



# **Advisory Committee on Assisted Reproductive Technology**

## **Informed Consent and Assisted Reproductive Technology**

Proposed advice  
to the Minister of Health

**Consultation Document**

# Feedback form

Please provide your contact details below.

Name:	<b>John Kleinsman PhD &amp; Sue Buckley</b>
If this feedback is on behalf of an organisation, please name the organisation:	<b>The Nathaniel Centre: The New Zealand Catholic Bioethics Centre</b>
Please provide a brief description of the organisation if applicable:	
Address/email:	<b>PO Box 12243 Wellington 6144 email: <a href="mailto:administrator@nathaniel.org.nz">administrator@nathaniel.org.nz</a></b>
Interest in this topic (eg, user of fertility services, health professional, researcher, member of the public):	<b>The Nathaniel Centre is an agency of the New Zealand Catholic Bishops' Conference. Its role is to address bioethical and biotechnology issues on behalf of the Catholic Church in New Zealand.</b>

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If information from your feedback is requested under the Act, the Ministry of Health (the Ministry) will release your feedback to the person who requested it. The Ministry will remove your name and/or contact details from the feedback if you check one or both of the following boxes. Where feedback is on behalf of an organisation, the Ministry will not remove the name of the organisation.

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## Introductory Comments

We welcome the opportunity to provide feedback on the issue of informed consent and assisted reproductive technology. Our approach to the moral/ethical issues associated with the use of assisted human reproductive technologies is based on a number of beliefs. Those that are particularly relevant to this Consultation Document are:

**(i) Unconditional respect for human life at all stages of its development**

Catholic teaching holds that without exception the living embryo has, from the moment of fertilisation, an absolute right to life. A unique human life is begun - it is already the human being it will always be and will only grow in size and complexity. On that basis all embryos are entitled to be treated with the same respect as persons.

**(ii) Upholding the genetic, gestational and social dimensions of family**

Whatever people believe about the acceptability of IVF, a clear moral distinction exists between *homologous* IVF and *heterologous* IVF. This distinction rests on the fact that homologous IVF conserves the natural links between parenthood, family and genetic origins.

Our sense of personal well-being is linked with a healthy self-identity, something that is intimately tied in with a *lived* knowledge of our biological ties. On this basis we believe that children have the right to grow up within the family networks that are generated by our biological ties. This right should only ever be compromised in situations where it is clearly in the interests of the child involved.

**(iii) The rights and well-being of the child**

In previous ACART Discussion documents we have recognised and complimented ACART on the fact that there were real attempts to consider the ethical issues from a perspective that actively considers the rights and well-being of the child that is to be conceived. It is disappointing that, apart from Appendix 2, the term “potential offspring” only arises once in this document. While it might be argued that this is understandable given the document’s specific focus on “informed consent”, in our view it highlights once again the serious short-comings of an “informed consent” approach for dealing with the ethical issues associated with the use of human assisted reproductive technologies.

As we have previously stated: ““An over emphasis on the sufficiency of individual informed consent ... reflects a failure to acknowledge the wider impact of technological interventions.”

We are pleased to respond to the questions asked in the Consultation Document. Our reasoning reflects the key beliefs we have outlined above.

# Questions for response

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## Question 1: Access to information that must be disclosed to patients and donors prior to consent

- (a) Do you agree there is a need for better access to the information that must be disclosed to patients and donors prior to consent?

Yes ☒ No ☐

- (b) Is there other information that should be given to patients and donors as part of the informed consent process?

Yes ☒ No ☐

Please give reasons for your views.

Informed consent is, by its very definition, predicated on access to information. The Code of Health and Disability Services Consumers' Rights upholds the right to be fully informed and improving access to information is in line with a commitment to both the spirit and the law of the Code. We agree with the reasoning set out by ACART. We believe that the information provided to couples utilising heterologous IVF should summarise research on the importance of biological connections for the well-being of any potential offspring.

## Question 2: Form of consent

- (a) Do you agree that consent to all assisted reproductive processes, where consent is required, must be in writing?

Yes ☒ No ☐

- (b) Do you have any other comments?

Yes ☐ No ☒

We agree with the reasoning and conclusions set out in the Consultation Document.

### Question 3: Donor consent to use gametes or embryos for training purposes

- (a) Do you agree that the consent of gamete and embryo donors should be obtained if their gametes, or embryos created from their gametes, may be used for training purposes?

Yes ☒ No ☐

- (b) Do you have any other comments?

Yes ☒ No ☐

Please give reasons for your views.

We believe that obtaining consent for training purposes is consistent with Right 6 of the Code of Health and Disability Services Consumers' Rights.

### Question 4: Placing conditions on donor consent

- (a) Do you agree that donors should continue to be able to place conditions on their consent?

Yes ☒ No ☐

- (b) If so, should there be any limits on the conditions placed?

Yes ☐ No ☒

- (c) Do you have any other comments?

Yes ☒ No ☐

Please give reasons for your views.

We agree that gamete and embryo donations are different from blood or organ donations because of the fact that they create on-going relationships. The current limits described in paragraph 87 should remain.

## Question 5: Ongoing information for donors on the use of their gametes

- (a) Do you agree that gamete donors should be given the option of receiving ongoing information on the use of their gametes for the following situations:

- (i) if the gamete is about to be used?

Yes ☒ No ☐

- (ii) on the outcome(s) of the donation?

Yes ☒ No ☐

- (b) Is there any other information that you think should be offered to gamete donors after consent has been given?

Yes ☐ No ☒

Please give reasons for your views.

As articulated in our introductory comments, our status as relational beings demands respect for the genetic, gestational and social dimensions of human procreation. Providing on-going information to donors is consistent with the relational responsibilities that flow from human procreation and, in the situation where an embryo has been created from donated gametes, provides the best chance of maximising the possibilities of an on-going relationship between the potential offspring and their biological parent. While the law in New Zealand does not permit anonymous donation, it strikes us that information relating to a child's biological origins still depends to a significant extent on the attitudes and willingness of the adults involved in the process.

## Question 6: Withdrawal or variation of consent by donors

- (a) Do you agree that gamete donors should be able to withdraw or vary consent to the use of their gametes up to the point of fertilisation?

Yes ☒ No ☐

- (b) If not, when do you consider the 'point of no return' should be?

Yes ☐ No ☐

Please give reasons for your views.

We agree that the limits set out in paragraphs 111 and 112 should not change. We also agree with the conclusion and reasoning set out in paragraph 118.

## Question 7: Consent of a partner, family or whānau to donation or use of donor gametes

- (a) Do you agree that the consent of **partners** to the donation or use of a donor's gametes should not be required?

Yes ☐ No ☒

- (b) Do you agree that the consent of **family or whānau** to the donation or use of a donor's gametes should not be required?

Yes ☒ No ☐

Please give reasons for your views.

7(a) As noted in the Consultation Document, the creation of a child differs from blood or organ donations (n. 95). This difference is based on the fact that the donation of gametes creates an enduring biological and parental legacy, whether or not this legacy is acknowledged or respected.

A spousal type relationship is based on a high level of trust and intimacy. In addition, it is of the essence of such relationships that they have a parental dimension. Direct involvement in parenting a child outside of such a relationship without disclosing it to one's spouse/partner is arguably a violation of the trust, as well as the sense of exclusivity, that lies at the core of any permanent couple relationship – it has the potential to destabilise such a relationship, including commitments to any children that a donor might already have with her or his partner or might have in the future.

7(b) We think it best, in the interests of transparency and relational integrity, that individuals be *encouraged* to consult their family or whānau (as happens generally with whānau arrangements, for example) but we do not think this should be mandatory.

## Question 8: Couple disputes about the future use of embryos

- (a) Do you agree that where one party in a couple disputes the future use of embryos that have been created for them, there should be a 'cooling-off' period of 12 months – and if not, why not?

Yes ☒ No ☐

- (b) Do you agree that, if the couple cannot agree about the use of the embryos within that period, the embryos should be disposed of – and if not, why not?

Yes ☐ No ☒

Please give reasons for your views.

8(a) As indicated in our introductory comments above, we do not see disputes over embryos as being solely about the rights of the adults involved – embryos have their own 'intrinsic' dignity which exists independently of the wishes and desires of any related adults. Giving couples time to work out any dispute over the embryos they have created is clearly consistent with the intrinsic dignity of the embryos concerned. We would strongly advocate that couples who find themselves in such a situation be given access to good quality counselling. We would hope that such counselling would include presenting the case for life from the perspective of the embryos.

8(b) In the event of a dispute not being resolved within the cooling-off period, a policy which mandates that embryos be 'allowed to die' after 12 months gives an automatic power of veto to the non-consenting party. From an ethical and legal perspective there is no clear logic to this as the rights of both parties should carry equal weight. In such cases we would advocate that the existing 10 year storage limitation period set out in the HART Act should apply and that the embryos remain in storage until that time or until agreement is reached, whichever comes first.

Framing conflicts about the future of embryos in terms of whose interests should prevail (nn. 141-142) – whether the male partner or the female partner – inevitably takes couples into a legal and therefore adversarial forum. We need to avoid an adversarial approach to conflicts over embryos because they are effectively based on (patriarchal) assumptions of 'ownership'. A non-patriarchal and more child-centred approach is premised on the idea that parents have *responsibilities towards* their offspring, including embryos, rather than *rights over* them. A responsibility-based approach, we suggest, is more likely to bring about a satisfactory resolution without, even unwittingly, reinforcing the 'ownership' paradigm wherein the rights and dignity of embryos are too easily lost to view.

We suggest that all couples need to be counselled about the possibility of such a conflict occurring before they consent to any procedures that will result in the creation of embryos.



## Question 9: Form of requirements for informed consent

- (a) Do you agree that requirements for informed consent should be set out in regulations?

Yes ☒ No ☐

- (b) Do you have any other comments?

Yes ☐ No ☒

Please give reasons for your views.

## Question 10: Comments or suggestions

- (a) Do you have any general comments or suggestions about the requirements for informed consent?

- (b) Do you have any other comments or suggestions about the issues discussed in this Consultation Document?

We are extremely concerned about the nature of the language used in question 8(b) – specifically the reference to embryos being “disposed of” (see also nn. 67, 151 and 152). In general parlance we dispose of ‘things’ – usually things that have no value to us and that are seen as ‘rubbish’. The presence of this language in the Consultation Document highlights for us one of the dangers inherent in the use of assisted reproductive technologies; replacing what is a very human and personal act (the conjugal act) with one that is of a more technical nature (IVF), no matter the motivation behind such a decision, means that the risk of commodification lies but a small step away. While not a step that is logically necessary, it can be a step we take without realising it. This step is often revealed by the language we find ourselves slipping into, including terms such as ‘dispose’. The presence of this language in the Consultation Document strikes us as further evidence of a lack of awareness in practice of the rights of any “potential offspring” as highlighted in our introductory remarks.

