Use of Gametes and Embryos in Human Reproductive Research

Summary of Submissions
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Introduction


ACART received 345 written submissions and 9 oral submissions were heard at meetings in Wellington and Auckland in early March 2007. In addition, approximately 160 people attended eight public consultation meetings, hui and fono.

ACART wishes to thank everyone who took the time to attend a public meeting, hui, fono, or focus group, or to make a written or an oral submission. These submissions played an important role in ACART’s deliberations, with Committee members often reflecting on one or another submission as ACART discussed the recommendations to the Minister of Health.

The submissions made to the Committee were taken into account within a larger analysis that informed ACART’s advice to the Minster of Health. ACART has considered not only the strength of public opinion, but also the strength of the arguments made.

This summary reflects the wide range of opinions held by New Zealanders on the use of gametes and embryos in human reproductive research. In particular, the Committee noted that this wide range of views existed not only across the population as a whole, but also within different social, cultural and ethnic groups.
Summary of Submitters’ Responses

This section provides a brief summary of submitters’ responses to each question.

The use of gametes in research

Most submissions fell into one of two positions:

• opposition to the use of gametes in research on the grounds that they are human life and, whatever the potential benefits, the destruction of gametes in the course of research is unacceptable

• support for the use of gametes in research on the grounds that they are not human life and there is great potential for such research to alleviate human suffering.

Some submissions in support of the use of gametes in research made specific points about possible future guidelines. These included that there should be:

• a ban on ‘egg sharing’ – an option in the United Kingdom whereby eggs are donated to research in return for reduced-cost fertility treatment

• a ban on donation of gametes from women and men who have not completed their families

• special informed consent requirements if the gametes are intended to be used to make embryos from which stem cell lines would be derived

• compensation of egg donors for any associated costs.

The use of embryos in research

While the majority of submissions supported a view that life begins at conception, there were two broad positions in relation to the use of embryos in research:

• opposition to the use of embryos in research on the grounds that they are human life and any manipulation, including in-vitro fertilisation (IVF) and pre-implantation genetic diagnosis (PGD), is akin to harming or killing a person

• support for at least some use of embryos in research on the grounds that they have a lesser moral status than persons who have been born, provided that such research has scientific merit and potential to benefit human health.

ACART held four hui with Māori. While many individual Māori who attended the hui and made written submissions expressed a wide range of attitudes to the use of embryos in research, there was in general, a call for more time and a greater degree of engagement at an iwi level. Concerns expressed included the importance of the kaupapa and decisions about the use of embryos in research; the incompatibility of such research with certain tikanga; the inability of those who attended to represent iwi; and concerns that Māori would not benefit from such research.

1 PGD: Where either the polar body of the egg or one or more cells obtained from an embryo between day 3 and 5 of development is tested to determine if that embryo carries the particular harmful gene under investigation (or abnormal chromosome rearrangement) with the purpose of replacing only unaffected embryos into the uterus in conjunction with IVF.
A strong concern that emerged at the hui was that at the point of fertilisation each embryo has a wairua that would be destroyed when the embryo itself is used during research.

A few submissions specifically supported a moratorium, mostly to allow more time to consider the alternatives to, and the ethical, commercial and scientific implications of, embryo research.

A number of submissions proposed that research using less ethically contentious sources of stem cells (eg, adult, amniotic, placental, foetal, and umbilical cord cells) be undertaken instead. Many cited examples of success in adult stem cell research and pointed out that there have been no clinical benefits and some harms from embryonic stem cell research. To a large extent, ACART’s discussion paper and submission questions were reframed by submitters into a debate about the merits of the various methods of stem cell research – even though ACART had not presented its information in this way.

Users of fertility services generally expressed a wish to have the choice to donate their ‘surplus’ embryos for research purposes, in addition to the current options of donating them to another couple for reproductive purposes or allowing them to thaw and perish.

Of those who supported some use of embryos in research, many cited the importance of ensuring compliance with aspects of the HART Act, including a continued prohibition on any use of embryos after the 14th day of development. Many submissions also made suggestions for any possible future guidelines, including:

- that the use of embryos in research may only proceed if research on non-human embryos or models has been exhausted
- that donors of embryos should have a choice and give informed consent about the purpose or type of research to which their embryos would be put, including clinical training
- that coercion, including subtle coercion, must be avoided.

**Purposes of research**

The majority of submitters who expressed support for research did not distinguish between different purposes. Others responding to this question repeated their opposition to gamete and/or embryo research.

A number of submissions made suggestions for any possible future guidelines, including:

- that as much research as possible should first be done using non-human gametes and embryos and models
- the need to address issues related to informed consent, ownership of human material and the commercial nature of research.
Sources of gametes and embryos for use in research

ACART asked the public for their views on the use of the following sources of embryo:

- donated non-viable embryos created via IVF treatment
- donated viable ‘surplus’ embryos created via IVF treatment
- embryos created via IVF specifically for research purposes
- embryos created via somatic cell nuclear transfer (SCNT) specifically for research purposes
- hybrid embryos created specifically for research purposes.

Relatively few people answered this question. A number of submitters were opposed to all forms of embryo research, while others supported the use of all these sources of embryos.

Some submitters said that there is a moral difference between the use of ‘surplus’ IVF embryos and embryos created specifically for research purposes. Some considered that it is acceptable only to use ‘surplus’ IVF embryos. Others were more comfortable with those created specifically for research purposes arguing that, as there is never any intent that they become persons, it is less problematic morally. One submitter commented that the use of the word ‘surplus’ imposed a lesser moral value to those embryos.

Few commented on the use of donated non-viable embryos created via IVF treatment and this seemed to be a relatively uncontentious source.

The vast majority who commented on the sources of embryos for research supported the development of guidelines for the use of ‘surplus’ IVF embryos in research.

Few commented specifically on the use of embryos created via IVF specifically for research purposes; however, as mentioned above there was some support for this source.

Few submissions commented specifically on the use of embryos created via SCNT for research purposes. Of the comments that were made, some expressed concerns about cloning humans and supported prohibition, or a moratorium as a second option. At the public meetings and hui, there was a general concern that allowing this source of embryos for research would eventually allow for the cloning of humans for reproductive purposes. However, the HART Act prohibits the formation of a cloned embryo for reproductive purposes and also bans the implantation into a human of such an embryo.

A small number commented on hybrid embryos. While some supported their use, particularly to bypass the need for large numbers of human eggs, others (including the fono and hui participants) supported prohibition due to its ‘unnaturalness’.

Genetic modification of gametes and embryos

A number of submitters were opposed to the genetic modification of gametes and embryos, considering it to be highly unethical, unnatural and dangerous. During this consultation, reference was made to the public debate on the genetic modification of food. Other submitters were supportive, with some qualifications, and made suggestions for any possible future guidelines, including:
• that this be the only option for undertaking the research, including that the research cannot be carried out using another type of cell, model and/or non-human gametes and embryos

• evidence of scientific merit, safety and benefit to human health.

Some submitters stressed the potential benefits that may arise from the genetic modification of embryos and their use in research.

A number of submitters expressed concern about genetic modification of the germ line and the unknown impact on future generations. The HART Act, however, prohibits the implantation of a genetically modified gamete, human embryo or hybrid embryo into a human being.

**Import and export of human gametes and embryos**

Some submitters acknowledged the advantages that the import and export of gametes and embryos may bring to New Zealand’s research community.

In relation to import, a major concern was how gametes and embryos would be sourced and how to ensure that the ethical standards in source countries would match standards in New Zealand.

In relation to export, most submitters believed that the export of gametes and embryos should be prohibited. Some concerns related to the difficulty of maintaining control and ensuring that any exported gametes and embryos remained subject to the same criteria as those used in research in New Zealand. A couple of submitters pointed out that people should be able to decide for themselves whether their gametes should be exported, based on informed consent.

Some submitters suggested that iwi would be unlikely to support the export of Māori gametes. This concern is based largely around the loss of control over whakapapa.

**The needs, values and beliefs of Māori**

*Principle f of the HART Act states that “the needs, values and beliefs of Māori should be considered and treated with respect”.*

There were few responses to this question in the written submissions and this section draws largely on the hui.

Just as with other cultural, social and ethnic groups, there is as large a diversity of view amongst individual Māori as there is across the population as a whole.

Concerns about process were raised at the hui. These included a lack of appropriate information, not enough time, and insufficient engagement with iwi across New Zealand. Māori attending the hui stressed that they could not speak for their iwi. The hui called for more time, so that iwi could be facilitated to consider these important issues and develop tikanga-based policies and guidelines on the use of gametes and embryos in research.
Several elements of tikanga were, however, identified as being of primary importance in this area of research:

- wairua
- kaitiakitanga
- whakapapa.

A significant amount of distrust was expressed – of government, of committees such as ACART, and of science and research. There was a call for the need for this kaupapa to be underpinned by the principles and articles of the Treaty of Waitangi.

**Different ethical, spiritual and cultural perspectives in society**

*Principle 9 of the HART Act states that “the different ethical, spiritual and cultural perspectives in society should be considered and treated with respect”.*

There were few responses to this question.

A number of submissions noted the wide range of ethical, spiritual and cultural perspectives in New Zealand, and the difficulty in developing policies that would respect all these perspectives.

It is apparent from the submissions that, not only is there a wide range of views across New Zealanders as a whole, but there is an equally wide range of views within demographic groups.

There was some support for the view that, in a pluralistic society like New Zealand, it would be best to allow individual choice. In that way no single cultural, ethical or spiritual view predominates and people can participate to the extent that they are comfortable. A couple of submissions, however, warned against such an approach.

A number of submissions stressed the importance of engaging with ethnic communities and the public generally in further consultation to develop policy and guidelines.

Some submitters made specific suggestions for any possible future guidelines. These largely focused on enabling an informed choice and informed consent.

**Further comments not covered by the earlier questions**

Submitters made comments on the quality of the discussion paper which ranged from praise for a thoroughly researched and accessible document to criticism of a poorly researched and inaccessible document. A similar range of comments were made on ACART’s consultation process.

Several submitters advocated further public consultation and education including ongoing dialogue with the public around the ethical, spiritual and cultural values that relate to this area.

Various individuals made isolated points, however, some points had the support of a number of submitters, including concern that some of the language used and in particular the term ‘pre-embryo’ was an attempt to frame the discourse in such a way that is pro-research. A similar argument was made by one submitter on the use of the term ‘surplus’ embryo.
A few submitters questioned the representation of different perspectives on ACART and its position on ethical issues. In particular, there was advocacy for the inclusion on ACART of someone from a spiritual perspective, a Pacific perspective and a developmental biology perspective.

Various submitters commented on matters they considered to be omissions from the discussion document, including a discussion of research using stem cells from other sources such as adult stem cells, umbilical cord blood stem cells, and animal cells.

Several submitters supported the establishment of an oversight body. One considered that the system for handling human tissue, gametes and embryos is fragmented and provides no overarching consistency or responsibility for protocols around donated material. It was suggested that an oversight body be established, in addition to existing ethics committees, to provide ongoing advice and consistency in relation to the unspecified use of tissue, including approval of overseas facilities for export, and monitoring of research. Hui participants discussed the need for a kaitiaki/guardianship role to either be undertaken by somebody already in the sector or for a new position to be established.

One submitter strongly recommended that the use of gametes and embryos in research be subject to regulations rather than guidelines, as they considered that guidelines are unenforceable. Regulation was seen as being particularly important for research involving genetic modification and the import and export of gametes.
List of Submitters

Individuals

Clare and Fergus Aitcheson
C Alvis
Mr and Mrs Amon
D Armstrong
W Armstrong
Kirsty Bamford
Audrey Barry
C Barrow
Sandra Bater
Ann Belay
Stephen Bell
Paul Berna
P Boake
Edward and Claudia Borich
Margaret Breeze
Anita Bruce
Rosemary and Gary Burrell
David Campbell
Jennifer Campbell
Marion Carey-Smith
Jocelyn Carroll
Paul Clarke
Khoti Clements
Sebastian Colson
Campbell Cossens
Tony Cossens
John Crowley
Carolyn Crummer
Christine Cullen
John Cullinane
Aletta Kampes and Patricia David
G Cook
J Cundy
Alan Davidson
Jessica Deane
Rosemary De Luca
J Devoy
P and S Diak
Mary Dillon
Mary Dorrington
Caitlin Doube
Merle Duxfield
Liam Egan
Paul Elwell-Sutton
Stephen and Wendy Entwhistle

Jenny Epplett and others
Kevin Fitzsimons
Maurice Ford
Jonathon Foster
John France
Simon Fraser
Susan Fraser
Steve and Jackie Freeman
Julie du Fresne Kynoch
Johanna Frings
Steven Gieseg
Catherine Gillies
Marewa Glover
Lesley Gray
Clementine Guppen
Maria Hammond
Alex Hargreaves
Sharon Harvey and others
Anita Hawke
Pamela Hefferman
John and Margaret Hegarty
Tara Helm
Claire Hickling
Stephen Hoare-Vance
Judy Howard
Lillian Hoyt
Denise and Chris Johnston
K Jones
Sophie Juno
Sharon Kaipo
Lynne Keene
Gregory Kent
John Kellett
Ria and Loek Klaassen
Arthur la France
B Lambert
Colleen Law
Christine Lewis
Ingrid Lindsay
Brittany Long
Kirstie McAllum
Jay McCabe
John McArthur
John McCaffrey
Patrick McCann
An additional 110 individuals made submissions, but asked that their personal details not be made publicly available.
### Organisations

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<th>Organisation</th>
<th>NZBio</th>
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<tr>
<td>Agresearch Ruakura Agricultural Centre</td>
<td>Pacific Health Section, University of Auckland (on behalf on fono participants)</td>
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<tr>
<td>Association of Catholic Women of New Zealand</td>
<td>Patients’ Rights Advocacy, Waikato</td>
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<td>Auckland Medical Aid Trust</td>
<td>Right to Life</td>
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<td>Bioethics Council</td>
<td>Royal Society of New Zealand</td>
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<tr>
<td>Catholic Women’s League of New Zealand</td>
<td>Ss Peter and Paul Parish, Lower Hutt</td>
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<tr>
<td>Catholics United for the Faith</td>
<td>St Andrew’s Anglican Church, Epsom</td>
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<td>CCS</td>
<td>St Andrew’s Presbyterian Church, Invercargill</td>
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<tr>
<td>Diamond Harbour Community Group</td>
<td>St Mary, Star of the Sea Catholic Church, Gisborne</td>
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<td>Families Commission</td>
<td>Te Whare o Kenehi</td>
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<td>Family Life International</td>
<td>University of Otago Molecular Biology Group</td>
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<tr>
<td>Family Planning Association</td>
<td>Voice for Life, Auckland</td>
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<tr>
<td>Federation of Women’s Health Councils</td>
<td>Voice for Life, Gore</td>
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<td>Fertility Associates</td>
<td>Voice for Life, Gisborne</td>
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<td>Fertility New Zealand National</td>
<td>Voice for Life, Hutt Valley</td>
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<td>Grace Presbyterian Churches</td>
<td>Voice for Life, Napier</td>
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<tr>
<td>Health and Disability Commissioner</td>
<td>Voice for Life, National Office</td>
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<td>Health Research Council Ethics Committee</td>
<td>Voice for Life, Nelson</td>
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<tr>
<td>Human Life Protection</td>
<td>Voice for Life, Paraparaumu</td>
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<tr>
<td>Humanist Society of New Zealand</td>
<td>Voice for Life, South Canterbury</td>
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<td>Institute for Strategic Leadership</td>
<td>Voice for Life, Southland</td>
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<td>Interchurch Bioethics Council</td>
<td>Voice for Life, Tauranga</td>
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<td>John Paul II Doctors’ Association of New Zealand</td>
<td>Voice for Life, Tawa</td>
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<td>Legion of Mary, Morrinsville</td>
<td>Voice for Life, Waikanae</td>
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<tr>
<td>Legion of Mary, Te Aroha</td>
<td>Voice for Life, Wanganui</td>
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<tr>
<td>Lutheran Church of New Zealand</td>
<td>Voice for Life, Wellington</td>
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<tr>
<td>Ministry for Research, Science and Technology</td>
<td>Whanganui District Health Board</td>
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<tr>
<td>Muscular Dystrophy Association of New Zealand</td>
<td>Women’s Health Action</td>
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<td>New Zealand Anti-Vivisection Society</td>
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<td>New Zealand Catholic Bishops Conference and Nathaniel Centre</td>
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<td>New Zealand Nurses’ Organisation</td>
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