Advisory Committee on Assisted Reproductive Technology Annual Report 2014/15

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Foreword

On behalf of the Advisory Committee on Assisted Reproductive Technology (ACART) I am pleased to present this Annual Report for 2014/15.

In November 2014 ACART provided a briefing to the incoming minister, Associate Minister of Health, Hon Peter Dunne who holds the delegated portfolio responsibilities for ACART's work. The briefing illustrates the breadth and extent of ACART's work programme. ACART is reliant on the wide range of expertise of its members and the Committee is pleased that Minister Dunne has agreed to extend ACART's membership from eight to ten members. These additional appointments will be made by June 2016.

ACART's functions involve issuing guidelines and giving advice to ECART on assisted reproductive procedures and human reproductive research, as well as providing advice to the Minister on related aspects of assisted reproductive technologies (ART).

This year ACART has worked on three substantial areas of advice for the Minister. Firstly, in December 2014, ACART completed its advice on the import and export of gametes and embryos. ACART's advice included recommendations for rules to govern the import and export of gametes and embryos, and initiatives to increase the supply of gametes (eggs and sperm) for donation in New Zealand. The Committee's view is that the Human Assisted Reproductive Technology Act (HART Act) should enable donors to be compensated for reasonable expenses incurred in the process of donation and that regulations are needed to define the scope of such expenses, including the scope of reasonable expenses for surrogates. We understand the Ministry of Health will provide the Associate Minister with advice about ACART's recommendations.

Secondly, ACART has continued to progress advice on the requirements for informed consent in the context of human assisted reproductive technology. One of the principles of the HART Act is that individuals should make informed choices and give informed consent; in ART this process can be complex and involve multiple parties. During the 2014/15 year, ACART progressed work to develop advice to the Minister on informed consent. ACART prepared a consultation document, which has since gone out for public consultation. We anticipate providing finalised advice to the Minister in 2016.

Thirdly, ACART is preparing advice on the use of cryopreserved ovarian tissue to restore ovarian function. The HART Act seeks to secure the benefits of assisted reproductive technology whilst protecting the health and safety of all individuals, particularly women and children, in the use of these technologies. Ovarian tissue *cryopreservation* was declared an established procedure in 2005, however the subsequent *use* of the tissue was not. On the basis of expert advice obtained in late 2014, ACART is developing advice to the Minister that the use of cryopreserved ovarian tissue to restore ovarian function become an established procedure. ACART will consult on this matter in 2016.

In conjunction with ACART's current review of three guidelines involving the donation of gametes and embryos, ACART will consider the need for the biological link policy.

ACART continues its close working relationship with the Ethics Committee on Assisted Reproductive Technology, the Ministry of Health and providers of fertility services.

Looking ahead, ACART plans to review the guidelines on posthumous use of gametes for conception. ACART also considers the current guidelines for human reproductive research are outdated and seeks confirmation from the Minister that its work programme will include a review of these guidelines. In keeping with its monitoring role of emerging technologies, ACART is closely following the developments with mitochondrial donation, gene editing and related international developments in ART.

Once again, I wish to take the opportunity to acknowledge the policy and administrative support the Committee receives from the hard-working and dedicated secretariat at the Ministry of Health.

Alison Douglass 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 2014/15.

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 2014/15

ACART meetings

ACART met as a full committee six times during 2014/15, with the support of the Secretariat. (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 2014/15

Guidelines projects

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 was on hold while other projects are progressed. However, the guidelines review work was presented to the Minister of Health in ACART's Briefing to the Incoming Minister (BIM) in November 2014 and further discussed at a meeting with the Associate Minister in March 2015. A Working Group was reconvened in June 2015 to progress work on this project. The guidelines review work now also includes reviewing the biological link policy.

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. ACART sought to replace the previous PGD guidelines, issued in 2005 by the former National Ethics Committee on Assisted Human Reproduction. 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 work was delayed while other work took priority in 2012 and 2013. In June 2014 the Deputy Chair, ECART Chair and an ECART member met with the Minister to discuss the amended guidelines.

In August 2014 ACART issued *Guidelines on Preimplantation Genetic Diagnosis (PGD) with Human Leucocyte Antigen (HLA) tissue typing.* The revised guidelines replace the previous 2005 PGD guidelines. The revised guidelines expand on PGD with HLA tissue typing to allow its use to find a tissue match for a sick child with a non-genetic disease. PGD with HLA tissue typing may only be used where the child to be treated will be a brother or sister of the resulting child.

Applications for PGD with HLA tissue typing must be submitted to ECART for ethical approval on a case-by-case basis. There are other applications of PGD that are established procedures under the Human Assisted Reproductive Technology Order 2005, and therefore do not require ethical review by ECART.

Advice projects

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

The movement of gametes and embryos into 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 consult the public 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. ACART issued a consultation document entitled *Import and Export of Gametes and Embryos: Background paper for stakeholder discussion.*

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

ACART provided the Minister of Health with finalised advice in December 2014. The finalised advice was published on ACART's website in March 2015. ACART's advice included: recommendations for rules to govern import and export of gametes and embryos; donor compensation; public health initiatives regarding fertility and gamete donation; and enhanced data collection on the use and outcomes of offshore fertility treatment and overseas donors and births.

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.

The current *Guidelines for Research on Gametes and Non-Viable Embryos*, developed by the former National Ethics Committee on Assisted Human Reproduction, prior to the HART Act (2004), remain in force. However, this effectively limits any human reproductive research to be undertaken in New Zealand. ACART considers that the current guidelines are well overdue for revision.

Human reproductive research and limitations of the current research guidelines were discussed in ACART's BIM in August 2014 and at a meeting with the Associate Minister of Health in March 2015. ACART has not undertaken any further work to date, but continues to monitor human reproductive research, including statutory requirements in other jurisdictions.

Advice to the Minister of Health on informed consent

In 2014/15 ACART continued to develop advice to the Minister of Health on informed consent focused on the context of human assisted reproductive technology.

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)). While the HART Act does not provide detailed requirements for informed consent, it provides for regulations to be made. 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.

As part of ACART's work to develop advice, the Committee undertook a subproject in 2014 that involved interviewing staff members at three Auckland fertility clinics. In March 2015, ACART published a report of the findings from the subproject. The report provided robust descriptive information on clinics' informed consent policies, rules and processes, and any challenges for clinics on informed consent.

In the first half of 2015 ACART also prepared a consultation document presenting the Committee's proposed advice to the Minister of Health on requirements for informed consent for human assisted reproductive technology. Public consultation on ACART's proposed advice is intended to take place in August 2015. ACART anticipates providing finalised advice to the Minister in 2016.

Advice to the Minister of Health on the use of cryopreserved ovarian tissue

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 and 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.

In April 2014 ACART agreed to commission a further technical report which also covered the cryopreservation of testicular tissue and the use of such tissue. Since the 2010 report was received there have been more reports about developments in the use of the procedure, and increased interest by New Zealand women in being able to use their stored cryopreserved ovarian tissue. The updated report prepared by Professor Claus Andersen at the University of Copenhagen was received in December 2014.

In early 2015 ACART reviewed the further technical report and agreed to begin developing advice to the Minister of Health that the use of cryopreserved ovarian tissue should become an established procedure. ACART agreed this current project would not include cryopreserved testicular tissue and will maintain a watching brief on international evidence about developments.

In giving its advice to the Minister, ACART is required by section 6 of the HART Act to provide the Minister with a report setting out: information about the procedure; an assessment of known risks and benefits to health; advice on acceptability of known risks; an ethical analysis; and advice whether the procedure should be declared an established procedure.

ACART plans to undertake public consultation in the first half of 2016 on its proposed advice to the Minister and to provide the final advice to the Minister in the second half of 2016.

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 and established 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.

Three further New Zealand-specific reports have now been received, for 2010, 2011 and 2012. 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.

Monitoring developments in human reproductive research

Section 35(2) of the HART Act also requires ACART to monitor developments in human reproductive research, as discussed on page 5.

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 agrees with the proposal and the details are set out below.

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 second annual report about ECART's decisions was provided at ACART's June 2014 meeting, to cover the period July 2013 to June 2014.

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 2014/15

Briefing to the Incoming Minister of Health

In November 2014, ACART provided a BIM. The BIM introduced ACART, highlighted ACART's relationship with the Minister, discussed ACART's current and upcoming work programme, and highlighted key issues that would be of interest to the Minister.

ACART's BIM was published on its website in March 2015.

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 member-inattendance.

Conference attendance

ACART supported members to attend the following conferences:

- Alison Douglass attended the European Society for Human Reproduction and Embryology conference in Lisbon, Portugal in June 2015.
- Mike Legge, Sue McKenzie, and Alison Douglass attended the Australasian Bioethics and Health Law Conference in June 2015.

Other external engagement

ACART wrote to the National Ethics Advisory Committee in March 2015, in response to their consultation on cross-sectoral ethics arrangements for health and disability research.

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 2011
- Advice to the Minister of Health on requirements for importing and exporting in vitro gametes and embryos for human reproductive research and human assisted reproductive technology
- Briefing to the Incoming Minister 2014
- Consultation document Proposed Advice to the Minister of Health on Informed Consent and Assisted Reproductive Technology
- Guidelines on Preimplantation Genetic Diagnosis with Human Leucocyte Antigen Tissue
 Typing
- Report: Informed Consent: Clinic policies, rules and processes.

ECART decisions 2014/15

Between 1 July 2014 and 30 June 2015 ECART considered 49 applications for assisted reproductive procedures and human reproductive research. There were:

- 22 applications for surrogacy involving fertility providers
- 9 applications for gamete donation between certain family members
- 13 applications for embryo donation for reproductive purposes
- 5 applications for the creation and use, for reproductive purposes, of an embryo created from donated eggs in conjunction with donated sperm
- no applications for research on gametes or non-viable embryos.

Of these applications, 29 were approved outright, 13 were approved subject to conditions, and 7 were deferred.

In addition, ECART considered 671 applications to extend the storage period of gametes or embryos. ECART approved 665 applications and declined 6 applications.

The details of these decisions are set out in ECART's Annual Report 2014/15.

Chair and Deputy Chair

Outgoing Chair

Dr John Angus resigned as Chair in June 2014 and resigned as a member in December 2014.

Current Chair

Alison Douglass was appointed Chair in January 2015. Alison was Acting Chair from July 2014 until her appointment.

Deputy Chair

Members selected Mike Legge as Deputy Chair in February 2015.

Contact with the Minister of Health

The Chair met the Associate Minister of Health, Hon Peter Dunne, on 4 March 2015.

Appendix 1: ACART membership

ACART members in the period

Dr John Angus – Chair (from November 2011 to 30 June 2014), continued as a 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 – Deputy Chair from February 2015 Kathleen Logan (from April 2015) Sue McKenzie Barry Smith

Secretariat staff members

Emma Doust, senior policy analyst (to December 2014) Betty-Ann Kelly, senior policy analyst (to June 2015) Martin Kennedy, senior policy analyst (from May 2015) Stella Li, policy analyst (from May 2015) Hayley Robertson, policy analyst (from August 2014)

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

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 Chair from January 2015.

Alison is a barrister and has been a practising lawyer since 1985, and specialises in health and disability law. She is the 2014 recipient of the New Zealand Law Foundation international research fellowship and is currently undertaking a law reform project on updating New Zealand's mental capacity law and practice. Prior to moving to the independent bar in 2008, Alison was a partner, then consultant, to a Wellington law firm, Tripe Matthews and Feist. She completed an LLB at the University of Canterbury (1984) and has a Master of Bioethics and Health Law from the University of Otago (1999).

Alison is the former convenor, now member, 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 was appointed Adjunct Senior Lecturer to the Dioethics 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.

Michael Legge

(Deputy Chair from February 2015)

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).

Dr 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.

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 16 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 particular interests include recurrent pregnancy loss and polycystic ovarian syndrome.

She lives in Auckland with her husband and three children.

Jonathan Darby

Membership role: Disability perspective

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

Growing up in Christchurch, Jonathan has lived experience of disability having being a paraplegic since birth. He is an enrolled barrister and solicitor of the High Court who has significant experience in the disability sector. He was a member of the Canterbury District Health Board Community and Public Health & Disability Advisory Committee (2011–2013). He is the current presiding member of the Lottery Individuals with disabilities distribution committee.

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 employed by Auckland Disability Law as their community worker.

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 has previously been a Member of the 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 as the Social Media and Event Manager at Career Engagement Group in Auckland. 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.

Kathleen Logan

Membership role: Ability to articulate the interests of children

Kathleen Logan was appointed to ACART in April 2015 for three years.

Kathleen works for the Children's Commissioner, Dr Russell Wills, and advocates for the rights and wellbeing of all children in New Zealand. Kathleen joined the Office of the Children's Commissioner in 2013.

In the past, Kathleen had a 13-year research career in human and animal reproduction and genetics, graduating in 1998 from Newcastle University Medical School (UK) with a PhD in reproductive physiology. Subsequently, she was a policy analyst in science research and investment for the Royal Society of New Zealand and then a science strategy advisor for the New Zealand government.

Kathleen lives in Wellington with her husband and two primary-aged children.

Sue McKenzie

Membership role: General layperson

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

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

Since the Christchurch earthquakes she has relocated to the country and now works fulltime on her Board positions. Her Board positions and responsibilities include:

- The Medical Radiation Technologists Board Convenor of the Education Committee and a member of the Professional Standards Committee.
- Trustee of the Rata Foundation Chair of the Housing Committee and a member of the Investment Committee
- Deputy Chair of the Greater Canterbury Response Forum working with the Ministry of Social Development on transforming Social Services.
- Member of the Canterbury/Aoraki Conservation Board member of the Land and Water Committee and chair of the Awards and Marketing Committee.

Sue is also a member of the Institute of Directors and a Justice of the Peace.

Barry Smith QSM

Membership role: Expertise in Māori customary values and perspectives

Barry Smith (Te Rarawa, Ngâti 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 Auckland Regional Tissue Banks Governance Advisory Board 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 Māori contexts is supported by the Health Research Council and 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	August 2014	October 2014	December 2014	February 2015	April 2015	June 2015
John Angus (Chair) (Term ended December 2014)	~	~	✓	-	_	-
Karen Buckingham	~	✓	✓	~	\checkmark	~
Alison Douglass	✓	✓	✓	~	А	~
Nikki Horne	✓	✓	✓	~	\checkmark	~
Michael Legge	А	✓	А	~	\checkmark	~
Barry Smith	✓	✓	✓	~	\checkmark	А
Jonathan Darby	✓	✓	✓	~	\checkmark	~
Sue McKenzie	✓	✓	✓	~	\checkmark	~
Kathleen Logan (Appointed April 2015)	_	_	_	_	\checkmark	~
Total members present	7	8	7	6	7	7

✓ 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 (until January 2015)	Prepared 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.		
Karen Buckingham Alison Douglass Michael Legge	The Working Group met on 18 August 2014 and 30 September 2014.		
Guidelines Review Working Group John Angus (until January 2015) Alison Douglass Mike Legge Kathleen Logan (from June 2015) Nikki Horne Karen Buckingham Barry Smith	Review of three donation guidelines (family gamete donation, embryo donation, use of donated eggs plus donated sperm), to include reviewing eligibility criteria and ACART's "biological link" policy. The Working Group was reconvened in June 2015.		
Informed Consent Working Group John Angus (until January 2015) Jonathan Darby Alison Douglass Nikki Horne Mike Legge Sue McKenzie	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 on 11 July 2014, 27 August 2014, 14 November 2014, 13 March 2015 and 13 April 2015.		
Human reproductive research working group Alison Douglass Mike Legge Sue McKenzie Barry Smith	Prepared advice on human reproductive research to be included in ACART's briefing to the incoming Minister of Health. The Working Group met on 14 July 2014.		
Use of cryopreserved ovarian tissue Karen Buckingham Alison Douglass (from February 2015) Mike Legge Sue McKenzie (from June 2015)	Procured an independent technical report about the use of cryopreserved ovarian tissue and began work on proposed advice to the Minister of Health that a procedure be declared an established procedure under section 5 of the HART Act. The Working Group held discussions by email during early 2015.		