Advisory Committee on Assisted Reproductive Technology Annual Report 2017/18

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Foreword

On behalf of the Advisory Committee on Assisted Reproductive Technology (ACART), the Chair is pleased to present this annual report for 2017/18.

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 guideline reviews was of the three donation guidelines (gamete donation, embryo donation and use of donated eggs with donated sperm), plus 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 use ART in forming a family. The consultation stage for this review generated public interest in late 2017.

ACART also made significant progress on its review of the *Guidelines on the Storage, Use, and Disposal of Sperm from a Deceased Man.*¹ These guidelines pre-date the current regulatory framework, including the Human Assisted Reproductive Technology (HART) Act 2004. The review seeks to canvas public opinion on important ethical questions about how people's gametes and embryos should be treated after they die. Stage one of the public consultation was submitted in June 2018, and ACART hopes this will generate significant interest to inform the stage-two consultation.

The current guidelines for human reproductive research, *Guidelines for Research on Gametes and Non-viable Embryos*² 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Minister of Health Hon Peter Dunne agreed that ACART's work programme should include a limited review of these outdated guidelines, subject to further consideration by Cabinet.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 May 2018, the Minister of Health, Hon Dr David Clark, also agreed to consider the scope of such a review.

Membership changes saw us farewell Deputy Chair Mike Legge who had reached the end of his six-year term as the member with expertise in assisted reproductive procedures. We welcomed Karen Reader as the new member with expertise in that role. We also farewelled Catherine Poutasi, who had been a member of ACART since April 2016.

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

² NECAHR. 2005. Guidelines for Research on Gametes and Non-viable Embryos. Wellington: National Ethics Committee on Assisted Human Reproduction.

ACART undertook a considerable amount of work in the 2017/18 period for a committee and secretariat of its size. We are very grateful to ACART's members who contribute significant expertise and time to enable this work to progress.

ACART also continued its close working relationship with ECART, the Ministry of Health (the Ministry) and providers of fertility services. I would like to take this opportunity to acknowledge the policy and administrative support the committee receives from the Ministry and to thank the Ministry for this ongoing support.

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Gillian Ferguson Chair, Advisory Committee on Assisted Reproductive Technology

Contents

Forewordii	ii
Introduction	1
Purpose of this report	1
Background	1
ACART's functions	1
ACART's work during 2017/18	3
ACART meetings	3
Guidelines projects in 2017/18	3
ACART's monitoring functions	4
Other issues considered by ACART during 2017/18	5
Conference attendance	6
Publications	6
ECART decisions 2017/18	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 meetings1	5
Appendix 3: ACART working groups16	6

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 2017/18.

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 invitro 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 2017/18

ACART meetings

ACART met as a full committee, with the support of the secretariat, six times during 2017/18. (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 further information on working group membership and meetings.)

Guidelines projects in 2017/18

Review of the donation 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 existing guidelines.

ACART 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 in Auckland, Wellington and Dunedin.

The submissions 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 in 2019. In the event that the Minister agrees with our advice, some changes would need to be made to the HART Order before the revised guidelines could be published.

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

The current guidelines were issued in 2000.³ 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. ACART undertook preliminary scoping work in 2014, 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.

³ NECAHR. 2000. Guidelines on the Storage, Use, and Disposal of Sperm from a Deceased Man. Wellington: National Ethics Committee on Assisted Human Reproduction.

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 2016 and 2017. By 30 June 2018, ACART had produced a stage-one consultation document and organised meetings with targeted stakeholders, such as fertility clinics, to discuss the document. Public consultation will run for eight weeks, and ACART will consider the submissions resulting from that consultation in late 2018.

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*,⁴ 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 approved ACART scoping a project for ACART 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.

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

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.

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

The seventh ANZARD report, covering the 2015 calendar year, was received in June 2018 and will be considered by ACART in October 2018. 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 2017/18, members and the secretariat shared relevant media and academic journal articles, and the secretariat distributed *Bionews* articles⁵ 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 2017/18

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.

⁵ 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/).

The following liaisons took place during the 2017/18 period.

- All committee meetings for each committee included a member of the other committee as a member-in-attendance.
- ACART wrote to ECART suggesting that the legislation be changed so that applications for extended storage could be processed by fertility clinics instead of by ECART.

Conference attendance

ACART supported committee members to attend the following conferences.

- Gillian Ferguson and Kathleen Logan attended the Rethinking Legal Parentage symposium, in Christchurch, in June 2018.
- John McMillan went to the Fertility Society of Australia (FSA) conference, in Adelaide, in October 2018.

Publications

In the 2017/18 year, ACART published on its website (www.acart.health.govt.nz):

- Advisory Committee on Assisted Reproductive Technology: Annual report 2015/16
- agendas of ACART meetings (after each meeting)
- minutes of ACART meetings (after their confirmation at each following meeting)
- submissions 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*
- advice to the Minister on the use of cryopreserved ovarian tissue becoming an established procedure
- Assisted Reproductive Technology in New Zealand 2013 (ANZARD)
- Assisted Reproductive Technology in New Zealand 2014 (ANZARD)
- 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 2017/18

Between 30 June 2017 and 30 June 2018, ECART considered 51 applications for assisted reproductive procedures and human reproductive research. There were:

- 28 applications for surrogacy involving fertility providers
- 9 applications for gamete donation between certain family members
- 9 applications for embryo donation for reproductive purposes
- 4 applications for the creation and use, for reproductive purposes, of an embryo created from donated eggs in conjunction with donated sperm
- 1 application for Preimplantation Genetic Diagnosis (PGD) with human leucocyte antigen (HLA) tissue typing.

Of these applications:

- 40 were approved outright
- 1 was approved subject to conditions
- 8 were deferred
- 2 were declined.

In addition, ECART considered 60 applications to extend the storage period of gametes or embryos. ECART approved 58 of these applications outright.

7

The details of these decisions will be set out in ECART's annual report for 2017/18.

Governance

Chair and Deputy Chair

Current Chair

Gillian Ferguson began her term as the Chair on 23 June 2017, for a period of three years. Gillian had originally been appointed to ACART in June 2016.

Deputy Chair

Mike Legge served as Deputy Chair from February 2015 to April 2018. Members supported Kathleen Logan to be appointed Deputy Chair following the end of Mike's term.

Contact with the Minister of Health

Gillian Ferguson and Kathleen Logan met the Minister, Hon Dr David Clark, on 2 May 2018.

Appendix 1: ACART membership

ACART members in the period

Associate Professor Michael (Mike) Legge – Deputy Chair – until April 2018 Jonathan Darby Gillian Ferguson Dr Colin Gavaghan Dr Kathleen Logan – Deputy Chair from April 2018 Sue McKenzie John McMillan Catherine Poutasi – until December 2017 Dr Barry Smith Dr Sarah Wakeman Dr Karen Reader – from December 2017

Secretariat staff members

Martin Kennedy, senior policy analyst Isabel Ross, policy analyst – until September 2017 Hayley Robertson, policy analyst – from October 2017 Administrative support was provided by Moana Tupaea.

Biographies of ACART members

Members during 2017/18

Michael Legge (Deputy Chair from February 2015 to April 2018)

Membership roles: Expertise in human reproductive research and ethics

Associate Professor Michael (Mike) 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 was subsequently appointed again until October 2017.

Mike 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).

Mike 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 (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 Inc. (1978) and The Institute of Biomedical Science, United Kingdom (1973).

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, having 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.

Gillian Ferguson (Chair from 23 June 2017)

Membership role: Consumer perspective

Gillian Ferguson was appointed to ACART in April 2016 for three years.

Gillian has been appointed to the role of a member who is able to articulate issues from a consumer perspective. She has used assisted reproduction in having her two children.

Gillian has a Masters' degree in law from the University of Cambridge and completed a law and arts degree at University of Otago.

She has extensive public policy experience in senior roles in Australia, most recently as the Executive Director of the New South Wales (NSW) Government Unit, Women NSW, for four years. Other roles in Australia have included providing policy advice in the NSW Department of Premier and Cabinet and at the NSW Law Reform Commission. Her earlier work in New Zealand included being Assistant Crown Counsel in the Bill of Rights team at the Crown Law Office.

Recently Gillian was appointed to The Film and Literature Board of Review. She is actively involved in the disability sector, including as a member of the Management Committee of the World Bank's Family Network.

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.

Catherine Poutasi (April 2016–December 2017)

Membership role: General layperson

Catherine Poutasi was appointed to ACART in April 2016 for three years. Catherine is Samoan and has close contacts with the Pacific community.

Catherine holds a Masters' degree in psychology from The University of Auckland and completed Bachelors' and Honours' study at the University of Otago and Victoria University of Wellington.

She is Director and owns Integrity Professionals Ltd. Integrity Professionals is a consultancy business based in Auckland and Wellington, New Zealand, and Wollongong, New South Wales, Australia. The firm's services include evaluations, monitoring, organisational reviews, research projects, service reviews, strategic planning and senior management advice, support and mentoring. Much of Catherine's work for central government and the community sector has had a health focus.

Before establishing her business, Catherine worked in policy and planning roles in central government agencies.

Barry Smith QSM

Membership role: Expertise in Māori customary values and perspectives

Barry Smith (Te Rarawa, Ngāti Kahu) was appointed to ACART in April 2013 for three years and has since been reappointed until April 2019.

Barry is 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 is 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 is a member of the Auckland Regional Tissue Bank's Governance Advisory Board and the Podiatrists Board of New Zealand.

Barry's current research work on ethics in Māori contexts is supported by the HRC 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 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.

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 2017	October 2017	December 2017	February 2018	April 2018	June 2018
Gillian Ferguson (Chair)	✓	~	~	~	~	~
Michael Legge (Deputy Chair until April 2018)	\checkmark	~	~	✓	~	NA
Jonathan Darby	~	~	~	~	~	~
Kathleen Logan (Deputy Chair from April 2018)	\checkmark	~	~	✓	~	~
Sue McKenzie	~	~	~	~	Apol	~
John McMillan	Apol	~	✓	~	~	~
Colin Gavaghan	\checkmark	~	~	✓	~	Apol
Karen Reader (Membership began December 2017)	NA	NA	~	~	~	~
Catherine Poutasi	~	~	Apol	NA	NA	NA
Barry Smith	\checkmark	Apol	Apol	~	~	~
Sarah Wakeman	\checkmark	~	~	~	Apol	~
Total members present	9	9	9	10	8	8

Present

Apol Apologies

NA Not applicable

Note: Catherine Poutasi resigned from ACART in January 2017.

Appendix 3: ACART working groups

Working group*	Responsibilities and meeting dates
Review of the Donation Guidelines Gillian Ferguson Mike Legge Kathleen Logan Barry Smith Jonathan Darby	 Review the three donation guidelines (family gamete donation, embryo donation, use of donated eggs with donated sperm) and surrogacy guidelines. The working group met on: 8 February 2018.
Guidelines for posthumous reproduction Gillian Ferguson Mike Legge Sue McKenzie John McMillan Colin Gavaghan Sarah Wakeman Nicola Peart (University of Otago, faculty of Law)	 Produce a stage-one consultation document to review the <i>Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man</i> and seek public feedback on posthumous reproduction. The working group met on: 9 March 2018.

* This list presents all committee members who were on a working group at some time during the 2017/18 period. Not all members were necessarily present at all meetings or on a working group at the same time as all the other listed members.