametes, reproductive tissue or embryos, that consent must be to a specific use. ACART's proposed definition of 'specific use' in the guidelines will be that 'the deceased gave informed consent to posthumous use by a specified person(s) who would be the intending parent(s)'.

This is discussed further in relation to Question

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 same case applies to embryos as to gametes and reproductive tissue.

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

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

But only with the proviso below.

Comments

The text above says:

It is standard practice for clinics to ask donors if they consent to their gametes being used after their death.

The draft guideline – rightly, in my view - limits such use of donor gametes to one specific circumstance. If the draft guideline above is adopted, the clinic should clearly specify that rather than simply being a blanket consent to “use after death”, such consent applies only to the situation where “there is already a child from the person who donated those gametes and the new child will be in the same family”.

This guideline also highlights the importance of detailed, accurate records where donors are involved, since it envisages that donors may be deceased. The law applying to donors and offspring (identification, information, contact) does not envisage offspring created from donated sperm or eggs after donor death. If such use is permitted, that law may require amendment.



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

This stipulation is crucial, but the definition of “specific use” is problematic, since the wording shifts in this document. See my comments on Questions 6 and 7 below.

particularly where the proposed use of the material or embryo involves “the involvement of a new partner or surrogate”. This situation would have to have been consented to in advance. No such use should be permitted unless the deceased person specifically consented to it.

However, the sentence at the end of the paragraph is ambiguous:

In particular, ACART proposes the focus should be on consent specifying who will be the parent.

It can be seen as undermining the requirement for specific consent outlined above, by focusing on the one surviving person originally associated with the deceased person. The emphasis should remain on the necessity of the deceased person specifically consenting to use which involves other people, as outlined above.

Question 6

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

No

Comments

The definition here is not sufficiently precise. Section 66 above states that it should be consent to “a specific use by a specific person” (my emphases below):

B. Consent must be for a specific use by a specified person

66. The HART Act does not specify how detailed or specific a person’s consent must be. Therefore, it is important for the guidelines to be clear about what must be specified in the consent. Specific consent might also help safeguard any potential offspring because **the gametes, stored embryo or reproductive tissue would be used to create a child in a family known to the deceased in circumstances the deceased had considered**: that is, the intending parent will have been specified by the now deceased.

This differs from the definition in section 90:

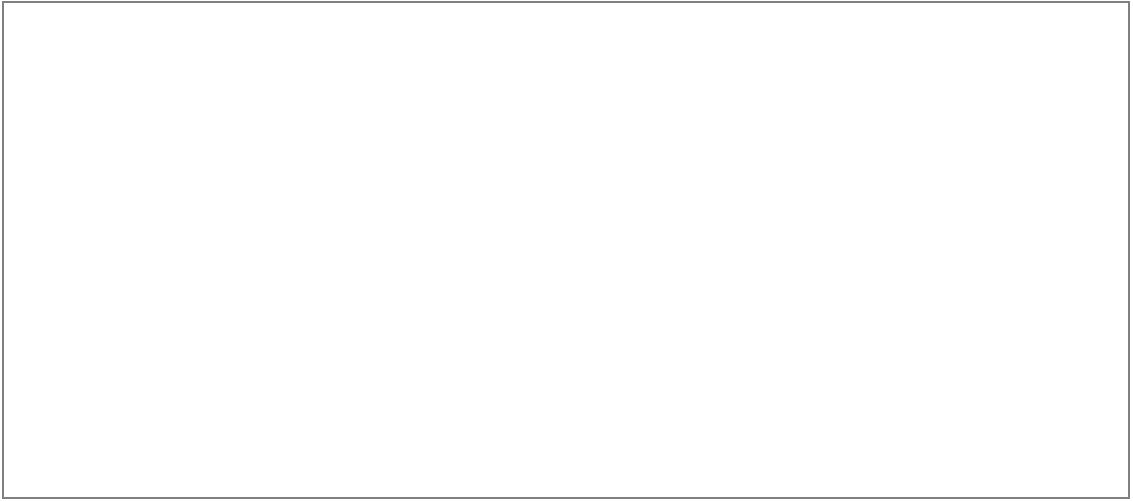
90. ACART proposes that when a person consents to the posthumous reproductive use of gametes, reproductive tissue or embryos, that consent must be to a specific use. ACART’s proposed definition of ‘specific use’ in the guidelines will be that **‘the deceased gave informed consent to posthumous use by a specified person(s) who would be the intending parent(s)’**.

To be absolutely clear, the required definition of consent should be consistently amended throughout to “specific posthumous use by a specific person”.

The consent to “specific posthumous use” would need to include consent to the putative involvement of others, as discussed in section 97 (my emphasis):

97. The key idea is to enable a surviving partner or other specified individual to use the reproductive material or stored embryo to have a child to parent. **That might include the involvement of a new partner or surrogate, which would be acceptable if the deceased person had consented to such involvement.** Whatever the circumstances, the deceased person must have **been clear about the specifics of the posthumous use** of their reproductive tissue, gametes or embryos created using their gametes. In particular, ACART proposes the focus should be on consent specifying who will be the parent.

If the consent does not include such specifics, then the involvement of others in this way should not be permitted. The safest form of consent may be one which allows the person to specifically exclude any such involvement, if they wish to do so. In other words, consent may exclude as well as include specific forms of use.



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

This should read:

“The intending parent(s) must provide evidence of consent to specific forms of posthumous use by specific person/s in order to use gametes, reproductive tissue or stored embryos from a deceased person in the proposed forms.”

C. The evidence of consent may be written or oral

Question 8

Do you agree that oral consent is acceptable?

This is a very difficult issue to decide on.

Comments

I am not sure that this provision would be workable in practice, since it would often seem to rely solely on the evidence of the person wishing to use the material or embryo.

Question 9

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

Yes / No

Comments

Clear rules of evidence for acceptable oral consent would need to be provided. However, it is difficult to envisage what forms such consent would need to take to be acceptable.



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 / No

Comments

I presume that this would apply where someone near to death gives consent, but retrieval does not or cannot take place before death; or alternatively, that some form of advance consent is given (for example, because of certain procedures being necessary) before premature death is even likely, or is uncertain.

It would be much clearer and more sensible to include the opportunity to give specific consent to posthumous retrieval, should that become necessary, when consent to posthumous use is given. The person concerned could then choose to consent only to posthumous use (where retrieval had already taken place before death), or to both posthumous use and posthumous retrieval.

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

Such a provision would seem to invalidate the exercise of informed consent. We do not expect others to consent to invasive procedures which have not been explained to them, and been understood, to a reasonable extent.



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

However, the grounds on which such retrieval could be authorised would be much more effectively provided if the changes to the form of consent outlined above were used, so that consent could be specifically given to post-death retrieval.

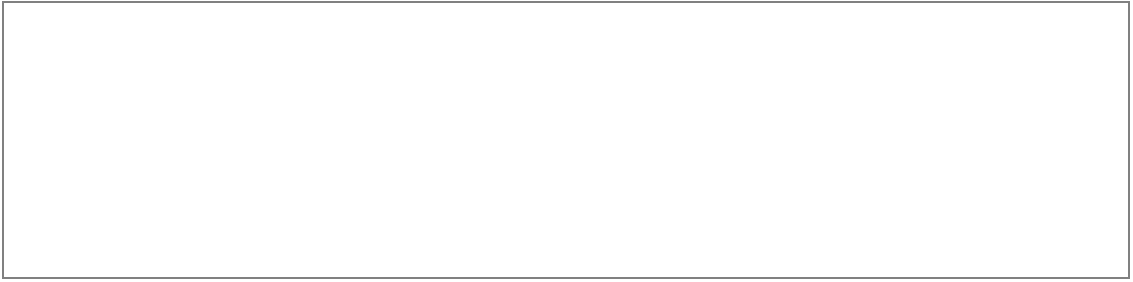
Question 13

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

But only provided the form of consent becomes specific on this point. I do not agree that such consent can be “inferred” from consent to posthumous 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

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

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

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

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

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

The title should include the element of decision, e.g.

Guidelines for Authorisation of the Posthumous Use...