

National Ethics Advisory Committee

Kāhui Matatika o te Motu

Annual Report 2023/24

Twenty second 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 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 role involves identifying 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.

As we will be changing reporting periods this report covers 18 months from January 2023 to June 2024. During this time, NEAC's key focus was on two ongoing projects.

First, the review of NEAC's 2007 document that provided ethical guidance for future pandemics in Aotearoa New Zealand. Our revised report, renamed *Finding Balance*, emphasises the use of shared values so people are better equipped to care for and make decisions for themselves, their whānau, and their neighbours. This report was published in April 2025.

NEAC also progressed work in updating the *Ethical Standards for Health and Disability Research*. Our work included updating outstanding sections and sought expertise to update the Standards. 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 over the last 18 months. Your input helps us to ensure that our work is useful and addresses the issues that you consider important.

During the reporting period there were some changes in NEAC membership. In March 2023, we farewelled Dr Cindy Towns and Dr Penny Haworth. I want to acknowledge their mahi and contributions to NEAC over their term. In September 2023, we welcomed Julia Black and Dr Tania Moerenhout as new members.

The Ministry of Health have continued to support us in meeting our statutory obligations and in getting the *Finding Balance* report to completion. The committee would like to place on the record our thanks to the staff of the Secretariat for their tireless work on research and clinical ethics in New Zealand. Their policy work, and their work in supporting the committees of the health and disability ethics system (ACART, ECART and the four HDECs), makes possible the necessary and continual process of building trust in the ethics of research and clinical decision-making across the

sector. We would also like to thank the former Manager of the ethics secretariat, Nic Aagard, for his stewardship of that support over many years.

On behalf of NEAC, I am pleased to present this annual report for 2023/2024.

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 (the Minister). 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 within 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 (2023/2024) 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/

National Ethics Advisory Committee's work programme in 2023/2024

NEAC's work programme

NEAC's primary functions 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.

The NEAC agrees its work programme with the Minister of Health, which is composed of the following projects from January 2023 to June 2024:

1. National Ethical Standards for Health and Disability Research and Quality Improvement.
2. Ethical Guidelines for a Pandemic.

National Ethical Standards for Health and Disability Research and Quality Improvement

NEAC has a statutory function to produce 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) must be met by health and disability researchers and are applied by ethics committees when reviewing applications for health and disability research to ensure that health research in New Zealand is meeting or exceeding these Standards. The current version of the Standards was published in December 2019.

Continuing on from the progress in 2022, NEAC's subgroup worked with the Secretariat and subject matter experts to draft and progress sections of the revised Standards that were identified in the 2022 public consultation as needing to be updated. NEAC considered the progress on the Standards at every committee meeting to develop the next iteration of the draft Standards.

Towards the end of 2023, NEAC worked with the Secretariat to develop a plan for consulting on the finalised iteration of the revised Standards in 2024 alongside working to finalise outstanding sections. This work was delayed due to a reduction in the resourcing of the Secretariat and will be picked up again in the second half of 2024 when staff have been recruited/resources become available.

The NEAC Secretariat also conducted some additional analysis, to understand how the Standards are used by the Health and Disability Ethics Committees, by reviewing which Standards are most commonly cited in provisional approvals and declines over the last two years. Following the initial data collection, the Secretariat reviewed what the data means for the operation of the Standards and shared this with NEAC to inform the proposed Standards.

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 2021, NEAC drafted an update to *Getting Through Together* called *Ethical Guidance for a Pandemic* (EGAP). The name was changed, as 'Getting Through Together' had become the Mental Health Foundation's key advertising slogan.

Following the online consultation in 2022, NEAC worked with the Secretariat to analyse the feedback and produce a summary of the submissions. The report summarising the submissions was published in June 2023.

This feedback informed the next iteration of the document, entitled *Finding Balance: Ethical principles for epidemics and pandemics* (Finding Balance), and prepared during the second half of 2023. NEAC worked with the Secretariat to finalise the report with a view to advising the Minister of Health of its publication in early 2025. NEAC also developed a short summary document to accompany the report.

NEAC Terms of Reference

In August 2023, NEAC received approval from the then Minister of Health to add a review of the terms of reference to their work programme. We will continue this work in 2024/2025.

Future work programme

With the completion of *Finding Balance* anticipated in early 2025, NEAC began scoping topics for their future work programme. Through discussions with the committee, the following topics were identified for scoping.

1. National approach to clinical ethics - the role of ethics in clinical practice and clinical ethics support services.
2. Access to healthcare – resource prioritisation, access to primary care, and health education.
3. Ethical use of health data in data driven technologies – the use of health data, especially in the development and use of data driven tech e.g. apps, AI products.
4. Health care professionals and conflicts of interest – a review of whether there is sufficient transparency and accountability when healthcare professionals have conflicts of interest.
5. Ethical use of precision medicine and genome editing - the ethical issues raised by these technologies in a New Zealand context.
6. Complaints process in health – whether this process is fair, transparent and equitable in supporting consumers in getting quality health and disability services.

We will be continuing this scoping work in 2024/2025 and will start a new programme of work in early 2025.

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 together as individuals and as a collective, and to discuss further goals and principles of the group.

The main group met as needed and discussions in 2023 and 2024 included how the Roopu was intended to function and the ways in which the group would work together and to support NEAC. There was also significant discussion around the importance of developing terms of reference for the Roopu which would 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 two key projects.

Research Ethics Review System

Part of NEAC's mandate is to support 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.

During the 2023/2024 period, NEAC assisted the Health and Disability Ethics Committees by supporting them in the timely recruitment of new members and providing input into the Ministry of Health's modernisation of ethics project.

Clinical ethics and moral distress of the health workforce

In March 2023, NEAC wrote to the Minister of Health to raise concerns about the wellbeing of the health workforce and the lack of available clinical ethics capacity to support those working in the health sector.

NEAC believes that interactions between patients and health care professionals are at the heart of health care. These interactions have an essential ethical dimension that may at times be challenging. Supporting professionals and organisations to meet those challenges can help ensure that patient care is provided in an ethically and culturally appropriate manner.

NEAC advised the Minister to consider strengthening the clinical ethics frameworks and support at a national level.

The Minister acknowledged NEAC's concerns and advised that these issues will be considered as part of the review of the Health Workforce Strategy and implementation of workforce initiatives.

Consultation responses

In 2023/2024, NEAC also responded to three consultations. These included the:

- Law Commission's first issues paper consultation on capacity and decision-making
- Ministry of Health's Long-term Insights Briefing on Precision Health
- Advisory Committee on Assisted Reproductive Technology's (ACART) consultation on Human Reproductive Research.

Meeting attendance

NEAC members and Secretariat staff attended a range of events in 2023/2024.

- On 29 March 2023, a meeting was held between the Health and Disability Commissioner, NEAC and the Ethics team regarding the Health Research Council's proposed consultation on the Code of Patient Rights, and particularly research with adult participants who are unable to provide informed consent.
- Members of NEAC and the Secretariat attended a meeting regarding an update on the Royal Commission of Inquiry into COVID-19 Lessons on 17 August 2023.
- Members of the Secretariat attended and presented to the New Zealand Association of Clinical Research 2023 Conference (NZACRES). The conference ran from 24-25 August 2023.
- Members attended the Sector Day, organised by the Ethics team and attended by seven ethics committees in Wellington on 7 December 2023. This was a chance for ethics committees to meet and discuss emerging ethical topics, medical research and policy developments. Several notable speakers were present including the Prime Minister's Chief Science Advisor and the Deputy Director General for Māori Health. Officials from Te Whatu Ora and the Health Research Council officials were also invited.
- Members of NEAC and the Secretariat attended a meeting with the Asian Bioethics Network on 4 September 2023 to present on the work of NEAC, hear about the work of similar bioethics committees in the Asia-Pacific region, and discuss ethical approaches to data and AI.
- The Chair represented NEAC on the International Steering Committee for the 14th Global Summit of National Ethics Committees (the Summit). The Summit was held from 17-19 April 2024 in San Marino.

National Ethics Advisory Committee Members 2023/2024

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.

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 Kōi Kōi Collective Trust in Otago 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.

Julia Black – Community perspectives

Julia is currently writing her dissertation for a Masters in Bioethics and Health Law at the University of Otago, with a focus on ethical and legal issues in precision oncology and has a B. Health Sci (Health Promotion). Her professional interests include advocacy for cancer patients and their families as they navigate the complex treatment and surveillance options available in both the private and public healthcare systems. Her motivation to contribute to these areas was driven by the death of her husband Malcolm Black from colorectal cancer in 2019. Julia also has a strong interest in adapting existing clinical and research methods to better honour and respect the cultural values and beliefs of Māori and the integration of A.I in healthcare. She is also the consumer representative on the Dunedin Colorectal Cohort governance committee.

Julia was appointed to NEAC in September 2023.

Maree Candish - Community perspectives

Maree grew up in Tairāwhiti and initially worked in the forestry industry there and in the Bay of Plenty. As a management consultant in natural resources fields, she helped governments, companies, and community organisations with systems, asset evaluation, quality management, and sustainable land use. She has lived and worked around the world with a focus on Australasia and Southeast Asia. She has a B. For. Sci. (First Class Hons), an MSc (Oxford) and an MBA (Melbourne).

In 2013 she and her son became sick with ME/CFS; they have remained disabled since that time. Maree is active in international advocacy related to post-infection conditions and consumer participation in health care management and research. She has contributed to the development of clinical guidelines and research programmes in a number of countries.

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 appointed to NEAC in December 2021.

Dr Penny Haworth - Consumer Perspectives

Penny is an Honorary Research Fellow at 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) as well as the Board of the Massey College of Humanities and Social Sciences for 5 years. She was an elected member of the Executive Committee for the International Study Association on Teachers and Teaching for 6 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.

Penny was appointed to NEAC in May 2020 and ended her term in March 2023.

Associate Professor Vanessa Jordan - Epidemiologist

Vanessa is an epidemiologist/methodologist specialising in trial design, biostatistics, systematic reviews and epidemiology. Vanessa holds a doctorate in epidemiology and biochemistry from the University of Otago and currently works as a senior research fellow at the University of Auckland and is academic coordinator for the post graduate 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 synthesized 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.

Vanessa was appointed to NEAC in May 2020.

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.

Dr Tania Moerenhout

Tania Moerenhout is a general practitioner and Lecturer at the Bioethics Centre of the University of Otago in Ōtepoti Dunedin. She combines academic work with a part-time clinical position. She graduated as a general practitioner in Belgium in 2009 and completed a PhD in philosophy in 2019 at Ghent University before moving to Aotearoa New Zealand in 2020. Her doctoral research examined ethical challenges related to electronic health record use with a focus on the patient-provider relationship and patient empowerment.

Her current research interests are situated in the field of digital health ethics. She is researching ethical challenges of online consultations and the ethical implications of the use of assistive technology in older adults' care. Next to this, she has an interest in the ethics of artificial intelligence use in health care, and virtual/augmented reality applications.

She is the convenor of the Digital Health Information Governance and Ethics paper in the Digital Health postgraduate programme at the University of Otago. Tania is Chair of the WONCA (World Organisation of Family Medicine) Working Party on Ethics and Professionalism and a member of the NZ Telehealth Forum Research, Audit, and Evaluation Working Group.

Tania was appointed to NEAC in September 2023.

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.

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 appointed to NEAC in August 2021.

Rochelle Style - Consumer Perspectives

Rochelle is a bioethicist who specialises in advising on ethical issues in health research, particularly the use of algorithms and artificial intelligence in healthcare.

She was previously a partner at law firm Bell Gully and worked closely with Pharmac, the Ministry of Health and others. Rochelle has been a member of the Clinical Ethics Advisory Group at Capital & Coast DHB, the Northern A Health and Disability Ethics Committee, and the Covid-19 Algorithms Governance Group established by the Ministry of Health. She was also a member of the expert Working Party convened to update the National Ethical Health Research Standards. More recently she has consulted on the legal and ethical issues raised by genetics and genomics research, and digital pathology. Her most recent appointment is membership of the National AI and Algorithm Expert Advisory Group for Manatū Hauora.

Rochelle was appointed to NEAC in December 2021.

Dr Seini Taufa

Dr Seini Taufa is a proud daughter of the Pacific with ties to Tonga, Fiji, and Wallis and Fatuna; she acknowledges her *tupu'anga* and the stepping stones laid by those who paved the way.

Seini is General Manager for Moana Research (Moana Connect), a Pacific-owned, led, and governed company in which she is a part owner and a founding member. She is also the Pacific Theme Lead for Growing up in New Zealand, the largest longitudinal study in New Zealand. Dr Taufa was previously based at the University of Auckland, where she taught for over ten years within the departments of Social and Community Health and Pacific Health, School of Population Health. She has a mixed methods background (quantitative and qualitative research), and her areas of interest include maternal and paternal health, social theories including unconscious bias, racism, and intersectionality.

Seini was appointed to NEAC in November 2022 and had to resign effective from early 2023 due to other commitments.

Dr Cindy Towns – Ethicist

Dr Cindy Towns is a Consultant Physician at Wellington Hospital in Internal Medicine and Geriatrics. She is an adjunct senior lecturer with the Bioethics Centre at the University of Otago and a Senior Lecturer at the Wellington School of Medicine. Cindy does research in Geriatrics, Internal Medicine (General Medicine), and Ethics. She has developed a special interest in the acute hepatic porphyria.

Cindy was appointed to NEAC in May 2020 and ended her term in March 2023.

Member Attendance at NEAC Meetings in 2023/2024

Meeting attendance in 2023/2024	16 March 2023	25 May 2023	20 July 2023	21 September 2023	23 November 2023	29 February 2024	11 April 2024
Professor John McMillan (Chair)	✓	✓	✓	✓	✓	✓	✓
Shannon Te Ahu Hanrahan (Deputy Chair)	✓	✓	✓	✓	Apol	✓	✓
Julia Black^	NA	NA	NA	✓	✓	✓	✓
Maree Candish	✓	✓	✓	✓	✓	✓	✓
Edmond Carrucan	Apol	✓	✓	✓	✓	Apol	✓
Dr Penny Haworth*	✓	✓	✓	NA	NA	NA	NA
Associate Professor Vanessa Jordan	✓	✓	✓	✓	✓	✓	Apol
Dr Lindsey Te Ata o Tū MacDonald	✓	Apol	Apol	✓	✓	Apol	✓
Dr Tania Moerenhout^	NA	NA	NA	✓	✓	Apol	Apol
Nora Parore	✓	✓	✓	✓	✓	✓	✓
Dr Hansa Patel	✓	✓	✓	✓	Apol	✓	✓
Rochelle Style	✓	✓	✓	✓	✓	✓	✓
Seini Taufua	NA	NA	NA	NA	NA	NA	NA
Dr Cindy Towns*	✓	NA	NA	NA	NA	NA	NA
Total members present	10	9	9	10	8	7	8

✓ = Present Apol = Apologies NA = Not applicable

Notes:

* Dr Cindy Towns' and Dr Penny Haworth's terms officially ended in March 2023 but they continued to attend meetings until two new members were appointed in September 2023.

^ Julia Black and Dr Tania Moerenhout terms started in September 2023.

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.