Advisory Committee on Assisted Reproductive Technology Annual Report 2021/2022

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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 2021/22.

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 work to amend the guidelines for extending the storage of gametes and embryos and made progress on its consultation document to review the guidelines for human reproductive research.

One of ACART's current guideline reviews is of the guidelines for posthumous reproduction. Following the stage one public consultation in 2018, ACART spent the 2019/20 financial year preparing the stage two consultation document accompanied by proposed draft guidelines. The second round of consultation for this review took place in July 2020. In the 2021/22 financial year ACART wrote advice to the Minister of Health and finalised the revised guidelines. ACART expects to publish the guidelines following the Minister's acknowledgment of the advice.

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.

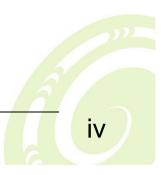
ACART could not have progressed the projects without the expert and dedicated support of its Secretariat at the Ministry of Health. We appreciate the support of these staff as well as the administrative and other Ethics staff involved in assisting us to maintain the Committee.

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

Calum Barrett 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 2021/2022.

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/aboutus/terms-reference).

ACART's work during 2021/22

ACART meetings

ACART met as a full committee, with the support of the secretariat, six times during 2021/22. (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 2021/22

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. 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.

During the 2021/22 financial year ACART finalised its advice to the Minister on this topic and submitted the advice in March 2022. The advice includes the revised guidelines and supplementary information to share with the sector. (ACART understands that the Ministry of Health will provide parallel advice to the minister.)

ACART also created an implementation plan so that the revised guidelines can be introduced with the full understanding of the sector.

Amend the guidelines for extending the storage of gametes and embryos

In the 2021/22 financial year, ACART finalised the consultation document, which was due to be published early in the 2022/23 year.

The review is investigating the removal of an erroneous provision and clarifying the circumstances in which extensions can be made to the storage of gametes and embryos.

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

During 2020/21, ACART had worked to clarify the legal status of the use of cryopreserved testicular tissue (CTT). The use of CTT was not explicitly stated as an Established Procedure in the HART Order. ACART understood that there are also different understandings of the legal status of the use of the tissue and believed 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.

In 2020/21 the consultation was held and ACART subsequently submitted advice in March 2022. ACART's advice recommended that the HART Order be amended to state that the cryopreservation of testicular tissue be stated as part of the established procedure.

Guidelines for Research involving Human Gametes and Embryos

In 2021, ACART started work on a draft consultation document for *Guidelines for Research involving Human Gametes and Embryos*. Current guidelines for human reproductive research were published in 2005, ACARTs consider it timely to review these with a view to providing updated guidelines that still enable society to benefit from developments in ART while reflecting the views and attitudes of the day.

In the 2021/2022 financial year ACART developed the consultation document. ACART anticipates publishing the document late in 2022. Based on the outcome of this consultation, ACART will develop draft guidelines which will later be the subject of a second round of consultation.

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.

Ten further New Zealand-specific reports have now been received from UNSW Sydney for 2010, 2011, 2012, 2013, 2014, 2015, 2016, 2017, 2018 and 2019. ACART anticipates continuing to contract for annual New Zealand-specific reports, following the release of each ANZARD report.

The ninth ANZARD report, covering the 2018 calendar year, was received in October 2021. This report was considered and distributed to stakeholders by ACART. The tenth ANZARD report, covering the 2019 calendar year, was received in June 2022. ACART plans to consider and distribute this to stakeholders. All previous years' reports are publicly available on ACART's website.

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 2021/22, members and the secretariat shared relevant media and academic journal articles, and the secretariat distributed *Bionews* articles¹ 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.

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 2021/22

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.

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

¹ 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/).

Publications

In the 2021/22 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)
- Assisted Reproductive Technology in New Zealand 2018 (ANZARD)
- Submissions analysis: Stage two consultation on proposed guidelines for the posthumous use of gametes, reproductive tissue and stored embryos

ECART decisions 2021/22

Between 30 June 2021 and 30 June 2022, ECART considered 76 applications for assisted reproductive procedures and human reproductive research. There were:

- 42 applications for surrogacy involving fertility providers
- 17 applications for embryo donation for reproductive purposes
- 6 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
- 10 applications for the donation of eggs or sperm between certain family members
- 0 applications for preimplantation genetic diagnosis with human leucocyte antigen tissue typing
- 0 applications for human reproductive research.

Of these applications:

- 44 were approved at first review
- 16 were approved subject to conditions
- 4 approved with recommendations
- 10 were deferred
- 2 were declined.
- In addition, ECART considered 126 applications to extend the storage period of gametes, embryos, or tissue. ECART approved 124 of these applications outright.

The details of these decisions will be set out in ECART's annual report for 2021/2022.



Governance

Chair and Deputy Chair

Current Chair

Calum Barrett was originally appointed to ACART for a period of three years beginning on 31 May 2019. Calum was appointed deputy chair of ACART in February 2021. He was subsequently re-appointed, for a second term, and as chair in December 2021.

Kathleen Logan was originally 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. Kathleen continued in her role while a new representative for the Office of the Children's Commissioner was sought.

Deputy Chair

Karaitiana Taiuru has formally served as Deputy Chair since March 2022

Contact with the Minister of Health

There was no formal meeting with the Minister of Health during this reporting period.

Appendix 1: ACART membership

ACART members in the period

Calum Barrett – Chair for the three-year period beginning on 22 December 2021, Dr Kathleen Logan – Chair until October 2021, Acting Deputy Chair in December 2021 Rosemary De Luca Seth Fraser Dr Karen Reader Catherine Ryan Dr Karaitiana Taiuru – Deputy Chair from March 2022 Dr Analosa Veukiso-Ulugia Dr Sarah Wakeman Edmond Fehoko Shannon Te Ahu Hanrahan Debbie Wilson

Secretariat staff members

Zoe Benge, Advisor Martin Kennedy, Senior Policy Analyst Sadie Miles, Assistant Advisor Hayley Robertson, Senior Policy Advisor Mirae Wilson, Advisor

Biographies of ACART members

Members during 2021/22

Dr 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.

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 was appointed Deputy Chair in April 2021, and Chair in December 2021.

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.

Rosemary De Luca

Membership role: Ethics

Rosemary was appointed to ACART in August 2020 for a period of two years.

Rosemary is a research associate of the University of Waikato, in the Division of Education. She graduated from the Universities of Auckland and Waikato and is an educator. Latterly, she supervised the research and theses of several masters and doctoral students, most from Pasifika and Asian countries.

Rosemary's interests are in communication and ethics, emphasising diversity, equity, autonomy, personal values and societal norms, practical and theoretical aspects of narrative, and philosophy of language.²

From 1990, Rosemary was instrumental in the ethics of research and clinical practice, including assisted reproductive technologies. See De Luca R. (2003) *Perspectives on Informed Consent: An Investigation into Attitudes and Practices in Relation to Informed Consent to Medical Treatment in a Group of New Zealand Hospitals*; and De Luca R.(2004) The New Zealand Way: ART within an Ethical Framework. In J. Gunning & H. Szoke, (eds) *The Regulation of Assisted Reproductive Technology*. Ashgate: UK. pp. 95-107. The chapter was written prior to the Human Assisted Reproductive Technology Act (2004),

² De Luca, R. (2012). Attempting to standardise ethical review within the complexity of health-related research. *Communication & Medicine* 9:3, 269-277 doi:10.1558/cam.v9i3.269.

referencing the preparatory work that preceded this Act. Rosemary has been awarded membership of the New Zealand Order of Merit for services to ethics.

Rosemary is the mother of three adult children and nonna of five grandchildren.

Seth Fraser

Membership role: Ability to articulate issues from a disability representative

Seth was appointed in August 2020. Seth grew up in Wellington. He is a practising barrister sole with significant experience in the disability sector of the law. Seth has represented numerous clients with disabilities in various Courts, including being appointed amicus curiae in both the High Court and Court of Appeal to assist litigants with disabilities.

Seth is currently completing a Masters in laws and holds a Bachelor of film with Honours (2006) from Victoria University. He also holds a Graduate Diploma in Digital Media from the National College of Design.

Seth is married with three children.

Dr 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.

Catherine Ryan

Membership role: General layperson

Catherine was appointed to ACART in August 2020 for two years.

Catherine is a graduate of Education and Law. She has taught law at the University of Waikato Commerce Faculty and worked in Private Practice and as Legal advisor for Waitemata DHB.

Catherine's medical experience is in Research Ethics at Waikato DHB and Clinical Ethics for Auckland, Waitemata and Counties Manukau DHBs. At present, Catherine is a member of Counties Manukau Clinical Ethics Committee.

Catherine is a member of 2 Medsafe Committees; Medicines Adverse Reaction Committee and Medicines Assessment Advisory Committee.

Catherine is a Trustee of the Waikato DHB Complaints Service which facilitates resolution of complaints between the Provider and the Consumer.

Dr Karaitiana Taiuru

Membership role: Expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective

Dr Karaitiana Taiuru PhD, JP

Ngāi Tahu, Ngāti Rārua, Ngāti Kahungunu

Karaitiana was appointed to ACART in August 2020.

Karaitiana completed his PhD in Māori Genetic Data - Inalienable Rights and Tikanga Sovereignty in 2021 at Te Whare Wānanga o Awanuiārangi, after a life time of being immersed in Te Ao Māori and mātauranga. He is a nationally recognised Tikanga Māori expert with significant networks with lwi and Māori organisations.

Karaitiana holds several national board and academic appointments as the expert Māori advisor and currently works at the University of Otago Christchurch as a Researcher.

Karaitiana is a father of six children who range in ages from adults to young children and is a Poua to three mokopuna.

Dr 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.

Dr 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.

Edmond Fehoko

Membership role: Layperson with community perspectives

Dr Edmond Fehoko was appointed to ACART in 2021. Dr Fehoko is a Health Research Council of New Zealand Pacific Postdoctoral Fellow at the University of Auckland and is a Senior Lecturer in Human Nutrition at the University of Otago. Dr Fehoko has published in areas such as infertility and assisted reproductive technologies from a Pacific perspective.

Some of Edmond's previous roles include Pacific Partners Consultant at Manukau Institute of Technology, a Learning Advisor and Pasifika Student Support Advisor at AUT University. He is a member of the Auckland Tongan Council and Member of the Royal Society of New Zealand.

Edmond is engaged with a range of research projects relating to improving health in New Zealand and is fluent in Tongan.

Shannon Te Ahu Hanrahan

Membership role: Layperson with community perspectives

Whakatōhea, Ngāti Manawa, Ngāi Tūhoe, Ngāti Tūwharetoa, Rangitāne and Ngāi Tahu

Shannon was appointed to ACART in December 2021. Shannon is an experienced and skilled professional who has recently relocated back to New Zealand from the United Kingdom, where he held a number of public health related roles such as Director of Policy and Research Director at Campaign for Fairer Gambling UK, and Programme Manager of Workplace Health and Wellbeing at West Sussex County Council UK.

Shannon has recently been appointed to the National Ethics Advisory Committee and will bring a useful ethics perspective to ACART. Shannon also brings a Māori and rainbow community perspective to ACART.

Debra Wilson

Membership role: Layperson with expertise in the law

Debra was appointed to ACART in December 2021.

Debra is an Associate Professor of Law at the University of Canterbury where she teaches in the areas of Medical and Criminal Law.

Debra has a strong interest in researching and teaching medical law, particularly relating to surrogacy. She has previous Fellowships in Medical Law for a range of universities such as Oxford University and Cambridge University. Debra is a member of the Expert Advisory Panel for the New Zealand Law Commission (Surrogacy Laws) and has previously been an Expert Advisor to the United Kingdrom Law Commission on Surrogacy Reform.

Appendix 2: Member attendance at full ACART meetings

Member	Aug 2021	Oct 2021	Dec 2021	Mar 2022	May 2022	June 2022
Kathleen Logan	~	✓	~	~	~	~
Calum Barrett	✓	\checkmark	~	~	~	~
Rosemary De Luca	✓	\checkmark	~	~	~	Apol
Seth Fraser	✓	\checkmark	~	~	~	~
Karen Reader	✓	\checkmark	~	~	~	~
Catherine Ryan	~	\checkmark	~	~	Apol	~
Karaitiana Taiuru	✓	\checkmark	~	~	~	~
Analosa Veukiso-Ulugia	~	\checkmark	~	n/a	n/a	n/a
Sarah Wakeman	~	\checkmark	~	~	~	~
Edmond Fehoko	n/a	n/a	n/a	~	Apol	Apol
Shannon Te Ahu Hanrahan	n/a	n/a	n/a	~	~	~
Debra Wilson	n/a	n/a	n/a	~	~	~
Total members present	9	9	9	11	9	9

✓ Present

Apol Apologies

Appendix 3: ACART working groups

Working group	Responsibilities and meeting dates			
Proposal that the HART Order should explicitly state that the use of cryopreserved testicular tissue is an established procedure. Kathleen Logan, Karen Reader, Sarah Wakeman	Consider the submissions to the consultation.Finalised out of session by email.			
<i>Guidelines for Research involving</i> <i>Human Gametes and Embryos.</i> Rosemary De Luca, Kathleen Logan, Karen Reader, Karaitiana Taiuru	 Finalise the consultation document and develop ACARTs statement of embryo status. October. A working group meeting was held. (Final edits were made out of session by email.) 			
Amend the guidelines for extending the storage of gametes and embryos. Calum Barrett, Seth Fraser, Analosa Veukiso-Ulugia	Finalise the consultation document.October. A working group meeting was held.			
Posthumous reproduction: review of the Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man. Calum Barrett, Kathleen Logan, Karen Reader, Sarah Wakeman	Consider the draft guidelines and advise to the minister. Finalised out of session by email. 			
<i>Review of ACART's ethical framework.</i> Rosemary De Luca. Catherine Ryan, Karaitiana Taiuru	Scope a possible review of the framework.September. A working group meeting was held.			