

National Ethics Advisory Committee

Kāhui Matatika o te Motu

Annual Report 2024/25

Twenty third Annual Report to the Minister of Health

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Foreword

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

Tēnei te mihi i runga i ā tātou mate kua wheturangitia. 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 92 of the Pae Ora (Healthy Futures) Act 2022 (the Act).

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

In 2024/25, NEAC completed its ethical guidance for pandemics in Aotearoa New Zealand. The report, entitled *Finding Balance: Ethical principles for epidemics and pandemics*, guides key decision makers to make ethical decisions and emphasises shared values to equip people to care for and make decisions for themselves and others. This report was published in April 2025.

In 2024/25, NEAC convened the Clinical Ethics Working Group to address a Ministerial request for advice on ethical decision-making to support clinicians and patients considering use of innovative and experimental interventions.

NEAC also continued its update of the *Ethical Standards for Health and Disability Research*, focusing on chapters that most need updating. We look forward to continuing this work in 2025/2026.

We would like to thank the many organisations and individuals who contributed to our work. Their input ensures that NEAC's work is useful and addresses relevant and important issues.

During 2024/25, we farewelled Lindsey Te Ata o Tū MacDonald, Professor John McMillan, Shannon Te Ahu Hanrahan, Rochelle Style and Nora Parore. Lindsey Te Ata o Tū MacDonald served as Acting Chair from August 2024 until I was appointed Chair in November 2024. We would like to thank those members for their invaluable contributions. In the same period, three other new members joined (Filipo Katavake-McGrath, Fiona Miles, and Karaitiana Taiuru) and two members were reappointed (Edmond Carrucan and Hansa Patel).

The Ministry of Health has continued to support NEAC to meet its statutory obligations and to complete the *Finding Balance* report. NEAC would like to place on the record our thanks to the staff of the Secretariat for their work. Their policy work and support for the committees of the health and disability ethics system (ACART, ECART and the four HDECs), makes possible the trust in the ethics of research and clinical decision-making across the sector.

On behalf of NEAC, I am pleased to present this annual report for 2024/2025.

A handwritten signature in blue ink, appearing to read 'Elizabeth Fenton', written in a cursive style.

Dr Elizabeth Fenton

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. Its statutory functions, under section 92 of the Pae Ora (Healthy Futures) Act 2022 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 in the context of the Act and key health and disability policy statements. Section 92(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

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.

Members of the Committee during the reporting period are listed on pages 6 to 10¹.

Role of the National Ethics Advisory Committee Secretariat

The NEAC Secretariat provides dedicated analytical policy and administrative support to NEAC and is employed by the Ministry of Health.

Contact details for the National Ethics Advisory Committee

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

¹ Information about current membership is available at: [neac.health.govt.nz/about-us/committee-members/](https://www.neac.health.govt.nz/about-us/committee-members/)

National Ethics Advisory Committee's work programme in 2024/2025

NEAC's work programme

The NEAC agrees its work programme with the Minister of Health. For this reporting period, July 2024 to June 2025, NEAC's projects were:

1. Ethical Guidelines for a Pandemic ("Finding Balance").
2. Responding to a request for advice from the Minister on clinical ethics decision-making.
3. Reviewing the National Ethical Standards for Health and Disability Research and Quality Improvement.

From August to November 2024, NEAC had an acting Chair and there was a temporary slowing of the work at that time.

Ethical Guidelines for a Pandemic

In 2007, NEAC published *Getting Through Together: Ethical values for a Pandemic*. In 2019, NEAC agreed to update the publication, but drafting was halted in 2020 by the COVID-19 pandemic. Instead, NEAC published *Ethics and Equity: Resource Allocation and COVID-19*.

In 2022, NEAC consulted on a revised *Getting Through Together* document, called *Finding Balance: Ethical Guidance for a Pandemic*. The name was changed, as 'Getting Through Together' had become the Mental Health Foundation's key advertising slogan.

Following the consultation, NEAC summarised the submissions and published the summary in June 2023. The submissions informed the next iteration of the document and NEAC published *Finding Balance: Ethical principles for epidemics and pandemics* in April 2025. NEAC also wrote a summary document to accompany the report.

Advice on clinical ethics support for innovative and experimental interventions

NEAC established its Clinical Ethics Working Group to respond to a Ministerial request for advice on how clinicians, providers, and patients considering innovative and experimental interventions can be supported.

The working group focused on building a robust evidence base to inform NEAC's advice to the Minister. This work included a review of national and international approaches to clinical ethics support and analysis of gaps in the current system in Aotearoa New Zealand, both in terms of access to innovative and experimental interventions and ethics support for clinicians. Stakeholder engagement was a key component, with input from clinicians, ethicists, Māori health experts, and sector representatives to ensure solutions were practical and Te Tiriti-led. The working group regularly consulted NEAC to ensure alignment and collective oversight throughout the process.

National Ethical Standards for Health and Disability Research and Quality Improvement

NEAC has a statutory function to determine ethical standards for the health research sector, including for commercially sponsored clinical trials. NEAC's *National Ethical Standards for Health and Disability Research and Quality Improvement* (the Standards) set out the ethical requirements researchers must meet or exceed when undertaking health and disability research and are applied by ethics committees when reviewing applications for health and disability research. The current version of the Standards was published in December 2019.

Building on progress from previous reporting periods, NEAC has continued to review the Standards in response to issues identified during the 2022 public consultation and subsequent engagement with stakeholders. While NEAC had planned to consult on the revised Standards in 2023, this was delayed due to resourcing constraints. Work resumed in the second half of 2024 and continued into 2025, focusing on three priority chapters: Health data and new technologies, compensation for participants in commercially sponsored clinical trials, and quality improvement activities. The review of these chapters is focused on ensuring the Standards reflect changes in the New Zealand and international research and regulatory landscape since 2019 and continue to align with contemporary ethical principles.

Anticipated 2025-2026 work programme

With the completion of the *Finding Balance* report, NEAC can now dedicate greater focus to other areas of its work programme. The Minister-commissioned clinical ethics work, along with the review of the NEAC Standards, represents a significant and high-priority body of work, and it is anticipated that the majority of NEAC's time will be directed to these topics.

In March 2025, the Chair had an introductory meeting with the Minister and discussed NEAC's current and future work programme. NEAC anticipates the following work will continue over the next reporting period, subject to Ministerial direction:

- A focus on completing clinical ethics guidance and practical decision-making tools for clinicians, providers and patients considering innovative or experimental treatments. This work will be carried out in consultation with Health NZ.
- Progression of the revisions of the research standards. This will involve consultation with the sector and key stakeholders and include sections relating to compensation for participants in commercially sponsored clinical trials, health data, and quality assurance activities.
- A report back to the Minister, on the progress of the first phase of work on clinical ethics.

Over the past year, NEAC has further scoped work and progressed elements of its work programme as resources and time permitted. Progress against these priorities and the wider work programme will be evaluated in the forthcoming year.

Other work of the National Ethics Advisory Committee

Mahi of the Rangatiratanga Roopu

In 2022, NEAC established the Rangatiratanga Roopu, a subgroup within NEAC chaired by the Deputy Chair to explore how NEAC can best work as individuals and as a collective, and to discuss further goals and principles of the group. Further work, in 2023 and 2024, included more discussions about how the roopu was intended to function and support NEAC.

In 2024, the roopu developed terms of reference and these terms would also inform a wider review of NEAC's terms of reference, including where NEAC sits within the Pae Ora (Healthy Futures) Act and what the Pae Ora principles mean for NEAC.

The Roopu also held hui to consider and contribute to relevant sections of NEAC's key projects.

Compensation and Insurance for Clinical Trials

In the first half of 2025, NEAC provided feedback to the Health Research Council Ethics Committee (HRCEC) on its draft *Independent Comment on Compensation for Injury in Research*.

In its response NEAC emphasised fairness, timely access to care, and culturally responsive processes, while exploring options such as strengthening the National Ethical Standards and addressing the statutory exclusion of industry-sponsored trials from ACC cover. NEAC also participated in the HRCEC's roundtable on compensation for clinical trial participants. This response forms part of NEAC's ongoing review of the chapter in the Standards on compensation for participants in commercially sponsored clinical trials.

Organ Donation New Zealand Ethical Framework

In October 2024 a representative of the New Zealand Blood Service, presented the Organ Donation New Zealand Ethical Framework, to NEAC. The Framework is designed to support organ donation after assisted dying (ADD). NEAC provided feedback on the value of establishing a Tikanga Advisory Group and working with the disabled community in the development of the Framework.

NEAC's response highlighted the ethical need to balance participation in ADD against any undue pressure to participate, and therefore suggested appropriate protections are put in place.

Research Ethics Review System

Part of NEAC's mandate is to support the operation of the health and disability ethics committees by providing direction, guidance and leadership to ensure the quality and consistency of ethical review in the health and disability sector.

During the 2024/2025 period, NEAC engaged with the Health and Disability Ethics Committees on critical topics and participated in conversations addressing common challenges in the ethics review system. These discussions focused on strengthening collaboration, improving consistency in review processes, and exploring opportunities to enhance the overall effectiveness of the system.

Meeting attendance

In 2024/25, NEAC members and Secretariat staff attended the following events.

- **HRCEC Roundtable Discussion.** NEAC representatives participated in a roundtable discussion chaired by the HRCEC regarding insurance compensation for clinical trial participants.
- **HRC Joint Training Day.** The Chair and Secretariat attended the HRC/IEC/HDEC (Institutional Ethics Committee/Health and Disability Ethics Committee) training day, where the Chair provided an overview of NEAC's role and its review of the National Ethical Standards.
- **National advisory group for use of routinely collected data for research.** The Chair attended a meeting of the new national advisory group focused on the use of routinely collected data for research.

National Ethics Advisory Committee Members

2024/2025

Current members

Dr Elizabeth Fenton: Ethics expertise. Chair

Elizabeth Fenton is a senior lecturer in the Bioethics Department at the University of Otago with a background in philosophy and public health. She was previously a fellow in the Program in Ethics and Health at Harvard University, and a senior policy and research analyst at the U.S. Presidential Bioethics Commission under the Obama administration. Her research focuses on ethical issues in public health, global health, and health policy.

Appointed November 2024.

Julia Black: Community perspectives

Julia holds a Master of Bioethics and Health Law from the University of Otago, with early research focused on ethical and legal issues in precision oncology, and a Bachelor of Health Sciences (Health Promotion). Motivated by the death of her husband, Malcolm Black, from colorectal cancer in 2019, her work centres on advocacy for patients and whānau navigating complex treatment options across both public and private healthcare settings, and the ethical questions that arise in these contexts. She has a strong interest in ensuring that ethical frameworks and research methodologies better honour and respect the cultural values and beliefs of Māori and also the integration of A.I in healthcare.

Julia is the consumer representative on the Dunedin Colorectal Cohort governance committee.

Appointed September 2023.

Maree Candish: Community perspectives

As a management consultant in natural resource fields and with Masters degrees in science and business, Maree helped governments, companies and community organisations around the world with systems and policies, asset evaluation, quality management and sustainable land use.

In 2013 she and her son became sick with ME/CFS after a viral infection; they have remained disabled since that time. Maree is active in advocacy related to post-infection conditions and consumer participation. She is on the boards of national and international organisations and contributes to the development, management and assessment of clinical care and research programmes for post-infection conditions.

Maree was appointed to NEAC in November 2022.

Edmond Carrucan: Legal perspectives

Ngāti Hako, Tainui, Ngāti Porou

Edmond is a promising Māori legal academic and has expertise in Tikanga Māori. Edmond was formerly employed as a Junior Crown Prosecutor at Meredith Connell. He is undertaking a PhD in Law.

Edmond was initially appointed to NEAC in December 2021 then reappointed in December 2024.

Associate Professor Vanessa Jordan: Epidemiologist

Vanessa Jordan is an epidemiologist and research methodologist specialising in trial design, biostatistics, systematic reviews and epidemiology. She holds a doctorate in epidemiology and biochemistry from the University of Otago and is an Associate Professor in the Faculty of Medical and Health Sciences at the University of Auckland, where she is also the academic coordinator for the postgraduate paper on systematic review methodology. As a methods specialist, she works with researchers across public health, mental health, education, and clinical medicine, applying both qualitative and quantitative research approaches. She has a particular interest in generative AI use in research and ethics.

Vanessa has served as the New Zealand Cochrane Fellow since 2003. Cochrane is an international charity dedicated to improving global health by ensuring that decisions in health and healthcare are informed by high-quality, relevant, synthesised research evidence. Within Cochrane, she is an internationally recognised trainer in systematic review methodology, a Cochrane Trustee, and Chair of the international Cochrane Conflict of Interest Panel.

Vanessa was appointed to the National Ethics Advisory Committee in May 2020 and reappointed in September 2023.

Dr Filipo Katavake-McGrath: Community perspectives

Filipo Katavake-McGrath (Kāti Huirapa ki Arowhenua raua kō Puketeraki, Tonga) is an economist and qualitative researcher with a focus on the social and economic equity of communities who have been publicly targeted by politicians and the media over many decades. Dr Katavake-McGrath runs monitoring programmes on: government progress against redress recommendations made by the Abuse in Care Inquiry, the economic wellbeing of Pacific Peoples, and management of idiopathic symptoms. Filipo has conducted research into racism contained within legislation as well as parliamentary and legislative processes.

Appointed November 2024.

Dr Fiona Miles: Health professional

Fiona has been a paediatric intensivist at Starship Children's hospital for over twenty five years. Her passions are ethics, equity, communication, conflict resolution, resilient health care and clinical excellence. She is Chair of the Te Toka Tumai Clinical Ethics Committee and has a PhD on Decision-Making for Critically Ill Children in Aotearoa NZ- A Mana Enhancing Tikanga Approach. She teaches medical mediation skills to health care professionals and is an accredited medical mediator.

Appointed in November 2024

Dr Tania Moerenhout: Health professional

Tania Moerenhout is a general practitioner and Senior Lecturer at the Department of Bioethics of the University of Otago/Ōtākou Whakaihu Waka in Ōtepoti Dunedin. She combines academic work as a bioethicist with a part time clinical position as a GP.

She completed her medical degree and a PhD in philosophy (ethics) in Belgium before moving to Aotearoa in 2020. Her research interests lie in digital health ethics, with a particular focus on telehealth and online consultations, assistive technology for older adults, artificial intelligence, and the integration of ethical principles into health technology design.

She is a Board member of the WONCA (World Organisation of Family Medicine) Working Party on Ethics and Professionalism, as well as a member of the Royal Australasian College of Physicians' ethics committee.

Appointed September 2023.

Dr Hansa Patel: Health researcher

Hansa is a science technician involved in Clinical Research and provides coordination duties for a family-run paediatric health service. After living and working around the world, she settled in New Zealand and recently completed a PhD in Clinical Research focusing on osteoporosis risk factors. Her clinical research interests include the voices of young people, bone health, habitual sporting activity, alcohol and smoking, dental fluorosis, and sexually transmitted diseases.

Hansa was initially appointed to NEAC in August 2021 then reappointed in November 2024.

Dr Karaitiana Taiuru: Te Ao Māori expertise

Iwi affiliations: Ngāi Tahu, Ngāti Kahungunu, Ngāti Toa.

Karaitiana Taiuru holds several ethics roles with tertiary providers and government with both human and Artificial Intelligence. He is also the Deputy Chair of ACART.

Appointed November 2024.

Members whose terms ended during the reporting period

Shannon Te Ahu Hanrahan: Te Ao Māori perspectives and Deputy Chair

Shannon returned in 2020 to New Zealand from the United Kingdom after running his own public health consultancy business providing policy advice and commissioning support to clients in government, the National Health Service, provider, and voluntary and community sectors. Shannon was the public health advisor to the United Kingdom government's Responsible Gambling Strategy Board and was involved in several United Kingdom human rights campaigns such as marriage equality and improving access for pre-exposure prophylaxis (PrEP) for men-who-have-sex-with-men. Shannon currently holds the position of Executive Chair of Kō Kō Collective Trust in Opotiki which has a focus ensuring local public institutions (local government, schools, health and social

services and funders etc) are co-designed, co-developed and co-delivered around the needs, hopes and aspirations of local people and whānau for whom these institutions are intended to serve and, ultimately benefit.

Shannon was appointed to NEAC in August 2021 and his term ended in August 2024.

Professor John McMillan: Health Research Council nominee and Chair

John is a Professor at the Bioethics Centre at Otago University. He has served on a number of ethics, policy, and advisory groups in the United Kingdom, Australia, and New Zealand. His academic interests include research ethics, the methods of ethics and mental health ethics. Along with Alison Douglass and Greg Young, he is an author of the *Assessment of mental capacity: A New Zealand guide for doctors and lawyers* (VUP, 2020). His most recent monograph is *The Methods of Bioethics: An Essay in Metabioethics* (OUP 2018).

He is Editor in Chief of *The Journal of Medical Ethics* and a member of the *National Screening Advisory Committee*.

John was appointed to NEAC in August 2021 and his term ended in August 2024.

Dr Lindsey Te Ata o Tū MacDonald: Te Ao Māori Perspectives

Lindsey Te Ata o Tū MacDonald, Ngāi Tahu, is a senior lecturer in political philosophy at the University of Canterbury and a research associate of Kā Waimaero | Ngāi Tahu Centre. His early career was in New Zealand's State Services Commission and Te Puni Kōkiri (Ministry of Māori Development). He completed his PhD while lecturing in the Māori department at the University of Canterbury. In 2008 he joined the Department of Political Science and International Relations at the University of Canterbury.

In 2007, he became the Māori member of the University of Canterbury Human Ethics Committee and served as Chair between 2012 and 2016. He has been a member of the New Zealand Ethics Committee since 2013, a not-for-profit independent ethics committee assisting researchers unable to access University ethics committees, serving as Chair 2017-19. That committee is now the Aotearoa Research Ethics Committee, and Lindsey is co-chair of their management trust.

Lindsey was appointed to NEAC in December 2021 and his term ended in November 2024.

Nora Parore: Health Researcher

Nora Parore has whakapapa links to Ngāti Whātua, Ngāpuhi, Ngāti Wai, Te Roroa, Ngāti Kahu ki Whangaroa. Nora is an experienced and practising community pharmacist with post graduate clinical qualifications; a Māori health research fellow at Te Herenga Waka - Victoria University of Wellington and a current doctoral candidate researching policy and health service development in the pharmacy sector for whānau Māori. As the committed member and past Vice President of the Māori Pharmacists' Association, Nora is able to share her varied work experience in the sector with her peers. Nora, her husband, and her son live in Te Whanganui a Tara.

Nora was appointed to NEAC in August 2021 and her term ended in August 2024.

Member Attendance at NEAC Meetings in 2024/2025

Meeting attendance in 2023/2024	24 July 2024	24 October 2024	18 December 2024	6 March 2025	8 May 2025
Professor John McMillan (Chair)	✓	NA	NA	NA	NA
Shannon Te Ahu Hanrahan (Deputy Chair)	Apol	NA	NA	NA	NA
Julia Black	✓	✓	✓	✓	✓
Maree Candish	✓	✓	✓	✓	✓
Edmond Carrucan	✓	✓	✓	✓	✓
Dr Elizabeth Fenton (Chair)*	NA	NA	✓	✓	Apol
Associate Professor Vanessa Jordan	✓	✓	✓	✓	✓
Dr Filipo Katawake-McGrath	NA	NA	✓	✓	✓
Dr Lindsey Te Ata o Tū MacDonald (Deputy Chair)*	✓	✓	✓	Apol	✓
Dr Fiona Miles	NA	NA	✓	✓	✓
Dr Tania Moerenhout	✓	✓	✓	✓	✓
Nora Parore	Apol	NA	NA	NA	NA
Dr Hansa Patel	✓	✓	✓	✓	✓
Dr Karaitiana Taiuru	NA	NA	✓	✓	✓
Total members present	8	7	11	10	10

✓ = Present Apol = Apologies NA = Not applicable

Notes:

- A meeting had been scheduled for August 2024 but was cancelled.
- Professor John McMillan's term ended in August 2024.
- Shannon Te Ahu Hanrahan's term ended in August 2024.
- Dr Elizabeth Fenton began as Chair in December 2024.
- Dr Lindsey Te Ata o Tū MacDonald became Deputy Chair when Shannon Hanrahan's term ended. Dr MacDonald was Acting Chair from August to November 2024.
- Nora Parore's term ended in August 2024.

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. Members 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 publicly 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 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 \$452 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 \$336 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.