

National Ethics Advisory Committee
Kāhui Matatika o te Motu
Annual Report 2013

Twelfth Annual Report to the Minister of Health

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National Ethics Advisory Committee
Kāhui Matatika o te Motu

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 works to a broad definition of ethics – identifying what matters and how best to act accordingly – and its credible membership, collaborative relationships and open, inclusive and thorough processes are all important contributors to its policy advice.

At the beginning of the year, NEAC provided advice to the Minister of Health on the ethical aspects of sharing identifiable health information with the Ministry of Social Development, as part of their work to identify children at risk of maltreatment.

NEAC continued work on projects related to enhancing the cross-sectoral research ethics arrangements, advance care planning and monitoring the changes to the Health and Disability Ethics Committees. Work also began on new projects related to organ allocation and dementia.

NEAC revised its terms of reference in light of a review of its governance policies on confidentiality, responding to the media and conflicts of interest. The Minister of Health agreed to the new terms of reference in December 2013.

This year saw the appointment of one new member and recruitment of new secretariat staff. Members and secretariat staff attended a number of meetings in 2013 to promote NEAC and its work.

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

On behalf of NEAC, I am pleased to present this annual report for 2013.

A handwritten signature in blue ink that reads "Victoria Hinson".

Victoria Hinson
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 Advisory Committee on Health and Disability Support Services Ethics – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health (the Minister). 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
- 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 requires that NEAC '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

NEAC is designed to effectively contribute to good health outcomes for New Zealanders. 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.

Dr Neil Pickering, a senior lecturer in the Bioethics Centre at the University of Otago, was appointed in 2013 as the new Health Research Council of New Zealand nominee on the Committee.

All members of the Committee are listed on page 18 to 25.

National Ethics Advisory Committee's work programme in 2013

Overview

A consideration of ethics involves identifying what matters and how best to act accordingly. NEAC works to this definition of ethics, producing work that is both principled and practical and not identifiable with one sector group or interest. NEAC agrees its work programme with the Minister.

Research ethics

In 2013, NEAC met with a range of stakeholders to identify issues with and gaps in the current health and disability research ethics arrangements. New Zealand's complex research ethics environment, involving a range of organisations and stakeholders, standards and accountabilities, is likely to result in overlaps, inconsistencies and related practical issues. NEAC intends to prepare a discussion document and undertake consultation in mid-2014.

In early 2013, NEAC provided advice to the Minister on the ethical aspects of sharing identifiable health information with the Ministry of Social Development for use in their predictive risk modelling work to identify children at greatest risk of maltreatment.

As a result of this work and other related developments, NEAC started a project on the use of health information. This project will explore the ethical issues associated with different types of health information use, including sharing individual care records and linking administrative databases, and assess the adequacy of current processes and guidelines.

NEAC continues to assist the Ministry of Health (the Ministry) to measure and monitor the extent to which changes to the Health and Disability Ethics Committees (HDECs) have contributed to improving the system of ethical review of health and disability research.

NEAC maintains an interest in Māori research ethics and is taking active steps to be kept up to date on further developments in this area.

Services ethics

NEAC's report *The Ethical Principle of 'Do No Harm' and Industrial Action* was published in May 2013. This report outlines NEAC's view that all parties have a responsibility to 'do no harm' during industrial action, both in relation to the planning for, and conduct during, a strike.

NEAC released its draft advice *Ethical Challenges in Advance Care Planning* in November 2013 for stakeholder feedback. The advice aims to provide practical assistance, through the use of case studies, to help ensure good outcomes for consumers and health professionals from the advance care planning process.

NEAC started a new project on the ethical issues associated with organ allocation. The focus this year has been on gathering information, through meetings with several transplant units and other interested parties, on the current processes for allocating organs and issues associated with these processes.

Another new project is NEAC's work on the ethical issues associated with caring for people with dementia. NEAC looks forward to working with Alzheimers New Zealand, the National Dementia Cooperative and other interested organisations as they progress this work.

Research ethics work in 2013

Enhancing the cross-sectoral research ethics arrangements

Objective

NEAC's objective for work in this area was to identify the gaps, overlaps, inconsistencies and areas that lack clarity in the current arrangements for ethical review of health and disability research. This will ultimately result in advice to the Minister on current issues and how these may be addressed.

This work will also inform NEAC's 2015 review of the *Ethical Guidelines for Intervention Studies* (revised edition, NEAC 2012) and the *Ethical Guidelines for Observational Studies* (revised edition, NEAC 2012).

Background

New Zealand has a complex health and disability research ethics environment, involving a range of organisations and stakeholders. There is significant potential for the many sources of ethics committee standards and accountabilities to produce overlaps, inconsistencies and related practical issues. The research community has also expressed concern about the absence of a comprehensive framework for all research bodies.

In 2012, the secretariat researched cross-sectoral arrangements in New Zealand, Australia and the United Kingdom and started an environmental scan of cross-sectoral ethics arrangements for health and disability research and related activity in New Zealand.

Key progress in 2013

In 2013, the environmental scan of cross-sectoral ethics arrangements was completed, and NEAC met with a range of stakeholders to identify issues and gaps with the current arrangements. NEAC intends to prepare a discussion document and undertake a targeted consultation process in mid-2014. The discussion document will summarise the current ethics arrangements, provide examples of good practice, identify issues and outline possible ideas for enhancing the current arrangements.

Predictive risk modelling

Objective

NEAC's objective was to provide advice to the Minister on the relevant ethical standards that apply to predictive risk modelling research being undertaken by the Ministry of Social Development and to indicate whether the research proposal appears to meet those standards.

Background

The Ministry of Social Development is leading research to establish the feasibility of a predictive risk modelling system that, if effective, might help identify children at greatest risk of maltreatment.

The Minister requested advice from NEAC on the ethical aspects of sharing identifiable health information with the Ministry of Social Development for use in the predictive risk modelling research.

Key progress in 2013

NEAC provided advice to the Minister in February 2013; this advice is available on NEAC's website. NEAC found that the researchers had proposed appropriate ways of minimising risks related to identifiable health information, stigmatisation and data security. In relation to these concerns, the research meets NEAC's ethical standards.

NEAC considered that the broad social benefits offered by the research outweigh the immediate privacy concerns, provided that the data security concerns are managed and the research findings are shared.

NEAC supported retaining the datasets for further research, including replicating and confirming the research findings. However, additional governance and privacy safeguards would be required to ensure appropriate storage and use of the data over the longer term.

NEAC noted that it may be timely to open up public discussion on access to identifiable health information and data linkage for research purposes. This suggestion will be considered as part of NEAC's project on the use of health information.

Use of health information

Objective

NEAC's objective for this work is to identify ethical issues associated with different types of health information use and assess the adequacy of current processes and guidelines.

Background

Technological advances are resulting in an increased ability to bring together different sources of health information, resulting in a more comprehensive picture of health status and service use both at an individual and an aggregated level.

Health professionals are increasingly able to access and share health information stored electronically, for example, through shared care records. Developments on the methodology front also mean that health information in administrative databases can be brought together in different ways, providing new insights into the relationships between demographic factors, health conditions and service use.

Key progress in 2013

The secretariat prepared a scoping paper on the use of personal health information, and this paper was considered at NEAC's October 2013 meeting. NEAC agreed to further work on this project, including meetings with a small group of stakeholders in 2014.

Monitoring Health and Disability Ethics Committees

Objective

NEAC's objective was to assist the Ministry to measure the quality of HDECs review based on the four core outcome measures of robustness, efficiency, transparency and consistency, as well as to obtain data to inform the planned 2015 review of NEAC's ethical guidelines for research.

Background

A number of changes have been made to the HDECs review process since 1 July 2012. These include: introducing new standard operating procedures and an online application system, replacing the seven previous HDECs with four new HDECs and reducing committee membership from 12 to 8.

In order to help mitigate concerns about the potential impact of these changes, the Minister asked the Ministry to work with NEAC on monitoring and reviewing the changes.

Key progress in 2013

NEAC has continued to provide advice to the Ministry on its monitoring programme. This has included providing feedback on suggested ways of measuring the quality of HDECs review, for example, quantitative measures, annual surveys and dummy research applications. NEAC also provided detailed comment on draft surveys for stakeholders (researchers) and HDEC members. The Ministry intends to release the surveys in early 2014.

Māori health and disability research ethics

Objective

NEAC's objectives for work in this area were to facilitate understanding of Māori research ethics; improve the quality of research for Māori, including the ability of researchers to assist Māori communities; and contribute to Māori health and development.

Background

In 2009, NEAC supported work to develop Te Ara Tika – Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members, published by the Health Research Council of New Zealand in 2010.

To assist in developing the framework, NEAC prepared a resource document, *Māori Research Ethics: An overview*, which summarised writings on and issues for Māori research ethics.

Key progress in 2013

In 2013, NEAC reviewed its work on Māori research ethics, including the status of the resource document and how it might best be used. NEAC agreed to make the document available as a resource for others undertaking work in this area. NEAC also agreed that it is important to be kept up to date on any further work on Māori research ethics.

Services ethics work in 2013

The ethical principle of ‘do no harm’ and industrial action

Objective

NEAC’s objective for work in this area was to promote discussion on how the ethical principle of ‘do no harm’ applies during industrial action.

Background

NEAC recognises that the right of health and disability workers to strike is important and that industrial relations in the health and disability sector are complex and can affect a wide range of groups.

NEAC wished to highlight the widely shared ethical values that can be applied to guide discussions and to inform the decision-making and conduct of all of those involved when industrial action is contemplated or undertaken, including health and disability workers, unions and employers in the health sector.

Key progress in 2013

NEAC’s report *The Ethical Principle of ‘Do No Harm’ and Industrial Action* was published in May 2013. It outlines NEAC’s view that all parties have a responsibility to ‘do no harm’ during industrial action, both in relation to the planning for, and conduct during, a strike.

Advance care planning

Objective

NEAC's objective for work in this area was to develop advice on the ethical challenges that health professionals face in advance care planning.

Background

In November 2011, NEAC agreed it was timely to contribute to growing interest and momentum in the area of advance care planning. Advance care planning is a voluntary process of discussion and shared planning for future health care between a person and health professionals. At present, advance care planning is primarily offered in the context of oncology services, aged care and services for people with long-term health conditions.

NEAC developed draft advice after meeting with a range of health professionals in 2012 to discuss the ethical challenges in advance care planning. The draft advice aims to provide practical assistance to help ensure good outcomes for consumers and health professionals from the advance care planning process. Case studies are used to highlight common ethical challenges that arise. The draft advice does not consider euthanasia or assisted dying, or resource allocation.

Key progress in 2013

NEAC's draft advice *Ethical Challenges in Advance Care Planning* was released in November 2013 for stakeholder consultation, and NEAC received 43 submissions. It is expected that NEAC's final advice will be published in 2014.

Organ allocation

Objective

NEAC's objective for work in this area was to bring a broader perspective on what New Zealanders think about the current processes for organ allocation, particularly in the areas where clinicians are having to make judgements based on non-medical criteria (for example, the patient's commitment to a successful outcome or psychosocial factors).

Background

The first phase of the project focused on understanding the process for getting onto the transplant list and the barriers associated with this process. This included exploring any disparities in accessing donated organs between groups, for example, ethnic groups or people with disabilities, and the causes of disparities.

NEAC's work on organ allocation will complement the Ministry's initiatives to increase organ donation. In the 2012 Budget, the Government announced an extra \$4 million over four years to encourage more organ donations.

Key progress in 2013

NEAC's work in 2013 has involved gathering information, through meetings with several transplant units and other interested parties, about current processes for allocating organs and issues associated with these processes.

Dementia

Objective

NEAC's objective for work in this area was to prepare a practical resource on the ethical issues associated with caring for people with dementia.

Background

New Zealand has an ageing population and an increasing number of people with dementia. The majority of people with dementia live at home and, for most, care is provided by family and friends. Ethical issues frequently arise in the everyday decisions that carers need to make.

NEAC's work on dementia will complement the Ministry's New Zealand Framework for Dementia Care. The Ministry's Framework provides a guide that district health boards can use as they work with primary, secondary and community health and social support services to develop dementia care.

Key progress in 2013

NEAC met with Alzheimers New Zealand and the National Dementia Cooperative to explore the ethical issues associated with caring for people with dementia and hear about the difficulties and concerns experienced by carers. Both organisations expressed interest in working with NEAC on this project.

Other work in 2013

Memorandum of Understanding with the Ministry of Health

Key progress in 2013

A new Memorandum of Understanding between NEAC and the Ministry was agreed and came into force on 27 June 2013. The purpose of the Memorandum of Understanding is to make clear the relationship between, and obligations of, NEAC and the Ministry.

Revised terms of reference

Key progress in 2013

NEAC reviewed and updated its terms of reference. Several amendments were made to reflect new NEAC policies on confidentiality, responding to the media, conflicts of interest and duties and responsibilities of members and the committee as a whole. NEAC agreed changes to the composition of the committee to give more flexibility to how the required expertise is represented across the membership, while retaining some of the specific member categories. The revised terms of reference also include a new statement that stakeholders will be provided with feedback following consultation.

The Minister agreed to the new terms of reference in December 2013.

Promotion work

Key progress in 2013

NEAC members and secretariat staff attended a number of events to promote the role of NEAC and its work to key target audiences. NEAC members made presentations at the New Zealand Association of Clinical Research members' symposium in August and at the Auckland Ethics Development Day in November.

National Ethics Advisory Committee members

Victoria Hinson – chair

Victoria Hinson is a consultant with extensive experience of New Zealand legislative policy analysis and development. Since moving to New Zealand in 1992, she has worked with a variety of government departments and agencies across a range of areas, including accident compensation, disability, occupational health and safety, human rights and criminal law.

Victoria holds a Bachelor of Arts in international relations and Russian/Russian area studies from the American University in Washington, DC, as well as a Juris Doctor degree from Northwestern University's School of Law in Chicago. She is a licensed American attorney and a member of the Illinois Bar. Victoria has previously served on the Dental Council of New Zealand, including as deputy chair. She is currently chair of a Complaints Assessment Committee for the Veterinary Council of New Zealand, as well as acting as a professional conduct committee layperson member for the New Zealand Psychologists Board.

Victoria was appointed NEAC chair in June 2011.

Martin Wilkinson – deputy chair, ethicist

Martin Wilkinson is an associate professor in political studies at The University of Auckland. He works mainly in applied ethics, with special research interests in transplantation and public health. His book *Ethics and the Acquisition of Organs* was published in November 2011 in the Oxford University Press Issues in Biomedical Ethics series. He was chair of the Bioethics Council from 2006 to 2009.

Martin was appointed NEAC deputy chair in November 2012.

Julian Crane – health researcher

Julian Crane is a general physician by training and director of the Wellington Asthma Research Group and a co-director of the Health Research Council of New Zealand's Housing and Health Research Programme at the University of Otago, Wellington.

Julian's main research interests are asthma and allergic disease, the effects of housing on respiratory health and, more recently, studies of smoking cessation. Julian has also been involved in the International Study of Asthma and Allergies in Childhood (ISAAC) research collaboration.

Julian was appointed to NEAC in July 2012.

Nola Dangen – lawyer

Nola Dangen is a lawyer, having graduated with a LLB from The University of Auckland.

Nola spent many years in private practice, as a partner in a medium/large law firm, a smaller law firm and then in sole practice until 2005, when she sold her practice. Since 2006, she has practised as a locum lawyer/consultant lawyer, assisting lawyers in times of need.

Nola's fields of practice are: contract law, commercial law, property law, building and construction law, wills, trusts and estate law – in fact almost any law except litigation.

Nola spent many years assisting in the governance of law within both the New Zealand Law Society and the Auckland District Law Society and is presently vice president of the Independent Law Society, based in Auckland.

Nola was appointed to NEAC in June 2012.

Adriana Gunder (QSM) – general layperson

Adriana Gunder has a doctoral degree in biological sciences and a post-doctoral degree in biophysics. She 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. She is also involved with community and charity organisations (New Zealand Red Cross, Cancer Society of New Zealand and Mission Bay-Kohimarama Residents Association Inc). Adriana is a Justice of the Peace.

She is also currently a member of the New Zealand Health Practitioners Disciplinary Tribunal and the Ethics Committee on Assisted Reproductive Technology.

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

Adriana was reappointed to NEAC in October 2012.

Andrew Hall – community/consumer

Andrew Hall sustained a spinal cord injury in 1983 as a 19-year-old at Massey University. After completing an agricultural economics degree at Lincoln University, Andrew undertook computer programming work in New Zealand and Australia. He has also farmed in Central Otago.

Andrew is a senior business analyst for the Canterbury District Health Board, working on the development and deployment of a new, combined South Island-wide Patient Administration System. Previously, he worked for three years as the software manager for Dynamic Controls, the world's largest supplier of wheelchair and scooter control systems. Before that, he was chief executive of the New Zealand Spinal Trust, a consumer support and service-providing organisation. He is now a board member of the New Zealand Spinal Trust and of the Christchurch Early Intervention Trust (The Champion Centre), as well as being a trustee on both the Ben Lei'a Trust and the Pacific Disability Support Trust.

Andrew was reappointed to NEAC in October 2012.

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 in 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 centre, a number of individual Health Research Council of New Zealand grants and other research involving significant collaborations within Massey University and with other universities and health service providers, both nationally and internationally.

Maureen was appointed to NEAC in June 2012.

Fiona Imlach Gunasekara – epidemiologist

Fiona is currently a researcher at the Royal New Zealand Plunket Society. She completed a PhD in epidemiology in 2007 at the University of Otago, Wellington. Her research interests include: socioeconomic and health inequalities, poverty, child health, alcohol and methods for longitudinal data analysis. She has previously worked as an academic, in the health informatics sector, and in a number of health-related agencies.

Fiona is a fellow of the New Zealand College of Public Health Medicine and completed a Bachelor of Medicine and Surgery and a Masters of Public Health at The University of Auckland.

Fiona was appointed to NEAC in October 2012.

Robert Logan – health professional

Robert Logan has had extensive experience over many years in the health sector, with a variety of roles in clinical practice, management and governance. Recent positions have included chair of the National Health Committee, the Chief Medical Officers group, the Health Workforce Taskforce and, until recently, chief medical officer at the Hutt Valley District Health Board.

Robert was reappointed to NEAC in October 2012.

Wayne Miles – health professional

Wayne is 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 Health Research Council of New Zealand College of Experts. He chairs The Royal Australian and New Zealand College of Psychiatrists Community Collaboration Committee and is a New Zealand Medical Association board member. Past roles have included president of The Royal Australian and New Zealand College of Psychiatrists and chairperson of the Council of Medical Colleges in New Zealand.

Wayne was appointed to NEAC in November 2012.

Jacob Te Kurapa – community/consumer

Ko Mataatua te Waka; Ko Manawaru te Maunga; Ko Ohinemataroa te Awa; Ko Mataatua te Marae; Ko Ngati Tawahaki te Hapu; Ko Tuhoe te Iwi; Ko Hakopa Te Kurapa taku ingoa. Tihei Mauri Ora!

Jacob is a ministerial appointee to the Medical Council of New Zealand, and he is serving a second term as a ministerial appointee to Bay of Plenty District Health Board. Jacob is a former member of the New Zealand Health Practitioners Disciplinary Tribunal. Jacob's background is in health promotion, and he has qualifications in this field. Jacob also led a team of dedicated health promoters in Murupara in a range of health services, including rheumatic fever, diabetes, community action youth and drugs, youth development and youth programmes.

Jacob is currently the chairperson of the Murupara Community Board and was the youngest elected councillor during his nine-year term (2001–2010) in office to the Whakatāne District Council.

Jacob currently resides in Murupara and is also a Justice of the Peace.

Jacob was reappointed to NEAC in June 2012.

Neil Pickering – Health Research Council of New Zealand nominee

Neil is a senior lecturer 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, and his book *The Metaphor of Mental Illness* was published by Oxford University Press in 2006 in their International Perspectives in Philosophy and Psychiatry series.

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 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.

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 2013 comprised:

- Helen Martin, group administrator
- Stella Li, policy analyst
- Chris Wilson, policy analyst (until August 2013)
- Gillian Parry, senior policy analyst (until September 2013)
- Beverley Braybrook, principal policy analyst (from August 2013)
- Emma Doust, senior policy analyst (from September 2013).

Contact details for the National Ethics Advisory Committee

Contact details for NEAC:

Phone	64 4 496 2000
Email	neac@moh.govt.nz
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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.

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

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.

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.

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

The National Ethics Advisory Committee will have a maximum of 12 members appointed by the Minister of Health.

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).

The membership must also have expertise in the following areas:

- ethics
- research (qualitative and quantitative)
- epidemiology
- law.

Terms and conditions of appointment

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.

Unless a person sooner vacates their office, every appointed member of the Committee will continue in office until their successor comes into office.

Any member of the Committee may at any time resign as a member by advising the Minister of Health in writing.

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.

The Minister of Health 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

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 is not present or is unable to act (eg, if the has a conflict of interest).

Duties and responsibilities of a member

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.

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.

Committee members should have a commitment to work in the best interests of the Committee.

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.

Members are expected to act responsibly with regard to the effective and efficient administration of the Committee and the use of Committee funds.

Members will:

- be diligent, prepared and participate
- be respectful, loyal and supportive
- not denigrate or harm the image of the Committee.

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

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.

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.

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.

The Chairperson will ask members to declare any actual or perceived interests at the start of each meeting.

Confidentiality

General

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.

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

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.

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.

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.

Members are free to express their own views within the context of Committee meetings, or as part of the general business of the Committee.

Members may communicate general meeting discussions with other Committee members that were not present during at the meeting.

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

At no time will a Committee member discuss the conduct or performance of another member who is not present at the ‘in committee’ session.

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.

‘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

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.

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.

The Chairperson, members and Secretariat will not support any action or public statement that is derogatory or in any way damaging to the Committee.

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

The National Ethics Advisory Committee will agree a work programme with the Minister of Health.

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

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.

The Committee will ensure that stakeholders are provided with feedback following consultation, in line with good consultation practice.

Performance measures

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.

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

Meetings will be held at such times and places as the National Ethics Advisory Committee or the Chairperson of the Committee decides.

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.

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.

Subject to the provisions set out above, the Committee may regulate its own procedures.

Reporting

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

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

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*.

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.

The attendance fee for members is set at \$320 per day (plus half a day's preparation fee).

The Ministry of Health pays for actual and reasonable travel and accommodation expenses of the Committee members.