

**Advisory Committee on
Assisted Reproductive
Technology
Annual Report 2019/20**

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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 2019/20.

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 and began two new proposals to seek the interested public's feedback to (a) clarify the use of cryopreserved testicular tissue as an established procedure and (b) to amend the guidelines for extending the storage of gametes and embryos.

One of ACART's current guideline reviews is of the guidelines for posthumous reproduction. Following the stage one public consultation in 2018, ACART has spent the 2019/20 calendar year preparing the stage two consultation document accompanied by proposed draft guidelines. The second round of consultation for this review will take place in July 2020.

ACART has also continued to progress the final stages of the review of the Donation and Surrogacy guidelines. ACART recommended the changes to the guidelines to the Minister of Health in September 2019.

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

ACART could not have progressed the projects in 2019/20 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



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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 2019/20.

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 2019/20

ACART meetings

ACART met as a full committee, with the support of the secretariat, six times during 2019/20. (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.)

Advice projects in 2019/20

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, and also merged the four existing guidelines for donations and surrogacy.

ACART consulted the public twice on possible new guidelines for surrogacy and the donation of sperm, eggs and embryos. The first consultation was from September to November 2017 and the second round of consultation ran from February to March 2019. Following the second round of consultation ACART finalised the guidelines and advice and submitted it to Associate Minister of Health Hon Jenny Salesa in September 2019. The Chair of ACART subsequently discussed the advice and guidelines with Associate Minister Salesa in March 2020.

ACART also prepared supplementary advice to issue to the sector when it publishes the guidelines and, likewise, prepared frequently asked questions and explanatory material for responding to any enquiries.

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

The current guidelines were issued in 2000.¹ 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.

¹ NECAHR. 2000. *Guidelines on the Storage, Use, and Disposal of Sperm from a Deceased Man*. Wellington: National Ethics Committee on Assisted Human Reproduction.

During the 2019/20 financial year, members have been developing the stage two consultation document, accompanied by draft guidelines which will be released for public consultation in July 2020 for a period of eight weeks. Following this consultation period, ACART will consider the submissions and responses and publicly release the submissions on ACART's website followed by a report to the Minister of Health.

ACART also prepared frequently asked questions and explanatory material for responding to any enquiries after the new guidelines are published.

Amend the guidelines for extending the storage of gametes and embryos

In the 2019/20 calendar year, ACART began work on a consultation document to ask the public about a proposed change to the guidelines for extending the storage of gametes and embryos. The guidelines contain a provision that asks gamete donors to consent to the extension of storage of embryos that have been formed using their gametes. This policy is contrary to ACART's policy position (that once gametes have been used the gamete donor has no say in what happens to the embryos created) and the general understanding of the sector that is the same as ACART's.

During the year, ACART worked through this policy matter and investigated whether any other provisions might need to be amended. At the end of the 19/20 financial year the consultation document was nearing completion and ACART anticipated having it ready for publication by the end of the 2020 calendar year. A standard consultation process would be followed before the Minister would be advised and the guidelines would be published.

Proposal that the HART Order should explicitly state that the use of cryopreserved testicular tissue is an established procedure

During the period of 2019/20, ACART started work on a draft consultation document to clarify the legal status of the use of cryopreserved testicular tissue (CTT). Currently, the use of CTT is not explicitly stated as an established Procedure in the HART Order but Fertility clinics believe that the tissue can be used. ACART understands that there are also different understandings of the legal status of the use of the tissue, and believes that there is no practical reason for the use of CTT to not be classified as an established procedure in the Order. This change would mean that the HART Order would be aligned with what happens in practice.

The focus of the consultation document is on (a) the techniques currently used for collecting sperm, their safety and efficacy, and (b) comparing those techniques with what the Order describes as established procedures, noting the gap of cryopreserved testicular tissue.

ACART intends to complete this work and go out for public consultation in late 2020 or early 2021.

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.

ANZARD Report

In 2012, ACART entered 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 draws on calendar-year data and is placed on ACART's website.

Seven further New Zealand-specific reports have now been received from UNSW Sydney for 2010, 2011, 2012, 2013, 2014, 2015 and 2016. ACART anticipates continuing to contract for annual New Zealand-specific reports, following the release of each ANZARD report.

The eighth ANZARD report, covering the 2017 calendar year, will be received in late 2020 and will then be considered and distributed to stakeholders by ACART. All previous years' reports are publicly available on ACART's website.

We will commission the 2018 report in late 2020.

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 2019/20, members and the secretariat shared relevant media and academic journal articles, and the secretariat distributed *Bionews* articles² and Human Fertilisation and Embryology Authority updates to members.

² 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).

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.

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 2019/20

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 2019/20 period.

- All committee meetings, for each committee, included a member of the other committee as a member-in-attendance. On some occasions, this was not possible due to Budget restrictions and the COVID-19 period.

Conference attendance

ACART supported Dr Karen Reader to attend the Fertility Services Australia conference held in Hobart in September 2019. Dr Reader prepared a summary of the seminars for members.

Publications

In the 2019/20 year, ACART published on its website (www.acart.health.govt.nz):

- agendas of ACART meetings (after each meeting)
- minutes of ACART meetings (after their confirmation at each following meeting)
- a targeted second consultation document and submissions for the consultation on *Proposed Donation Guidelines: For family gamete donation, embryo donation, use of donated eggs with donated sperm and surrogacy: consultation document*
- *Assisted Reproductive Technology in New Zealand 2016* (ANZARD).



ECART decisions 2019/20

Between 30 June 2019 and 30 June 2020, ECART considered 52 applications for assisted reproductive procedures and human reproductive research. There were:

- 31 applications for surrogacy involving fertility providers
- 11 applications for embryo donation for reproductive purposes
- 8 applications for the creation and use, for reproductive purposes, of an embryo created from donated eggs in conjunction with donated sperm
- 1 application for the posthumous use of stored sperm
- 1 application for preimplantation genetic diagnosis with human leucocyte antigen tissue typing.

Of these applications:

- 44 were approved outright
- 7 were deferred
- 1 was declined.

In addition, ECART considered 136 applications to extend the storage period of gametes, embryos or tissue. ECART approved 39 of these applications outright.

The details of these decisions will be set out in ECART's annual report for 2019/20.



Governance

Chair and Deputy Chair

Current Chair

Kathleen Logan had originally been appointed to ACART on 1 April 2015 for a three-year term. Kathleen was subsequently re-appointed for a second term, then 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 Associate Minister of Health, Hon Jenny Salesa on 5 March 2020 to update the Minister on ACART's work programme and agree on new items of work.



Appendix 1: ACART membership

ACART members in the period

Jonathan Darby

Dr Colin Gavaghan – Deputy Chair from December 2019

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

Sue McKenzie

Dr Sarah Wakeman

Dr Karen Reader

Dr Analosa Veukiso-Ulugia

Calum Barrett

Secretariat staff members

Martin Kennedy, Senior Policy Analyst

Hayley Robertson, Senior Policy Advisor

Administrative support was provided by Moana Tupaea.

Biographies of ACART members

Members during 2019/20

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, and was appointed the Chair by the Minister of Health in May 2019.

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.

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 Bachelor of Laws (2011), a Bachelor 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 2019 | October 2019 | December 2019 | February 2020 | April 2020 | June 2020 |
|------------------------------|-------------|--------------|---------------|---------------|------------|-----------|
| Jonathan Darby | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Kathleen Logan | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Sue McKenzie | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Colin Gavaghan | ✓ | ✓ | Apol | ✓ | ✓ | ✓ |
| Karen Reader | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Sarah Wakeman | ✓ | Apol | ✓ | ✓ | ✓ | ✓ |
| Analosa Veukiso-Ulugia | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Calum Barrett | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Total members present | 8 | 7 | 7 | 8 | 8 | 8 |

✓ Present

Apol Apologies



Appendix 3: ACART working groups

| Working group | Responsibilities and meeting dates |
|---|---|
| <p><i>Review of the Donation and Surrogacy Guidelines</i></p> <p>Kathleen Logan 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 in Christchurch on:</p> <ul style="list-style-type: none"> • 4 July 2019. |
| <p><i>Review of the Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man</i></p> <p>Kathleen Logan Sue McKenzie Colin Gavaghan Karen Reader Nicola Peart</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 Dunedin on:</p> <ul style="list-style-type: none"> • 9 July 2019. |
| <p><i>Proposal to amend the guidelines for extending the storage of gametes and embryos</i></p> <p>Jonathan Darby Colin Gavaghan Analosa Veukiso-Ulugia Calum Barrett</p> | <p>To discuss the first draft of the draft consultation document that ACART will present to the public with the proposed revised guidelines for extending the storage of gametes and embryos.</p> <p>The working group met via zoom on:</p> <ul style="list-style-type: none"> • 11 June 2020. |
| <p><i>Proposal that the HART Order should explicitly state that the use of cryopreserved testicular tissue is an established procedure</i></p> <p>Kathleen Logan Sue McKenzie Karen Reader Sarah Wakeman</p> | <p>To discuss the first draft of ACART's consultation document on the advice that the use of cryopreserved testicular tissue should be defined as an established procedure in the HART Order.</p> <p>The working group met via zoom on:</p> <ul style="list-style-type: none"> • 11 June 2020. |