

**Advisory Committee on
Assisted Reproductive
Technology
Annual Report 2018/19**

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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 2018/19.

ACART's functions involve issuing guidelines and giving advice to the Ethics Committee on Assisted Reproductive Technology (ECART) on assisted reproductive procedures and human reproductive research, as well as providing advice to the Minister of Health on related aspects of assisted reproductive technology (ART). This year, ACART has continued to progress two substantial revisions of existing guidelines.

One of ACART's current guideline reviews is of the three donation guidelines (gamete donation, embryo donation and use of donated eggs with donated sperm), together with the surrogacy guidelines (to be merged into a single set of guidelines). The review includes consideration of the ongoing need for the 'biological link' policy (requiring a genetic or gestational link between at least one intending parent and the resulting child). A change to this policy would remove unjustifiable discrimination, as well as some existing barriers to the use of ART in forming a family. The second round of consultation for this review was completed in early 2019, which has informed the development of revised guidelines and advice to the Minister that members are working on.

The current guidelines for human reproductive research, *Guidelines for Research on Gametes and Non-viable Embryos*¹ also pre-date the HART Act 2004. In March 2017, the then Associate Minister of Health Hon Peter Dunne agreed that ACART's work programme should include a limited review of these outdated guidelines, subject to further consideration by Cabinet. In 2018, Minister Clark agreed ACART should scope a project to provide advice to the Government on human reproductive research. At the time of writing, the scope of the project is yet to be determined.

Membership changes saw us farewell John McMillan who had reached the end of his three-year term as the member with expertise in ethics. I acknowledge Professor McMillan for his clear thinking and considerable expertise in ethics.

Barry Smith, who was a member of ACART from April 2013 until April 2019, sadly passed away in February. Barry's work on the Committee was highly valued and he shall be missed dearly by all.

We welcomed Dr Analosa Veukiso-Ulugia to the Committee, who was appointed to a lay position with expertise in Pacific people's health and related social science.

¹ NECAHR. 2005. *Guidelines for Research on Gametes and Non-viable Embryos*. Wellington: National Ethics Committee on Assisted Human Reproduction.

We also welcomed Calum Barrett to the Committee, who was appointed to the position to represent the views of fertility consumers.

ACART and ECART members continued to attend one another's meetings where budget allowed, and I thank ECART members and Chair for the constructive working relationships they have with ACART.

ACART could not have progressed the projects in 2018/19 without the expert and dedicated support of its secretariat at the Ministry of Health. We appreciate the support of these staff as well as the administrative and other Ethics staff involved in assisting us to maintain the Committee.

Finally, I am most grateful to ACART's members who contribute significant expertise and time to enable this work to progress.



Dr Kathleen Logan

Chair, Advisory Committee on Assisted Reproductive Technology



Contents

Foreword	iii
Introduction	1
Purpose of this report.....	1
Background	1
ACART's functions	1
ACART's work during 2018/19	3
ACART meetings	3
Guidelines projects in 2018/19.....	3
ACART's monitoring functions	4
Other issues considered by ACART during 2018/19	6
Conference attendance.....	6
Publications	6
ECART decisions 2018/19	7
Governance	8
Chair and Deputy Chair.....	8
Contact with the Minister of Health	8
Appendix 1: ACART membership	9
ACART members in the period	9
Secretariat staff members	9
Biographies of ACART members	9
Appendix 2: Member attendance at full ACART meetings	14
Appendix 3: ACART working groups	15



Introduction

Purpose of this report

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

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

Background

ACART was established under section 32 of the HART Act 2004 and first met in September 2005. Appendix 1 gives biographical information on ACART's membership during 2018/19.

ACART is a Crown entity, appointed by the Crown, and as such has responsibilities under Te Tiriti o Waitangi as a treaty partner to tangata whenua. ACART considers and treats with respect the needs, values, and beliefs of Māori, in line with section 4(f) of the HART Act.

ACART's functions

ACART's functions, as set out in section 35 of the HART Act 2004, are to:

- issue guidelines and give advice to ECART on the matters that ECART must take into account when considering whether to give, change or cancel an approval for an extension to the applicable period for storing 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 on aspects of, or issues arising out of, kinds of assisted reproductive research and, without limitation, provide advice as to whether:
 - the HART Act 2004 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 2004

- any established procedure should be modified or 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 2004 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 in performing its functions
- perform any other function that the Minister 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/about-us/terms-reference).



ACART's work during 2018/19

ACART meetings

ACART met as a full committee, with the support of the secretariat, six times during 2018/19. (Appendix 2 sets out member attendance at these meetings.) Working groups met as required between full committee meetings to progress specific projects. (Appendix 3 sets out detailed information on working group membership and meetings.)

Guidelines projects in 2018/19

Review of the donation and surrogacy guidelines

This project looked at whether it is still necessary to require a biological link between at least one intending parent and a resulting child and if and when a 'medical need' should be required. ACART also assessed the possibility of merging the four existing guidelines for donations and surrogacy.

ACART initially consulted the public from September to November 2017. A total of 28 individuals and groups made submissions, and members of the public attended public meetings held in Auckland, Wellington and Dunedin.

The second round of consultation ran from February to March 2019. This round presented further amended guidelines in response to the submissions from the initial round.

The submissions to both rounds provided valuable information, which we have taken in to account in preparing the revised guidelines and advice to the Minister. We anticipate having advice ready to send to the Minister by the middle of 2019 and guidelines ready to publish at the same time. In the event that the Minister agrees with our advice, one change would need to be made to the HART Order before we could issue the final revised guidelines.

Posthumous reproduction: review of the *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*

The current guidelines were issued in 2000.² They pre-date the HART Act 2004 and reflect the technologies of the time. For instance, techniques for successful cryopreservation of eggs had not been established in 2000.

² NECAHR. 2000. *Guidelines on the Storage, Use, and Disposal of Sperm from a Deceased Man*. Wellington: National Ethics Committee on Assisted Human Reproduction.

In 2014, ACART undertook preliminary scoping work, gathering information about the regulatory framework that addresses the collection, storage and use of gametes and embryos from deceased and comatose individuals. It concluded that the guidelines should be reviewed and their scope broadened to include the use of gametes (sperm and eggs) and embryos from deceased and comatose people.

In 2015, the then Associate Minister of Health Hon Peter Dunne agreed to this review being made part of ACART's work programme, and ACART has been working on the matter during 2018 and 2019.

ACART began eight weeks public consultation from July to September 2018 on the stage one consultation document, meeting targeted stakeholders such as fertility clinics, and a group of young people aged 15 to 18 to discuss their views on the issues in the document. Following this consultation period, ACART considered the submissions and responses and publicly released a summary of the submissions in February 2019.

From February to June 2019, members developed the stage two consultation document, accompanied by draft guidelines which will be released for public consultation by mid-2020.

Guidelines on, and advice to, the Minister of Health about human reproductive research

Section 37 of the HART Act 2004 requires ACART to provide the Minister with information, advice and, if it thinks fit, recommendations on certain matters relating to the use of gametes and embryos in human reproductive research.

The current *Guidelines for Research on Gametes and Non-Viable Embryos*,³ developed before 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.

In 2018, Minister Clark agreed ACART should scope a project to provide advice to the Government on human reproductive research. A limited review of the guidelines was already on ACART's work programme. At the time of writing, the scope of the project is yet to be determined.

ACART's monitoring functions

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

Section 35(2) of the HART Act 2004 requires ACART to monitor the application and health outcomes of assisted reproductive procedures and established procedures.

³ NECAHR. 2005. *Guidelines for Research on Gametes and Non-viable Embryos*. Wellington: National Ethics Committee on Assisted Human Reproduction.

ANZARD Report

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

Six further New Zealand-specific reports have now been received from UNSW Sydney for 2010, 2011, 2012, 2013, 2014 and 2015. ACART anticipates continuing to contract for annual New Zealand-specific reports, following the release of each ANZARD report.

The seventh ANZARD report, covering the 2016 calendar year, will be received in July 2019 and will be considered by ACART at their Committee meeting in October 2018. All previous years reports are publicly available on ACART's website.

We will commission the 2017 report in late 2019.

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 2004 also requires ACART to monitor developments in human reproductive research. During 2018/19, members and the secretariat shared relevant media and academic journal articles, and the secretariat distributed *Bionews* articles⁴ and Human Fertilisation and Embryology Authority updates to members.

Monitoring ECART decisions

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 agreed with the proposal, and the details are set out below.

ACART will continue the current practice of including in its 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.

⁴ A London-based email newsletter and website funded by the Progress Educational Trust (PET) to provide news and comment on genetics, assisted conception, embryo/stem cell research and related areas (see: www.bionews.org.uk/).

ECART is required to give ACART a copy of the decisions from each meeting as soon as practicable after an ECART meeting. The ECART secretariat provides a summary of the decisions at each ACART full meeting for members' information.

Other issues considered by ACART during 2018/19

Links with ECART

The HART Act 2004 requires that ACART and ECART liaise with one another. 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.

The following communications took place during the 2018/19 period.

- All committee meetings, for each committee, included a member of the other committee as a member-in-attendance.

Conference attendance

ACART did not support committee members to attend any conferences in the year 2018/19.

Publications

In the 2018/19 year, ACART published on its website (www.acart.health.govt.nz):

- *Advisory Committee on Assisted Reproductive Technology: Annual report 2016/17.*
- agendas of ACART meetings (after each meeting).
- minutes of ACART meetings (after their confirmation at each following meeting).
- submissions to, and minutes of meetings for, the consultation on *Proposed Donation Guidelines: For family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy: consultation document*. A second consultation document for this project was also published early 2019.
- *Assisted Reproductive Technology in New Zealand 2015 (ANZARD).*
- the submissions analysis and raw submissions received from the stage-one consultation document: *Posthumous Reproduction: A review of the current Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man to take into account gametes and embryos.*



ECART decisions 2018/19

Between 30 June 2018 and 30 June 2019, ECART considered 49 applications for assisted reproductive procedures and human reproductive research. There were:

- 26 applications for surrogacy involving fertility providers
- 4 applications for gamete donation between certain family members
- 6 applications for embryo donation for reproductive purposes
- 13 applications for the creation and use, for reproductive purposes, of an embryo created from donated eggs in conjunction with donated sperm.

Of these applications:

- 23 were approved outright
- 2 were established procedures seeking non-binding ethical review
- 5 were approved subject to conditions
- 15 were deferred
- 4 were declined.

In addition, ECART considered 66 applications to extend the storage period of gametes, embryos or tissue. ECART approved all of these applications outright.

The details of these decisions will be set out in ECART's annual report for 2018/19.



Governance

Chair and Deputy Chair

Current Chair

Kathleen Logan had originally been appointed to ACART in 1 April 2015 for a three-year term. Kathleen was subsequently appointed as Chair for the term starting 31 May 2019 and expiring 1 April 2021.

Deputy Chair

Colin Gavaghan has formally served as Deputy Chair since December 2018.

Contact with the Minister of Health

Kathleen Logan met the Minister, Hon Dr David Clark, on 21 February 2019.



Appendix 1: ACART membership

ACART members in the period

Jonathan Darby

Dr Colin Gavaghan

Dr Kathleen Logan – Acting Chair from August 2018 and Chair from 31 May 2019

Sue McKenzie

John McMillan – until April 2019

Dr Barry Smith – until February 2019

Dr Sarah Wakeman

Dr Karen Reader

Analosa Veukiso-Ulugia – from February 2019

Calum Barrett – from May 2019

Secretariat staff members

Martin Kennedy, Senior Policy Analyst

Hayley Robertson, Senior Policy Advisor

Tristan Katz, Advisor

Administrative support was provided by Moana Tupaea.

Biographies of ACART members

Members during 2018/19

Jonathan Darby

Membership role: Disability perspective

Jonathan Darby was originally appointed to ACART in April 2013 for three years and was reappointed in April 2016 for a further three years.

Jonathan grew up in Christchurch. He has experience of disability, being a paraplegic since birth. He is an enrolled barrister and solicitor of the High Court, with significant experience in the disability sector of the law. He has been a member of Canterbury District Health Board Community & Public Health and Disability Support Advisory Committee (CPH&DSAC) (2011–2013). He is the current presiding member of the Lottery Individuals with Disabilities distribution committee.

Jonathan 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.

Kathleen Logan

Membership role: Ability to articulate the interests of children

Dr Kathleen Logan was appointed to ACART in April 2015 for three years and has since been reappointed until 2021. Kathleen was appointed Deputy Chair by members in April 2018.

Kathleen is a senior advisor in the Office of the Children's Commissioner. She advocates for the rights and wellbeing of children in New Zealand and is interested in child development and improving childhood outcomes.

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 (Newcastle, England) 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 a science strategy advisor for the New Zealand Government.

Sue McKenzie

Membership role: General layperson

Sue McKenzie was appointed to ACART in April 2013 for three years and has since been reappointed until April 2019.

She has had two careers over the last 30 years – lecturing as a senior academic at tertiary level and working as 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.

After the Christchurch earthquakes, Sue relocated to the country and now works full time on her Board positions. Her Board positions and responsibilities include the New Zealand Medical Radiation Technologists Board (as Convenor of the Education Committee and a member of the Professional Standards Committee), a trustee of the Rātā Foundation (Chair of the Housing Committee and a member of the Investment Committee), Chair of the Greater Canterbury Response Forum, working with the Ministry of Social Development to help transform social services, and a 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.

John McMillan

Membership role: Expertise in ethics

Professor John McMillan was appointed to ACART in April 2016 for three years.

John is Director of the Bioethics Centre at the University of Otago. Before this appointment he was an Associate Professor at the School of Medicine, Flinders University, South Australia; Senior Lecturer at the Hull York Medical School, England (2004–09), the University of Cambridge (2002–04) and the University of Oxford (1998–2002), where he taught ethics to philosophy and medical students.

He is the author of over a hundred book chapters and articles, including several that are particularly relevant to ACART's work.

Barry Smith QSM

Membership role: Expertise in Māori customary values and perspectives

Barry Smith (Te Rarawa, Ngāti Kahu), who was a member of ACART from April 2013 until April 2019, unfortunately passed away in February.

Barry was a population health analyst with Lakes District Health Board (DHB) based in Rotorua. He was previously a contract analyst and assessor with the Ministry of Health.

Barry was a member of the Health Research Council of New Zealand's (HRC's) College of Experts and chairs the HRC's Ethics Committee and the Lakes DHB Research and Ethics Committee. He was a member of the Auckland Regional Tissue Bank's Governance Advisory Board and the Podiatrists Board of New Zealand.

Barry's was conducting research supported by the HRC and the Royal Society of New Zealand Marsden Fund on ethics in Māori contexts. He held 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 Queen's Service Medal (QSM) in 2008.

Sarah Wakeman

Membership role: Expertise in assisted reproductive procedures

Dr Sarah Wakeman was appointed to ACART in 2016 for the three-year period beginning on 2 December 2016.

Sarah is a graduate of the University of Otago Medical School and trained as an obstetrician and gynaecologist in Hawke's Bay and Christchurch. She then went on to sub-specialise in reproductive endocrinology and infertility, spending time working in Christchurch and Melbourne, and gained her Certificate in Reproductive Endocrinology and Infertility (CREI) in 2008. She has been working in the area of infertility for 16 years. She is the medical director of Fertility Associates, Christchurch, which provides both public and private fertility-related services. She has special interests in recurrent miscarriage, genetic testing and fertility preservation. She has ongoing involvement in clinical research and teaching medical students and graduates.

Sarah is married and has three school-aged children.

Karen Reader

Membership role: Expertise in human reproductive research

Karen Reader was appointed to ACART from December 2017 for three years.

Karen is a Research Fellow in the Department of Anatomy at the University of Otago, undertaking research and teaching in reproductive biology and ovarian cancer. She was awarded a Rutherford Foundation New Zealand Postdoctoral Fellowship in 2015 and a Lottery Health Fellowship in 2017.

Karen completed her PhD in 2014 at the University of Otago and AgResearch, studying oocyte (egg) quality. Before this, she worked in the Reproductive Biology Group at AgResearch for 13 years, researching ovarian factors that regulate fertility. During this time, Karen established an in-vitro fertilisation laboratory for sheep fertility research. She has a strong interest in both the scientific and ethical aspects of human assisted reproductive technologies.

Analosa Veukiso-Ulugia

Membership role: General layperson (with expertise in Pacific people's health)

Dr Analosa Veukiso-Ulugia was appointed to ACART for a period of three years beginning on 6 December 2018.

Analosa is a Sāmoan lecturer in the School of Counselling, Human Services and Social Work at the University of Auckland. A health professional specialising in Pacific youth health, Analosa is committed to the empowerment of Pacific communities, in the area of

sexual health and wellbeing. Analosa draws on over 15 years of clinical, community, research and management experience.

Analosa completed her PhD in 2017 on the Sexual Health Knowledge, Attitudes and Behaviour of Samoan Youth in Aotearoa New Zealand.

Calum Barrett

Membership role: representing the perspectives of fertility service users or those born from fertility services.

Calum Barrett was appointed to ACART for a period of three years beginning on 31 May 2019.

Calum currently works for the Tertiary Education Commission, having previously worked in policy roles with the Royal Australasian College of Surgeons and New Zealand Police.

He holds a Bachelors of Laws (2011), a Bachelors of Arts (2013), and a Masters in Bioethics and Health Law awarded with Distinction (2015), the dissertation of which proposed ACART guidelines for the regulation of Mitochondrial Replacement Therapy in New Zealand.

Calum lives in Wellington with his wife and two young children.

Colin Gavaghan

Membership role: Expertise in relevant areas of law

Colin Gavaghan was appointed to ACART in May 2017 for three years, for the period from 23 June 2017 to 22 June 2020.

Colin is the first holder of the New Zealand Law Foundation Chair in Law and Policy in Emerging Technologies, at the University of Otago, where he also teaches medical and criminal law. Before that, he was a lecturer at the University of Glasgow.


In 2006, Colin completed a PhD, focusing on the law and ethics of pre-implantation genetic diagnosis. This formed the basis for his book, *Defending the Genetic Supermarket: The law & ethics of selecting the next generation* (Routledge-Cavendish 2007). He has also published widely on issues relevant to ACART's work.

Appendix 2: Member attendance at full ACART meetings

Member	August 2018	October 2018	December 2018	February 2019	April 2019	June 2019
Jonathan Darby	✓	✓	✓	✓	✓	✓
Kathleen Logan	✓	✓	✓	✓	✓	✓
Sue McKenzie	Apol	✓	✓	✓	✓	✓
John McMillan	✓	✓	✓	✓	✓	NA
Colin Gavaghan	✓	✓	✓	✓	✓	✓
Karen Reader	✓	✓	✓	✓	✓	✓
Barry Smith	✓	✓	Apol	Apol	NA	NA
Sarah Wakeman	✓	✓	✓	✓	Apol	✓
Analosa Veukiso-Ulugia	NA	NA	NA	✓	Apol	Apol
Calum Barrett	NA	NA	NA	NA	NA	✓
Total members present	7	8	7	8	6	7

- ✓ Present
- Apol Apologies
- NA Not applicable

Note: Analosa Veukiso-Ulugia started with ACART in February 2019. Calum Barrett started with ACART in May 2019.



Appendix 3: ACART working groups

Working group	Responsibilities and meeting dates
<p><i>Review of the Donation Guidelines*</i></p> <p>Gillian Ferguson Mike Legge Kathleen Logan Barry Smith Jonathan Darby Colin Gavaghan Sue McKenzie Sarah Wakeman</p>	<p>Review the three donation guidelines (family gamete donation, embryo donation, use of donated eggs with donated sperm) and surrogacy guidelines.</p> <p>The working group met on:</p> <ul style="list-style-type: none"> • 14 November 2018.
<p><i>Guidelines for posthumous reproduction</i></p> <p>Kathleen Logan Sue McKenzie John McMillan Colin Gavaghan</p>	<p>Consider the summary of submissions prepared by the Secretariat following public consultation of the stage-one consultation document to review the <i>Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man</i>, and decide on next steps.</p> <p>The working group met in Wellington on:</p> <ul style="list-style-type: none"> • 17 December 2018.

* Not all members served at the same time. At the time of writing this report the members were Kathleen Logan, Colin Gavaghan, Sue McKenzie and Sarah Wakeman.