



National Ethics Advisory Committee

Kāhui Matatika o te Motu

National Ethics
Advisory Committee
Kāhui Matatika o te Motu
Annual Report 2019

Eighteenth Annual Report
to the Minister of Health

National Ethics Advisory Committee

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Foreword

E ngā iwi, e ngā mana, e ngā reo. E ngā karangatanga maha, tēnei te mihi.

Tēnei te mihi i runga i ā tātou mate kua whetūrangitia. Rātou kua piki ake ki Paerau ki te huihuinga o te Kahurangi, moe mai rā.

Hoki mai ki ā tātou te hunga ora e pīkau nei ngā mahi mo ā tātou whānau. Tēnā tātou katoa.

This annual report sets out the activities of the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) and summarises its advice on matters referred to it under section 16 of the New Zealand Public Health and Disability Act 2000.

NEAC is an independent advisor to the Minister of Health and operates independently of the Ministry of Health and its work. NEAC's statutory functions are broad and strategic. They include advising the Minister of Health on ethical issues of national significance in respect of health and disability matters and determining nationally consistent ethical standards across the health system. NEAC's view of ethics involves identifying what matters, explaining how the sector can act and encouraging ethical decision-making.

NEAC's main focus during 2019 has been the review of our 2012 ethical guidelines for researchers, *Ethical Guidelines for Observational Studies* and *Ethical Guidelines for Intervention Studies*. The intention of the revised standards, entitled *National Ethical Standards for Health and Disability Research and Quality Improvement*, is to ensure adequate protection of participants while reducing unnecessary impediments to, and facilitating the progress of, ethical research. As at July 2019 we have continued work on drafting final chapters of the revised standards, with a particular emphasis on strengthening standards concerning disability and Māori research ethics.

In October, NEAC proudly hosted the second Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees (AP-NEC-2), in collaboration with the World Health Organization and with the support of the United Nations Educational, Scientific, and Cultural Organization. AP-NEC is held once every two years and brings together national ethics committees, as well as ethics/bioethics focal points in governments, from around the world to share their thoughts and experiences in relation to bioethical issues.

NEAC has also been following with interest the Health and Disability Commissioner's consultation regarding research with individuals who are unable to give informed consent (that is, concerning Right 7(4) of the New Zealand's Code of Health and Disability Services Consumers' Rights). Feedback from our public consultation on the revised standards showed us that many participants also support work on fair and equitable access to health research in the Commission's work programme.

We would like to thank the many organisations and individuals who contributed to our work and public consultations this year. Your input helps us to ensure that our work is useful and addresses the issues that you consider important.

In January this year, we farewelled Adriana Gunder, a member who made a significant contribution to NEAC governance over many years. We were very pleased to welcome two new members in June: Mary-Anne Woodnorth and Gordon Jackman.

We have continued to be exceptionally well supported by the Secretariat at the Ministry of Health over a period of significant change.

On behalf of NEAC, I am pleased to present this annual report for 2019.

A handwritten signature in black ink, appearing to be 'Neil Pickering', with a stylized flourish at the end.

Neil Pickering

Chair

National Ethics Advisory Committee

Kāhui Matatika o te Motu

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Introduction to the National Ethics Advisory Committee

Functions of the National Ethics Advisory Committee

The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health. Its statutory functions, under section 16 of the New Zealand Public Health and Disability Act 2000 (the Act), are to:

- advise the Minister on ethical issues of national significance in respect of health and disability matters (including research and health services)
- determine nationally consistent ethical standards across the health sector
- provide scrutiny for national health research and health services.

NEAC works within the context of the Act and key health and disability policy statements. Section 16(6) of the Act states that NEAC must, 'at least once a year, deliver to the Minister a report setting out its activities and summarising its advice on the matters referred to it under this section'.

Membership of the National Ethics Advisory Committee

The Minister appoints the members of NEAC, who come from a range of professions and backgrounds and bring expertise in ethics, clinical leadership, health service provision, health and disability research, epidemiology, law, Māori health and consumer advocacy.

Mary-Anne Woodnorth and Gordon Jackman joined the Committee this year, and NEAC farewelled Adriana Gunder.

Short biographies for all committee members appear on pages 7 to 9.

Work in 2019

Review of Ethical Guidelines for Researchers

Progress in 2019

Since 2012, NEAC's main focus has been the comprehensive review of its *Ethical Guidelines for Intervention Studies* and *Ethical Guidelines for Observational Studies*. The main objectives of the review were to ensure the guidelines were fit for purpose and consistent with other relevant guidance. The update also addressed ethical issues associated with developments in research methods and emerging topics.

NEAC had four face-to-face meetings and a number of teleconferences in 2019 to develop the revised standards. It launched these in December 2019 as the *National Ethical Standards for Health and Disability Research and Quality Improvement*. The new standards update and expand on the 2012 guidelines, bringing the two guidelines into one document. They cover existing gaps and address new ethical issues that have become apparent since 2012.

The new standards foster awareness among all researchers of ethical principles, and enhance more rapid translation of research into clinical practice and health services delivery. The new standards set the criteria for researchers to follow when conducting health and disability research. Independent ethics committees and accredited Health and Disability Ethics Committees (HDECs) use them to ensure that health research in New Zealand is meeting or exceeding best practice.

NEAC has updated many sections of the standards, addressing ethical issues raised by new technologies such as genomics, artificial intelligence and biobanking. The new standards update the regulatory framework, and work in tandem with the Therapeutic Products and Medicines Bill and the Ministry of Health's Health Research Strategy 2017–2027. The new standards form part of a strengthened regulatory framework, to support a productive and safe clinical trials research environment in New Zealand.

NEAC and the Secretariat began to work with the sector to implement the new standards and ensure they are fit for purpose. As part of this work, NEAC and the Ministry of Health will host a roadshow throughout New Zealand in early 2020, providing training in and guidance on the new standards.

NEAC decided that the new standards require some further work in the context of two particular major ethical gaps that will require more considered thought in future:

- quality improvement ethics and related activities
- emergency ethics/pandemic ethics.

Disability Research Ethics in the New Standards

Feedback from the 2018 general consultation on a draft iteration of the new standards identified that guidance was lacking for certain research domains. Further content was required for areas including, among others, disability research ethics.

Accordingly, the Secretariat began work on a full new chapter in the new standards on this subject. It produced a talking-point skeleton chapter, based on a literature review. Then, on 6 May 2019, NEAC hosted a workshop with the aim of finalising the chapter. Academics and stakeholders were among those invited, and the day consisted of talks focusing on academics' work in the field. Time was also set aside for group discussion. Attendees' comments proved very useful for the Secretariat, and resulted in a strong chapter providing practical guidance for research both involving and initiated by disabled people. One valuable contribution from attendees at the workshop was a nuanced definition of the concept of disability itself, on which commentary has been made in the new standards.

Participants were complimentary of management of the workshop, and approved of the principle of prioritising disabled peoples' voices when generating ethical guidance for disability research. Subsequently, Victoria University of Wellington is publishing an academic article on the process undertaken by the Secretariat in this area.

Māori Research Ethics in the New Standards

In the past, New Zealand's system of ethical review has been challenged for not adequately considering Māori interests and ethical perspectives, including the rights of the collective, principles of tikanga and mātauranga Māori, and culturally significant ethical boundaries.

Taking into account the historical separation of Māori and Western bioethics, the new standards set out two sets of principles that collectively form the basis of the standards: Te Ara Tika principles and bioethics principles. This structure is something unique to New Zealand, and enriches our quality of ethical research.

Te Ara Tika is a set of Māori ethical principles that draws on a foundation of tikanga (Māori protocols and practices). 'Te Ara Tika' means 'the right path'. The term is used in the new standards to cover a generic set of principles commonly shared by many generations and communities of Māori; however, the set has application to all people in Aotearoa New Zealand.

The updated section on Māori research in the new standards are just one step forward. They represent the first time we have joined Māori bioethics together with Western bioethics in the context of health research, rather than having a separate set of principles or a separate guidance document. The new standards recognise and integrate ethical research guidance by Māori for decades including *He Tangata Kei Tua: Guidelines for Biobanking with Māori*, published by Te Mata Hautū Taketake.

Quality Improvement and the Health Quality & Safety Commission

Public consultation during 2018 demonstrated that quality improvement activities represented a significant gap in the existing guidance. During 2019, the Secretariat met a number of times with representatives from the Health Quality & Safety Commission (HQSC) to discuss how quality improvement activities would fit into the revised Standards.

High-level discussions with the HQSC over time have resulted in the addition of a chapter in the new standards on quality improvement activities, as well as ethical guidance for the conduct of related activities, such as health services and implementation research.

The Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees

NEAC hosted the second Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees (AP-NEC-2) in October 2019 in collaboration with the World Health Organization and with the support of the United Nations Educational, Scientific, and Cultural Organization.

The Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees is held once every two years, and brings together national ethics committees, as well as ethics/bioethics focal points in governments, from around the world to share their thoughts and experiences in relation to bioethical issues.

The meeting was held at New Zealand's national museum, Te Papa Tongarewa, and ran from 21 to 23 October with the theme of Reducing Inequities through Solutions-Oriented Bioethics with an aim theme in the planning to ensure the meeting was as sustainable as possible.

The Republic of Korea held the inaugural AP-NEC meeting in 2017. For the Wellington meeting, NEAC chose to develop previous discussions, and respond to the Global Summit's 'Call for Action' through a focus on equity in health and what solutions bioethics can offer to inequity. The concept of equity in health is an ethical principle, closely related to human rights; in particular, the right of all humans to experience good health. Bioethics has a role to play in addressing inequity both nationally and internationally. Solutions-orientated bioethics draws on the practical and sometimes pragmatic aspects of bioethics, where real world situations are ethically analysed using the bioethics framework. Achieving equity in health involves ethical deliberation across public health, global health, research, and clinical ethics.

The Regional Meeting took place between meetings of the Global Summit of Bioethics Committees. The Global Summit is a biennial forum at which national bioethics representatives can share information and experiences on ethical issues in health and public health. It is a platform for discussion and formulates consensus on a wide range of prominent ethical topics.

Monitoring Health and Disability Ethics Committees

Part of NEAC's mandate is to assist the Ministry to measure and monitor the extent to which changes to HDECs contribute to improving the system of ethical review for health and disability research. To ensure that HDECs have adequate guidelines with which to make decisions about health research applications, a number of changes have been made to the standards governing health research in New Zealand with the release of the NEAC's new standards in December 2019.

Services Ethics Work in 2019

Dementia Tracking

In late 2018, NEAC received a request from Dr Phil Wood (Chief Advisor, Healthy Ageing, Ministry of Health), on behalf of Land Search and Rescue (LandSAR), for advice on the use of cell phone-based tracking devices with people suffering from dementia. A LandSAR working group had been established to address the understandable concern over tracking individuals without their consent. The conflict between the need to protect people with dementia, who are prone to 'night-walking', with the desire to respect their autonomy led LandSAR to consult NEAC.

NEAC considered this request against previous advice issued to the Associate Minister of Health in 2016 on dementia care in New Zealand. True to the principles of this advice, NEAC advised that while it seems intuitive that tracking restricts independence, for people living with dementia cell phone-based tracking devices in fact offer greater independence for those living in both the community and residential care, as this tool greatly increases their ability to move around safely. Paradoxically, tracking devices can help maintain basic freedoms in this situation. However, as is true of applied ethics in general, we note that decisions must be made contextually, on a case-by-case basis.

Other Work in 2019

Progress in 2019

NEAC members and Secretariat staff attended a range of events in 2019, including:

- the New Zealand Association of Clinical Research conference, August 2019
- AP-NEC-2, October 2019
- the Australasian Association of Bioethics and Health Law and New Zealand Bioethics Conference, November 2019.
- NEAC made a submission to the Medical Council of New Zealand on its consultation to revise its statement on information, choice of treatment and informed consent.

National Ethics Advisory Committee Members

Neil Pickering – Chair, Health Research Council of New Zealand Nominee

Neil is an associate professor in the Bioethics Centre at the University of Otago. He has published on a range of ethical issues, and has been a member of a number of research projects both in New Zealand and in his previous job in the United Kingdom. His primary area of research is philosophy of mental health.

He was a member of the University of Otago Human Research Ethics Committee from 1999 to 2005. He was also on the Health Research Council of New Zealand (HRC) Ethics Committee from 2005 to 2010, and was acting chair from 2007 to 2008. He is currently a member of the editorial board of the *Journal of Bioethical Inquiry* and a member of the committee of the Australasian Association of Bioethics and Health Law.

Neil was appointed to NEAC in April 2013 and reappointed in July 2016. He was appointed deputy chair in September 2016, and was acting chair from October 2016. During 2019 Neil was appointed chair.

Maureen Holdaway – Health Researcher

Maureen is the deputy director for the Research Centre for Māori Health and Development, Massey University, and a registered nurse with extensive experience in primary health care.

Maureen has worked in the health and education sectors for many years. Her key areas of research expertise are Māori and indigenous health development, primary health care and health workforce development.

Maureen has collaborated on national and international studies focusing on indigenous health and development. She is a named investigator on two core programme grants for the Research Centre for Māori Health and Development, a number of individual HRC grants and other research involving significant collaborations within Massey University and with other universities and health service providers, both nationally and internationally.

Maureen was reappointed to NEAC in 2019.

Kahu McClintock – Representing the Interests of Māori

Kahu McClintock (Waikato/Maniapoto, Ngāti Mutunga and Ngāti Porou) is the manager research at Te Rau Matatini/Te Rau Ora. Kahu has worked in the health and disability sector for over 20 years, with a special focus on Māori health research and child and adolescent mental health.

Kahu was a member of the Māori Health Committee within the HRC from 2008 to 2014, and chair of Ngā Kanohi Kitea Community Research Committee within the HRC during that term. She is the lead for Te Rā o Te Waka Hourua.

Kahu was reappointed to NEAC in 2019.

Adriana Gunder (QSM) – Community/Consumer

Adriana was involved in biological and medical research for many years, mainly in Italy and the United Kingdom.

Adriana had polio when she was an infant; as a consequence, she feels strongly about disability and accessibility issues and is involved with disability organisations. Adriana has served on the Board of the New Zealand Red Cross (2012–2014), the New Zealand Health Practitioners Disciplinary Tribunal (2010–2015) and the Ethics Committee on Assisted Reproductive Technology (2010–2016).

Adriana is involved with community and charity organisations and is a Justice of the Peace. She is a current member of the Medical Sciences Council.

Adriana was awarded the Queen’s Service Medal for service to the community in June 2012.

Adriana resigned from NEAC in January 2019.

Wayne Miles – Health Professional

Wayne is the director of Awhina Research and Knowledge, Waitemata District Health Board and a clinical associate professor at the Department of Psychological Medicine, the University of Auckland. He has had extensive experience as a psychiatrist, a clinical leader and a clinical researcher.

Wayne has been an HDEC member for seven years, and is a member of the HRC College of Experts. His past roles have included president of the Royal Australian and New Zealand College of Psychiatrists and chair of the Council of Medical Colleges in New Zealand.

Wayne was re-appointed to NEAC in 2019.

Liz Richards – Community/Consumer

Liz is an independent director and trustee for the Tasman Bays Heritage Trust. Her previous roles include chair of the Top of the South Health Alliance, chair of the Upper South A Health and Disability Ethics Committee and deputy chair of the Canterbury Community Trust and the Nelson Marlborough District Health Board. Liz has also been active in governance roles for a number of community organisations in the Nelson region.

Liz has worked in health promotion and public sector housing management, and lectured in housing studies at Salford University.

Liz was reappointed to NEAC in 2019.

Hope Tupara – Health Professional

Hope Tupara works from home, mostly in private contract research and as a practising midwife. She has published papers in the New Zealand College of Midwives Journal, the *Cambridge Quarterly of Health Care Ethics* and the *American Journal of Bioethics*.

Hope has a special interest in iwi development, the Māori Women's Welfare League and Whānau Ora.

Hope was re-appointed to NEAC in 2019.

Dana Wensley – Lawyer

Dana is interested in issues that transcend the traditional boundaries between law, medicine and ethics, and specialises in regulatory responses to emerging genetic technologies. She has held posts as research fellow at the Human Genome Research Centre (University of Otago) and assistant editor of the *Bulletin of Medical Ethics* (London). She currently serves as consumer representative on the Hospital Advisory Committee of the Nelson Marlborough District Health Board.

Dana was re-appointed to NEAC in 2019.

Mary-Anne Woodnorth – Health Researcher

Mary-Anne is a trained biomedical researcher. She has worked in a variety of research settings throughout her career, within both industry (Neuren Pharmaceuticals) and government (HRC). She has led the Research Office of Auckland District Health Board, New Zealand's largest clinical research facility, since 2010.

These days Mary-Anne's interests centre on improving the environment for high-quality Aotearoa/New Zealand health research by supporting promising individuals to become research active, promoting the publication and sharing of research findings and examining the impact of research on clinical practice.

Mary-Anne was appointed to NEAC in 2019.

Gordon Jackman – Representing the Interests of Disability

Gordon is chief executive officer of the Duncan Foundation, an organisation that supports people with neuromuscular conditions. He is on the board of the Supported Lifestyle Hauraki Trust and the Thames Public Art Trust. He worked on the East Coast as an archaeologist for many years. He has had a parallel career as an environmental consultant, specialising in environmental toxicology, contaminated site management, wastewater treatment and forestry certification. He had polio when he was 10 months old and has been active in the disability sector most of his life.

Gordon was appointed to NEAC in 2019.

Member Attendance at NEAC Meetings in 2019

Meeting attendance in 2019	30 April 2019	17 July 2019	5 November 2019	27 November 2019
Neil Pickering (chair)	✓	✓	✓	✓
Liz Richards	✓	Apol	✓	✓
Wayne Miles	✓	Apol	✓	✓
Maureen Holdaway	✓	✓	✓	✓
Kahu McClintock	✓	✓	✓	✓
Hope Tupara	✓	✓	Apol	✓
Dana Wensley	✓	✓	✓	✓
Mary-Anne Woodnorth	NA	✓	✓	✓
Gordon Jackman	NA	✓	✓	✓
Total members present	7	7	8	9

✓ = Present Apol = Apologies Note: Mary-Anne Woodnorth and Gordon Jackman's membership began in June 2019.

National Ethics Advisory Committee Secretariat

Role of the National Ethics Advisory Committee Secretariat

The NEAC Secretariat provides dedicated analytical policy and administrative support to NEAC. It is located in the Ministry of Health.

Membership of the National Ethics Advisory Committee Secretariat

The NEAC Secretariat in 2019 comprised:

- Rob Mchawk, Manager Ethics
- Nic Aagaard, Principal Advisor
- Hayley Robertson, Senior Advisor
- Mark Joyce, Advisor
- Joel Tyrie, Advisor
- Moana Tupaea, Group Administrator.

Contact Details for the National Ethics Advisory Committee

Contact details for NEAC are as follows:

Email	neac@health.govt.nz
Postal Address	PO Box 5013, Wellington 6145
Website	www.neac.health.govt.nz

Appendix: Terms of reference for the National Ethics Advisory Committee

These terms of reference came into effect in December 2013.

1. The National Advisory Committee on Health and Disability Support Services Ethics (the National Ethics Advisory Committee) is a ministerial advisory committee established under section 16 of the New Zealand Public Health and Disability Act 2000 (the Act). The National Ethics Advisory Committee is established by and accountable to the Minister of Health.

Functions of the Committee

2. The National Ethics Advisory Committee's statutory functions are to:
 - provide advice to the Minister of Health on ethical issues of national significance in respect of any health and disability matters (including research and health services)
 - determine nationally consistent ethical standards across the health and disability sector and provide scrutiny for national health research and health services.
3. As part of its functions the Committee is also required to:
 - consult with any members of the public, persons involved in the funding or provision of services, and other persons that the committee considers appropriate before providing advice on an issue (section 16(4) of the Act refers)
 - at least annually, deliver to the Minister of Health a report setting out its activities and summarising its advice on the matters referred to it under section 16 of the Act by the Minister of Health.
4. In undertaking its functions, the Committee is expected to:
 - provide advice on priority issues of national significance as requested by the Minister of Health
 - provide advice to the Minister of Health regarding ethical issues concerning emerging areas of health research and innovative practice. The advice is to include the Committee's rationale for its advice and any relevant evidence and/or documentation
 - provide advice to the Minister of Health regarding aspects of ethical review in New Zealand, including the setting of principles and guidelines in relation to each of the different types of health research and innovative practice. The advice is to include the Committee's rationale for its advice and any relevant evidence and/or documentation
 - develop and promote national ethical guidelines for health research and health and disability support services. The guidelines should address how to conduct different types of health research (including ethical issues relating to Māori health research) and innovative practice in an ethical manner and should establish parameters for, and provide guidance on, the ethical review of such types of health research and health and disability support services

- monitor and review the operation of the health and disability ethics committees for the purposes of providing direction, guidance and leadership to ensure the ongoing quality and consistency of ethical review in the health and disability sector
- undertake its tasks in a manner consistent with the principles of the Treaty of Waitangi
- develop guidelines on conducting observational studies in an ethical manner and establish parameters for the ethical review of observational studies (including guidance on weighing up the harms and benefits of this type of research).

Composition of the Committee

5. The National Ethics Advisory Committee will have a maximum of 12 members appointed by the Minister of Health.
6. The Committee's membership must include:
 - two health professionals (one of whom must be a registered medical practitioner)
 - three community/consumer representatives (must not be health professionals, health researchers, or professional members)
 - one member nominated by the Health Research Council of New Zealand
 - two or more Māori members (one of whom must have a background in Māori research and/or ethics).
7. The membership must also have expertise in the following areas:
 - ethics
 - research (qualitative and quantitative)
 - epidemiology
 - law.

Terms and Conditions of Appointment

8. Members of the National Ethics Advisory Committee are appointed by the Minister of Health for a term of up to three years. The terms of members of the Committee will be staggered to ensure continuity of membership. No member may be appointed for more than six consecutive years unless an additional period of up to 12 months is confirmed to allow for continuity of projects.
9. Unless a person sooner vacates their office, every appointed member of the Committee will continue in office until their successor comes into office.
10. Any member of the Committee may at any time resign as a member by advising the Minister of Health in writing.
11. Any member of the Committee may at any time be removed from office by the Minister of Health for inability to perform the functions of office, bankruptcy, neglect of duty, or misconduct, proved to the satisfaction of the Minister.

12. The Minister may from time to time alter or reconstitute the Committee, or discharge any member of the Committee or appoint new members to the Committee for the purpose of decreasing or increasing the membership or filling any vacancies.

Chairperson and Deputy Chairperson

13. The Minister will from time to time appoint a member of the National Ethics Advisory Committee to be its Chairperson. The Chairperson will preside at every meeting of the Committee at which they are present. The Chairperson may appoint a member as Deputy Chairperson, in consultation with the Minister. The Deputy Chairperson may exercise the powers of the Chairperson in situations where the Chairperson is not present or is unable to act (eg, if the Chairperson has a conflict of interest).

Duties and Responsibilities of a Member

14. This section sets out the Minister of Health's expectations on the duties and responsibilities of a person appointed as a member of the National Ethics Advisory Committee. This is intended to aid members by providing them with a common set of principles for appropriate conduct and behaviour and serves to protect the Committee and its members.
15. As an independent statutory body, the Committee conducts its activities in an open and ethical manner, and operates in an effective and efficient way within the parameters of its functions as set out in its Terms of Reference.
16. Committee members should have a commitment to work in the best interests of the Committee.
17. Members are expected to make every effort to attend all the Committee meetings and devote sufficient time to become familiar with the affairs of the Committee and the wider environment within which it operates.
18. Members are expected to act responsibly with regard to the effective and efficient administration of the Committee and the use of Committee funds.
19. Members will:
 - be diligent, prepared and participate
 - be respectful, loyal and supportive
 - not denigrate or harm the image of the Committee.
20. The Committee as a whole will:
 - ensure that the independent views of members are given due weight and consideration
 - ensure fair and full participation of members
 - regularly review its own performance
 - act in accordance with the principles of the Treaty of Waitangi.

Conflicts of Interest

21. Members must perform their functions in good faith, honestly and impartially, and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. They must also be, and be seen to be, independent of the Minister of Health and the Ministry of Health. Proper observation of these principles will protect the National Ethics Advisory Committee and its members and will ensure it retains public confidence.
22. Members attend meetings and undertake Committee activities as independent persons responsible to the Committee as a whole. Members are not appointed as representatives of professional organisations and groups. The Committee should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.
23. Members are required to declare any actual or perceived interests to the full Committee. The Committee will then determine whether or not the interest represents a conflict, and if so, what action will be taken.
24. The Chairperson will ask members to declare any actual or perceived interests at the start of each meeting.

Confidentiality

General

25. The public has a right to be informed about the issues being considered by the National Ethics Advisory Committee. The Committee should have procedures in place for the release of information and processing requests for information.
26. Individual members must observe the following duties in relation to Committee information. These provisions ensure that the Committee as a whole maintains control over the appropriate release of information concerning issues before it.

General Meeting Discussions

27. Key discussion points in meetings are recorded in the meeting minutes. Upon request, a member's dissenting views may be recorded in the meeting minutes.
28. Members must ensure that the confidentiality of Committee business is maintained. Members must be clear about what Committee matters are permitted to be discussed with people that are not Committee members and, in doing so, should be familiar with the information that is publically available about the Committee's work.
29. Meetings of the Committee, including agenda material and draft minutes, are confidential. Committee members must ensure that Committee documents are kept secure to ensure that the confidentiality of Committee work is maintained. Committee correspondence or papers can only be released with the approval of the Committee.

30. Members are free to express their own views within the context of Committee meetings, or as part of the general business of the Committee.
31. Members may communicate general meeting discussions with other Committee members that were not present during at the meeting.
32. At no time should members individually divulge details of Committee matters or decisions of the Committee to persons who are not Committee members. Disclosure of Committee business to anyone outside the Committee must be on the decision of the Committee, or between meetings, at the discretion of the Chairperson. In choosing to release or withhold information, the Committee must comply with the provisions of the Official Information Act 1982 and the Privacy Act 1993.

'In Committee' Discussions

33. At no time will a Committee member discuss the conduct or performance of another member who is not present at the 'in committee' session.
34. The meeting minutes will note that an 'in committee' session took place. A record of 'in committee' discussions will be kept in the Chairperson's notes.
35. 'In committee' discussions can be communicated with other Committee members who were not present during the 'in committee' session. This can either be done formally by the Chairperson or informally by another Committee member.

Media Policy

36. Only the Chairperson is authorised to comment publicly on the affairs and policies of the Committee, and where appropriate, the Chairperson will advise the Minister of Health in advance. The Chairperson may delegate comment to other Committee members.
37. Where the Chairperson has delegated comment to another Committee member, the member must publicly support a course of action decided by the Committee. If unable to do so, members must not publicly comment on decisions.
38. The Chairperson, members and Secretariat will not support any action or public statement that is derogatory or in any way damaging to the Committee.
39. Members have the right to comment to the media on any matter in their professional capacity, as long as they do not attribute the comment to the Committee or imply that they are speaking on behalf of the Committee. If a member is forewarned of being asked to comment to the media, they should advise the Committee accordingly. If a Committee member is not forewarned, they should advise the Chairperson immediately after making comment to the media.

Working Arrangements

40. The National Ethics Advisory Committee will agree a work programme with the Minister of Health.
41. In carrying out its Terms of Reference, the Committee must:
 - provide the Minister of Health with advance notice of any media statements or reports to be published
 - ensure its advice is published and widely available
 - ensure that, in developing any advice and guidelines, an appropriate balance exists between protecting the rights and wellbeing of patients and research participants, and facilitating health research and innovative practice
 - ensure that, where appropriate, any advice or guidelines contain clear guidance on the application of ethical principles that is appropriate to the type of health research or innovative practice being considered (due regard should be given to the different nature of qualitative and quantitative approaches to research)
 - ensure that any advice and guidelines comply with the laws of New Zealand
 - ensure appropriate consultation has occurred in accordance with the requirements set out below.

Consultation

42. In meeting its obligations to consult before providing advice to the Minister, the National Ethics Advisory Committee will, where appropriate, make reasonable attempts to consult with:
 - health and disability ethics committees
 - the Advisory Committee on Assisted Reproductive Technology
 - the Health Research Council Ethics Committee
 - any other Ethics Committee established by the Minister of Health
 - organisations that represent affected patients or other groups of the community
 - relevant whānau, hapū and iwi
 - a reasonably representative sample of affected patients or members of the public or, if the Committee thinks it more appropriate, a reasonably representative sample of people who would be entitled to consent on behalf of the affected patients or members of the public
 - a reasonably representative sample of affected health researchers and/or affected health professionals
 - relevant government bodies.
43. The Committee will ensure that stakeholders are provided with feedback following consultation, in line with good consultation practice.

Performance Measures

44. The National Ethics Advisory Committee will be effectively meeting its tasks when it provides relevant and timely advice to the Minister of Health based on research, analysis and consultation with appropriate groups and organisations.
45. The Committee must:
 - agree in advance to a work programme with the Minister of Health
 - achieve its agreed work programme
 - stay within its allocated budget.

Meetings of the Committee

46. Meetings will be held at such times and places as the National Ethics Advisory Committee or the Chairperson of the Committee decides.
47. At any meeting, a quorum will consist of six members. A quorum must include either the Chairperson or Deputy Chairperson. An effort will be made to ensure reasonable representation of community/consumer members and members with specialist knowledge and experience.
48. Every question before any meeting will generally be determined by consensus decision-making. Where a consensus cannot be reached a majority vote will apply. Where a decision cannot be reached through consensus and a majority vote is made, the Chairperson will have the casting vote.
49. Subject to the provisions set out above, the Committee may regulate its own procedures.

Reporting

50. The National Ethics Advisory Committee will:
 - keep minutes of all Committee meetings which outline the issues discussed and include a clear record of any decisions or recommendations made
 - prepare an annual report to the Minister of Health setting out its activities and comparing its performance to its agreed work programme and summarising any advice that it has given to the Minister of Health (as per section 16(6) of the Act). The report is to include the Committee's rationale for its advice and any relevant evidence and/or documentation. This report will be tabled by the Minister of Health in the House of Representatives pursuant to section 16(7) of the Act.

Secretariat

51. The Ministry of Health will provide dedicated analytical policy and administrative support to the National Ethics Advisory Committee through Secretariat staff, consistent with the Memorandum of Understanding between the Committee and the Ministry of Health.

Secretariat staff are Ministry employees and are funded through the Committee's allocated budget.

Fees and Allowances

52. Members of the National Ethics Advisory Committee are entitled to be paid fees for attendance at meetings. The level of attendance fees are set in accordance with Cabinet Office Circular CO (12) 6, *Fees framework for members appointed to bodies in which the Crown has an interest*.
53. The Chairperson will receive \$430 per day (plus half a day's preparation fee) and an allowance of two extra days per month to cover additional work undertaken by the Chairperson.
54. The attendance fee for members is set at \$320 per day (plus half a day's preparation fee).
55. The Ministry of Health pays for actual and reasonable travel and accommodation expenses of the Committee members.

