

**National Ethics Advisory Committee**  
**Kāhui Matatika o te Motu**  
**Annual Report 2020**

**Nineteenth Annual Report to the Minister of Health**

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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.

In early 2020, NEAC in conjunction with the Ministry of Health hosted a number of training roadshows for key users to familiarise them with and educate them on the revised National Ethics Standards for Health and Disability Research.

NEAC received agreement from the Associate Minister of Health Hon Jenny Salesa to the following work programme for 2020 during a meeting with the Chair in May 2020.

NEAC's main focus during 2020 shifted in response to the COVID-19 pandemic to develop a framework for resource allocation that addresses equity in allocating and prioritising resources. NEAC's publication, *Ethics and Equity: Resource Allocation and COVID-19* (the Framework), adds an equity lens to decision-making and assesses how equity sits alongside other ethical principles and Te Tiriti o Waitangi.

Following the development of the Framework, NEAC began a review of our 2007 document *Getting Through Together: Ethical values for a pandemic*, which considers key ethical issues that are likely to arise during a pandemic. NEAC believes it needs to be updated to consider ethical issues that have emerged since 2007, to take account of the experience and learnings from COVID-19 and to make it broadly applicable to pandemics in general – while noting that any pandemic will have a unique context and involve its own set of ethical issues. The update will include new sections on the use of digital technologies such as for contact tracing, specific guidance on public health interventions, the impact of a pandemic on routine standards of care, equitable allocation of resources and greater consideration of equity.

NEAC has also been following with interest the Health and Disability Commissioner's work on research with individuals who are unable to give informed consent (that is, concerning Right 7(4) of New Zealand's Code of Health and Disability Services Consumers' Rights). Feedback from our public consultation on the revised standards in 2018 showed us that many participants also support work on fair and equitable access to health research in the Commissioner'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.

This year we farewelled Maureen Holdaway, a member who made a significant contribution to NEAC governance over many years. We were very pleased to welcome three new members in 2020: Dr Cindy Towns, Dr Penny Haworth and Dr Vanessa Jordan.

We have continued to be exceptionally well supported by the Secretariat at the Ministry of Health over a period of significant change and through the challenges brought by COVID-19.

On behalf of NEAC, I am pleased to present this annual report for 2020.



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.

Dr Cindy Towns, Dr Penny Haworth and Dr Vanessa Jordan joined the Committee this year, and NEAC farewelled Dr Maureen Holdaway.

Short biographies for all committee members in 2020 appear on pages 6 to 10.

## NEAC Standards Roadshow

Following the release of the revised National Ethics Standards for Health and Disability Research (the Standards) in December 2019, NEAC in conjunction with the Ministry of Health hosted a number of training roadshows for key users to familiarise them with and educate them on the Standards in February 2020.

Public sessions, held in Auckland, Hamilton, Wellington, Christchurch and Dunedin, were free and were exceptionally well attended. For those who missed out on tickets, the sessions were filmed and added to NEAC's webpage along with the training slides as a learning resource.

## Release of *Ethics and Equity: Resource Allocation and COVID-19*

*Ethics and Equity: Resource Allocation and COVID-19* (the Framework) is a high-level, principles-based guidance document for the health and disability sector that was developed in response to COVID-19 but has wider application. It helps health workers and policy makers to consider ethical matters when allocating resources for COVID-19. The Framework is based on ethical principles and Te Tiriti o Waitangi principles that address equity in allocating and prioritising resources.

The Framework was developed within the context of COVID-19, with the awareness that in some instances individuals could need to prioritise one value over another, as values will sometimes be incompatible. The Framework aims to help decision-makers identify ethical tensions and recommends establishing decision-making groups to work through these tensions and uphold the transparency of decision-making.

### **NEAC's Framework includes Te Tiriti principles and equity as a core principle**

The Framework sets out four essential ethical principles and four Te Tiriti principles that medical staff, service planners and policy analysts should consider when responding to pandemics.

The ethical principles have been developed on the basis of international literature. NEAC has adopted the Ministry of Health's definition of equity, which recognises that people differ in their levels of advantage and so require different approaches and resources to gain equitable health outcomes.

In a resource allocation setting, health workers and policy makers should consider how resources can be allocated to mitigate the adverse consequences of pandemic response measures while avoiding or minimising any growth in inequity.



## **The development of the final Framework**

NEAC publicly consulted on a first draft of the Framework during June and July 2020. It then produced and published a summary of submissions, which provides a high-level overview of the feedback received.

While NEAC was developing the consultation document, many key stakeholders and submitters were dealing first-hand with the subject matter under consideration, namely resource allocation during the COVID-19 pandemic. Accordingly, many lessons drawn from submitters' real-life experience came to light and informed the final version of the Framework.

During the public consultation, submitters strongly supported the draft Framework's assumption that pandemics can exacerbate existing inequities, and so they prompt the need for different approaches to achieve equity. Many people highlighted the connection between resource allocation and the wider issue of equity in the context of the COVID-19 pandemic. NEAC acknowledged this, and addressed the issue both in the Framework and in its update of *Getting Through Together* (see below).

## **Review of *Getting Through Together: Ethical values for a pandemic***

Before the COVID-19 pandemic, revision of the 2007 document *Getting Through Together* had already been on NEAC's work programme and it took priority following the onset of the pandemic. NEAC believes it needs to be updated to consider ethical issues that have emerged since 2007, and to take account of the experience and learnings from COVID-19 – noting that any pandemic will have a unique context and involve its own set of ethical issues.

Experience from the COVID-19 pandemic also revealed that the current document is difficult to use and would benefit from an updated structure. As the target audience of a pandemic ethics document is wide, including decision-makers, government and the public, the document should be clear and easy to navigate.

NEAC began scoping the update of *Getting Through Together*, which will consider key ethical issues that are likely to arise during any pandemic. In late 2020, NEAC began the update, incorporating the Framework for resource allocation as an updated section, relevant feedback from the Framework's consultation and learnings from the COVID-19 pandemic. The update will include the use of digital technologies, specific guidance on public health interventions, the impact of a pandemic on routine standards of care, and greater consideration of equity.

NEAC will engage with decision-makers across government, district health boards and the World Health Organization to identify what key areas are likely to benefit from ethical guidance in a pandemic response, which will help to determine what type of guidance would be most helpful to decision-makers. NEAC will also consider the substantial amount of academic work on ethics and pandemics in the national and international literature when developing its advice.

NEAC will publicly consult on the updated document in late 2021.

## **Health and Disability Research with Adult Participants Who Are Unable to Provide Informed Consent**

In 2017, the Health and Disability Commissioner (the Commissioner) publicly consulted on changes to the application of the Code of Health and Disability Services Consumers' Rights (the Code) to health and disability research involving adult consumers who are unable to consent to their participation in the research. Those consumers might, for example, be unconscious, or have significant cognitive impairments that prevent them from understanding the implications of the decision to participate.

In April 2020, NEAC met with Associate Commissioners to discuss the report released by the Commissioner. The report suggests that further work is needed to define minimal risk in research and it was suggested that a group would need to be established to guide this work. At this meeting, participants discussed the Commissioner's raft of recommendations and changes to the Code, along with NEAC's potential involvement in updating the research Standards and the Ministry of Health's role in updating the wider ethical review structure. NEAC sought agreement to its work programme, which the Associate Minister of Health Hon Jenny Salesa granted in May 2020.

## **Monitoring Health and Disability Ethics Committees**

Part of NEAC's mandate is to help the Ministry to measure and monitor the extent to which changes to health and disability ethics committees (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, NEAC plans to annually review the standards governing health research in New Zealand so that they remain fit for purpose.

## Other Work in 2020

### Progress in 2020

NEAC members and Secretariat staff attended a limited range of meetings in 2020 and submitted on one public consultation. Their participation included:

- providing ethical input into a discussion on a tool for prioritising care in intensive care units in March 2020
- making a submission to the Medical Council of New Zealand on its consultation on proposed changes to its telehealth statement in relation to prescribing medicine for the first time to a patient, and its draft discussion paper on when artificial intelligence is involved in the care of patients.

# National Ethics Advisory Committee Members

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

Neil Pickering 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 as part of its International Perspectives in Philosophy and Psychiatry series.

Neil 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.

Appointed April 2013 and reappointed July 2016. Appointed Acting Chair September 2016. Appointed Chair 2019.

## **Dr 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.

Reappointed to NEAC in 2019.

## **Dr Kahu McClintock – Representing the Interests of Māori**

Kahu McClintock (Waikato/Maniapoto, Ngāti Mutunga and Ngāti Porou) is the Manager Research at Te Rau Matatini. 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 holds a Dip Nursing (Psychiatric), Higher Dip Teaching, BEd, MPhil (Māori) and DPhil (Psychiatry).

Kahu was a member of the Māori Health Committee, New Zealand Health Research Council from 2008 to 2014, and Chair of Ngā Kanohi Kitea Community Research

Committee, New Zealand Health Research Council during that term. She is the lead for Te Rā o Te Waka Hourua.

Appointed July 2015.

### **Dr Wayne Miles – Health Professional**

Wayne Miles is Director of Awhina Research and Knowledge, Waitematā 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 is Deputy Chair of The Royal Australian and New Zealand College of Psychiatrists Practice, and the Partnership and Policy Committee. Past roles have included President of The Royal Australian and New Zealand College of Psychiatrists, Chairperson of the Council of Medical Colleges in New Zealand, and a New Zealand Medical Association board member.

Appointed November 2012 and reappointed March 2016.

### **Liz Richards – Representing the Interests of Consumers**

Liz Richards is an independent director currently chairing the Top of the South Health Alliance and is a trustee for the Tasman Bays Heritage Trust. Previous roles include 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 as well as lecturing in housing studies at Salford University. She has a Professional Qualification of the Chartered Institute of Housing and an MA in Housing from the University of Central England in Birmingham.

Appointed October 2015.

### **Dr Hope Tupara – Health Professional**

Hope Tupara works from home, mostly in private contract research and as a practising midwife. She has an MA in Midwifery and a PhD in Public Health. 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.

Appointed October 2015.

### **Dr Dana Wensley – Legal Consultant**

Dana Wensley has an LLB (Hons) from University of Auckland and a PhD in Medical Law and Ethics from King's College, London. Her research transcends the traditional boundaries between law, medicine and ethics. 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. Dana has served as community representative on the Hospital Advisory Committee of the Nelson Marlborough District Health Board and is interested in health equity and allocation of resources at local and national levels. In 2016 she was elected to the Tasman District Council and has served as Chair of the Accessibility for All Forum (Nelson/Tasman). Dana currently chairs the Regulatory Committee of Tasman District Council.

Appointed October 2015.

### **Dr Mary-Anne Woodnorth – Health Researcher**

Mary-Anne Woodnorth originally trained to be a biomedical researcher at the University of Otago and has a PhD in Neuroscience. Since then she has worked in a variety of research settings throughout her entire career, including industry (Neuren Pharmaceuticals) and government (Health Research Council). 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.

Appointed June 2019.

### **Gordon Jackman – Representing the Interests of Disability**

Gordon Jackman is CEO of the Duncan Foundation, an organisation that supports people with neuromuscular conditions. He is on the boards of the Supported Lifestyle Trust of Hauraki and the Thames Public Art Trust. He has an MA (1st) in Archaeology and 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 for most of his life.

Appointed June 2019.

### **Dr Penny Haworth – Representing the Interests of Consumers**

Penny Haworth is an honorary research fellow in the Institute of Education, Massey University. Her education career spans over 40 years, with the last 25 years spent at Massey University. She holds a PhD, MA with distinction, BEd, Diploma in Second Language Teaching, and Diploma in Teaching with distinction. In her role as an associate professor, she served on both the Massey University Human Ethics Committee (Southern B) and the board of the Massey College of Humanities and Social Sciences for

five years. She was also an elected member of the Executive Committee for the International Study Association on Teachers and Teaching for six years.

Penny has led multiple research projects, with a particular focus on the development of teacher efficacy and intercultural pedagogy with culturally diverse learners, and was lead researcher in an Early Childhood Centre of Innovation, a decile 1 kindergarten in partnership with a Samoan Upu Amata. She has published extensively in New Zealand and overseas. She has been an invited expert on Ministry of Education advisory committees and has held voluntary positions on several committees, including Little People of New Zealand and Phoenix Supported Employment.

Appointed May 2020.

### **Dr Cindy Towns – Ethicist**

Cindy Towns is a general physician and community geriatrician based at Wellington Hospital. She holds an MBChB and PhD (Biomedical Ethics) from the University of Otago and a BSc (Hons) from Idaho State University. She is a clinical senior lecturer at the Wellington School of Medicine and an honorary senior lecturer with the University of Otago Bioethics Centre.

She has published on a broad range of ethical and clinical subjects and has ongoing interests in ethical standards in hospital care, equity in health care and GBLTQ health. She gives GBLTQ cultural competency lectures to students, doctors and wider health professional groups. Clinically, she has a special interest in the rare disease porphyria and sits on the Medical Advisory Board of the Australian Porphyria Association. She serves on the Ethics Committee for the Royal Australasian College of Physicians (RACP) and has been a previous member of the RACP Specialist Advisory Committee for Geriatrics. She is a past member of the Doctors in Training Council of the New Zealand Medical Association and past President of the New Zealand Medical Students' Association. She has served previously on the Medical Training Board and medical reference groups advising the Ministers of Health and Education.

Appointed May 2020.

### **Dr Vanessa Jordan – Epidemiologist**

Vanessa Jordan is an epidemiologist/methodologist specialising in trial design, biostatistics, systematic reviews and epidemiology. She holds a PhD in Epidemiology and Biochemistry from the University of Otago. Currently she works as a senior research fellow at the University of Auckland and is academic coordinator for the postgraduate paper on systematic review methodology run at the School of Population Health. As a methods specialist, she works with researchers in public health, mental health, education and clinical medicine, and as such works with both qualitative and quantitative research methods.

Vanessa also holds the position of New Zealand Cochrane Fellow. Cochrane is an international charity organisation with a vision of a world of improved health where decisions about health and health care are informed by high-quality, relevant and up-to-date synthesised research evidence. As part of this organisation, she is an internationally

recognised trainer in the methods used to complete Cochrane systematic reviews and holds an elected position on the international Cochrane Council.

Appointed May 2020.



## Member Attendance at NEAC Meetings in 2020

Meeting attendance in 2020	21 Jan 2020	19 May 2020	24 Jun 2020	8 Jul 2020	19 Aug 2020	24 Sep 2020	3 Nov 2020	8 Dec 2020
Neil Pickering (chair)	✓	✓	✓	Apol	✓	✓	✓	✓
Liz Richards	✓	✓	✓	✓	✓	✓	✓	✓
Dr Wayne Miles	✓	✓	✓	✓	✓	✓	✓	✓
Maureen Holdaway	✓	✓	NA	NA	NA	NA	NA	NA
Dr Kahu McClintock	✓	✓	Apol	✓	✓	✓	✓	✓
Dr Hope Tupara	✓	✓	✓ (for 1 hour)	✓	✓	✓	✓	Apol
Dr Dana Wensley	✓	✓	✓	✓	✓	✓	✓	✓
Dr Mary-Anne Woodnorth	Apol	✓	✓	✓	✓	✓	✓	✓
Gordon Jackman	✓	✓	✓	✓	✓	✓	✓	✓
Dr Penny Haworth	NA	NA	✓	✓	✓	✓	✓	✓
Dr Cindy Towns	NA	NA	✓	✓	✓	✓	✓	✓
Dr Vanessa Jordan	NA	NA	✓	✓	✓	✓	✓	✓
<b>Total members present</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>10</b>	<b>11</b>	<b>11</b>	<b>11</b>	<b>10</b>

✓ = Present

Apol = Apologies

Note: Dr Penny Haworth, Dr Vanessa Jordan and Dr Cindy Towns became NEAC members in May 2020. Dr Maureen Holdaway's NEAC membership ended in May 2020.

# 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 in 2020

The NEAC Secretariat in 2020 comprised:

- Rob McHawk, Manager Ethics
- Nic Aagaard, principal advisor
- Hayley Robertson, senior advisor
- Lucy Campbell, policy analyst
- 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	<a href="mailto:neac@health.govt.nz">neac@health.govt.nz</a>
Website	<a href="http://www.neac.health.govt.nz">www.neac.health.govt.nz</a>

# 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.