Advisory Committee on Assisted Reproductive Technology Annual Report 2012/13

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Foreword

I am pleased to present this Annual Report for 2012/13.

The complexity of ACART's work continues. New techniques and uses of assisted reproductive procedures in circumstances not previously contemplated raise new challenges to existing guidelines and processes. Societal acceptance of such uses is changing.

The Committee's most significant piece of work this year has been the response to a complaint to the Human Rights Commission that the existing guidelines on surrogacy discriminate against gay men. The mediation that followed the complaint led in late 2011 to ACART initiating a review of some aspects of the surrogacy guidelines. In the course of this review several legal questions have arisen which are taking time to resolve. The work reflects the complexity of the issues ACART addresses, noted above, and the complicated regulatory framework it works within.

Other significant projects were finalising the guidelines on extending storage of gametes and embryos, which were issued in August 2012; work to develop advice on import and export of gametes and embryos that included consultation with the public; and work on a review of embryo donation guidelines and donated eggs with donated sperm guidelines.

I am grateful to ACART members for their 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 the three members whose terms ended in the past year: Associate Professor Andrew Shelling who was Deputy Chair, Mrs Judy Turner, and Mrs Cilla Henry. ACART has benefited greatly from their expertise and wisdom. Three new members joined the Committee: Dr Barry Smith, Mrs Sue McKenzie, and Mr Jonathan Darby.

In the course of its work programme in the period this report covers, ACART has worked closely with the Ethics Committee on Assisted Reproductive Technology, the Ministry of Health, and providers of fertility services. Information and insights from these sources are of considerable assistance to ACART.

The Committee has been very ably supported by the staff members in the Secretariat. I wish to record my appreciation for their high level of professionalism. Thanks are due to the Ministry of Health for its ongoing support. The Committee also has a constructive relationship with the Minister of Health, the Hon Tony Ryall.

Finally, I 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.

Dr John Angus Chair, Advisory Committee on Assisted Reproductive Technology

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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 2011/12 (including current and former members).

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 2011/12

ACART meetings

ACART met as a full committee, with the support of the Secretariat, five times during 2012/13. (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 2012/13

Issuing Guidelines on Extending the Storage Period of Gametes and Embryos

ACART consulted with the Minister in June 2012 on finalised extended storage guidelines following public consultation, and concluded consultation the same month. The guidelines were issued to ECART in August 2012, and came into effect on 3 September 2012.

Review of eligibility criteria in *Guidelines on Surrogacy Arrangements* involving Providers of Fertility Services 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 considered 41 submissions including written submissions and meeting notes. ACART then finalised the proposed guidelines. Legal advice received indicated some issues that needed to be resolved. The Minister requested Crown Law advice on the matter.

ACART has been in discussion with the Ministry of Health and the Minister of Health to work through the legal issues.

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 guidelines should be amended to enable the donation of an embryo created from donated gametes. ACART decided high level policy positions in May 2013.

The project is on hold until new surrogacy and family gamete donation guidelines have been issued. This will enable the review to take into account the outcomes of the first stage of the guidelines review.

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 decided to do 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.*

The consultation elicited 24 submissions. In addition, members held 19 meetings with a wide variety of individuals and groups. The meetings were a useful opportunity to explore the rationale for points of view. People were generous in sharing information and perspectives.

ACART plans a second stage of public consultation in late 2013 to seek feedback on proposed advice to the Minister of Health, with a view to providing finalised advice to the Minister in the first half of 2014.

Ethical Framework

In 2012 ACART developed an Ethical Framework, based on a paper commissioned from Professor Gareth Jones. The framework sets out and makes transparent the moral principles that guide ACART's deliberations and that are the basis for the guidelines and advice it develops. In 2013 ACART published an *Ethical Framework Process and Checklist*. The *Ethical Framework Process and Checklist* is designed to be used by ACART when assessing problems and developing options.

Other guidelines and advice projects

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 (PGD) diagnosis with human leukocyte 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 guidelines have been discussed with the Minister and await a formal response.

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.

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.

ACART has needed to give higher priority to other projects during 2012/13, but plans to resume the project in 2014 with a view to public consultation on proposals in 2014/15.

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.

In 2013 ACART contracted with the University of New South Wales for a New Zealand report to cover 2010, at that time the most recent data available. The 2010 report was received in June 2013 and will be placed on ACART's website when finalised.

ACART anticipates continuing to contract for annual New Zealand-specific reports.

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 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.

During 2012/13 ACART continued its established practice of monitoring relevant human reproductive research through circulating papers of interest to members, including journal articles and reports from conference attendance. This has enabled ACART to learn about procedures which may come to notice as being of interest to New Zealanders.

In March 2013 members received a Secretariat paper setting out human reproductive research currently approved in Australia and the United Kingdom.

ACART members with expertise in human reproductive research have contributed by providing oral and written updates about areas of research of interest to members.

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.

This approach will be less resource intensive than a full bimonthly report, and will be more useful for identifying trends in applications and decisions. The first annual report about ECART's decisions will be 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 2012/13

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.

Use of cryopreserved ovarian tissue

The storage of ovarian tissue does not require ECART approval, but the use of such tissue does. However, ECART is not able to consider applications to use such tissue, because ACART has not issued any guidelines.

In 2010 ACART commissioned a technical report on the feasibility of undertaking this procedure in New Zealand. A key finding was the limited information and evidence available on the safety and efficacy of the procedure and outcomes. In 2011 members decided not to proceed with further work but would continue to monitor the developments on this procedure.

In March 2013 members noted that the use of cryopreserved ovarian tissue continues to develop. Members acknowledged the possibility of increased interest in New Zealand in the procedure, and agreed to continue monitoring the development and use of the procedure.

Submission on Marriage (Definition of Marriage) Amendment Bill

ACART's submission in October 2012 did not express a view on the merits of the Bill. The submission provided the Select Committee with a summary of the Committee's findings, in the review of the surrogacy guidelines, on outcomes for children parented by single men and male couples, and gave details of the sources used. The submission said that ACART had concluded that what counted for children was family functioning, not family structure.

ACART also noted that if the Bill progressed, it would be useful to clarify the effect of the amendment on the use of the word "spouse" in the Adoption Act 1955.

Submission to Police on "Cost Recovery for Certain Police Services"

ACART made a submission in February 2013 to the Police about the proposal that the Police vet service was a potential candidate for cost recovery. ACART's *Guidelines on Embryo Donation for Reproductive Purposes* require that profiles of potential recipients of donated embryos include any police vet information.

The submission said that the Police vet in the context of embryo donation has both a public and a private benefit, and therefore cost recovery for this purpose appears to be suitable. The anticipated level of cost recovery (\$3–\$7 including GST, and \$10 for urgent requests) would have a very small additional financial impact on the significant overall costs incurred by people paying for fertility treatment that involves using donated embryos.

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
- ACART contributed feedback to ECART's proposed application form for applications to extend the storage period of gametes and embryos, in accord with the *Guidelines on Extending the Storage Period of Gametes and Embryos* issued by ACART in August 2012
- ACART invited ECART submissions on the two consultations in the period.

Conference attendance

ACART's Chair attended three conferences in 2012/13 as an invited speaker:

- the Australian Association of Bioethics and Health Law Conference in Auckland in July 2012 (co-presenter with ACART member Alison Douglass on informed consent in the context of assisted reproduction)
- the Fertility Society of Australia Annual Meeting in Auckland in October 2012.(presented on regulating assisted reproduction)
- the Medical Law Conference in Wellington in March 2013 (co-presenter with Winnie Duggan on informed consent in the context of assisted reproduction).

Nikki Horne also attended the Fertility Society of Australia Annual Meeting on behalf of ACART.

Michael Legge attended a consumer information day in Auckland in March 2013 as an invited speaker, in place of the Chair. Michael spoke on ACART's consultation on ethical and policy issues associated with the import and export of gametes and embryos.

Member training

ACART held a training day for new members in May 2013. The programme included presentations on ACART's processes and work; the role of the Ministry of Health in relation to ACART's work; bioethics in a Māori context; consumer perspectives; and the work of fertility counsellors.

Publications

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

- its Annual Report 2011/12
- agendas of ACART meetings, after each meeting
- minutes of ACART meetings, after their confirmation at each following meeting
- Assisted Reproductive Technology in New Zealand 2009
- Submissions and meeting notes from public consultation on proposed amendments to the *Guidelines on Surrogacy Arrangements involving Providers of Fertility Services* and *Guidelines on Egg or Sperm Donation between Certain Family Members*
- Import and Export of Gametes and Embryos: Background paper for stakeholder discussion
- Submissions and meeting notes from public consultation on ethical and policy issues associated with the import and export of gametes and embryos
- Ethical Framework for ACART
- Ethical Framework Process and Checklist.

ECART decisions 2012/13

Between 1 July 2011 and 30 June 2012 ECART considered 55 applications for assisted reproductive procedures and human reproductive research. There were:

- 25 applications for surrogacy arrangements involving fertility providers
- 12 applications for gamete donation between certain family members
- 10 applications for embryo donation for reproductive purposes
- three 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
- three applications for extension to ECART approval (for previously approved applications).

Of these applications, 43 were approved outright, eight were approved subject to conditions, and four were deferred.

The details of these decisions are set out in ECART's Annual Report 2012/13.

Governance

Chair and Deputy Chair

Chair

Dr John Angus was first appointed as Chair in October 2011 and reappointed in April 2013.

Deputy Chair

Members selected Alison Douglass as Deputy Chair in July 2013.

Contact with the Minister of Health

The Chair met the Minister of Health on 11 April 2013.

Appendix 1: ACART membership

ACART members

Current members

Dr John Angus – Chair (from November 2011) Alison Douglass – Deputy Chair (from July 2013) Dr Karen Buckingham Jonathan Darby Nikki Horne Associate Professor Michael Legge Sue McKenzie Dr Barry Smith

Other members during the period

Cilla Henry (to March 2013) Judy Turner (to March 2013) Associate Professor Andrew Shelling – Deputy Chair (to December 2012)

Secretariat staff members

Betty-Ann Kelly, senior policy analyst Stella Li, policy analyst (from July 2012) Chris Wilson, policy analyst (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)

Membership role: Articulate interests of children.

Dr John Angus was appointed as an ACART member in November 2010 for three years, and subsequently appointed as Chair in October 2011 for one year. In April 2013 his term as Chair was extended until December 2013.

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.

John has led policy work on child support, the care and protection of children and support for vulnerable families.

John is married with two adult sons and two granddaughters. He lives in Central Otago.

Alison Douglass (Deputy Chair)

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.

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 currently co-chair of the ACC Research Ethics Committee and convenor of the New Zealand Law Society Health Law Committee, which provides submissions on health law reform. 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.

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 for three years.

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 12 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 young 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 is also a member of the Canterbury District Health Board Community and Public Health & Disability Advisory Committee (2011–present). He holds a Bachelor of Laws (2007), a Bachelor of Arts (2007), a New Zealand Diploma in Business, and a Diploma in Management.

Nikki Horne

Membership role: Consumer perspective.

Nikki Horne was appointed to ACART in November 2010 for two years, and has since been reappointed until November 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 Fertility New Zealand – Auckland Group for four years. Her specific roles have included facilitating consumer contact support groups, organising information evenings, and clinic liaison.

Nikki currently works part time as the Creative Director at Career Engagement Group in Auckland. Before this role she worked for eight years as Events Manager for Obex Medical Ltd. Her time there included managing all events, conferences and functions for the company across a broad range of medical specialties, including embryology.

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 April 2013 for two years he took on the additional role of expertise in human reproductive research.

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

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 past 20 years: lecturing at tertiary level, and business consultancy. She also has a long voluntary association with various business and community groups at a local and national level.

Until 2011 Sue was a senior academic staff member at the Canterbury Polytechnic Institute of Technology, lecturing in business and communication subject areas. Her consultancy business advises corporate and small business client.

Sue is a Trustee of The Canterbury Community Trust. Her current Trust responsibilities include chairing the Housing Committee and membership of the Direct Property Committee. She is also a member of the Community Response Forum, which is charged with taking the leadership and governance role in the delivery of social services across the greater Canterbury region.

At a national level she is a member of the Medical Radiation Technologists Board. For two years she has been a member of the Accreditation Panel reviewing the undergraduate and postgraduate Medical Imaging and Radiation Therapy programmes at UNITEC and the University of Otago.

Other current and past roles held by Sue include being a Justice of the Peace, roles in the National Party, and membership of the National Council of Women of New Zealand.

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 Lakes District Health Board (DHB) and a contract analyst and assessor with the Ministry of Health. He is a member of the Health Research Council's College of Experts and other HRC committees, will chair the Health Research Council Ethics Committee (from October 2013) and currently chairs the University of Otago Pharmacovigilance Ethics Advisory Group and the Lakes DHB Research and Ethics Committee.

Barry also chaired the defunct Bay of Plenty Regional Ethics Committee (2002–2004) and Multi-region Ethics Committee (2008–2009). He is a member of the Middlemore Tissue Bank Governance Committee and the Podiatrists Board of New Zealand. Barry holds a Bachelor of Science (1970) in chemistry and mathematics, a Master of Philosophy (Hons) (1974) and PhD (1990) in sociology, a Graduate Diploma of Arts (2004) in music and a Diploma of Teaching (1970). He was awarded the Queens Service medal in 2008.

Members whose term ended during 2012/13

Andrew Shelling (Deputy Chair)

Membership role: Expertise in human reproductive research.

Associate Professor Andrew Shelling was appointed to ACART in August 2006 have completed two terms in March 2013 when he retired as a member.

Andrew 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. He 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.

Andrew is currently Associate Dean (Research) in the Faculty of Medical and Health Sciences at The University of Auckland, and was previously deputy head of the Department of Obstetrics and Gynaecology, The University of Auckland. He is extensively involved in teaching reproduction, genetics and cancer at the university. He has recently served as president of the New Zealand branch of the Human Genetics Society of Australasia. He is currently an associate editor of the journal *Human Reproduction*, one of the leading journals in the area of reproductive research. He is a trustee for the Nurture Foundation for Reproductive Research.

Cilla Ruruhira Henry QSM

Membership role: Expertise in Māori customary values and perspectives.

Cilla Henry was appointed to ACART in July 2007, and had completed two terms when she retired as a member in March 2013.

Cilla grew up under the mantle of the Kīngitanga movement, deeply entrenched in Waikato kawa (protocol) and tikanga (teachings). Her hapū connections are Ngāti Wairere and Ngāti Hako Hauraki.

Cilla is a Te Kauhanganui tribal representative, Hukanui Marae; a Māori specialist consultant in the bicultural therapy model for the Department of Corrections Psychological Services, Hamilton, working with Māori inmates at Waikeria Prison; a trustee of Raukura Waikato Social Services; and a consumer representative for the Ministry of Consumer Affairs.

She is also a member of the National Council of Women of New Zealand and the Māori Women's Welfare League, and a representative on the Care and Protection Panel for Children and their Families (Child, Youth and Family). She was appointed a Justice of the Peace in 1996 and received the Queen's Service Medal for public service in 2003.

Judy Turner

Membership role: General layperson.

Mrs Judy Turner was appointed to ACART in October 2011, and her term ended in March 2013.

Judy is currently Deputy Mayor of Whakatane District Council (2011–present). Prior to this, she was a contractor in the community and charitable sector, and was previously a Member of Parliament (2002–2008). She is currently a trustee for the Life Education Trust (Eastern Bay of Plenty), a trustee for Habitat for Humanity (Eastern Bay of Plenty) and an Advisory Board member for Whakatane Youth Engagement Services, to name a few such positions. She is also deputy leader of United Future.

Appendix 2: Member attendance at full ACART meetings

Member	13 July 2012	28 September 2012	23 November 2012	8 March 2013	17 May 2013
John Angus (Chair)	✓	✓	✓	✓	~
Karen Buckingham	✓	✓	\checkmark	✓	~
Alison Douglass	✓	✓	\checkmark	✓	~
Cilla Henry	~	✓	\checkmark	\checkmark	
Nikki Horne	~	✓	~	\checkmark	~
Andrew Shelling	А	✓	~	\checkmark	
Michael Legge	А	✓	✓	~	~
Judy Turner	~	✓	\checkmark	\checkmark	
Barry Smith					~
Jonathan Darby					\checkmark
Sue McKenzie					\checkmark
Total members present	6/8	8/8	8/8	8/8	8/8

✓ Present

A Apologies

Appendix 3: ACART working groups

Working group	Responsibilities and meeting dates	
Import and Export of Gametes and Embryos Working Group	Continuing work on proposed advice to the Minister on the import and export of gametes and embryos under sections 38 and 39 of the HART Act	
Andrew Shelling (Chair, until March 2013)		
John Angus (Chair, from April 2013)	Met in February 2013, June 2013	
Karen Buckingham		
Michael Legge		
Alison Douglass		
Guidelines Review Working Group	Review of eligibility criteria in ACART's surrogacy and	
John Angus (Chair)	family gamete donation guidelines, as part of addressing	
Nikki Horne	a complaint to the Human Rights Commission, and subsequent review of eligibility criteria in the embryo donation and donated eggs/donated sperm guidelines	
Judy Turner		
Andrew Shelling	Met in September 2012, April 2013	
Karen Buckingham		