

Consultation on Aspects of Assisted Reproductive Technology

Summary of Submissions:
Part Three – Embryo donation for reproductive purposes

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Introduction

On 6 July 2007 the Advisory Committee on Assisted Reproductive Technology (ACART) released *Advice on Aspects of Assisted Reproductive Technology: A consultation paper on policy issues*.

The consultation paper included draft guidelines on:

- surrogacy arrangements involving providers of fertility services
- the donation of gametes between certain family members
- embryo donation
- pre-implantation genetic diagnosis (PGD).

The consultation paper also proposed parameters for advice on related issues, including:

- the use of donated eggs and donated sperm
- embryo splitting
- the import and export of donated gametes and embryos
- informed consent.

The consultation paper was mailed to 272 individuals and groups that had previously registered interest with ACART, including government agencies, regional Te Puni Kōkiri offices, researchers, academics, providers of fertility services, fertility consumer groups, ethics committees, bioethics organisations, and religious groups, and was emailed to other government agencies and organisations.

The consultation process was advertised in all major metropolitan newspapers on Wednesday 15 August and Saturday 18 August 2007 and in the *Sunday Star-Times* on 26 August 2007. A press release was sent out to 60 news outlets, including all radio and television stations.

ACART held consultation meetings with provider staff and representatives from Fertility NZ throughout August 2007.

A hui was held on 13 August 2007 and a public oral submissions hearing was held on 5 September 2007, both in Wellington.

Submissions closed 7 September 2007. ACART received 44 written submissions and four oral submissions.

This document summarises the submissions received on the draft guidelines for embryo donation (question 3 in the consultation paper).

Summary of submissions on assisted reproductive procedures

The consultation paper asked submitters to indicate if they agreed that the following procedures should remain assisted reproductive procedures,¹ that is, subject to guidelines developed by ACART and ethical review by the Ethics Committee on Assisted Reproductive Technology (ECART):

- surrogacy arrangements involving providers of fertility services
- embryo donation
- donation of gametes between certain family members
- certain uses of PGD.

The majority of submitters agreed that all four procedures should remain assisted reproductive procedures.

Several submitters disagreed in principle with assisted reproductive technology, although some of these, noting that assisted reproductive technology is well established in New Zealand, agreed with having a process for the ethical review of procedures.

Reasons for supporting ethical review included:

- ethical, emotional, and psycho-social issues
- the need to protect the interests of children born as a result of the procedures
- the relative newness of the procedures
- the ramifications for families, which are unknown and potentially significant
- the lack of evidence of the long-term psycho-social and medical safety of the procedures.

Several submitters noted that part of their rationale for supporting ethical review was that ACART would monitor the application and health outcomes of assisted reproductive procedures and revisit whether the procedures would continue to require ECART review.

Feedback from providers was divided between support for the procedures to remain assisted reproductive procedures and a desire for a different kind of framework. Some providers wanted more autonomy and for ECART to function in an advisory capacity, so clinics could approach it for advice and guidance at any stage of the process. Providers envisaged being able to refer cases for established procedures to ECART where there were specific ethical concerns or a perception of enhanced risk.

¹ An assisted reproductive procedure is defined by the Human Assisted Reproductive Technology Act 2004 (HART Act) as a procedure performed for the purpose of assisting human reproduction that involves the creation of an in vitro human embryo; or the storage, manipulation, or use of an in vitro human gamete or an in vitro human embryo; or the use of cells derived from an in vitro human embryo; or the implantation into a human being of human gametes or human embryos; but does not include an established procedure under section 6 of the HART Act.

Part Three – Embryo donation for reproductive purposes

The majority of submissions supported embryo donation for reproductive purposes remaining an assisted reproductive procedure.

Three reasons were given in support of ethical review.

- The procedure is very new.
- Couples need “intense counselling”.
- Case-by-case consideration by ECART is useful and should be continued with the intention of developing guidelines for clinics to use for straightforward scenarios. A target should be set for the number of cases that need to be reviewed before clinical guidelines can be developed (eg, 20–30 cases).

Submitters who did not support ethical review stated that ethical review:

- of every case is unnecessary, but there should be an appeals process available
- is unnecessary because it is a medical decision whether recipients need donor embryos.

Other comments and suggestions included the following.

- Embryo donation is “too much” for some people (because of the requirement to meet recipients and have counselling, and the impact on their children having full siblings).
- ACART should develop a “family lens” to take account of the collective interests of families and wider implications for whānau of assisted reproductive procedures.
- Couples with strong views about the status of embryos are particularly likely to be interested in embryo donation.

Responses to question 3: What are your views on the proposed guidelines for embryo donation?

While there was a level of support for the guidelines, many submitters sought clarification of different aspects of the draft wording and further details of certain requirements, including counselling and medical and legal advice.

The majority of the submissions focused on one or more of the areas outlined below.

Counselling

Submissions on the counselling provisions for embryo donation included the following.

- Counselling should be available after the birth of the child.
- Joint counselling should not be mandatory where couples wish to make an “unconditional gift” of their embryos.
- The guidelines should specify that counselling must address issues around surplus embryos and the disposal of embryos, so that couples understand that they have the option of donating to research, and that if they are donating to another couple it is clear who has the right of disposal.

Health and wellbeing of children

Many submitters considered that the guidelines should include provisions relating to children born from embryo donation. Suggestions included the following.

- There should be provision for contact arrangements. Suggestions for contact ranged from a minimal arrangement involving a card and photo once a year to provision for visitation during childhood. One submitter thought the child should know the extended family of the donors, and others thought the children of the donors and recipients should know each other.
- The potential impact on children should be addressed, for example, by providing for the child’s rights by appointment of an advocate for the child, addressing the psychological effects on the child, requiring follow-up by child health providers, and stating that the potential child’s rights are paramount in the guidelines.
- Counselling should involve donors and recipients meeting to discuss the children.
- The guidelines should include reference to the information-keeping provisions in the HART Act to ensure that children find out about their genetic origins.

Some submitters wanted more information about the impact on children born from embryo donation, stating that it should be possible to find this out from child psychologists or adoption experts.

One submitter suggested that the age gap between potential offspring should be a consideration when determining if donation is appropriate.

Donation to more than one family

Many submitters considered that donation to more than one family should be permitted. The most commonly cited support for this was that adoption is not restricted to one family. Other reasons included that: donor sperm is used more widely; in Australia donation is permitted to more than one family; and allowing donation to more than one family would afford donors and recipients the same rights as the general population.

Other submitters supported the restriction of donation to one family, noting that New Zealand's small population makes this appropriate.

One submitter suggested that provision needs to be made to ensure that donation has not occurred in any other jurisdiction.

Embryos from donated gametes

Several submitters considered that embryos from donated gametes should be able to be donated if the gamete donors consented.

Need for written consent

Many submitters considered the requirement for written consent for embryo donation too restrictive. Reasons included that it ignored the possibility of eyewitness testimony and that it imposed a higher standard than was imposed for medical procedures.

Donation when one partner is deceased

Several submitters wanted embryos to be able to be donated without written consent if one donor was deceased. It was suggested that donors be given the option of relinquishing their decision to their surviving partner.

Other submitters did not support donation where one parent was deceased, irrespective of whether there was written consent, because of the needs of the potential child.

One submitter requested clarification on what happens if the recipient dies, suggesting an additional guideline allowing ECART to be provided with evidence of agreement for storage.

Surplus embryos

Many submitters were concerned about surplus embryos. One submitter said, “[i]t is tragic that procedures that result in the production of ‘surplus’ embryos ... have been permitted at all. But donation ... is better than destroying them ... Within those considerations I believe the [embryo donation] guidelines are good and necessary”.

Many other submitters suggested that surplus embryos should not be created in the first place and emphasis should be placed on this by ACART. Comments included the following.

- Viewpoints are often clouded when decisions are made, meaning patients may not have properly considered the outcome (of having surplus embryos).
- The issue of surplus embryos is not discussed enough with patients.
- Some people will not consider donating embryos because to them, they are the children that they have tried so hard to have. They may find donation to research an option, but many will just wait the 10 years (the maximum period permitted for storage) as they do not know what else to do.
- Some religious couples create only the number of embryos that they will need (ie, they use all their embryos).

Some submitters considered that embryo donation should be more widely available, and questioned why fertile couples could not be embryo donors or recipients. Other submitters considered that the option of embryo donation should be more widely communicated so that, for example, couples applying to adopt are advised of this option.

Education

Education was a key topic for many submitters who had been through in vitro fertilisation treatment personally. The general theme was that education was required, so patients and the public would have a better understanding of embryo donation. Comments included that:

- education is important for people to make better-informed decisions
- normalising these issues for children from the outset is important, and parents need to be educated that it is better for the child to know their genetic origins rather than not know them
- thousands of surplus embryos are in freezers, and people need to be educated that it is acceptable and possible to donate them
- an equivalent of adoption “open days” could be run for people to come together and share their experiences.

One submitter suggested that embryo donation is becoming more common in Australia and that it will probably also become more common in New Zealand.

Opposition to the guidelines

Submitters who did not support the guidelines ranged from those who were opposed in principle (ie, the donation of embryos was commodification and akin to donating a human being) to those who considered that the guidelines were unnecessarily cautious and that embryo donation should not be subject to ECART approval because the interim guidelines (from the National Ethics Committee on Assisted Human Reproduction) are detailed and set out a careful process that providers of fertility services could follow.

Other issues raised

Other issues raised included the following.

- Concern around the donation process, including that there is a mismatch between donors and recipients, in that if recipients assert their wishes there is a perception that they may lose their donors; that donors get to see all the recipients' details, making potential recipients nervous about getting chosen; and that more stringent screening provisions should be in place for recipients.
- Embryo donors should have their own children before being permitted to donate.
- Issues around informed consent, including concerns that consent given under duress or pressure (particularly with regard to the creation of surplus embryos) may not be informed consent.
- A minimum number of embryos for donation could be considered, as many couples have only one embryo in storage. On the other hand, the viability of the embryos should also be considered.