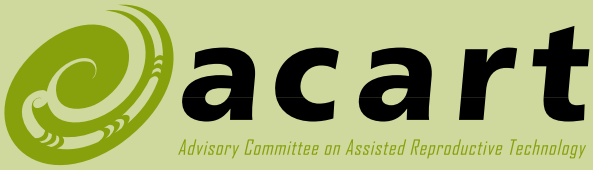


Advisory Committee on Assisted Reproductive Technology

Annual Report 2007–2008

Including the 2007/08 Annual Report of the Ethics Committee on Assisted Reproductive Technology

Annual Report 2007–2008 including the 2007/08 Annual Report of the Ethics Committee on Assisted Reproductive Technology

Citation: Advisory Committee on Assisted Reproductive Technology. 2008.
Annual Report 2007–2008, including the 2007/08 Annual Report of the Ethics Committee on Assisted Reproductive Technology.
Wellington: Advisory Committee on Assisted Reproductive Technology.

Published in November 2008
by the Advisory Committee on Assisted Reproductive Technology.
PO Box 5013, Wellington, New Zealand

ISBN: 978-0-478-31839-5 (print)
ISBN: 978-0-478-31842-5 (online)
HP 4702

This document is available on the ACART website
(http://www.acart.health.govt.nz)
and the ECART website (http://www.ecart.health.govt.nz)

Contents

Part One:
Advisory Committee on Assisted Reproductive Technology Annual Report 2007/08

Chair's Foreword

On behalf of the Advisory Committee on Assisted Reproductive Technology (ACART) I am pleased to present this annual report for the 2007/08 financial year.

ACART's terms of reference require it to develop advice for the Minister across a very broad area, including the use of assisted reproductive technologies in both treatment and research. It is also charged with developing guidelines for the Ethics Committee on Assisted Reproductive Technology (ECART) and undertaking a broad monitoring role. This work is demanding and complex.

In this, the third year of ACART's existence, the committee's workload has been high as completion dates for many projects required the committee to work simultaneously in a number of areas. In undertaking this extensive work programme the committee has been very ably supported by the secretariat, and I wish to record my thanks here to the secretariat for their high level of professionalism. I also wish to thank the Ministry of Health for their ongoing support. I am also very grateful to ACART members for their outstanding commitment to the committee's work and their willingness to provide both time and expertise. Without such involvement the progress achieved would not have been possible. I particularly wish to thank those members who completed their terms during this period.

The year commenced with the release of ACART's paper *Advice on Aspects of Assisted Reproductive Technology: A consultation paper on policy issues* for public consultation. This was followed by the issuing of two new guidelines for ECART, the delivery of advice to the Minister on pre-implantation genetic diagnosis and embryo splitting, and the development of new guidelines for embryo donation (to be issued to ECART in late 2008). The year closed with the release of two consultation papers: advice on the use of frozen eggs and proposed guidelines for pre-implantation genetic diagnosis. Each of these pieces of work required working through the detailed processes set down in the Human Assisted Reproductive Technology (HART) Act.

As part of its monitoring function, ACART has established a scanning panel to monitor developments in treatment and research, with members drawn from researchers and others with expertise in this area. I am very grateful to these people for their willingness to contribute to the future watch aspect of ACART's functions.

ACART has interacted closely with ECART, the Minister of Health, the Ministry of Health and providers of fertility services. We have greatly valued the insights each of these has provided as we work through the intricacies of implementing our responsibilities under the HART Act.

I also wish to express my appreciation to those who have assisted ACART's work by responding to requests for submissions. Members of various groups and organisations and individual members of the public have been most helpful, and their input has greatly enhanced ACART's understanding of complex issues. ACART was particularly grateful to the Bioethics Council for the work it undertook in raising public awareness of issues relating to the various consultations.

I look forward to continuing this important work in the coming year.

Sylvia Rumball
Chair, Advisory Committee on Assisted Reproductive Technology

Introduction

Purpose of this report

Section 42(3) of the Human Assisted Reproductive Technology Act 2004 (the HART Act) requires the Advisory Committee on Assisted Reproductive Technology (ACART), as soon as practicable after each 12-month period ending on 30 June, to provide the Minister of Health with a report on:

- its progress in carrying out its functions
- the number and kinds of decisions given by the Ethics Committee on Assisted Reproductive Technology (ECART) in that period.

Background

The HART Act established two committees: the Advisory Committee on Assisted Reproductive Technology and the Ethics Committee on Assisted Reproductive Technology.

ACART's functions

ACART's functions, as set out in section 35 of the HART Act, are to:

- issue guidelines and advice to ECART on any matter relating to any kind of assisted reproductive procedure or human reproductive research, and keep such guidelines and advice under review
- advise the Minister of Health on aspects of, or issues arising out of, kinds of assisted reproductive research and, without limitation, advice as to whether:
  - the HART Act or another enactment should be amended to prohibit or provide for any kind of assisted reproductive procedure or human reproductive research
  - any kind of procedure or treatment should be declared an established procedure on the basis of the information, assessment, advice and ethical analysis required under section 6 of the HART Act
  - any established procedure should be modified or should cease to be an established procedure
  - a moratorium should be imposed on any kind of assisted reproductive procedure or human reproductive research
  - regulations should be made under section 76 of the HART Act to regulate the performance of any kind of assisted reproductive procedure or the conduct of any kind of human reproductive research
- liaise with the ethics committee on general and specific matters relating to assisted reproductive procedures or human reproductive research
- consult with anyone who, in the opinion of ACART, is able to assist it to perform its functions
- perform any other function that the Minister of Health assigns to it by written notice.

For the purposes of performing the above functions, ACART must monitor:

- the application, and health outcomes, of assisted reproductive procedures and established procedures
- developments in human reproductive research.

ECART's functions

ECART's role is to consider and determine applications for approvals for assisted reproductive procedures or human reproductive research, and to keep under review approvals previously given. Approval can only be given if the activity is consistent with guidelines or advice given by ACART.

ACART Work during 2007/08

Background

ACART has established the following work streams:

- advice to the Minister of Health on human reproductive research (as required under section 37 of the HART Act)
- advice to the Minister of Health on assisted reproductive procedures (section 38) and guidelines and advice for ECART (section 35(1)(a))
- advice to the Minister of Health on new assisted reproductive procedures (section 6)
- monitoring (sections 35(2), 30, 42(3)(b)
- governance and administration.

Progress on these work streams and on other work undertaken by ACART during 2007/08 is outlined below. Information about how ACART manages its work programme is set out on pages 13–15.

Progress made in 2007/08

Advice to the Minister of Health on human reproductive research

Section 37 of the HART Act requires ACART to provide the Minister of Health with information, advice and, if it thinks fit, recommendations on the following matters in relation to the use of gametes and embryos in human reproductive research:

- cloned embryos
- donations of human embryos
- genetic modification of human gametes and human embryos
- human gametes derived from foetuses or deceased people
- hybrid embryos
- requirements for informed consent
- the import into or export from New Zealand of in vitro human gametes or embryos.

ACART provided the Minister of Health with advice on human reproductive research on 29 June 2007,[1] following an extensive public consultation in the 2006/07 financial year.

A summary of submissions received by ACART in response to the consultation paper on human reproductive research has been published on ACART's website.

Currently, ECART may continue to consider applications for human reproductive research involving gametes and non-viable embryos in accordance with the *Guidelines for Research on Gametes and Non-viable Embryos*. These guidelines were published in 2004, prior to the HART Act coming into force, by the National Ethics Committee on Assisted Human Reproduction (NECAHR). The guidelines need to be reviewed by ACART. ACART intends to progress this work as part of the 2008/09 work programme, in the context of policy decisions made by the Minister of Health in relation to human reproductive research.

Advice to the Minister of Health on assisted reproductive technology

Section 38 of the HART Act requires ACART to provide the Minister of Health

[1] ACART is yet to consider the use of human gametes from foetuses.

with information, advice and, if it thinks fit, recommendations on the following matters in relation to human assisted reproductive technology:

- donation of embryos
- embryo splitting
- gametes derived from deceased people
- requirements for informed consent
- selection of embryos using pre-implantation genetic analysis
- the import into or export from New Zealand of in vitro donated cells or embryos.

The majority of ACART's work during 2007/08 has been focused on assisted reproductive procedures.

In July 2007 ACART released its consultation paper, *Advice on Aspects of Assisted Reproductive Technology: A consultation paper on policy issues*. This consultation paper asked for the public's views on:

- draft guidelines for ECART to use when reviewing applications to perform particular assisted reproductive procedures
- other areas of assisted reproductive technology, where ACART wished to gauge public opinion before giving advice to the Minister, including:
  - the use of donated eggs with donated sperm for reproductive purposes
  - embryo splitting
  - the import and export of donated gametes or embryos
  - informed consent.

Submissions closed in September 2007. During 2007/08 ACART published summaries of the submissions received on surrogacy arrangements, donation of eggs or sperm between certain family members, and embryo splitting. ACART intends to publish soon summaries of submissions on the remaining topics consulted on in 2007. The publication of these summaries has occurred at intervals as particular pieces of work were completed. This was in accordance with the agreement ACART had with the Minister of Health concerning the priority of the various issues.

A summary of the matters progressed following ACART's consultation are set out below.

New guidelines for ECART

On 22 November 2007 ACART issued two new guidelines to ECART:

- *Surrogacy Arrangements involving Providers of Fertility Services*
- *Donation of Eggs or Sperm between Certain Family Members*.

The guidelines replace the interim guidelines on in vitro fertilisation surrogacy and within-family gamete donation.

ACART has also undertaken work to prepare new guidelines for embryo donation, and pre-implantation genetic diagnosis (PGD) with human leukocyte antigen (HLA) tissue typing. These are discussed further below.

Embryo donation

In May 2008 ACART consulted with the Associate Minister of Health, Hon Steve Chadwick, on new guidelines for embryo donation. ACART expects to issue the embryo donation guidelines to ECART in late 2008.

Embryo splitting

In May 2008 ACART provided advice on embryo splitting to the Associate Minister

of Health under section 38(b) of the HART Act 2004. ACART's advice was as follows:

- embryo splitting is not clinically relevant
- at present no action needs to be taken, because embryo splitting cannot proceed in the absence of guidelines
- ACART will review this position and provide further advice to the Minister if, in future, embryo splitting should become clinically relevant.

The Associate Minister has agreed to ACART's recommendations.

Pre-implantation genetic diagnosis (PGD)

In May 2008 ACART provided advice on PGD to the Associate Minister of Health under section 38(e) of the HART Act 2004. ACART recommended to the Associate Minister of Health that the restriction on the use of PGD with human leukocyte antigen (HLA) tissue typing for genetic conditions be removed, so that it may also be used for conditions that are not inherited (eg, leukaemia). ACART also recommended that the possible use of the procedure be extended to benefit close relatives rather than being restricted to genetic siblings. The Associate Minister has accepted these recommendations.

In view of this, ACART has developed draft guidelines to be used by ECART in considering and determining applications to use PGD with HLA tissue typing. At the close of the 2007/08 financial year ACART released a consultation paper on draft guidelines on PGD with HLA tissue typing.

Use of donated eggs with donated sperm for reproductive purposes

ACART has begun work to develop guidelines for the use of donated eggs with donated sperm for reproductive purposes. This is a priority work stream, in recognition of the interest in being able to use this assisted reproductive procedure. ACART anticipates consulting on draft guidelines during the 2008/09 year.

Other projects

ACART continues to work through the other matters consulted on in 2007. It is currently scoping the projects associated with:

- gametes from deceased persons
- requirements for informed consent
- import and export of gametes and embryos.

These projects relate to the use of gametes and embryos in both assisted reproductive procedures and human reproductive research. ACART will progress this work in the 2008/09 financial year.

Advice to the Minister of Health on new assisted reproductive procedures

The use of frozen eggs

In June 2005 the collection and cryopreservation (freezing) of human eggs was declared to be an established procedure, meaning that it could be undertaken by a fertility clinic prior to ACART developing its view on the use of frozen eggs. However, the subsequent use of frozen eggs was specifically excluded from this established procedure because the risks could not be adequately assessed due to the novelty of the technique. When ACART was established, the then Minister of Health, Hon Annette King, asked, among other things, for advice on the use of frozen eggs in fertility treatment.

During the past financial year ACART has reviewed recent evidence and considered

the risks, benefits and ethical issues associated with the use of frozen eggs. ACART finalised its discussion document on 9 May 2008 and will be consulting on the use of frozen eggs in fertility treatment from late July to early September 2008.

In vitro maturation

In June 2005 the collection of immature eggs and the use of eggs that have been matured by in vitro maturation (IVM) were excluded from the established procedures, meaning that these procedures could not be performed by fertility clinics until ACART developed its view on this procedure.

In May 2008 ACART commissioned a technical report on the risks and benefits of the collection of immature eggs and the use of eggs that have been matured through IVM. ACART will receive this technical report in September 2008 and will then consider the risks, benefits and ethical issues associated with IVM and develop advice to the Minister of Health. ACART will consult publicly before finalising and giving its advice to the Minister of Health.

Monitoring

Section 35(2) of the HART Act requires ACART to monitor the application and health outcomes of assisted reproductive procedures and established procedures, and developments in human reproductive research. In addition, ACART's Terms of Reference require it to monitor the decisions of ECART to ensure they fall within the guidelines set by ACART.

ACART monitored the application of assisted reproductive procedures through information provided by clinics on applications approved by ECART. Applications for assisted reproductive procedures in New Zealand from 1 June 2007 to 30 June 2008 are set out in Appendix 1. ACART monitored ECART's decisions by reviewing a copy of those decisions and related applications. Further comment about ECART's decisions is set out on pages 18–19.

The outcomes of assisted reproductive procedures were monitored through the annual report of the Australia and New Zealand Assisted Reproduction Database (ANZARD). ACART also monitored international trends through the reports of organisations such as the European Society of Human Reproduction and Embryology and the International Federation of Fertility Societies.

In the first half of 2008 ACART established a horizon-scanning network to help it to foresee and make timely responses to emerging developments in assisted reproductive technology. The horizon-scanning network is led by ACART member Associate Professor Andrew Shelling, and comprises Dr Debbie Blake, Dr John Peek, Joi Ellis, and Associate Professor Larry Chamley. Reports from the horizon-scanning network will be published.

In addition, to help ensure that its work programme is focused on the needs of consumers and providers of fertility services, ACART asked fertility services providers, ECART and the Ministry of Health to signal any procedures they consider New Zealanders might wish to pursue in the next three years. No emerging issues were reported to ACART during the 2007/08 financial year. It appears that ACART's proposed work programme identifies the key policy issues.

Other work

During the 2007/08 financial year ACART has also worked to progress matters forwarded to ACART from ECART, and to liaise with ECART and the Ministry of Health about matters relating to the operation of the HART Act.

Matters of significance forwarded to ACART from ECART

ECART forwarded a number of matters to ACART during 2007/08. A list of the significant matters and the actions taken are set out below:

Menopause as a 'medical condition'

ECART queried whether menopause would fit within the definition of medical condition in ACART's guidelines. ACART decided to consider this matter as part of a wider project concerning age and other non-clinical determinants of access to services. ACART has drafted terms of reference for this project. It will be progressed in the next financial year.

Applications involving a combination of assisted reproductive procedures

ACART considered whether applications that combine more than one assisted reproductive procedure can be considered by ECART (eg, surrogacy with embryo donation). ACART is likely to issue advice on this matter to ECART in the first half of 2008/09.

ECART's monitoring role

ECART proposed to ACART that the two committees may benefit from collaborating on monitoring. ACART's work on monitoring has had a relatively low priority compared to a number of other projects during 2007/08, but it is expected that this area will have a stronger focus during 2008/09 and ACART will be discussing the need for collaboration with ECART and the Ministry of Health.

Adopted siblings and within-family gamete donation

ECART has advised that it received an application for donation of gametes between an adopted sister and brother. ECART declined the application because the Guidelines do not allow donation between sister and brother, and the HART Order in Council definition of sister includes 'adopted sister'. ACART noted the confusion around the interpretation of terms in the Guidelines, and agreed to add interpretative guidance.

Export of donor sperm

ECART received an application to export donated sperm. ECART referred the application to ACART because ECART had no guidelines to consider the matter. ACART undertook work to consider the current parameters for the import and export of donated gametes and embryos under the HART Act. ACART sought advice from the Ministry, and it was clarified that the import and export of donated gametes and embryos are not assisted reproductive procedures under the HART Act and therefore not subject to ethical review by ECART. Clinics have been informed that there are no legal barriers to the import into and export out of New Zealand of gametes and embryos, but that a number of ethical issues apply.

ACART is continuing to develop its advice to the Minister on the import and export of embryos and gametes, as required under the HART Act. This advice may lead to conditions or regulations being imposed on the import and export of gametes and embryos.

Legal arrangements for the care of a child born as part of a surrogacy arrangement

ECART asked ACART to consider whether a preference for adoption following surrogacy arrangements could be supported in ACART's guidelines, or in ECART's surrogacy application forms. Discussions between ACART and ECART are ongoing.

Whether ACART can issue generic guidelines

ECART expressed a strong preference for ACART to issue generic guidelines that would allow ECART to consider any presenting case on the basis of an ethical review of the particular situation. At present, those who require an assisted reproductive procedure, but whose circumstances do not fit within existing guidelines, are unable to have treatment in New Zealand. ACART has agreed to keep this matter under review.

The use of donor sperm with donor egg

ECART raised with ACART a need for guidelines to allow ECART to consider applications for the use of donated egg with donated sperm for reproductive purposes. ACART reprioritised the work so that guidance on this issue was available as soon as possible.

Matters of significance raised with the Ministry of Health

ACART raised a number of matters with the Ministry of Health during 2007/08. A list of the significant matters and responses (where known at the time of publishing) are set out below.

Import and export of gametes and embryos

ACART sought clarification about the parameters of the import and export of gametes and embryos under the HART Act. The Ministry wrote to all providers in June 2008 to explain the situation concerning import and export, as outlined above.

Human reproductive research

ACART sought clarification about whether human reproductive research involving human participants falls within the jurisdiction of the HART Act.

Governance

Conference attendance

ACART members attended the following conferences with full or partial financial support:

- Fertility Society of Australia, Hobart, 8–12 September 2007
- American Society for Reproductive Medicine, Washington, 13–17 October 2007
- Bioethics Conference, Dunedin, 1–3 February 2008
- International Consumer Support for Infertility, Budapest, 23 February 2008.

Publications

ACART published the following documents in the 2007/08 financial year:

- *Advice on Aspects of Assisted Reproductive Technology: A consultation paper on policy issues* (July 2007)
- *Use of Gametes and Embryos in Human Reproductive Research: Summary of submissions* (September 2007)
- *Consultation on Aspects of Assisted Reproductive Technology: Summary of submissions: Part One – Surrogacy Arrangements involving Providers of Fertility Services* and *Part Two – Donation of Eggs or Sperm between Certain Family Members* (March 2008)
- *Advice to the Associate Minister of Health: Embryo splitting* (May 2008).

The following guidelines were issued to ECART:

- *Surrogacy Arrangements involving Providers of Fertility Services* (November 2007)
- *Donation of Eggs or Sperm between Certain Family Members* (November 2007).

Website

ACART's website serves as a key point of contact with fertility service providers, consumers and other interested parties. The website address is: http://www.acart.health.govt.nz.

How ACART manages its work programme

ACART has a considerable number of substantial policy projects to undertake at any one time. Given that ACART only meets on average six times per year for a full-day meeting, it has had to develop a sub-structure to progress projects. Each significant project has a committee member who leads that work, supported by a working group of committee members and ACART staff. These working groups meet between ACART meetings and/or conduct their work by teleconference or email. In 2007/08 ACART used the following working groups to ensure it could deliver on its work programme.

Working group	Responsibilities
Executive Group Sylvia Rumball (Chairperson) Ken Daniels Maui Hudson	Responsible for governance and administrative matters, as delegated by ACART.
'Treatment' Working Group Ken Daniels (Chairperson) John Forman Maui Hudson Richard Fisher Christine Rogan Sylvia Rumball	Responsible in 2007/08 for leading work on: • guidelines on surrogacy arrangements involving providers of fertility services • guidelines on the donation of eggs or sperm between certain family members • guidelines on embryo donation for reproductive purposes • use of donated sperm with donated eggs, and development of guidelines to cover this procedure • scoping a project on the import and export of gametes and embryos for reproductive purposes • scoping a project on informed consent • scoping a project on the use of gametes from deceased persons • scoping a project on the collection of gametes from deceased persons • considering whether and how to allow for combined assisted reproductive procedures.

PGD Working Group

Gareth Jones (Chairperson)
Andrew Shelling
John Forman
Mark Henaghan
Richard Fisher

Responsible in 2007/08 for leading work on:

- advice to the Minister on PGD
- guidelines on PGD with HLA tissue typing
- development of a public fact sheet on the established procedure for PGD.

Use of Frozen Eggs Working Group

Andrew Shelling
Christine Rogan
Gareth Jones
Richard Fisher

Responsible in 2007/08 for leading work on:

- commissioning a technical report on the risks and benefits of the use of frozen eggs
- conducting a risk acceptability assessment of the use of frozen eggs
- preparing a consultation paper on the use of frozen eggs.

In Vitro Maturation Working Group

Andrew Shelling
Richard Fisher

Responsible in 2007/08 for leading work on commissioning a technical report on the risks and benefits of the collection of immature eggs and the use of eggs that have been matured by in vitro maturation.

Monitoring Working Group

Andrew Shelling (Chairperson)
Ian Hassall
Mark Henaghan
Maui Hudson
Richard Fisher
Sylvia Rumball

Responsible in 2007/08 for:

- considering an approach to monitoring the application and outcomes of assisted reproductive procedures and established procedures
- developing an approach (ie, a horizon-scanning network) to monitor developments in human reproductive research
- establishing the horizon-scanning network.

ACART's working groups work under the delegated authority of ACART. Working groups undertake in-depth thinking on issues and provide ACART with minutes of their meetings, along with reports and recommendations to ACART, which the full ACART committee discusses before determining whether or not to accept the recommendations of the working groups.

ACART steers the working groups on an ongoing basis, and the final output – whether a consultation paper, guidelines for ECART, advice to ECART, or advice to the Minister – is approved by a full ACART meeting.

ACART Membership

Table 1 summarises the membership of ACART during the 2007/08 financial year, along with each member's area of expertise and expiry date of term of office. Further biographical information is contained in Appendix 4. Table 2 shows the attendance at ACART meetings for 2007/08.

Table 1: A summary of ACART members

	Expertise/perspective	Year term of office expires
Lay members		
Prof Sylvia Rumball (Chairperson)	Ethics	2008*
Adjunct Prof Ken Daniels (Deputy Chairperson)	Policy	2009
Prof Gareth Jones	Ethics	2008*
Christine Rogan	Consumer	2008*
Maui Hudson	Māori	2010
Cilla Henry	Māori	2010
Dr Ian Hassall	Children's Commissioner's nominee	2010
John Forman	Disability	2010
Robyn Scott	Consumer	2010
Prof Mark Henaghan	Law	2009
Non-lay members		
Assoc Prof Andrew Shelling	Human reproductive research	2009
Dr Richard Fisher	Assisted reproductive procedures	2010

* Term expired 23 June 2008. The appointments process is due to be completed in the first part of 2008/09. Appointments will be notified on ACART's website.

Table 2: Member attendance at ACART meetings, 2007/08

	Meetings attended						
Member	**14 September 2007**	**12 October 2007**	**9 November 2007**	**14 December 2007**	**14 March 2008**	**9 May 2008**	**Total**
Prof Sylvia Rumball (Chairperson)	X	X	X	X	X	X	6/6
Adjunct Prof Ken Daniels (Deputy Chairperson)	X	A	A	X	X	A	3/6
Prof Gareth Jones	X	X	X	X	X	X	6/6
Dr Ian Hassall	X	X	X	X	X	X	6/6
Christine Rogan	X	X	A	X	X	X	5/6
Cilla Henry	X	X	X	X	X	A	5/6
Maui Hudson	X	X	X	A	X	X	5/6
John Forman	A	X	X	X	X	X	5/6
Robyn Scott	A	A	X	X	A	A	2/6
Prof Mark Henaghan	X	X	A	X	X*	X	5/6
Assoc Prof Andrew Shelling	A	X	A	X	X	X	4/6
Dr Richard Fisher	X	X	X	X	X	X	6/6
Total members present	**9/12**	**10/12**	**8/12**	**11/12**	**11/12**	**9/12**	

* ½ day attendance
A Apologies
X Present
Note: members also attend working group meetings and ad hoc teleconference discussions.

Secretariat members

Ian Hicks	Analyst (August 2005 – January 2008)
Willow McKay	Analyst (October 2005 – July 2007)
Sally Stewart	Senior Analyst (August 2006 – present)
Vanessa James	Contractor (July 2007 – February 2008)
Vicky Baynes	Policy Analyst (January 2008 – present)
Betty-Ann Kelly	Senior Analyst (February 2008 – present)

Ethics Committee Decisions

This report covers ECART's decisions for the 2007/08 financial year. Between 1 July 2007 and 30 June 2008 ECART considered:

- 18 applications for surrogacy (including one application deferred from the previous year)
- 11 applications for gamete donation between certain family members
- 9 applications for embryo donation for reproductive purposes.

ECART also considered one application for human reproductive research. The application was approved subject to conditions.

The details of these decisions are set out in Appendix 1.

In total, 38 applications that ECART considered for assisted reproductive procedures were approved. Of these, 20 were approved outright, 12 were approved subject to conditions, and four were deferred and subsequently approved.

ECART declined two applications, both for gamete donation between certain family members. One application did not proceed because the guidelines plus HART Order 2005 precluded the application (gamete donation between adopted sister and brother). The second application was declined for the following primary reasons:

- concern that the parties had not made an informed choice or given informed consent
- concern for the wellbeing of the donor
- the relationship between the donors and recipients was not long established.

Monitoring the decisions of ECART

ACART is required under its terms of reference to 'monitor the decisions of ECART to ensure that they fall within the guidelines as intended by ACART'. During 2007/08 ACART has been particularly interested to see how the new guidelines on surrogacy and within-family gamete donation are working in practice. During the past financial year the following matters have been noted by ACART.

The use of donor eggs with donor sperm when one donor is a family member

During the 2007/08 financial year ECART approved an application for the use of a donor egg from a family member in conjunction with donor sperm. ECART considered this matter was consistent with the interim *Guidelines on Within-family Gamete Donation*.

ACART issued new guidelines to ECART in November 2007, *Guidelines on Donation of Eggs or Sperm between Certain Family Members*. The use of donor sperm and donor eggs, including the use in 'within-family arrangements', no longer falls within the guidelines issued to ECART.

ACART is however, continuing with its work on the use of donated egg with donated sperm to provide specific guidelines on this assisted reproductive procedure, if appropriate.

The use of an assisted reproductive procedure with an established procedure

During the 2007/08 year ECART considered two applications for surrogacy in combination with egg donation (ie, where the egg donor is not the surrogate or intending parents). Although this situation was not foreseen by ACART when drafting the guidelines, the decision was consistent with the current guidelines.

The definition of 'family member'

ACART has noted some confusion around who is a family member for the purposes of the *Guidelines on Donation of Eggs or Sperm between Certain Family Members.* ACART has noted the potential for confusion in the definitions in the HART Order, and will be progressing work to ensure consistency in the next financial year, including the addition of interpretative guidance to its guidelines.

Duration of approvals for surrogacy

In the 2007/08 financial year ECART undertook work concerning the duration of approvals for surrogacy. All surrogacy approvals now carry a condition that the approval will expire three years from the date of ECART's decision letter. ACART has noted this development.

Appendix 1: Applications Considered by ECART, 2007/08

Table A1.1: Applications for assisted reproductive procedures considered by ECART during the 2007/08 financial year

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
8/5/07	26/7/07	Clinic-assisted surrogacy	Approved	Not yet commenced	Treatment is on hold.
26/7/07	11/9/07	Clinic-assisted surrogacy	Declined 26 July 2007 due to concerns about the intending mother's health. Further information was submitted to ECART's meeting on 11 September 2007. Approved subject to: • the intending parents being approved by Child Youth and Family for adoption • there being no further evidence of recurrence of disease immediately prior to treatment commencing.	Due to commence late 2008	
26/7/07	20/11/07	Embryo donation	Deferred to progress the following matters: • discussion about the disposal of any surplus embryos • donors' older child to be included in counselling, if appropriate • provision of further information about: – the term 'special needs' used in relation to one party's child – the donor woman's reproductive history. Subsequently approved.	January 2008	Five embryo transfers. No pregnancy.
26/7/07	26/7/07	Clinic-assisted surrogacy	Approved subject to the intending parents being informed of the requirements of section 14 of the HART Act.	September 2007	One ectopic pregnancy. Treatment discontinued.
26/7/07	26/7/07	Clinic-assisted surrogacy	Approved subject to: • single embryo transfer to the birth mother • the intending parents being approved by Child Youth and Family for adoption.	March 2008	Surrogate pregnant.

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
26/7/07	26/7/07	Donation of gametes between family members	Approved subject to discussion and agreement between the parties on the length of time unused embryos should be stored.	October 2007	Recipient woman pregnant.
26/7/07	26/7/07	Donation of gametes between family members	Declined as the *Guidelines on Donation of Gametes between Certain Family Members* prevent donation where any child would be formed by eggs and sperm from brother and sister, and section 3 in the HART Order in Council includes adopted sister in the definition of sister.	N/A	
26/7/07	26/7/07	Embryo donation	Approved.	September 2007	Three embryo transfers. No pregnancy.
11/9/07	11/9/07	Clinic-assisted surrogacy	Approved subject to the birth mother being advised by her medical attendant of the increased risk of miscarriage.	March 2008	Two IVF cycles. Treatment continuing with remaining embryos.
11/9/07	11/9/07	Clinic-assisted surrogacy	Approved.	N/A	Treatment not commenced because intending mother became pregnant while awaiting ECART approval.
11/9/07	11/3/08	Clinic-assisted surrogacy and egg donation	Deferred on 11 September 2007 and 20 November 2007 meeting due to concerns about the intending mother's health. Subsequently approved subject to confirmation that the intending mother's health had not worsened, and with the condition that approval be cancelled if the intending mother's health deteriorates due to a serious complication, or a relapse before pregnancy occurs.	May 2008	No pregnancy. Clinic unsure if treatment is complete or ongoing.
11/9/07	11/9/07	Donation of gametes between family members	Approved subject to the donor being advised that given the recurrent implantation failure the problems for the intending mother may not be egg related.	October 2007	Two fresh embryos transferred. No pregnancy. Remaining frozen embryo sent to another fertility services provider.

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
11/9/07	11/9/07	Donation of gametes between family members	Approved.	December 2007	Recipient woman pregnant.
11/9/07	11/9/07	Clinic-assisted surrogacy	Approved.	January 2008	One fresh embryo transfer and one frozen embryo transfer. No pregnancy.
20/11/07	11/3/08	Embryo donation	Approved.	June 2008	Treatment on hold.
20/11/07	20/11/07	Embryo donation	Approved subject to: clarification whether the issue of disposal of surplus embryos had been discussed and agreed to by all parties, and donors being informed that, in keeping with the Guidelines, their consent to donate can be withdrawn up until transferral of the embryo to the recipient woman	January 2008	First two embryo transfers unsuccessful. Undergoing third embryo replacement August 2008.
20/11/07	20/11/07	Clinic-assisted surrogacy	Approved.	February 2008	Two IVF cycles unsuccessful. Third cycle to be commenced September 2008.
20/11/07	20/11/07	Export of donated sperm	Declined because no guidelines exist and referred to ACART pursuant to s.18(2) of the HART Act.	N/A	
20/11/07	20/11/07	Clinic-assisted surrogacy with egg donation	Approved.	First treatment planned July 2008.	
20/11/07	20/11/07	Donation of gametes between family members	Declined for the following reasons: • concern that the parties had not made an informed choice or given informed consent as they have had little time to discuss the issues involved in the donation • concern for the wellbeing of the donor • the relationship between the donors and recipients was not long established.	N/A	

20/11/07	20/11/07	Donation of gametes between family members and sperm donation*	Approved. ECART agreed that this was a combination of an established procedure (sperm donation) with an assisted reproductive procedure.	January 2008	Treatment is still in progress.
20/11/07	20/11/07	Embryo donation	Approved subject to: • the donors being informed that, in keeping with the Guidelines, their consent to donate can be withdrawn up until transferral of the embryo to the recipient woman • clarification from the applicant on whether the issue of disposal of surplus embryos had been discussed and agreed to by all parties.	March 2008	Miscarriage. Treatment ongoing.
20/11/07	20/11/07	Clinic-assisted surrogacy	Approved.	N/A	Treatment discontinued.
20/11/07	4/2/08	Clinic-assisted surrogacy	Approved subject to clarification on whether the resulting child will be adopted or provisions made for guardianship and day-to-day care under the Care of Children Act.	2005	Miscarriage. Treatment continuing with remaining embryos.
20/11/07	20/11/07	Embryo donation	Approved subject to: • donors being informed that, in keeping with the Guidelines, their consent to donate can be withdrawn up until transferral of the embryo to the recipient woman • clarification from the applicant on whether the issue of disposal of surplus embryos had been discussed and agreed to by all parties.		No pregnancy from embryo transfers. Treatment continuing with remaining embryos.
4/2/08	4/2/08	Clinic-assisted surrogacy	Approved.	May 2008	Early miscarriage. Some frozen embryos remain.
4/2/08	4/2/08	Clinic-assisted surrogacy	Approved.	April 2008	One embryo transfer. No pregnancy. Treatment ongoing.
4/2/08	4/2/08	Donation of gametes between family members	Approved.	April 2008	Treatment is still in progress.

* This application was considered under the former guidelines. Consistent with the HART Order 2005, the use of donor sperm with donor egg is not currently provided for in the new *Guidelines on Donation of Eggs or Sperm between Certain Family Members*.

11/3/08	11/3/08	Donation of gametes between family members	Approved.	April 2008	Recipient woman pregnant.
9/12/03 NECAHR 15/5/08 ECART	24/3/04 NECAHR 15/5/08 ECART	Clinic-assisted surrogacy	Approved* subject to: • all involved parties being made aware of payments in relation to section 14 of the HART Act 2004 • the birth parents having considered life insurance cover for the birth mother.	Not yet commenced.	
7–8/6/05 NECAHR 15/5/08 ECART	7–8/6/05 NECAHR 15/5/08 ECART	Clinic-assisted surrogacy	Approved* subject to: • all involved parties being made aware of payments in relation to section 14 of the HART Act 2004 • the birth parents having considered life insurance cover for the birth mother.	Not yet commenced.	
15/5/08	15/5/08	Clinic-assisted surrogacy	Approved.*	Not yet commenced.	
15/5/08	15/5/08	Embryo donation	Approved.	Not yet commenced.	
15/5/08	15/5/08	Clinic-assisted surrogacy	Approved* subject to receiving information from the birth mother's medical specialist about the birth mother's health.	Not yet commenced.	
15/5/08	15/5/08	Donation of gametes between family members	Approved.	Not yet commenced.	
15/5/08	15/5/08	Donation of gametes between family members	Approved.	Not yet commenced.	
15/5/08	15/5/08	Donation of gametes between family members	Approved.	Not yet commenced.	
15/5/08	15/5/08	Embryo donation	Approved.	Not yet commenced.	
15/5/08	15/5/08	Embryo donation	Approved.	Not yet commenced.	

* All approvals for surrogacy now carry a condition that approvals will expire three years from the date of ECART's decision letter.

Table A1.2: Research applications considered by ECART during the 2007/08 financial year

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
15/5/08	15/5/08	Research on gametes and non-viable embryos	The Committee approved this application subject to: • a letter showing that consultation with Māori has taken place. • better definition of the population being studied, along with the inclusion/exclusion criteria for participation • more time for participants to withdraw consent (ECART suggests seven days), and only keeping participant names attached to the sample until that time has passed • development of a separate information sheet and consent form (Health & Disability Ethics Committees template to be a guide), and to include the following: the researcher's contact details, the purpose of the research, details on how to withdraw, details on how participants can access the final report, and confirmation that there are no implications for the participants' fertility treatment and overall health • clarification of the roles of the university and the fertility clinic: who is conducting the research, who will keep the data, and for how long? Full approval will be given once the conditions have been met.	Not yet commenced.	

Table A1.3: Update on applications previously approved by NECAHR and included in an annual report[2]

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
23/3/05	28–29/11/05	Clinic-assisted surrogacy	Approved subject to confirmation that the intending parents would have Department of Child, Youth and Family approval to adopt under the Adoption Act 1955.		Not pregnant; no embryos remaining.
7–8/6/05	28–29/11/05	Clinic-assisted surrogacy	Deferred by NECAHR and referred to ACART as above. Subsequently approved subject to the birth mother being a permanent resident in New Zealand prior to treatment beginning, and payment being made in accordance with section 14 of the HART Act.	March 2006	Birth at 32 weeks.
7–8/6/05	28–29/11/05	Clinic-assisted surrogacy	NECAHR referred the application to ACART due to concern that the relationship between the intending mother and the birth mother was not that of 'close friends'. ACART agreed that 'close friend' needs to be clarified, and will do this as part of its consultation in preparation for advising the Minister on assisted reproductive procedures in 2007. ACART referred the application back to ECART for consideration based on the existing *Guidelines on IVF Surrogacy* and the HART Act 2004. Approved subject to payment of costs being in line with section 14 of the HART Act.	N/A	Discontinued.
7–8/6/05	7–8/6//05	Clinic-assisted surrogacy	Approved.	August 2005	Birth at 38 weeks – twins.

[2] Applications are reported until final outcome (ie, birth, no pregnancy and no continuing treatment etc). The table does not include applications where the final outcome has already been reported.

Table A1.4: Update on applications previously approved by ECART and reported in an annual report[3]

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
13/9/05	13/9/05	Donation of gametes between family members	Approved.	February 2006	Two IVF cycles. No pregnancy. Clinic unsure if treatment is complete or ongoing.
28–29/11/05	28–29/11/05	Clinic-assisted surrogacy	Deferred, pending clarification of a number of issues and subsequently approved.	March 2006	Birth at 29 weeks – twins.
28–29/11/05	28–29/11/05	Clinic-assisted surrogacy	Approved	April 2006	Birth at 40 weeks.
28–29/11/05	28–29/11/05	Clinic-assisted surrogacy	Approved subject to the condition that payment of costs must be in line with section 14 of the HART Act.	July 2006	Miscarriage. Treatment discontinued.
28–29/11/05	28–29/11/05	Clinic-assisted surrogacy	Approved.	August 2006	Birth at 34 weeks.
28–29/11/05	26/04/06	Clinic-assisted surrogacy	Approved subject to the provision of a detailed medical report in relation to the birth mother.	June 2006	Two early miscarriages. No embryos remaining.
7–8/06/05	28–29/11/05	Clinic-assisted surrogacy	Declined by NECAHR because the surrogate initially proposed did not fit within the *Guidelines on IVF Surrogacy*; that is, she was not a permanent New Zealand resident. Subsequently approved by ECART.	February 2006	Birth at 40 weeks.
28–29/11/05	14/3/06	Clinic-assisted surrogacy	Deferred pending the provision of a more detailed medical report in relation to the intending mother, a specialist medical report, a more substantial legal report in relation to the birth mother, and an update on the intended parents' interactions with CYF regarding their suitability to adopt. Subsequently approved.	March 2006	No pregnancy achieved.
28–29/11/05	14/3/06	Clinic-assisted surrogacy	Deferred, subject to the provision of a more substantial legal report and a specialist medical report in relation to the birth mother. Subsequently approved.	April 2006	Birth at 39 weeks.
14/3/06	11/5/06	Clinic-assisted surrogacy	Deferred pending the provision of independent legal reports and a report on a joint counselling session, in accordance with the *Guidelines on IVF Surrogacy*. Subsequently approved.	August 2006	Birth at 40 weeks.

[3] See note 2 above.

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
14/3/06	14/3/06	Clinic-assisted surrogacy	Approved.		Birth at 25 weeks.
14/3/06	14/3/06	Clinic-assisted surrogacy	Approved.	March 2006	Birth at 39 weeks.
13/6/06	13/6/06	Clinic-assisted surrogacy	Approved.	July 2006	Miscarriage. Treatment discontinued.
13/6/06	13/6/06	Donation of gametes between family members	Approved subject to proof of residency in New Zealand.	N/A	Clinic understands parties planned to have treatment in Australia.
13/6/06	13/6/06	Clinic-assisted surrogacy	Approved.	July 2006	Birth at 41 weeks.
13/6/06	13/6/06	Clinic-assisted surrogacy	Approved.	N/A	Discontinued as the intending parents have chosen to adopt.
15/8/06	15/8/06	Clinic-assisted surrogacy	Approved.	November 2006	Birth at 38 weeks.
15/8/06	13/3/07	Clinic-assisted surrogacy	Approved subject to: • the children of the intending father being involved in implications counselling prior to treatment commencing • not more than one fresh embryo being transferred, or not more than two frozen embryos being transferred, due to the increased risk to the birth mother. The second condition was reviewed at two later meetings (10/10/07 and 28/11/06), and was varied to approve the transfer of two fresh embryos to the surrogate mother provided the surrogate mother still consents to the surrogacy arrangement after she has received advice, from a suitably qualified medical practitioner who is independent of the intending parents and the supervising medical team, on the likelihood of twins and the possible harm and negative consequences – to herself and the twins – associated with such a transfer.	March 2007	Surrogate not pregnant. Clinic assumes treatment is complete.
10/10/06	10/10/06	Clinic-assisted surrogacy	Approved subject to the birth mother being given further legal advice about her legal situation if the intended parents do not adopt the child.	May 2007	Birth at 39 weeks.

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
10/10/06	28/11/06	Donation of gametes between family members	Deferred to request more information from the medical specialist about the birth mother's medical condition that precludes normal reproduction or unexplained infertility that has not responded to other treatments. Subsequently approved.	May 2007	Recipient woman pregnant. Details of any birth not yet known.
28/11/06	28/11/06	Clinic-assisted surrogacy	Approved.	March 2007	Three embryo transfers with no pregnancy. Intending parents are pursuing further treatment.
28/11/06	28/11/06	Clinic-assisted surrogacy	Approved.	N/A	Treatment discontinued.
28/11/06	28/11/06	Donation of gametes between family members	Approved.	May 2007	Birth at 40 weeks.
28/11/06	28/11/06	Clinic-assisted surrogacy	Approved subject to the intending parents meeting with Child Youth and Family, all parties being made aware of the increased risk of foetal abnormality due to the intending mothers' age, and further legal advice being sought by the intending parents.	September 2007	Two IVF cycles; no pregnancy achieved. Clinic unsure whether treatment is complete or ongoing.
13/3/07	13/3/07	Clinic-assisted surrogacy	Approved.	April 2007	Birth at 40 weeks.
13/3/07	13/3/07	Clinic-assisted surrogacy	Approved subject to changes to the surrogacy agreement.	April 2007	Birth at 42 weeks.
13/3/07	13/3/07	Embryo donation	Approved.	June 2007	Birth at 35.5 weeks.
13/3/07	13/3/07	Clinic-assisted surrogacy	Approved.		Initially delayed due to the health of the birth mother. One fresh embryo transfer and one frozen embryo transfer. No pregnancy as yet.
8/5/07	8/5/07	Clinic-assisted surrogacy	Approved.		Two frozen embryo cycles. No pregnancy as yet.

Date of first review	Final decision	Procedure	Decision	Date commenced	Outcome
8/5/07	8/5/07	Clinic-assisted surrogacy	Approved subject to the intending parents being informed of the requirements around payment of costs in s.14 of the HART Act.	August 2007	Surrogate pregnant, due 2008.
8/5/07	8/5/07	Donation of gametes between family members	Approved.	April 2008	Recipient woman pregnant, due 2009.
8/5/07	8/5/07	Clinic-assisted surrogacy	Approved subject to the birth parents taking further legal advice on the requirements of s.14 of the HART Act, and the issue of life insurance for the birth mother.	January 2008	One IVF cycle, frozen embryo transfer. Treatment is ongoing.

Appendix 2: Information on Applications

The following tables set out the numbers and outcomes of applications for:

- surrogacy
- donation of eggs or sperm between certain family members
- embryo donation.

ECART has not considered any applications for PGD with HLA tissue typing. ECART has considered one application for use of sperm from a deceased man.[4] Table A2.1 sets out the numbers and outcomes of surrogacy applications from 1 January 1997 to 30 June 2008.

Table A2.1: Applications for surrogacy, 1997–2008

Year	Number approved[a, b]	Number declined[a]	Number deferred
1997	1	0	0
1998	2	1[c]	4
1999	4	0	3
2000	5	1	2
2001	6	1	1
2002	1	0	3
2003	5	0	3[d]
2004	5[e]	0	1
2005	15	4	0
2006	16	0	1
Total	**60**	**7**	**18**

Year	Number approved[a, b]	Number declined[a]	Number deferred
July 2006–June 2007	13	1	1
July 2007–June 2008	18	0	0
Total	**31**	**1**	**1**

Notes

a The number of 'approved' and 'declined' applications for each year may include some applications that were deferred in previous years.

b Includes applications approved outright and applications approved subject to conditions.

c In 1999 the National Ethics Committee on Assisted Human Reproduction considered a variation to the original application in 1998 and approved it.

d One application was subsequently withdrawn.

e Includes two applications that were provisionally approved in 2004 and then granted final approval in 2005.

[4] Reported in ACART's 2006/07 Annual Report.

Table A2.2 sets out the numbers and outcomes of applications for donation of eggs or sperm between certain family members from 1 July 2005 to 30 June 2008.

Table A2.2: Applications for the donation of eggs or sperm between certain family members, 2005–08

Year	Number approved[a,b]	Number declined[a]	Number deferred
July 2005–June 2006	2	1	1
July 2006–June 2007	5	0	0
July 2007–June 2008	9	2	0
Total	**16**	**3**	**1**

Notes

a The number of 'approved' and 'declined' applications for each year may include some applications that were deferred in previous years.

b Includes applications approved outright and applications approved subject to conditions.

Table A2.3 sets out the numbers and outcomes of applications for embryo donation from 1 July 2006 to 30 June 2008.

Table A2.3: Applications for embryo donation, 2006–08

Year	Number approved[a,b]	Number declined[a]	Number deferred
July 2006–June 2007	1	0	0
July 2007–June 2008	9	0	0
Total	**10**	**0**	**0**

Notes

a The number of 'approved' and 'declined' applications for each year may include some applications that were deferred in previous years.

b Includes applications approved outright and applications approved subject to conditions.

Table A2.4: Applications approved by ECART, by ethnicity,[5] September 2005–June 2008

	Number in ethnic group	Total
Surrogacy		
Intending mother		49
European	44	
Asian	5	
Intending mother's partner		49
European	49	
Birth mother		49
European	42	
Māori	5	
Asian	1	
Māori/Pacific	1	
Birth mother's partner		34
European	28	
Māori	5	
Pacific	1	
Within-family gamete donation		
Recipient woman		16
European	13	
Māori	1	
Asian	1	
Other ethnicity	1	
Recipient woman's partner		16
European	12	
Māori	2	
Asian	1	
Other ethnicity	1	
Donor egg		12
European	9	
Māori	1	
Asian	1	
Other ethnicity	1	
Donor sperm		4
European	3	
Māori	1	

[5] ACART has used the groupings in the standard sole/combination output (ethnicity data protocols).

	Number in ethnic group	Total
Embryo donation		
Donor woman		10
European	10	
Donor man		10
European	10	
Recipient woman		10
European	9	
Māori/European	1	
Recipient man		10
European	9	
Māori/European	1	
Total		
European	238	269
Māori	15	
Asian	9	
Other ethnicity	3	
Pacific	1	
Māori/Pacific	1	
Māori/European	2	

Appendix 3: Terms of Reference – Advisory Committee on Assisted Reproductive Technology

The Advisory Committee on Assisted Reproductive Procedures and Human Reproductive Research ('the Advisory Committee on Assisted Reproductive Technology', or ACART) is established under section 32 of the Human Assisted Reproductive Technology (HART) Act 2004. These Terms of Reference outline the role and functions of ACART.

Functions of ACART

ACART has the following functions:

- to issue guidelines and advice to the Ethics Committee on Assisted Reproductive Technology (ECART) on any matter relating to any kind of assisted reproductive procedure or human reproductive research and to keep such guidelines and advice under review
- to provide the Minister of Health with advice on aspects of, or issues arising out of, kinds of assisted reproductive procedure or human reproductive research and, without limitation, advice as to whether:
  - the HART Act should be amended to prohibit or provide for any kind of assisted reproductive procedure or human reproductive research
  - any kind of procedure or treatment should be declared an established procedure, on the basis of the information, assessment, advice, and ethical analysis required to declare a procedure to be an established procedure under section 6 of the HART Act
  - any established procedure should be modified or should cease to be an established procedure
  - a moratorium should be imposed on any kind of assisted reproductive procedure or human reproductive research
  - regulations should be made under section 76 of the HART Act to regulate the performance of any kind of assisted reproductive procedure or the conduct of any kind of human reproductive research
- to liaise with ECART on general and specific matters relating to assisted reproductive procedures or human reproductive research
- to consult with any persons who, in the opinion of ACART, are able to assist it to perform its functions
- any other function that the Minister of Health assigns to ACART by written notice.

For the purposes of performing the above functions, ACART must monitor:

- the application, and health outcomes, of assisted reproductive procedures and established procedures
- developments in human reproductive research.

ACART should also monitor the decisions of ECART to ensure that they fall within the guidelines as intended by ACART. If, after consideration of one of ECART's decisions, ACART considers that the decision falls outside its guidelines, ACART should inform ECART of this.

Guiding principles

ACART shall be guided by the following principles.

- The health and wellbeing of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure.
- The human health, safety and dignity of present and future generations should be preserved and promoted.
- While all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application and the health and wellbeing of women must be protected in the use of these procedures.
- No assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent.
- Donor offspring should be made aware of their genetic origins and be able to access information about those origins.
- The needs, values and beliefs of Māori should be considered and treated with respect.
- The different ethical, spiritual and cultural perspectives in society should be considered and treated with respect.

Guidelines

ACART may issue guidelines to ECART only after it has:

- consulted on the proposed guidelines with the Minister of Health
- on the basis of a discussion paper or an outline of the proposed guidelines, given interested parties and members of the public a reasonable opportunity to make submissions
- taken any such submissions into account.

When ACART issues guidelines to ECART, it must:

- give copies of the guidelines to the Minister, the Director-General of Health, to ECART and to providers; and
- publish the guidelines on the internet and in any other publications (if any) that the Committee thinks appropriate; and
- give public notice of the issue of the guidelines by publishing in any publication that it considers appropriate for the purpose a notice that states:
  - the date and subject matter of the guidelines
  - the internet website on which they are published.

Specific advice

ACART must, within timeframes agreed with the Minister, provide the Minister with information, advice, and if it thinks fit, recommendations on the following matters in relation to the use of gametes and human embryos in human reproductive research:

- cloned embryos
- donations of human embryos
- genetic modification of human gametes and human embryos
- human gametes derived from foetuses or deceased persons
- hybrid embryos
- requirements for informed consent
- the import into, or export from, New Zealand of *in vitro* human gametes or *in vitro* human embryos.

ACART must, within the timeframes agreed with the Minister, provide the Minister with information, advice, and if it thinks fit, recommendations on the following matters in relation to human assisted reproductive technology:

- donations of human embryos
- embryo splitting
- gametes derived from deceased persons
- requirements for informed consent
- selection of embryos using pre-implantation genetic diagnosis
- the import into, or export from, New Zealand of *in vitro* donated cells or *in vitro* donated gametes.

ACART may give advice on the above areas only after it has:

- on the basis of a discussion paper or an outline of the proposed advice, given interested parties and members of the public a reasonable opportunity to make submissions; and
- taken any such submissions into account.

Public meetings on proposed significant advice

If, in the opinion of ACART, a significant number of persons wish to make oral submissions on a proposal to give specific advice on any of the above human reproductive research or human assisted reproductive technologies, ACART must hold as many meetings as are required to enable those submissions to be made.

ACART must:

- notify the persons who wish to make oral submissions of the time and place of any meeting to be held
- publish a notice on the internet and in any other publication the committee thinks appropriate that states the time, place, and purpose of any such meeting and that will be held in public.

Consultation

Before ACART gives advice to the Minister or issues guidelines to ECART, it must consult on the proposed advice or guidelines with:

- any members of the public that the committee considers appropriate
- appropriate government departments and agencies
- any other person or group that the committee considers appropriate.

Composition and membership

The Minister may appoint any person to be a member of ACART and must, before doing so, consult any persons who, in the Minister's opinion, are able to provide advice on prospective appointees who have the required expertise and the ability to reflect relevant perspectives and concerns, including, without limitation, the perspectives and concerns of women.

Guiding principle

The primary guiding principle for appointing members to ACART is to ensure that ACART has the appropriate expertise, skills, knowledge and perspectives to provide advice and guidelines of the highest quality.

Member numbers

ACART must consist of not fewer than 8 and not more than 12 members appointed by the Minister of Health.

Lay/non-lay membership

At least half of the total membership of ACART must be lay persons.

For the purposes of these Terms of Reference, a layperson is a person who, at no time during the person's membership of ACART or in the three years before becoming a member of ACART:

- is a health practitioner within the meaning of the Health Practitioners Competence Assurance Act 2003; or
- is involved in health research; or
- is employed by or associated with, or has a pecuniary interest in, a fertility service provider.

Ex-officio attendance

The chairperson of ACART, or a member of ACART nominated by the chairperson of ACART for the meeting, may attend each meeting of the National Ethics Committee on Assisted Reproductive Technologies (ECART). The ACART member or chairperson attending the advisory group meeting is not a member of the committee.

The chairperson of ECART or a member of ECART nominated by the chairperson of ECART for the meeting may attend each meeting of ACART. ECART member or chairperson attending the ACART meeting is not a member of the committee.

Member categories

ACART's membership must include:

- one or more members with expertise in assisted reproductive procedures
- one or more members with expertise in human reproductive research
- one or more members with expertise in ethics
- one or more Māori members with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective
- one or more members with the ability to articulate issues from a consumer perspective
- one or more members with the ability to articulate issues from a disability perspective
- one or more members with the ability to articulate the interests of children who, at the time of his or her appointment, holds the office of Children's Commissioner or is a representative or employee of the person who holds that office
- one or more members with expertise in relevant areas of the law.

Whole committee requirements

Members should possess an attitude that is accepting of the values of different professions and community perspectives, and it is important that ACART comprise people from a range of backgrounds and ethnicities. All members of ACART are expected to have an understanding of how the health sector responds to Māori issues and their application to ethical review.

Despite being drawn from groups identified with particular interests or responsibilities in connection with health and community issues, advisory committee members are not in any way the representatives of those groups. They are appointed in their own right, to participate in the work of ACART as equal individuals of sound judgement and relevant experience.

Terms and conditions of appointment

Members of ACART are appointed by the Minister of Health for a term of office of up to three years. The terms of office of members of ACART will be staggered to ensure continuity of membership. Members may be reappointed from time to time. No member may hold office for more than six consecutive years.

Persons who have served six consecutive years as members of the previous National Ethics Committee on Assisted Human Reproduction (NECAHR) shall not be immediately eligible for appointment to ACART.

A person may not be a member of ACART and ECART simultaneously.

Unless a person sooner vacates their office, every appointed member of ACART shall continue in office until their successor comes into office. Any member of ACART may at any time resign as a member by advising the Minister of Health in writing.

The Minister may, by written notice, terminate the appointment of a member or chairperson of the advisory committee.

The Minister may from time to time alter or reconstitute ACART, or discharge any member of ACART, or appoint new members to ACART for the purpose of decreasing or increasing the membership or filling any vacancies.

Chairperson and deputy chairperson

The Minister may appoint any person to be a chairperson of ACART and must, before doing so, consult any persons who, in the Minister's opinion, are able to provide advice on prospective appointees who have the required expertise and the ability to reflect relevant perspectives and concerns, including, without limitation, the perspectives and concerns of women.

ACART may appoint one of its members to be deputy chairperson.

The chairperson will preside at every meeting of ACART at which they are present.

Duties and responsibilities of a member

This section sets out the Minister of Health's expectations regarding the duties and responsibilities of a person appointed as a member of ACART. This is intended to aid members of ACART by providing them with a common set of principles for appropriate conduct and behaviour and serves to protect ACART and its members.

As an independent statutory body, ACART has an obligation to conduct its activities in an open and ethical manner. ACART has a duty to operate in an effective manner within the parameters of its functions as set out in its Terms of Reference and in accordance with the HART Act.

General

ACART members should have a commitment to work for the greater good of the Committee.

There is an expectation that members will make every effort to attend all ACART meetings and devote sufficient time to become familiar with the affairs of ACART and the wider environment within which it operates.

Members have a duty to act responsibly with regard to the effective and efficient administration of ACART and the use of ACART funds.

Conflicts of interest

ACART members must perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect ACART and its members and will ensure that it retains public confidence.

Members attend meetings and undertake committee activities as independent persons responsible to ACART as a whole. Members are not appointed as representatives of professional organisations and or particular community bodies. ACART should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.

Members should declare, and the committee regularly review their actual and potential conflicts of interest.

ACART must exhibit transparency in avoiding or managing any real or perceived conflict of interest.

Confidentiality and information sharing

The public has a right to be informed about the issues being considered by ACART. The chairperson of ACART must ensure that the agenda and minutes are published on the internet as soon as possible after they are confirmed by the members of the committee. ACART should have procedures in place regarding the release of information and processing requests for information.

Individual members must observe the following duties in relation to ACART information. These provisions ensure that ACART as a whole maintains control over the appropriate release of information concerning issues before it.

- Meetings of ACART, including agenda papers and draft minutes, are confidential. Members must ensure that the confidentiality of ACART business is maintained.
- Members are free to express their own view within the context of committee meetings or the general business of ACART.
- Members must publicly support a course of action decided by ACART. If unable to do so, members must not publicly comment on decisions.
- At no time should members individually divulge details of ACART matters or decisions of ACART to persons who are not ACART members. Disclosure of ACART business to anyone outside ACART must be on the decision of ACART, or at the discretion of the chairperson of ACART between meetings. In choosing to release or withhold information, the Committee must comply with the Official Information Act 1982 and the Privacy Act 1993.

- ACART members must ensure that ACART documents are kept secure to ensure that the confidentiality of committee work is maintained. Release of committee correspondence or papers can only be made with the approval of ACART.

Meetings of the Committee

Meetings shall be held at such times and places as ACART or the chairperson of ACART decides.

When ACART has 12 members, at least seven members must be present to constitute a majority. When the number of appointed members is less than 12, a quorum is the minimum number constituting a majority. The quorum must include a reasonable representation of members with health practitioner, research, ethical and community/consumer expertise, knowledge and perspectives.

Every question before any meeting shall generally be determined by consensus decision-making. Where a consensus cannot be reached a simple majority vote will apply. In such circumstances, the chairperson shall have the casting vote.

Subject to the provisions set out above, ACART may regulate its own procedures.

Reporting requirements

ACART must, as soon as practicable after each 12-month period ending on 30 June, give the Minister of Health a report:

- on its progress in carrying out its functions; and
- on the number and kinds of decisions given by ECART in that period.

Fees and allowances

Members of ACART are entitled to be paid fees for attendance at meetings. The level of attendance fees are set in accordance with the State Services Commission's framework for fees for statutory bodies.

The chairperson will receive $430 per day (plus half a day's preparation fee) and an allowance of two extra days per month to cover additional work undertaken by the chairperson. The attendance fee for members is set at $320 per day (plus half a day's preparation fee). The Ministry of Health pays actual and reasonable travel and accommodation expenses of ACART members.

Servicing of ACART

ACART will agree a work programme with the Minister of Health. ACART will be serviced by permanent staff, sufficient to meet the Committee's statutory requirements, who will be based in the Ministry of Health.

Appendix 4: Biographies of ACART Members

Sylvia Rumball CNZM (Chairperson)

Professor Sylvia Rumball is assistant to the Vice Chancellor (Research Ethics) at Massey University. She has a PhD in chemistry and for many years taught chemistry and undertook research in structural biology at Massey University.

She has extensive international, national and local experience on ethics committees and ethics-related bodies through past membership of the UNESCO International Bioethics Committee, the New Zealand National Commission for UNESCO, the Health Research Council Ethics Committee, the Massey University Human Ethics Committee and the MASH Trust Ethics Committee; current membership of the Ethics Advisory Panel of the Environmental Risk Management Authority; as past chairperson of the National Ethics Committee on Assisted Human Reproduction; and as current chairperson of the Massey University Human Ethics Chairs Committee.

Professor Rumball is also a member of the International Council for Science (ICSU) Committee on Freedom and Responsibility in Science, a member of the Massey University Council, an auditor for the New Zealand Universities Academic Audit Unit, and a member of the Board of the National Centre for Advanced Bioprotection Technologies.

In 1998 she was made an Officer of the New Zealand Order of Merit for services to science, and in 2008 she was promoted to Companion. She is also the recipient of a Palmerston North City Council Civic Award, a Distinguished Alumni Award from the University of Canterbury and a New Zealand Science and Technology medal.

Gareth Jones CNZM

Professor Gareth Jones is Deputy Vice Chancellor (Academic and International) at the University of Otago, where he is also professor of anatomy and structural biology. He qualified in medicine and neuroscience (BSc Hons, MBBS) at University College London (UCL) and has DSc and MD degrees from the University of Western Australia and the University of Otago, in science and bioethics respectively. He was made a Companion of the New Zealand Order of Merit in 2004 for his contributions to science and education. He has published extensively in neuroscience, anatomy education and bioethics. His recent publications include: *Speaking for the Dead: Cadavers in biology and medicine* (2000; second edition, 2009), *Stem Cell Research and Cloning* (co-editor, 2004), *Medical Ethics* (co-author, 4th edition, 2005), *Designers of the Future* (2005), *Bioethics* (2007), and *Tangled Web: Medicine and theology in dialogue* (co-editor, 2008).

John Forman

John Forman is a parent of adult twins with a rare genetic disorder, alpha mannosidosis, and his family experience with physical and intellectual disability has drawn him into a range of health and disability sector networks over the past 30 years. He has also spent many years in disability support service provision, mainly in community mental health. Since the late 1990s John has focused on the development of patient/family support networks in New Zealand and internationally, with an emphasis on partnership with health professionals, policy agencies and researchers to promote prevention, treatments and cures for rare disorders.

He has volunteer roles on the boards of several local and international advocacy groups. His paid role is Executive Director of the New Zealand Organisation for Rare Disorders, where he advocates for the increased application of genome knowledge and biotechnology to control health and disability problems, with a sharp eye on the ethical issues to ensure safety for the patients and their families.

Richard Fisher

Dr Richard Fisher is a gynaecologist with a sub-specialty practice in reproductive medicine. He is a co-founder of Fertility Associates and has been an active advocate for infertile couples for 20 years. He is the only New Zealander to have been elected president of the Fertility Society of Australia. Richard is a member of a number of professional associations and is a member of the Institute of Directors in New Zealand Inc. He is married and has four children. Richard brings a medical professional's viewpoint to ACART, which is tempered by a recognition of the need for community involvement and decision-making in this area.

Christine Rogan

Christine Rogan has worked to actively promote health for 15 years. She is a past president and life member of the Auckland Infertility Society and became the first National Development Officer for the New Zealand Infertility Society (now called Fertility NZ). She currently works as a health promotion advisor with a non-government public health organisation. In addition, Christine is a non-medical Performance Assessment Committee Member for the Medical Council of New Zealand and the Dental Council of New Zealand. Christine has a tertiary qualification in social sciences from Massey University and lives on the North Shore of Auckland with her daughter.

Ken Daniels (Deputy Chairperson)

Ken Daniels is adjunct professor in the School of Social Work and Human Services at the University of Canterbury. He was appointed to establish social work education and training at Canterbury in 1975 and retired in 2004. For over 30 years he has been actively involved in studying, writing, counselling and policy development in the psychosocial aspects of assisted reproductive technology (ART). His particular focus has been on the children and families that result from ART.

He served for nine years on NECAHR – the last three as deputy chairperson. Professor Daniels has carried out research in a number of countries and has been used as a policy consultant in several overseas jurisdictions. He has published extensively, and his book *Building a Family with the Assistance of Donor Insemination* is used by parents and professionals throughout the world. Professor Daniels is also chairperson of Richmond New Zealand.

Mark Henaghan

Mark Henaghan is professor and dean of law at the University of Otago and principal

investigator of the Human Genome Project, Law and Ethics for the Future, which is sponsored by the Law Foundation New Zealand. The project has produced three major reports: *Choosing Genes for Future Children: Regulating preimplantation genetic diagnosis;* and *Genes Society and the Future,* volumes 1 and 2. Professor Henaghan's primary research interests are family law and medico-legal law involving children.

Andrew Shelling

Associate Professor Andrew Shelling is head of the Medical Genetics Research Group, which is primarily interested in understanding the molecular changes that occur during the development of genetic disorders, focusing on infertility and reproductive cancers, but also including cardiac disorders.

Dr Shelling has a special interest in understanding the cause of premature menopause, and his research is internationally recognised for identifying genetic causes of this common cause of infertility. He initiated the development of a support group for women with premature menopause in New Zealand. Dr Shelling is currently deputy head of the Department of Obstetrics and Gynaecology, University of Auckland, and is extensively involved in teaching reproduction, genetics and cancer at the university. Dr Shelling has recently served as president of the New Zealand branch of the Human Genetics Society of Australasia and Associate Editor for the journal *Human Reproduction*, which is one of the leading journals in the area of reproductive research. He is a trustee for the Nurture Foundation for Reproductive Research.

Ian Hassall

Dr Ian Hassall is a New Zealand paediatrician and children's advocate. He was New Zealand's first Commissioner for Children from 1989 to 1994. His career has entailed working for children and their families as clinician, strategist, researcher and advocate. He is at present senior lecturer in the Children and Families Programme of the Institute of Public Policy at Auckland University of Technology (AUT).

Dr Hassall teaches the Master of Arts (Children and Public Policy) at AUT. He is a member of the Steering Group and Project Team for Every Child Counts, a coalition of child advocacy and service organisations, whose aim is to place children centrally in government decision-making. He is married to Jenny, is father to four children and grandfather to five. He is the Children's Commissioner's nominee to ACART.

Cilla Ruruhira Henry QSM

Cilla Henry grew up under the mantle of the kīngitanga movement, deeply entrenched in Waikato kawa (protocol) and tikanga (teachings). Hapū connections are Ngāti Wairere and Ngāti Hako Hauraki. Cilla is married with three children and five mokopuna.

Cilla is a Māori specialist consultant, Department of Corrections Psychological Services Hamilton, working with Māori inmates at Waikeria Prison, and a trustee of the Health Consumer Service Trust. She is the Māori Women's Welfare League representative on the Care and Protection Panel for Children (Child Youth & Family Service), and on the National Council of Women New Zealand. Cilla is passionate about the care, protection and wellbeing of children.

Cilla was appointed justice of the peace (JP) in 1996, and received the Queens Service Medal for Public Service in 2003.

Maui Hudson

Maui Hudson (JP) lives in Rotorua, and his iwi affiliations are with Whakatōhea, Ngā Ruahine and Te Māhurehure. Maui has professional qualifications from Auckland

University of Technology (AUT) in physiotherapy, ethics and Māori health, and currently works for the Institute of Environmental Science and Research Ltd (ESR) in a Māori development position. In this role he is responsible for internal development, providing cultural and ethical advice to researchers, and establishing research relationships with Māori and Pacific communities. Maui is the principal investigator on the Health Research Council-funded project Ngā Tohu o te Ora: Traditional Māori Wellness Outcome Measures, and has research interests in the area of ethics and the interface between matauranga Māori and science. Maui is a member of the Health Research Council Ethics Committee and has previously been a member of ECART and the Auckland Regional Health and Disability Ethics Committee. He is married and has three children.

Robyn Scott

Robyn Scott's background is in both not-for-profit management and education. She studied at Wellington College of Education (now the Faculty of Education, Victoria University of Wellington) and Victoria University of Wellington before embarking on a career in primary school teaching and the teaching of speech and drama and music. From there she moved to managing a not-for-profit organisation, working particularly in the area of health support and health advocacy.

Robyn is currently executive director of Philanthropy New Zealand and is charged with leading and developing this key organisation that works to motivate and inspire philanthropists and grant makers.

Robyn lives in Wellington with her husband and two school-aged children. Outside work she enjoys a range of mostly family activities that tend to centre around children's sport and cultural events, and also enjoys travel and reading. She is an alumna of Leadership New Zealand, having graduated in 2006.

Part Two:
Ethics Committee on Assisted Reproductive Technology: Annual Report 2007/08

Ethics Committee on Assisted Reproductive Technology

Annual Report 2007/08

Chair's Foreword

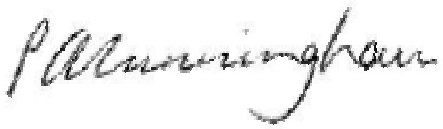
I am pleased to present the third Annual Report of the Ethics Committee on Assisted Reproductive Technology (ECART).

The Advisory Committee on Assisted Reproductive Technology (ACART) issued two new guidelines in November 2007: *Surrogacy Arrangements involving Providers of Fertility Services* and *Donation of Gametes between Certain Family Members.* ECART updated the application forms for these procedures accordingly, with input from the fertility clinics and ACART.

For the assisted reproductive procedures that do not have updated guidelines (namely, embryo donation), ECART has reviewed applications using the interim guidelines that were developed by the National Ethics Committee on Assisted Human Reproduction.

In May 2008 ECART reviewed its first application for research on gametes. To ensure the relevant expertise was present, a chairperson of a Health and Disability Ethics Committee attended the ECART meeting during the review of the application. This worked well, although the process brought to ECART's attention the need for updated guidelines and application forms for research proposals.

I wish to thank ECART members for their hard work during 2007/08 and wish them and the new chairperson all the best for 2008/09.



Philippa Cunningham
Outgoing Chairperson
Ethics Committee on Assisted Reproductive Technology

Introduction

Purpose of this report

The Terms of Reference of the Ethics Committee on Assisted Reproductive Technology (ECART) require it to submit an annual report to the Minister of Health. The annual report must include information on:

- members
- assisted reproductive technology applications reviewed (which, as ACART has the legislative responsibility for reporting on ECART's decisions, are set out in Appendix 1 of ACART's report)
- training
- complaints received
- issues causing ECART difficulty in reviewing applications
- issues referred to the Advisory Committee on Assisted Reproductive Technology (ACART).

Background

ECART was established under the Human Assisted Reproductive Technology Act 2004 (the HART Act). The functions of ECART are to:

- consider and determine applications for assisted reproductive procedures or human reproductive research
- keep under review any approvals previously given, including those applications approved prior to the existence of ECART and, without limitation, to monitor the progress of any assisted reproductive procedures performed or any human reproductive research conducted under current approvals
- liaise with ACART on matters relating to assisted reproductive procedures and human reproductive research, and to forward to the advisory committee reports received under section 19(5) of the HART Act together with any comments or requests for advice that ECART considers appropriate
- consult with any persons who, in the opinion of the committee, are able to assist it to perform its functions
- perform any other functions the Minister of Health assigns to the committee by written notice.

ECART can only consider applications for approval for activities covered by guidelines or advice issued or given by ACART. If such guidelines or advice do not exist, ECART must decline the application and refer the matter to ACART.

Progress in 2007/08

ECART met six times over 2007/08 to review 38 applications for assisted reproductive procedures and one application for research on gametes and non-viable embryos.

Since its establishment in August 2005, ECART has reviewed applications for assisted reproductive procedures based on guidelines that were developed under the National Ethics Committee on Assisted Human Reproduction (NECAHR). The HART Act 2004 made provisions for these guidelines to be treated as interim guidelines up until 21 November 2007. The Advisory Committee on Assisted Reproductive Technology (ACART) issued two new guidelines on 22 November 2007: *Surrogacy Arrangements involving Providers of Fertility Services* and *Donation of Gametes between Certain Family Members.* ECART updated the application forms for these procedures accordingly, with input from the fertility clinics and ACART.

For those assisted reproductive procedures that do not have updated guidelines (namely embryo donation), ECART continued to review applications using the interim guidelines developed by NECAHR.

In early 2008 ECART received a query from a fertility clinic which prompted the committee to develop a stance on the duration of surrogacy approvals. The committee consulted with the fertility clinics on the proposed limitations, and after incorporating their feedback the following wording was added to all surrogacy approvals:

> 'This approval for Clinic-Assisted Surrogacy carries limitations (below) which would result in expiration of the approval. Reapplication after expiry would normally require updated independent medical and counselling reports, an updated joint counselling report, and the previous legal reports. However, the clinic is encouraged to contact the ECART Secretariat to discuss what is most appropriate for the application in question.
>
> 'This approval will expire three years from the date of this letter. The approval will however immediately expire if the surrogate or intending mother has a birth, or any of the parties develop, or have a significant change of, a major medical or social condition. Examples of a significantly changed social condition may include, but are not limited to, any of the involved parties experiencing:
>
> - a permanent separation from a partner
> - the death of someone important to the surrogacy arrangement, or
> - a change of country of residence.'

Other highlights include ECART posting a sample legal report on its website as a guide for lawyers completing the legal section of a surrogacy application. Also, better guidance for preparing a research application was added to the website following ECART's first review of a research application.

A summary of the number and kinds of decisions made by ECART is included in ACART's annual report, as required by the HART Act. This summary is contained in Appendix 1 of that report.

In ECART's review of applications, a number of issues arose in relation to guidelines and advice from ACART. These issues have been forwarded to ACART to inform its advice to the Minister of Health on assisted reproductive procedures. These issues are:

- ECART's ability to review applications involving combinations of assisted reproductive procedures (or 'dual applications')
- the donation of gametes between brother and sister where one of the siblings is adopted
- the export of donor sperm
- legal arrangements for the care of a child born as part of a surrogacy arrangement, especially concerns that a preference for adoption is no longer allowed
- generic guidelines for one-off ('unique') applications
- the use of donor egg in conjunction with donor sperm

Training

Full training was held on 19 November 2007 for all new and existing members.

ECART Membership

Table 1: Membership of ACART

	Expertise/perspective	Term of office expires 23 June
Lay members		
Philippa Cunningham (Chairperson)	Law	2008
Eamon Daly	Disability	2008
Lynley Anderson	Ethics	2008
Deb Rowe	Māori	2010
Rob Thompson	Community	2010
Huia Tomlins-Jahnke*	Māori	2009
Hazel Irvine†	Counselling	2009
Jackie Freeman†	Consumer	2009
Non-lay members		
Dr Christine Forster (Deputy Chairperson)	Assisted reproductive research	2010
Prof John Hutton	Human reproductive procedures	2008

* Appointed 12 October 2006.
† Appointed 23 August 2006.

Table 2: Member attendance at ECART meetings 2007/08

	Meetings attended (6 total)						
Member	**26 July 2007**	**11 Sept 2007**	**20 Nov 2007**	**4 Feb 2008**	**11 March 2008**	**15 May 2008**	**Total**
Lynley Anderson	X	X	X	X	X	X	**6/6**
Philippa Cunningham	X	X	X	X	X	X	**6/6**
Eamon Daly	X	X	X	X	X	X	**6/6**
Christine Forster	X	X	X	X	X	X	**6/6**
Jackie Freeman	A	A	X	X	X	X	**4/6**
John Hutton	X	X	X	X	X	A*	**5/6**
Hazel Irvine	X	A	X	X	X	X	**5/6**
Deb Rowe	A	A	X	X	X	X	**4/6**
Rob Thompson	X	X	X	X	X	X	**6/6**
Huia Tomlins-Jahnke	X	A	X	X	A	A	**3/6**
Total members present	**8/10**	**6/10**	**10/10**	**10/10**	**9/10**	**8/10**	

* Freddie Graham of Fertility Associates Auckland attended in John Hutton's place.
A Apologies
X Present

Complaints

ECART received one complaint between 1 July 2007 and 30 June 2008. The application in question had been approved with two conditions, and the complaint related to the length of time it took to resolve disagreement about varying the conditions. ECART replied to the complainant expressing regret for the delay and explaining that advice from overseas experts had to be obtained, which took time.

The Ministry of Health also received one complaint regarding an ECART decision, which the Ministry responded to.

ECART does not have a formal appeals process similar to that of the Health and Disability Ethics Committees. This issue is one that ACART has referred to the Minister of Health.

Appendix 1: ECART Terms of Reference

Public Authority of the Ethics Committee on Assisted Reproductive Technology (ECART)

ECART is established and designated under section 27 of the Human Assisted Reproductive Technology (HART) Act 2004. These Terms of Reference outline the role and functions of ECART.

Relations with other public sector organisations

ECART shall liaise with other relevant ethics committees on matters of common interest, such as cases where jurisdiction is unclear. ECART shall inform the Ministry of Health and the Advisory Committee on Assisted Reproductive Technology (ACART) of any matters that arise in its operation that potentially have policy significance.

Functions of ECART

ECART has the following functions:

- to consider and determine applications for assisted reproductive procedures[6] or human reproductive research[7]
- to keep under review any approvals previously given, including those applications approved prior to the existence of ECART, and, without limitation, to monitor the progress of any assisted reproductive procedures performed or any human reproductive research conducted under current approvals
- to liaise with ACART on matters relating to assisted reproductive procedures and human reproductive research and, to forward to the advisory committee reports received under section 19(5) of the HART Act together with any comments or requests for advice that ECART considers appropriate
- to consult with any persons who, in the opinion of the committee, are able to assist it perform its functions
- any other functions that the Minister of Health assigns to the committee by written notice.

---

6 'Assisted reproductive procedure'

(a) means 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

(b) does not include an established procedure.

7 'Human reproductive research' means research that uses or creates a human gamete, a human embryo or a hybrid embryo.

Guiding principles

ECART shall be guided by the following principles:

- The health and wellbeing of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure.
- The human health, safety and dignity of present and future generations should be preserved and promoted.
- While all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application and the health and wellbeing of women must be protected in the use of these procedures
- No assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent.
- Donor offspring should be made aware of their genetic origins and be able to access information about those origins.
- The needs, values and beliefs of Māori should be considered and treated with respect.
- The different ethical, spiritual and cultural perspectives in society should be considered and treated with respect.

Operation of ECART

ECART must operate:

- in accordance with the HART Act and any other enactment
- in accordance with these Terms of Reference
- in accordance with any guidelines or advice issued by ACART or transitional guidelines gazetted by the Minister of Health under section 79 of the Human Assisted Reproductive Technology Act; and
- in accordance with Chapters 1–4 of the *Operational Standard for Health and Disability Ethics Committees*; and
- expeditiously, having regard, in particular, to the effect that undue delay may have on the reproductive capacity of individuals.

On any point of conflict, the guidelines issued by ACART will have precedence over the *Operational Standard*.

Composition and membership

Guiding principle

The primary guiding principle for appointing members to ECART is to ensure that ECART has the appropriate expertise, skills, knowledge and perspectives to conduct ethical review of the best quality in accordance with its functions, as defined by the HART Act.

Member numbers

ECART must consist of not fewer than eight and not more than 12 members appointed by the Minister of Health.

Lay/non-lay membership

At least one half of the total membership of ECART shall be lay persons, including a lay chairperson and a non-lay deputy chairperson.

For the purposes of these Terms of Reference, a lay person is a person who, at no time during the person's membership of ECART or in the three years before becoming a member of ECART:

- is a health practitioner within the meaning of the Health Practitioners Competence Assurance Act 2003; or
- is involved in health research; or
- is employed by or associated with, or has a pecuniary interest in, a provider.

Member categories

ECART's lay membership shall include:

- one or more members with the ability to articulate issues from a consumer perspective
- one or more members with the ability to articulate issues from a disability perspective
- one or more members with expertise in ethics
- one or more members with expertise in law.

ECART's non-lay membership shall include:

- one or more members with expertise in assisted reproductive procedures
- one or more members with expertise in human reproductive research.

Ex-officio attendance

The chairperson of ECART or a member of ECART nominated by the chairperson of ECART for the meeting may attend each meeting of ACART. The ECART member or chairperson attending the ACART meeting is not a member of the committee.

The chairperson of ACART or a member of ACART nominated by the chairperson of ACART for the meeting may attend each meeting of ECART. The ACART member or chairperson attending the ECART meeting is not a member of the committee.

Whole committee requirements

At any time, consistent with the requirements for District Health Boards under the New Zealand Public Health and Disability Act 2000, ECART shall have at least two Māori members. Māori members should have a recognised awareness of te reo Māori, and an understanding of tikanga Māori. All members of ECART are expected to have an understanding of how the health sector responds to Māori issues and their application to ethical review.

Members should possess an attitude that is accepting of the values of other professions and community perspectives, and it is important that ECART comprise people from a range of backgrounds and ethnicities.

Despite being drawn from groups identified with particular interests or responsibilities in connection with health and community issues, ECART members are not in any way the representatives of those groups. They are appointed in their own right, to participate in the work of ECART as equal individuals of sound judgement, relevant experience, and adequate training in ethical review.

Terms and conditions of appointment

Members of ECART are appointed by the Minister of Health for a term of office of up to three years. The terms of office of members of ECART shall be staggered to ensure continuity of membership. Members may be reappointed from time to time. No member may hold office for more than six consecutive years.

After serving the maximum six-year term, members shall not be considered for reappointment until at least three years after their retirement from ECART or any other health and disability ethics committee.

Persons who have served six consecutive years as members of the previous National Ethics Committee on Assisted Human Reproduction (NECAHR) shall not be eligible for appointment to ECART until at least three years after their retirement from NECAHR. Persons who have served less than six years on NECAHR will be eligible to be appointed to ECART for a term that is equal to six years minus the term already served by that person on NECAHR, or a shorter period.

A person may not be a member of ECART and ACART simultaneously.

Unless a person sooner vacates their office, every appointed member of ECART shall continue in office until their successor comes into office. Any member of ECART may at any time resign as a member by advising the Minister of Health in writing.

The Minister may, by written notice, terminate the appointment of a member or chairperson of the advisory committee.

The Minister may from time to time alter or reconstitute ECART, or discharge any member of ECART, or appoint new members to ECART for the purpose of decreasing or increasing the membership or filling any vacancies.

Chairperson and deputy chairperson

The Minister must appoint a lay member of ECART to be its chairperson. The terms and conditions of appointment for members of ECART also apply to the person appointed as chairperson. The chairperson shall preside at every meeting of ECART at which they are present.

ECART may appoint a non-lay member as deputy chairperson.

The chairperson and deputy chairperson may act with the delegated authority of ECART between meetings.

Duties and responsibilities of a member

This section sets out the Minister of Health's expectations regarding the duties and responsibilities of a person appointed as a member of ECART. This is intended to aid members of ECART by providing them with a common set of principles for appropriate conduct and behaviour and serves to protect ECART and its members.

General

ECART members should have a commitment to protecting the interests of human participants, including a potential child when this is appropriate, while promoting excellence in research and innovative practice.

There is an expectation that members will make every effort to attend all ECART meetings and devote sufficient time to become familiar with the affairs of ECART and the wider environment within which it operates.

Members have a duty to act responsibly with regard to the effective and efficient

administration of ECART and the use of ECART funds.

Conflicts of interest

ECART members should perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect ECART and its members and will ensure it retains public confidence.

ECART members attend meetings and undertake ECART activities as independent persons responsible to ECART as a whole. Members are not appointed as representatives of professional organisations or particular community bodies. ECART should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.

Members should declare, and the committee regularly review their actual and potential conflicts of interest. ECART must exhibit transparency in avoiding or managing any real or perceived conflict of interest.

When ECART members believe they have a conflict of interest on a subject that will prevent them from reaching an impartial decision or undertaking an activity consistent with the committee's functions, they should declare that conflict of interest and withdraw themselves from the discussion and/or activity.

A member of ECART who has a proposal before ECART or who has an involvement in the proposal such as a supervisory role shall not take part in ECART's assessment of that proposal. The member may be present to answer questions about a proposal but should take no part in the discussion surrounding the consideration of the proposal or any decision relating to the proposal. This will allow the proposal to be considered in a free and frank manner.

ECART must exhibit transparency in avoiding or managing any real or perceived conflict of interest.

Confidentiality and information sharing

Agendas and minutes of all ECART meetings should be available to the public. Copies of applications may be made available to individuals outside ECART on request, subject to the Official Information Act 1982.

It is desirable for the members of ECART to have an opportunity to discuss issues arising from applications with key contacts and support people prior to the consideration of proposals. This process should be encouraged. However, due to the need to protect any personal information, names or identifying details should not be circulated or made known outside ECART. ECART will need to consider the Privacy Act 1993 and the Health Information Privacy Code 1994 in developing these processes.

Within ECART, members' expertise in particular communities of interest should be consulted and provide advice on the appropriate consultative process for all ethical issues concerning that community.

Committee meetings

Meetings of ECART shall be held as regularly as needed, as determined by the workload.

When ECART has 12 members, at least seven members must be present to constitute a quorum. When the number of appointed members is less than 12, a quorum is the minimum number constituting a majority. The quorum must include a reasonable representation of members with health practitioner, research, ethical and

community/consumer expertise, knowledge and perspectives.

As part of the accountability to the public they protect, it is desirable for the meetings of ECART to be open to the public. Meetings of ECART should therefore be:

i. open meetings for the discussion of broad issues, particularly if ECART is reviewing human reproductive research

ii. closed meetings when necessary to ensure the privacy and confidentiality of participants

iii. closed meetings when applicants provide good and sufficient reasons for this to occur, and the minutes of the meeting should reflect these reasons.

Information about the dates and times of committee meetings, including the closing date for the agenda, should be made available to the public.

Subject to the provisions set out in this document, ECART may regulate its own procedures.

Decision-making process

Wherever possible, ECART should determine matters by consensus decision. Where a consensus cannot be reached, a vote shall apply, with a two-thirds majority of those voting required for any decisions.

In relation to specific research or specific treatment involving Māori participants, it is important that Māori expertise be available to ensure that all issues are appropriately considered. Where it is not possible for Māori members to attend an ECART meeting or for those members' views to be sought and represented at the meeting, the matter should be deferred.

On occasion, individual members may wish to abstain from some or all of the decision-making process because of strong moral or religious reasons. Such abstentions shall not affect the approval process.

Advice from ACART

At any stage in its deliberations, ECART may seek advice from ACART on the interpretation of ACART's guidelines.

ECART actions

ECART may give its written approval:

- for the performance of assisted reproductive procedures by a nominated person; or
- for the conduct of human reproductive research by a nominated person.

ECART may not give its approval unless it is satisfied that the activity proposed to be undertaken under the approval is consistent with relevant guidelines or relevant advice issued or given by the advisory committee.

ECART may cancel an approval, in whole or in part, if it is satisfied:

- that one or more conditions stated in the approval have been breached; or
- that the activity undertaken, or purportedly undertaken, under the approval:
  - is inconsistent with any relevant guidelines and advice issued by the advisory committee on or before or after the date on which the approval was given; or
  - is inconsistent with the description set out in the application in which the approval was sought; or
  - breaches or has breached the HART Act or regulations made under section 76 of the HART Act; or
- that, since giving the approval, the ethics committee has become aware that the activity to which the approval

relates poses a serious risk to human health and safety.

The actions of ECART in relation to applications are set out in sections 19 to 23 of the HART Act.

For each application it reviews, ECART must state to the applicant whether its action is to approve, approve subject to conditions, defer, or decline that application. It should state its grounds for any action to defer or decline. For any action to approve subject to conditions, ECART should specify the conditions, the grounds for these, and its process for assessing whether these conditions are subsequently met. In all cases, it should state which matters its action is based upon, and which are instead matters of comment, information or advice to its applicant.

As soon as practicable after ECART grants an approval, it must give a copy of the approval and the relevant proposal to ACART.

Expert advice and consultation

Members may wish to consult on ethical issues with, for example, individuals, groups, iwi and hapū, and this should be encouraged and supported. Consultation should be carried out in a timely manner.

Where the chairperson or quorum of ECART members believes there is insufficient expertise on ECART to assess an application or an issue, the committee should seek additional expert advice.

Advice may be sought from recognised experts with:

i. specialist knowledge in the field of assisted reproductive technology
ii. knowledge of the experiences and perspectives of people with infertility
iii. knowledge of the experiences and perspectives of people with disabilities
iv. awareness of gender health perspectives
v. consumer and/or research participant perspectives
vi. an understanding of community health issues
vii. an understanding of relevant cultural perspectives
viii. an understanding of developing Māori research methodologies
ix. expertise in te reo Māori
x. expertise in ethical theory
xi. expertise in child and family health and wellbeing.

It should be noted that the above list gives examples, without restricting the range of external expertise that may be sought.

Where external consultation has taken place or advice has been sought, this should be documented, and recorded where appropriate in ECART's decision on a proposal.

Training for members

Training should be provided for new members and chairpersons within six months of appointment to ECART. Reasonable expenses incurred in attending training will be paid for, but a meeting fee is not paid for training.

Reporting requirements

The following provides a checklist of requirements for annual reporting. Annual reports should be submitted to the Minister of Health and will be tabled by the Minister of Health in the House of Representatives.

The annual report shall include information on the membership of ECART, including any change in ECART's membership or other substantive changes ECART or its chairperson feels should be noted.

The annual report should also include a list of the assisted reproductive technology proposals reviewed in the preceding year outlining the following details:

i. the research title or the type of treatment

ii. principal investigator

iii. institution where the research is to be/has been undertaken

iv. date of first review

v. date of final outcome

vi. outcome (which will be one of: approved, approved subject to conditions, deferred, declined)

vii. for each protocol deferred or declined, the reasons for the decision.

The annual report shall also include:

i. a list of training undertaken by ECART members, and a statement on processes for orientation and training of new ECART members.

ii. A list of complaints received by ECART (if any), the actions taken to resolve the complaint and a comment on the outcome of the complaint(s).

iii. Any areas of review that caused difficulty for ECART in making a decision on any particular protocol(s), and any questions on policy or other matters ECART referred to ACART for comment or guidance.

In compiling annual reports, ECART should take care not to provide information that would involve a breach of the Privacy Act 1993 and/or the Health Information Privacy Code 1994.

Fees and allowances

Members of ECART are entitled to be paid fees for attendance at meetings. The level of attendance fees are set in accordance with the State Services Commission's framework for fees for statutory bodies.

The chairperson shall receive an attendance fee of $330 per day (plus half a day's preparation fee). The attendance fee for members is set at $250 per day (plus half a day's preparation fee). The chairperson and deputy chairperson shall receive an allowance of up to one extra day each per month to cover additional work undertaken under the delegated authority of ECART. The Ministry of Health shall pay actual and reasonable travel and accommodation expenses of ECART members.

Servicing of ECART

The Ministry of Health shall employ staff and provide resources to service, advise and administer ECART out of the allocated budget for ethics committees.

Appendix 2: ECART Member Biographies

Philippa Cunningham (Chairperson) is a District Court judge based at Auckland. Prior to her appointment in March 2007 Philippa practised as a barrister, mainly in the areas of civil and family law, including some medical cases. Philippa trained and worked as a nurse prior to taking up law 23 years ago. She has a Diploma in Professional Ethics from the University of Auckland. Philippa has had an interest in the protection and promotion of health consumers' rights since her involvement in the Cervical Cancer Inquiry in 1988 as junior counsel to Judge Silvia Cartwright. Philippa was a member of the National Ethics Advisory Committee from December 2001 to 2004 and a member of the National Ethics Committee on Assisted Human Reproduction (NECAHR) from mid-2002 until its disestablishment in July 2005.

Dr Christine Forster (MNZM) (Deputy Chairperson) is a general practitioner in Auckland, and prior to medical training was a researcher in the area of reproductive endocrinology. Her former roles have included chairperson of the Abortion Supervisory Committee for six years, NECAHR member, and member of the Auckland Regional Ethics Committee. Christine completed the Diploma in Professional Ethics in 2004. She is married with four children.

Lynley Anderson is employed as a senior lecturer at the Bioethics Centre at Otago University. As part of her role she teaches ethics and professional development within the medical, physiotherapy, dentistry and midwifery schools at Otago. Lynley was the former and founding editor of the *Journal of Bioethical Inquiry* and the *New Zealand Bioethics Journal*. She is on the University of Otago Human Ethics Committee and is the former chairperson of the Ethics Committee of the New Zealand Society of Physiotherapists. She is married with three sons.

Eamon Daly is an ethics researcher/ advisor for information privacy and information and communication technologies. Prior to this Eamon was a teaching assistant in the Department of Philosophy at the University of Canterbury (2003), a researcher/advisor for the Office of Hon Ruth Dyson (2001/02) and a lecturer in ethics at Christchurch Polytechnic (1996). Eamon is studying for a PhD in philosophy at the University of Canterbury, and holds a Bachelor of Science (1991) and a Master of Science (1996) from that university. He has also been on research scholarships with the University of Canterbury, University of California and London School of Economics. Eamon was chairperson of the Bioethics Council's Assisted Human Reproduction Working Group (2002/03) and he is a member of the Human Rights Review Tribunal (2003 – present). He is an elected member of the Disabled Persons Assembly National Executive Committee (2002–present), an ethicist on the University of Canterbury Biosafety Committee (2002–present), and a member of the Disabled Persons Assembly National Executive Committee (2004–present).

Jackie Freeman (MTchLn, BEd, Dip. Teaching) is a part-time teacher who has taught mainly primary school children for 16 years. For the last 13 years Jackie has been a consumer of fertility services in New Zealand. Jackie is an active member of the Fertility NZ Executive: she is the key contact/representative for the

Canterbury region and works closely with other assisted reproductive technology consumers by facilitating contact groups and offering support. Recently Jackie has taken on the role of a consumer auditor for the Reproductive Technology Accreditation Committee (RTAC) accreditation process. She is married with three daughters.

Professor John Hutton (PhD, FRANZCOG, CREI) is a sub-specialist in reproductive medicine and the former medical director of Fertility Associates Wellington, which he established in 1993. He is also (part-time) professor of reproductive medicine at the Wellington School of Medicine and Health Sciences, where previously he was professor of obstetrics and gynaecology.

Hazel Irvine is a registered nurse, midwife, ACC-registered counsellor and psychotherapist, She was a founding member in 1979 of a women's health collective offering information, counselling and advocacy to women. Hazel has worked in the public hospital system as a nurse/midwife and as a manager. She has also had several years of private practice as a nurse/therapist, her main clientele being women, couples and families coping with fertility issues, pregnancy loss, childbirth and postnatal depression. In 1991 a Lion's Fellowship enabled Hazel to investigate independent nurse practitioners in Britain. In 1996 she travelled to the UK on a Churchill Fellowship to study the implementation of professional supervision for nurses and midwives.

In 2004 Hazel was one of a technical group formed by the Abortion Supervisory Committee to produce the *Guidelines for Mifepristone Medical Abortion in New Zealand.* She currently lives in Wellington with her partner and three sons, and is a Sea Scout leader and a keen gardener. She has a private practice offering professional supervision, counselling and psychotherapy, and also works part-time as a midwife and gynaecology nurse at Wellington Hospital.

Associate Professor Huia Tomlins-Jahnke is Ngāti Kahungunu, Ngāi Tahu, Ngāti Toa Rangatira and Ngāti Hine. She is currently an associate professor of Māori education in the College of Education at Massey University. Huia trained as a teacher and holds professional qualifications in education (BEd, MEd Hons). She worked for 12 years as a lecturer in Te Putahi a Toi School of Māori Studies at Massey, which has a strong health research and development focus. She has extensive experience in iwi research, and for her PhD investigated the nature of tribal service provision in health and social services. She has expertise in Māori theoretical, methodological and ethical frameworks and working with Māori communities. Huia is deputy chairperson of the Massey University Human Ethics Committee and a member of the Social and Human Sciences Sub Commission of the NZ National Commission for UNESCO, which has as a key focus the ethics of knowledge production. Huia is also a member of the Sub Commission's Pacific Ethics Consultation Steering Committee, and a recent appointee to the Bioethics Council.

Robin (Rob) Thompson (Ngāti Kahungunu) is currently a property consultant and development and construction project manager (1996–present). He has completed a Graduate Diploma in Public Health (Engineering). Mr Thompson is currently a community representative on Ngā Kai Tataki Māori Health for the Waitemata District Health Board and previous councillor and chairperson of the Taupo Borough Council, founding councillor for the Tongariro United Regional Council, and a councillor and chairperson for the Rodney District Council. He was a founding board member of the Tauhara College Board of Governors and is a past president and past district chairperson of Rotary in New Zealand. He is a former social worker involved with adoptions, fostering, families and the Youth Court.
Mr Thompson has extensive personal experience with in vitro fertilisation: his brother and sister-in-law were the first to have successful IVF children in Australasia, his eldest son and that son's wife have a child through IVF, and his daughter also has two children through IVF.

Deborah Rowe (Ngāi Tahu) is currently a nurse consultant for the Auckland District Health Board, an undergraduate and postgraduate lecturer at the University of Auckland, and a senior staff nurse at the Women's Health Neonatal Intensive Care Unit (2005–present). Prior to this she was a clinical charge nurse at National Women's Hospital (1997–2005) and a research fellow at the Liggins Institute of Research.

Miss Rowe is completing a PhD in Management and Nursing and has completed a Master of Health Science and Management, a postgraduate Diploma in Health Management at the University of Auckland, a Bachelor of Health Science Nursing at Auckland University of Technology, and a Diploma in Registered Comprehensive Nursing at Auckland Institute of Technology. She is a member of the Māori Advisory Committee National Screening Unit (2007–present), a Māori representative on the Newborn Screening Advisory Committee (2006–present), and a member of the Auckland District Health Board Māori Nurses Group. Miss Rowe is the previous chairperson of the Regional Committee of the Richmond Fellowship of New Zealand and a part-time community support worker for the Intellectually Handicapped of New Zealand.