Advisory Committee on Assisted Reproductive Technology Annual Report 2013/14

Citation: ACART. 2015. Advisory Committee on Assisted Reproductive Technology: Annual report 2013/14. Wellington: Advisory Committee on Assisted Reproductive Technology.

Published in July 2015 by the Advisory Committee on Assisted Reproductive Technology PO Box 5013, Wellington 6145, New Zealand

> ISBN: 978-0-478-44492-6 (online) HP 6133

This document is available on the ACART website: www.acart.health.govt.nz



Foreword

ACART undertook a considerable amount of work in the 2013–2014 year for a committee of its size, and I am pleased to report that several significant projects have been completed.

In December 2013 we issued *Guidelines on Surrogacy involving Assisted Reproductive Procedures and Guidelines on Donation of Eggs or Sperm between Certain Family Members*, meeting the commitments made in response to the complaint to the Human Rights Commission in 2011 to review and if necessary amend the surrogacy guidelines to remove unjustified discrimination on the grounds of sex and sexual orientation. In June 2014 consultation with the Minister of Health was completed on *Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue Typing*. The quidelines were issued in August 2014.

Another major piece of work, almost completed, has been the preparation of advice to the Minister of Health on the import and export of gametes and embryos for human reproductive research and human assisted reproductive procedures. This work has grown in importance as more New Zealand couples seek fertility treatment overseas, and then seek to bring embryos *in vitro* back into New Zealand. The advice, which was informed by two rounds of consultation with stakeholders, is being finalised for presentation to the Minister of Health by the end of the year.

ACART's work takes place in a world where assisted reproductive technologies, processes and practices are changing fast. Over the past two or three years advances in egg freezing have opened up the possibility of women insuring against later loss of fertility by storing eggs when they are younger. The use of cryopreserved ovarian and testicular tissue for fertility purposes is growing and the Committee has sought expert advice as part of keeping a watching brief on when it might be appropriate to consider guidelines for use in New Zealand. The processes of preimplantation genetic diagnosis are becoming less expensive and its use is likely to increase. Access to and the regulation of surrogacy in countries accessible to and used by New Zealanders for transborder reproduction is constantly changing. In the research domain there is pressure to widen the range of research able to be done in New Zealand, where the constraint in the current guidelines on research on viable embryos has proved a barrier to building knowledge through clinical trials.

In such a context the flexible regulatory regime in New Zealand of laws, regulations and guidelines has its strengths. The ability for changes to be made reflecting new knowledge and new practices without the requirement for legislative change is one such strength. On the other hand, such a process puts an obligation on a committee such as ACART to consult, to be open to different views and not to adopt doctrinaire positons.

My time as Chair of ACART came to an end on 30 June 2014. It has been a privilege to undertake the role for the three years of my tenure. I am grateful to ACART members over that time for their commitment to the Committee's work and their willingness to provide both time and expertise. We have sought to make the workings of ACART more transparent to stakeholders and the general public. I have also sought to build a constructive relationship with providers. I wish to acknowledge their willingness to provide information, comment on proposals and work with the Committee.

In the course of its work in the period this report covers, ACART has worked closely with the Ethics Committee on Assisted Reproductive Technology (ECART), and the Ministry of Health. Our consultations with the outgoing Minister of Health have been frank and constructive. I have appreciated the time he has taken to understand and consider complex matters in what is in material terms a very small area of the health portfolio.

I also wish to express my appreciation to those who have assisted ACART's work by responding to requests for submissions. Consumers, providers, members of various groups and organisations, and individual members of the public, have been most helpful: their feedback is a valuable contribution to our work in this past year.

The Committee has been very ably supported by the staff members in the Secretariat. I wish to record my appreciation of their hard work and high level of professionalism.

Finally I cannot let this opportunity pass without acknowledging the quality of the support work of Betty Ann Kelly, who leads the Secretariat. She has brought an extraordinary range of knowledge and skills to her support of the Committee. I am pleased to be able pay tribute publically to her many attributes, which include her knowledge of the ART patch in New Zealand and overseas, the use she makes of her networks in the field in particular amongst academics and researchers, her ability to turn discursive ACART discussions into coherent papers, and her highly proficient and ethical management of the boundaries between the Committee and the Ministry. Her work is outstanding, and ACART and the public of New Zealand benefit greatly from it.

Dr John Angus

Retiring Chair, Advisory Committee on Assisted Reproductive Technology

In memory of Dr John Angus MNZM, PhD (1948–2015)

John Angus was the Chair of ACART for the period of this Annual Report and oversaw its preparation, but died before publication.

John became a member of ACART in 2011 when he was Children's Commissioner. When he retired from that role he continued as a member of ACART. He was appointed as Chair in 2012 and continued in the role until he stepped down in June 2014. He remained as a member until December 2014.

As is evident from this annual report, ACART completed several major projects under John's leadership. These included: developing an ethical framework for ACART, issuing guidelines on extending storage of gametes and embryos, amending surrogacy and family donation guidelines, amending guidelines on preimplantation genetic diagnosis with human leucocyte antigen tissue typing, and advising the Minister of Health on requirements for importing and exporting gametes and embryos. John worked positively to raise the profile of ACART and to establish constructive relationships in the ART sector, including through meeting fertility clinic personnel, conference presentations, and statutory consultations.

John had a deep commitment to children's interests. He brought to ACART's work vast policy experience, both from within government and as an independent voice. ACART members recognise John's significant contribution to the work of the Committee and will remember him fondly for his thoughtfulness, humour, wisdom and compassion.

Alison Douglass, Chair, Advisory Committee on Assisted Reproductive Technology

Contents

Foreword	ii
Introduction	1
Purpose of this report	
Background	
ACART's functions	
ACART's work during 2013/14	
ACART meetings	
Key projects in 2013/14	
ACART's monitoring functions	6
Other issues considered by ACART during 2013/14	
Links with ECART	
Conference attendance	
Other external engagement	
Publications	
ECART decisions 2013/14	10
Governance	11
Chair and Deputy Chair	11
Contact with the Minister of Health	1
Appendix 1: ACART membership	12
ACART members in the period	12
Biographies of ACART members	13
Appendix 2: Member attendance at full ACART meetings	17
Appendix 3: ACART working groups	18

Introduction

Purpose of this report

Section 42(3) of the HART Act requires 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 made by ECART in that period.

Background

ACART was established under section 32 of the HART Act, and first met in September 2005. Appendix 1 gives biographical information on ACART's membership during 2013/14.

ACART's functions

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

- issue guidelines and give advice to ECART on the matters that ECART must take into
 account in considering whether to give, change or cancel an approval for an extension
 to the applicable period for the storage of a human in vitro gamete or a human in vitro
 embryo
- issue guidelines and give 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, provide 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 (that is, a procedure that does not require ECART approval) 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 ECART 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.

ACART's terms of reference are available on its website www.acart.health.govt.nz

ACART's work during 2013/14

ACART meetings

ACART met as a full committee, with the support of the Secretariat, six times during 2013/14. (Appendix 2 sets out member attendance at these meetings.) Working groups met as required between meetings to progress projects. (Appendix 3 sets out further information on working group membership and meetings.)

Key projects in 2013/14

Guidelines projects

Issuing Guidelines on Surrogacy involving Assisted Reproductive Procedures and Guidelines on Donation of Eggs or Sperm between Certain Family Members

ACART received a complaint from a male couple in August 2011, through the Human Rights Commission, that ACART's *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* discriminate on the basis of sex and sexual orientation, because the guidelines require ECART to determine that the 'intending mother' must meet criteria based on medical need. ACART agreed that the policy was prima facie discriminatory.

In June 2012 ACART completed work on a consultation document about proposed amendments to the surrogacy and family gamete donation guidelines. Public consultation took place between July and September 2012. ACART then consulted with the Minister of Health before issuing the amended guidelines, as required by section 41(2) of the HART Act.

ACART issued amended Guidelines on Surrogacy involving Assisted Reproductive Procedures and Guidelines on Donation of Eggs or Sperm between Certain Family Members to come into effect on 16 December 2013.

Review of eligibility criteria in *Guidelines on Embryo Donation for Reproductive*Purposes and Guidelines on the Creation and Use, for Reproductive Purposes, of
an Embryo created from Donated Eggs in conjunction with Donated Sperm

This review of eligibility criteria follows the review instigated by the 2011 complaint to the Human Rights Commission. ACART decided in March 2013 that the project should include reviewing whether the embryo donation guidelines should be amended to enable the donation of an embryo created from donated gametes. The project has been on hold while other projects are progressed, and will resume in early 2015.

Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue Typing

In May 2009 ACART consulted with the Minister of Health on guidelines for the use of preimplantation genetic diagnosis (PGD) with human leucocyte antigen (HLA) tissue typing. The guidelines are intended to replace the existing PGD guidelines, developed by the former National Ethics Committee on Assisted Human Reproduction.

After receiving ACART's consultation report, the Minister asked the National Ethics Advisory Committee (NEAC) to provide him with advice on the guidelines. After receiving NEAC's advice in August 2009, the Minister invited ACART to comment on some matters raised by NEAC.

ACART subsequently presented amended guidelines to the Minister in July 2011. The Deputy Chair, with the Chair of ECART and an ECART member, met the Minister on 9 June 2014 to discuss the guidelines. ACART issued *Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue Typing* which came into effect in August 2014.

Advice projects

Advice to the Minister of Health on import and export of gametes and embryos

The movement of gametes and embryos in and out of New Zealand can be seen in the context of recent growth in cross-border reproductive care. The HART Act requires ACART to:

- provide the Minister of Health with information, advice and, if it thinks fit, recommendations on the import into, or export from, New Zealand of in vitro human gametes or in vitro human embryos in respect of human reproductive research (section 37(1)(g))
- provide the Minister of Health with information, advice and, if it thinks fit, recommendations on the import into, or export from, New Zealand of *in vitro* donated cells or *in vitro* donated embryos in relation to human assisted reproductive technology (section 38(f)).

ACART must undertake public consultation on proposed advice before it advises the Minister of Health. For this project ACART has undertaken two rounds of public consultation.

The first consultation stage, between March and June 2013, focused on eliciting views on some key ethical and policy issues that arise from the differences between requirements in other countries and in New Zealand. The consultation was based on a paper ACART issued entitled *Import and Export of Gametes and Embryos: Background paper for stakeholder discussion.*

ACART then undertook in February–March 2014 the public consultation on proposed advice to the Minister of Health, as required by the HART Act. ACART issued a public consultation document *Import and Export of Gametes and Embryos: Proposed advice to the Minister of Health.*

The consultation elicited 17 submissions and the Chair held one meeting. ACART reported finalised advice to the Minister of Health in late 2014.

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 certain matters in relation to the use of gametes and embryos in human reproductive research.

In June 2007 ACART provided the then Minister of Health with advice on human reproductive research following extensive public consultation in the 2006/07 financial year. At the request of the Minister, ACART has not undertaken any work to develop guidelines or further advice. The current *Guidelines for Research on Gametes and Non-Viable Embryos*, developed by the former National Ethics Committee on Assisted Human Reproduction, remain in force.

ACART continues to monitor human reproductive research, including statutory requirements in other jurisdictions. ACART's Briefing to the Incoming Minister of Health includes discussion about human reproductive research.

Advice to the Minister of Health on informed consent

ACART is required to provide the Minister of Health with advice on requirements for informed consent in relation to the use of gametes and embryos in human reproductive research (section 37(1)(f) of the HART Act), and in relation to human assisted reproductive technology (section 38(d)).

ACART's current work to develop advice on informed consent is focused on the context of human assisted reproductive technology. ACART has concluded that informed consent in the context of human reproductive research is best addressed as part of any future work to review guidelines on human reproductive research.

The work in this period included a subproject with the goal of obtaining robust descriptive information on clinics' informed consent processes, and any challenges for clinics in respect of informed consent. Secretariat staff interviewed staff members in the three Auckland fertility clinics. The report of the subproject was sent to the clinics involved for review.

ACART plans to undertake public consultation in the first half of 2015 on its proposed advice to the Minister of Health.

ACART's monitoring functions

Monitoring the application and health outcomes of assisted reproductive procedures and established procedures

Section 35(2) of the HART Act requires ACART to monitor the application and health outcomes of assisted reproductive procedures and established procedures.

Quantitative data

A key way in which ACART monitors outcomes of assisted reproductive procedures is through the annual report of the Australia and New Zealand Assisted Reproduction Database (ANZARD). New Zealand fertility services providers contribute data to ANZARD.

During 2012 ACART finalised a contract with the University of New South Wales to produce a quantitative New Zealand-specific report on numbers, types and perinatal outcomes of assisted reproductive treatments, based on the annual ANZARD report (which in most aspects combines Australian and New Zealand data). The New Zealand report drew on 2009 data, and has been placed on ACART's website.

Two further New Zealand-specific reports have now been received, for 2010 and 2011. ACART anticipates continuing to contract for annual New Zealand-specific reports, following the release of each ANZARD report.

Psychosocial outcomes

ACART also monitors, through published papers, health and psychosocial outcomes for parties involved in assisted reproduction and resulting children. Research of interest includes:

- (New Zealand) Sonja Goedeke's doctoral research on embryo donation
- (New Zealand) Papers by Adjunct Professor Ken Daniels on outcomes for families formed from gamete donation
- (United Kingdom) Papers from longitudinal research looking at outcomes for children born from assisted reproduction.

Monitoring developments in human reproductive research

Section 35(2) of the HART Act also requires ACART to monitor developments in human reproductive research.

In New Zealand it is currently permissible to store cryopreserved ovarian tissue. However, it is not possible to use the material because the procedure is classified as an assisted reproductive procedure requiring ECART approval. However, ACART has not yet issued guidelines. Following a 2010 technical report on the procedure, ACART decided that the limited evidence about the safety of the procedure did not support undertaking further work at that stage.

However, ACART has maintained a watching brief on international evidence about outcomes of the procedure.

In April 2014 ACART agreed to commission a further technical report because of potential future demand in New Zealand for the use of cryopreserved ovarian and testicular tissue, and developments since the 2010 report was received. The updated report prepared by Professor Claus Andersen at the University of Copenhagen was received in December 2014.

Monitoring the decisions of ECART

ACART's terms of reference require it to monitor ECART's decisions, to ensure the decisions fall within the guidelines set by ACART. In April 2012 ACART considered options for the future operation of the function. In August 2012 ACART wrote to ECART seeking views on ACART's proposal. ECART is in agreement with the proposal.

ACART will continue the current practice of including in agendas the summaries of applications prepared by the ECART Secretariat, with the relevant ECART minutes. In addition, the ACART Secretariat will report annually to ACART about ECART applications and decisions.

The first annual report about ECART's decisions was provided to ACART's March 2014 meeting, to cover the period July 2012–June 2013.

ACART receives full copies of all applications to ECART. ECART is required to give ACART a copy of an approval and the relevant application, as soon as is practicable after giving an approval. The copies are available at ACART meetings for members to read if interested.

Other issues considered by ACART during 2013/14

Applicability of the Code of Health and Disability Services Consumers' Rights

ACART wrote to the Health and Disability Commissioner in November 2012 about potential gaps in the scope of the Code of Health and Disability Services Consumers' Rights in regard to embryo donors. Following a response from the Health and Disability Commissioner in February 2013, ACART invited him or a representative to discuss the matter at ACART's September 2013 meeting.

On 5 February 2014 ACART made a submission to the Health and Disability Commissioner's periodic review of the Health and Disability Commissioner Act 1994 and the associated Code of Health and Disability Services Consumers' Rights.

Preparation of Briefing to the Incoming Minister

Work began in the period on a Briefing to the Incoming Minister of Health (BIM). The purpose of the BIM was to:

- · introduce ACART to the incoming Minister
- · highlight ACART's relationship with the Minister
- discuss ACART's current and upcoming work programme
- highlight key issues that may be of interest to the Minister.

The Minister of Health has delegated responsibility for ACART to the Associate Minister of Health, the Honorable Peter Dunne. ACART forwarded the BIM to the Associate Minister of Health on 10 November 2014.

Links with ECART

The HART Act requires that ACART and ECART each liaise with the other committee. ACART is required to liaise with ECART on general and specific matters relating to assisted reproductive procedures and the conduct of any kind of human reproductive research.

ACART's liaison with ECART during the period included:

- a member of each committee attended meetings of the other committee as a memberin-attendance
- the Chairs of ACART and ECART, with Dr Freddie Graham (member of ECART) met on 3 October 2013 to discuss issues related to Preimplantation Genetic Diagnosis
- ACART invited ECART to provide feedback to the consultation on proposed advice on requirements for importing and exporting in vitro gametes and embryos.

Conference attendance

ACART supported members to attend three conferences in the period.

Sue McKenzie and Jonathan Darby attended the New Zealand Bioethics Conference *New questions new answers* in Dunedin, 24–26 January 2014.

Mike Legge attended the *International Symposium on Transforming Public Engagement on Controversial Science and Technology* in Hamilton, 17–18 February 2014.

Alison Douglass attended the Law Society conference *International Adoption and Surrogacy – family formation in the 21st Century* in Wellington on 9 April 2014.

Other external engagement

On 6 August 2013 the Chair attended a meeting of the National Ethics Advisory Committee (NEAC) at the invitation of NEAC.

On 2 September 2013 the Chair participated by teleconference in a meeting with Mr Anders Jonsson, a Swedish member of Parliament who was interested in learning about the policy and operation of surrogacy in New Zealand. Other meeting participants included the Chair of ECART, a counsellor from Fertility Associates Wellington, and Ministry of Health officials.

On 24 October 2013 the Chair met by teleconference with Dr Naoake Kuji, a Japanese obstetrician who was interested in learning about the policy and impacts of donor offspring having access to identifying information about donors.

Publications

ACART published on its website (www.acart.health.govt.nz):

- ACART's Annual Report 2012/13
- · agendas of ACART meetings, after each meeting
- minutes of ACART meetings, after their confirmation at each following meeting
- Assisted Reproductive Technology in New Zealand 2010
- amended and renamed Guidelines on Surrogacy involving Assisted Reproductive Procedures
- amended Guidelines on Donation of Eggs or Sperm between Certain Family Members
- amended and renamed advice to ECART Applications that fall under more than one of the guidelines issued by the Advisory Committee on Assisted Reproductive Technology
- consultation document *Import and Export of Gametes and Embryos: Proposed advice to the Minister of Health*
- submissions and meeting notes from public consultation about import and export of gametes and embryos.

ECART decisions 2013/14

Between 1 July 2013 and 30 June 2014 ECART considered 29 applications for assisted reproductive procedures and human reproductive research. There were:

- 12 applications for surrogacy involving fertility providers
- three applications for gamete donation between certain family members
- 10 applications for embryo donation for reproductive purposes
- two applications for the creation and use, for reproductive purposes, of an embryo created from donated eggs in conjunction with donated sperm
- two applications for research on gametes or non-viable embryos.

Of these applications, 17 were approved outright, six were approved subject to conditions, and six were deferred.

In addition, ECART considered 49 applications to extend the storage period of gametes or embryos. ECART approved 41 applications, declined two applications, and deferred six applications.

The details of these decisions are set out in ECART's Annual Report 2013/14.

Governance

Chair and Deputy Chair

Chair

Dr John Angus was first appointed as Chair in October 2011 and reappointed in April 2013. John resigned as Chair on 30 June 2014 and resigned as a member on 31 December 2014.

Deputy Chair

Members selected Alison Douglass as Deputy Chair in July 2013. Alison was Acting Chair from 1 July 2014 until her appointment as Chair in January 2015.

Contact with the Minister of Health

The Chair met the Minister of Health on 24 October 2013.

The Deputy Chair (with the Chair of ECART and a member of ECART) met the Minister of Health on 9 June 2014.

Appendix 1: ACART membership

ACART members in the period

Dr John Angus – Chair (from November 2011 to 30 June 2014), continuing as member until 31 December 2014.

Alison Douglass – Deputy Chair from July 2013, Acting Chair from 1 July 2014 and Chair from January 2015.

Dr Karen Buckingham

Jonathan Darby

Nikki Horne

Associate Professor Michael Legge

Sue McKenzie

Dr Barry Smith

Secretariat staff members

Betty-Ann Kelly, senior policy analyst Emma Doust, senior policy analyst (September 2013–December 2014) Stella Li (to August 2014)

Chris Wilson (to August 2013)

Additional administrative support was provided by the Business Services and Committee Support team in the Policy Business Unit of the Ministry of Health, in particular Helen Martin.

Biographies of ACART members

Current members

John Angus MNZM (Chair until 30 June 2014, member until 31 December 2014)

Membership role: Articulate interests of children

The late Dr John Angus was appointed as an ACART member in November 2010 for three years, and re-appointed in November 2013 for a further three years. He was appointed as Chair in October 2011 for one year. In April 2013 his term as Chair was extended until December 2013. He was re-appointed as Chair in March 2014 but resigned as Chair for health reasons at the end of June 2014. He remained on the Committee as a member until December 2014.

John was Children's Commissioner from 2009 to 2011. Prior to that, he had a long career as a senior social policy advisor within the Ministry of Social Development and its predecessors (1987–2006), and then as a social policy consultant (2006–2009).

John began his career as a historian after obtaining a BA (Hons) (1971) and then a doctorate in history from the University of Otago (1977). He went on to spend almost 10 years as a social worker in Dunedin for the Department of Social Welfare, and completed a Diploma in Social Work (Victoria University of Wellington 1982). John then moved into social policy. He has led work on a wide range of child and family policy including the care and protection of children, child support and support for vulnerable families.

John lived in Central Otago. He is survived by his wife, two adult sons and four granddaughters.

Alison Douglass (Deputy Chair to 30 June 2014, Acting Chair from 1 July 2014, Chair from January 2015)

Membership role: Expertise in relevant areas of the law

Alison Douglass was appointed to ACART in May 2011 for three years. Members selected her as Deputy Chair in July 2013, and she became Acting Chair from 1 July 2014.

Alison is a barrister, practising out of Wellington and Dunedin. She has been a practising lawyer since 1985, and specialises in health and disability law. Prior to moving to the independent bar in 2008, Ms Douglass was a partner, then consultant, to a Wellington law firm, Tripe Matthews and Feist. She completed an LLB at University of Canterbury (1984) and a Master of Bioethics and Health Law at University of Otago (1999).

Alison is the Convenor of the New Zealand Law Society Health Law Committee, which provides submissions on health law reform and until July 2014 Alison was co-chair of the ACC Research Ethics Committee. She was the legal member to the Interim, then National Ethics Committee on Assisted Human Reproduction (1993–2002) prior to the enactment of the HART Act, and is a former chair of the Wellington Ethics Committee.

She has worked part-time as a senior lecturer in health law and bioethics at the University of Otago, Wellington. In July 2014 Alison was appointed Adjunct Senior Lecturer to the Bioethics Centre, University of Otago.

Alison has published journal articles on assisted reproductive technology, and in 2006 prepared the *Report on the Regulatory Framework Governing Assisted Reproductive Technologies in New Zealand* for the Ministry of Health.

She lives in Dunedin and is married with three children.

Karen Buckingham

Membership role: Expertise in assisted reproductive procedures

Dr Karen Buckingham was appointed to ACART in November 2010 and is currently serving her second term on ACART. Her term expires in December 2016.

Karen is a graduate of the Auckland School of Medicine and trained as an obstetrician and gynaecologist in both New Zealand and the United Kingdom. She worked as a senior lecturer at the University of Auckland from 2003 to 2008 and as a consultant obstetrician and gynaecologist for the Auckland District Health Board from 2003 to 2012. For the past 14 years she has worked mainly in the field of reproductive endocrinology and infertility. She now works in private practice for Repromed and Auckland Gynaecology Group.

Karen has held a wide range of clinical, teaching and research roles in New Zealand and overseas. Her research interests include recurrent pregnancy loss, polycystic ovarian syndrome and antiphospholipid antibodies in infertility.

She lives in Auckland with her husband and three children.

Jonathan Darby

Membership role: Disability perspective

Mr Jonathan Darby was appointed to ACART in April 2013 for three years.

Jonathan is an enrolled barrister and solicitor of the High Court who has recently been involved in volunteer work with Christchurch Hospital (2010–present), and the International Paralympic Committee Athletics World Championships (2011). He holds a Bachelor of Laws (2007), a Bachelor of Arts (2007), a New Zealand Diploma in Business, and a Diploma in Management. He is a member of the Disability Law Team at Community Law Canterbury and is currently studying at Otago University towards a Graduate Diploma in Bioethics and Health Law.

Nikki Horne

Membership role: Consumer perspective

Nikki Horne was appointed to ACART in November 2010 for two years, and has since been reappointed until December 2015.

Nikki is a member of Fertility New Zealand, the national group for consumers of fertility services. She has served as a committee member of the Auckland Group for over six years and is also a representative on the Fertility New Zealand Board. Her specific roles have included facilitating consumer contact support groups, organising information evenings, and clinic liaison. Nikki was appointed as an independent trustee of The Fertility Funding Charitable Trust in 2014.

Nikki currently works part-time as the Social Media and Event Manager at Career Engagement Group in Auckland. Before this role she worked for eight years as Events Manager for Obex Medical Ltd.

Nikki is married with two daughters, both born after years of IVF treatment and recurrent miscarriage. After completing her family Nikki was an egg donor for another couple.

Michael Legge

Membership roles: Expertise in human reproductive research, and expertise in ethics

Associate Professor Michael Legge was initially appointed to ACART in October 2011 for one year with the role of expertise in ethics. When he was reappointed in 2013 for two years he took on the additional role of expertise in human reproductive research. He has been appointed until October 2015.

Michael recently retired as Associate Professor of Biochemistry, Associate Dean of Medical Education and Director of Medical Laboratory Science at the University of Otago, and holds an Honorary Associate Professorship with the university. He was previously National President of the Infertility Society of New Zealand (1995–1998).

Michael was a member of the University of Otago Human Ethics Committee (2000–2011). He is a member of the European Commission Ethical Review Panel (2006–present) and the European Commission Life Science Expert Panel (2003–present).

Michael completed a PhD in Experimental Embryology at the University of Essex (1988) and a Bachelor of Science in Mammalian Physiology at London South Bank University, United Kingdom (1972). He also completed a Fellowship with the Royal College of Pathologists of Australasia (2010), and is a Fellow of both The New Zealand Institute of Medical Laboratory Science (1978) and the Institute of Biomedical Science United Kingdom (1973).

Sue McKenzie

Membership role: General layperson

Mrs Sue McKenzie was appointed to ACART in April 2013 for three years.

Sue McKenzie has had two careers over the last 30 years: lecturing as a senior academic at tertiary level and a private business consultancy advising corporate and small business clients. She also has a long voluntary association with various business and community groups at local and national level.

Sue is a Trustee of the Canterbury Community Trust. Her current responsibilities include Chair of the Housing Committee, Member of the Managed Investment Committee and Member of the Direct Investment Committee. She is also Deputy Chair of the Greater Canterbury Community Response Forum working with and advising the Ministry of Social Development re transforming Social Services.

At a national level Sue is a member of the Medical Radiation Technologists Board. She is Convenor of the Education Committee and a member of the Accreditation Panel for Graduate and Postgraduate Medical Imaging and Radiation Therapy programmes. She is also a member of the Professional Standards Committee.

Sue lives at Charing Cross (near Christchurch), and is married with adult children and six grandchildren.

Sue is also a Justice of the Peace (JP).

Barry Smith QSM

Membership role: Expertise in Māori customary values and perspectives

Dr Barry Smith (Te Rarawa, Ngāti Kahu) was appointed to ACART in April 2013 for three years. Barry is a Population Health Analyst with the Lakes District Health Board based in Rotorua. He was a contract analyst and assessor with the Ministry of Health. Barry is a member of the Health Research Council College of Experts and chairs the Health Research Council Ethics Committee and the Lakes DHB Research and Ethics Committee. He is a member of the Middlemore Tissue Bank Governance Committee and the Podiatrists' Board of New Zealand.

He was a member of the 2014 National Science Challenge international health assessment panels organised through the Ministry of Business, Innovation and Employment. Barry's current research work on ethics in Maori contexts is supported by the Royal Society of New Zealand Marsden Fund. He holds a BSc in chemistry and mathematics, an MPhil and PhD in sociology, a Grad Dip Arts in music and a Dip Tchg. He was awarded the Queens Service Medal in 2008.

Appendix 2: Member attendance at full ACART meetings

Member	12 July 2013	13 Sept 2013	8 Nov 2013	14 Feb 2014	11 April 2014	13 June 2014
John Angus (Chair)	✓	✓	✓	✓	✓	Α
Karen Buckingham	А	✓	✓	✓	✓	✓
Alison Douglass	А	✓	✓	✓	✓	✓
Nikki Horne	✓	✓	✓	✓	✓	✓
Michael Legge	✓	✓	✓	✓	✓	✓
Barry Smith	✓	А	✓	✓	А	✓
Jonathan Darby	✓	✓	✓	✓	✓	✓
Sue McKenzie	✓	✓	✓	✓	✓	Α
Total members present	6	7	8	8	7	6

[✓] Present

A Apologies

Appendix 3: ACART working groups

Working group	Responsibilities and meeting dates
Import and Export of Gametes and Embryos Working Group John Angus (Chair, from April 2013) Karen Buckingham Michael Legge Alison Douglass	Continuing work on proposed advice to the Minister on requirements for the import and export of <i>in vitro</i> gametes and embryos under sections 37 and 38 of the HART Act. The Working Group met on 22 May 2014.
Guidelines Review Working Group John Angus (Chair) Alison Douglass Sue McKenzie Jonathan Darby	Review of eligibility criteria in ACART's surrogacy and family gamete donation guidelines, as part of addressing a complaint to the Human Rights Commission, and subsequent review of eligibility criteria in the embryo donation and donated eggs/donated sperm guidelines. The Working Group met on 15 August 2013.
Informed Consent Working Group John Angus (Chair until 13 May 2014, continued as member) Mike Legge (Chair from 14 May 2014) Jonathan Darby Nikki Horne	Continuing work on proposed advice to the Minister of Health on informed consent requirements for assisted human reproduction, as required by section 38(d) of the HART Act. The Working Group met (usually by teleconference): 16 December 2013 3 April 2014 12 June 2014
Human reproductive research working group Alison Douglass (Chair) Mike Legge Sue McKenzie Barry Smith	Preparing advice on human reproductive research to be included in ACART's briefing to the incoming Minister of Health. The Working Group met by teleconference: 13 February 2014 2 April 2014
Use of cryopreserved ovarian and testicular tissue Karen Buckingham Mike Legge	Establishment of a contract for an independent technical report about the use of cryopreserved ovarian and testicular tissue. The Working Group held discussions by email during May 2014.