

Consultation on Aspects of Assisted Reproductive Technology

Summary of Submissions:
Part Four – Preimplantation Genetic Diagnosis

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Introduction

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

The document included draft guidelines on surrogacy arrangements involving providers of fertility services, donation of gametes between certain family members, embryo donation and preimplantation genetic diagnosis (PGD), as well as proposed parameters for advice on related issues, including use of donated eggs with donated sperm, embryo splitting, import and export of donated gametes and embryos and informed consent.

The discussion document was mailed to 272 individuals and groups that had previously registered an 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, and in the *Sunday Star-Times* on 26 August. 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 New Zealand throughout August 2007.

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

Submissions closed on 7 September 2007. ACART received 48 submissions, including four oral submissions.

This document summarises the submissions received on PGD.

Should certain uses of PGD remain subject to guidelines?

It was noted during consultation that guidelines were necessary only for PGD with HLA tissue typing because PGD on its own was covered by the established procedure.

Submissions indicated strong support for certain uses (that is, those not part of the established procedure) of PGD remaining an assisted reproductive procedure¹ (ARP) and, thus, subject to guidelines.

The majority of submitters wanted a more rigorous and prescriptive framework around PGD than that proposed by ACART in its consultation document.

Submitters expressed considerably more disquiet about PGD than about other reproductive procedures, for example, one submitter expressed concern that PGD has great potential for use in ways that are not acceptable to New Zealand society, for example, sex selection, and advocated for strong regulatory oversight.

¹ An assisted reproductive procedure is defined by the Human Assisted Reproductive Technology (HART) Act 2004 as a procedure performed for the purpose of assisting human reproduction that involved 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 pursuant to section 6 of the HART Act.

Policy extension to allow testing of embryos for tissue typing for a non-genetic condition

Those opposed to the extension of New Zealand policy to allow tissue typing for a non-genetic condition cited the following reasons:

- commodification of the embryo and resulting child
- adverse impact on family dynamics
- adverse psychosocial impacts on the resulting child
- inability of the embryo/child to give informed consent
- inability of parents to give informed consent given the stress associated with having a gravely ill child.

One submitter stated that there was “deep discomfort” in the community about “this type of reproductive relationship” and that it was “widely unacceptable”. Another submitter considered that such an extension would push us further along the continuum that makes it easier to see children as commodities.

Two submitters opposed to the extension considered that ACART should, for now, monitor developments overseas for the psychosocial impacts on the resulting child, as well as for any emerging safety concerns about PGD.

Many of those who responded, but were neither supportive nor opposed, cited similar misgivings.

One submitter considered that concerns that the resulting child is an ‘object’ could be explored in counselling.

Two submitters pointed out that concerns about psychosocial impacts on the child and family were speculative and it could similarly be speculated that such outcomes would be positive.

Many of those supportive of an extension to the policy also cited concerns that the interests of the resulting child somehow be protected.

A few submitters suggested that the resulting child (or both children) should have an independent advocate. One submitter proposed that guidelines be developed covering the use of tissue from the resulting child until they reach maturity. Another considered that New Zealand needs a formal policy on repeat donation involving minors.

A number of submitters were concerned that use of cord blood only should be allowed, while other submitters stated that living donation is covered by health law, child law and informed consent, not by ACART.

Several submitters considered that, while this procedure was contentious, parents would love and care for the resulting child, and that this was not an easy option for parents to take. One submitter considered that it would not be ‘instrumentalising’² in such a circumstance.

Another submitter expressed concern about a possible future where parents with sick children, who had exhausted alternatives, felt pressured to undergo this procedure to cure the existing child.

² Using someone as a means to an end, rather than an end in themselves.

These concerns were seen by some as issues to be explored in counselling and considered by the Ethics Committee on Assisted Reproductive Technology (ECART) in its determination of applications.

A few submitters – both supportive of and opposed to the procedure – said there was no difference between the use of PGD with HLA tissue typing for a genetic disorder compared with a non-genetic disorder, for example, the psychosocial concerns apply to both. ACART should, thus, be consistent in its policy advice.

Two submitters suggested that ACART should await the outcome of the Bioethics Council dialogue³ before making a decision on this policy.

One submitter considered that, if the procedure is not permitted in New Zealand, parents will travel abroad for the treatment and it would be better to provide for domestic regulation and oversight of the procedure.

³ The Bioethics Council has conducted a public dialogue on pre-birth testing which includes preimplantation genetic diagnosis.

Proposed guidelines

Those opposed to the guidelines were concerned that every embryo is an actual, and not just a potential, human being, and it was inappropriate to select embryos on this basis. A few submitters saw PGD as an instrument to facilitate abortion, to which they were opposed.

Selection of an embryo with a genetic condition

Several submitters commented on the prohibition in the proposed guidelines on the selection of an embryo with a genetic disease. It was apparent that there was uncertainty as to whether the guideline “PGD is not used for the purpose of selecting an embryo with a genetic disease” also meant that such an embryo may not be selected for implantation when there is no alternative for the patient/s.

Some submitters considered that parents should have the autonomy to make such a choice, while two submitters opposed the prohibition; one stating that if a couple was willing to raise a child with disabilities then this must be allowed, the other stating that it may be a couple’s only chance to have a child, in which case it was a decision for the parents to make.

Two submitters supported the prohibition, although it is unclear how they interpreted the guideline.

Severity of condition

Some submitters raised concerns around the definition of a genetic disease – does it include carrier status, or a predisposition to a disease? Who decides what is serious enough?

Several submitters considered the draft guidelines too vague, expressing particular concern at the word “benefit”. Alternative suggestions included:

- demonstrate other sources of tissue and treatment have been explored but HLA tissue typing is the optimal procedure
- require that the condition is serious and no other treatment is reasonably available, or there is a realistic chance that treatment will be successful
- apply only for life-threatening situations.

Some submitters considered that PGD should be used only to treat a condition in a particular embryo; another considered that adult stem cell developments were sufficient to treat disease.

One submitter considered that the proposed guidelines were seriously lacking because they failed to limit the situations in which PGD may be used. This submitter stated that the use of PGD should be limited to situations where there is a high risk of serious abnormality and that it be prohibited for non-medical reasons. They considered that the guidelines should include requirements that:

- PGD be used only where there is a high risk of serious abnormality
- PGD may not be carried out for social reasons (including sex selection)
- PGD may not be carried out to alter the genetic constitution of an embryo.

Several other submitters expressed similar concerns, particularly that PGD must not be used for non-medical or social purposes.

Attitude towards disability

A few submitters considered that the language used by ACART is biased towards the medical model of disability, with the use of words like “disease” or “disorder” rather than “condition”, implying value judgements against those with disabilities.

One submitter considered that ACART should require that advice is provided to those undertaking PGD from people experienced in understanding disability knowledge and values. This would better prepare potential parents to decide whether to implant a certain embryo or not.

Counselling

Another submitter stated that medical advice and genetic counselling should be independent of the clinic, considering that some counselling is perceived as being more about selling the technology than facilitating truly informed decisions.

One submitter suggested that counselling provisions should be included in the guidelines because they are more specific than the Code of Health and Disability Services Consumers Rights and place responsibility for ensuring the provision of adequate information and genetic and psychosocial counselling on the provider.

Informed consent

One submitter considered that the information provided to ensure informed consent should be included in the guidelines.

One submitter suggested that informed consent guidelines should ensure that parents understand that treatment may not always be successful.

Rights of the child

Some submitters considered that the resulting child should have a legal advocate to consider their humanity and needs and rights. One submitter stated that the advocate should be familiar with the social model of disability and have a commitment to inclusion and diversity as reflected in the New Zealand Disability Strategy.

Several submitters suggested that the guidelines should include the proviso that the potential child will not be unduly harmed or disadvantaged.

Tikanga Māori and the use of PGD

One submitter considered that the full potential of the Tikanga was not reflected by ACART and that the guidelines should explicitly acknowledge relevant Tikanga to fully reflect the reality for people who need to make decisions around PGD, and who espouse these Tikanga principles.

Requirement that the procedure be used only to benefit a genetic sibling

One submitter suggested that restricting the treatment to full siblings was Eurocentric and that Māori would wish to see it extended to include cousins; another submitter stated that it wouldn't make genetic sense to expand the policy beyond siblings.

International benchmarking

Several submitters suggested that the guidelines should be consistent with the criteria in the United Kingdom as set by the Human Fertilisation and Embryology Authority.

Other issues

Sex selection

Two submitters stated that they were opposed to selection on the grounds of sex to address a familial disorder, seeing this as likely to lead to a more liberal policy on sex selection. Another submitter recommended a review of the prohibition on sex selection, considering that the public would be comfortable with this for the purposes of family balancing.

Low penetrance and late onset conditions

There were questions over whether lower penetrance diseases can be tested for, and whether it would be acceptable to use PGD to select against an embryo with genes that increase the risk of early onset breast cancer without going to ECART. One submitter proposed that consideration of the established procedure is necessary and, in particular, public dialogue is essential with respect to what might be seen as a wider range of uses of PGD than originally anticipated or intended.

Safety of PGD

A number of submitters raised concerns that recent research had found that PGD adversely affects the embryo, and considered that ACART should be monitoring this research and not extending the use of PGD in the meantime. Several submitters suggested the need for long-term follow up of children born following PGD. A couple of submitters considered that, because of these concerns, PGD should be used only on an embryo that would itself benefit from the procedure.

Public engagement

One submitter considered that further public engagement is needed about PGD, which involves complex decisions involving cultural, ethical and spiritual dimensions. Two submitters suggested that the Bioethics Council's dialogue on pre-birth testing would provide important information to assist ACART's decision-making.

List of submitters

Individuals

Brian Gerard Quin
Carolyn Hutton
David Fisk
Eric Blyth
Helen Davies
Hilary Stace
Hugh Moran
Jeanne Snelling
Joan Sullivan
John France
Karen Raaymakers
Lynette and Ian Mason
Maria Jones
Patricia A Hammond
Paul Clarke
Paul Elwell-Sutton
Phillipa Malpas
Robert Ludbrook
Susan Fraser
Dianne Yates MP

An additional four submitters requested that their personal details be kept confidential, and one submitter did not provide any personal details.

Organisations

Abortion Law Reform Association of New Zealand
Auckland Women's Health Council
Bioethics Council
Canterbury District Health Board
CCS Disability Action
Ethics Committee on Assisted Reproductive Technology
Families Commission
Federation of Women's Health Councils
Fertility Associates
Fertility New Zealand Canterbury
Fertility New Zealand Auckland
Health and Disability Commissioner
Health Law Committee, New Zealand Law Society
Humanist Society of New Zealand Inc
Ministry of Social Development
Right to Life New Zealand
The Fertility Centre
The Interchurch Bioethics Council
The Nathaniel Centre – the New Zealand Catholic Bioethics Centre
Voice for Life Wellington
Voice for Life
Women's Health Action Trust