

**National Ethics Advisory Committee**

**Kāhui Matatika o te Motu**

**Annual Report 2022**

**Twenty-first 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) for January to December 2022 and summarises its advice on matters referred to it in that year under section 92 of the Pae Ora (Healthy Futures) Act 2022, which replaced the New Zealand Public Health and Disability Act 2000 on 1 July 2022.

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

In 2022, NEAC's key focus was continuing two projects. The first was the review of its 2007 document, *Getting Through Together: Ethical values for a pandemic*, which provides ethical guidance for future pandemics in Aotearoa New Zealand.<sup>1</sup> For this project, the committee prepared and launched an online public consultation on the draft revised guidance called *Ethical Guidance on Pandemic* (EGAP) and reviewed the feedback. The consultation closed in November 2022, with the changes from feedback to be incorporated into the guidance document in 2023.

NEAC also progressed updating the National Ethical Standards for Health and Disability Research and Quality Improvement, considering the initial summary of submissions from the public consultation in late 2021. A subgroup was established to draft and progress sections of the revised standards, which were then reviewed and discussed at each committee meeting.

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

In 2022, Deputy Chair, Shannon Te Ahu Hanrahan, took on the role of Acting Chair for three months, while I was completing an academic sabbatical. I greatly appreciated Shannon taking on the role for me and leading the committee successfully during my absence.

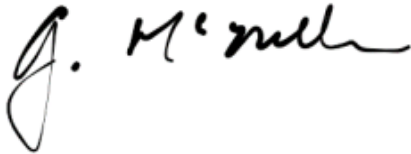
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<sup>1</sup> NEAC. 2007. *Getting Through Together: Ethical values for a pandemic*. Wellington: Ministry of Health. URL: <https://neac.health.govt.nz/publications-and-resources/neac-publications/getting-through-together-ethical-values-for-a-pandemic> (accessed 7 August 2024).

At the end of the year, we farewelled Dr Gordon Jackman and Dr Mary-Anne Woodnorth who both made significant contributions to our work programme during their terms. We were also very pleased to welcome two new members in 2022, Maree Candish and Dr Seini Taufua.

We have continued to be well supported by the Secretariat at the Ministry of Health over a period of significant change in the health and disability system.

On behalf of NEAC, I am pleased to present this annual report for 2022.

A handwritten signature in black ink, appearing to read 'J. McMillan', written in a cursive style.

Professor John McMillan  
**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 (the Act), are to:

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

The NEAC members are listed on pages 7 to 11.

# National Ethics Advisory Committee's work programme in 2022

## NEAC research ethics standards

### Progress in 2022

The National Ethical Standards for Health and Disability Research and Quality Improvement (the Standards) aim to help researchers undertake ethical health and disability research, producing quality outputs on research questions that matter. The Standards set the criteria for researchers to follow when conducting health and disability research and quality assurance and improvement. Independent ethics committees and accredited health and disability ethics committees can check health research in Aotearoa New Zealand is meeting or exceeding the Standards.

Continuing the work started in 2021, NEAC began the next iteration of the draft Standards. The responses to the 2021 survey indicated that the Standards are generally fit for purpose and supported by the research sector, although there were areas that were flagged as needing improvement. These included strengthening compliance with Te Tiriti o Waitangi | the Treaty of Waitangi (Te Tiriti) principles, further embedding *Te Ara Tika Guidelines for Māori Research Ethics*<sup>2</sup>, significantly revising the chapter on quality improvement activities and making minor modifications to commentary and wording throughout the Standards.

In 2022, NEAC considered the initial summary of submissions from the public consultation and established a subgroup to draft and progress sections of the revised Standards. The Standards review subgroup worked with the Secretariat to draft revisions, incorporate feedback, seek input from external experts and interested parties and develop the next iteration.

## Ethical guidelines for a pandemic

### Progress in 2022

In 2007, NEAC published *Getting Through Together: Ethical values for a pandemic*. In 2019, NEAC agreed to update the publication, but the work 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: Ethical values for a pandemic* called *Ethical Guidance for a Pandemic* (EGAP). The name was changed to EGAP because 'Getting Through Together' had become the Mental Health Foundation of New Zealand's key advertising slogan for their national mental health and wellbeing campaign.

On 26 July 2022, NEAC launched an online public consultation about the draft EGAP report. The draft guidelines considered the ethical issues that may arise during a pandemic. The EGAP

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<sup>2</sup> Pūtaiora Writing Group. n.d. *Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members*. Wellington: Health Research Council of New Zealand. URL: [www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics](http://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics) (accessed 7 August 2024).



document emphasised the use of shared values to ensure people are better equipped to care for and make decisions for themselves, their whānau and their neighbours in such an event.

The consultation closed on 1 November 2022 and received 428 submissions. In addition, NEAC also received 21 written submissions and held three online focus groups with stakeholders. The submissions were analysed by the NEAC Secretariat at the Ministry of Health and will be prepared for Committee consideration in the first half of 2023.

The summary of submissions will be published in mid-2023 and the EGAP documents revised in the second half of 2023.

## **Establishing a framework for NEAC decision-making and prioritisation**

NEAC established a subgroup to work with the Secretariat in developing a decision-making framework (the DM Framework) to help NEAC in deciding which items it should prioritise in its work programme. The DM Framework was developed and tested by running two of the current work programme items through its criteria, and it was approved for use in July 2022.

## **Establishing the Rangatiratanga Roopu**

In 2022, NEAC established the Rangatiratanga Roopu, a subcommittee of NEAC chaired by the Deputy Chair, Shannon Te Ahu Hanrahan, with one of its initial aims being to explore how NEAC's Māori members can support each other and best work together, one on one and as a collective, to support the work of NEAC.

The Roopu met regularly, and discussions in 2022 included how to build capacity and considering issues of cultural overload, a broader review of NEAC's terms of reference, including where NEAC sits within the Act and what the Act's principles might mean for NEAC. Other issues discussed include principles of equity and the role of the Deputy Chair in NEAC's terms of reference.

NEAC also engaged with other policy committees around developing a shared approach to engaging with Māori and other stakeholders and amendments made to the other committees' terms of reference regarding ensuring either the Chair or Deputy Chair of the committee is Māori.

## **Monitoring research ethics committees**

Part of NEAC's terms of reference is to monitor and review the operation of research ethics committees to provide direction, guidance and leadership and ensure the ongoing quality and consistency of ethical review in the health and disability sector. To ensure research ethics committees have adequate guidance for making decisions about health research applications, it's important to understand research ethics committees' members' experiences with the revised ethical standards. NEAC welcomed feedback from institutional and health and disability committee members.

HDEC Chairs attended NEAC meetings in 2022. They advised on prevalent emerging issues in the HDECs' space and noted in particular the high volume of applications in 2022.

NEAC members also fed into proposed changes to update the disability questions in the HDEC screening forms in conjunction with Chairs.

## Health and Disability Ethics Committees modernisation project

### Progress by the in 2022

NEAC were asked to provide advice on work by the Ministry's Ethics team to further develop the modernisation work.

In 2022, the Minister was provided with an update on the modernisation of ethics project. As a result, it was agreed that the Health and Disability Ethics Committees' (HDECs) terms of reference should be amended to:

- embed Te Tiriti
- refine member categories
- clarify the definition of lay membership
- establish a deputy chair role for non-lay members
- refine and clarify member responsibilities
- extend the membership term to five years
- add a requirement to receive training.

The current HDEC system was designed in response to the Government's Health Committee 2012 inquiry into improving Aotearoa New Zealand's environment to support innovation through clinical trials. It has been a decade since these changes were introduced, and it is timely to do a wider review of the research ethics review system. The Ethic's team will be undertaking further analysis to support the continued modernisation of the ethics review system.

# Health Services Ethics Work in 2022

## Compensation and commercial trials

In 2022, proposed revisions to the Accident Compensation Act 2001 were considered through the Accident Compensation Corporation (ACC) Amendment Bill.

In support of a joint letter signed alongside the New Zealand Association of Clinical Research, NEAC wrote to the Minister regarding excluding access to ACC for participants in commercially sponsored clinical trials. In particular, NEAC highlighted the challenges involved in determining whether a study had adequate insurance. The letter sought to raise the Minister's awareness of the ethical issues involved in excluding these participants from ACC compensation and noted that it is difficult for HDECs to determine whether a commercial trial has adequate insurance.

## Other Work in 2022

### Progress in 2022

NEAC members and Secretariat staff were involved in a range of events in 2022, including:

- attending the World Health Organization (WHO) Global Summit of National Ethics/Bioethics Committees in Portugal, 15–17 September 2022
- (This meeting was attended by the Manager, Ethics, who delivered a presentation developed in collaboration with the Chair and Deputy Chair and titled He Mahi Raranga – the weaving of different cultural approaches in health research: the Aotearoa New Zealand experience.)
- meeting with the Health Research Council of New Zealand to discuss the best ways to train existing and new ethics committee members in the health research space, 29 July 2022
- attending online the Australasian Association of Bioethics and Health Law Conference, November 2022
- regularly meeting with the Health and Disability Commissioner to discuss research that involves adult participants who are unable to provide informed consent
- representatives attending WHO and Asia-Pacific Regional Meeting for National Bioethics/Ethics Committees meetings (and reporting back at subsequent NEAC meetings)
- two members presenting at The Global Health Network virtual seminar on indigenous communities, vulnerability and the COVID-19 pandemic on 20 June 2022.

# National Ethics Advisory Committee Members

## Professor John McMillan – Chair, Health Research Council of New Zealand nominee

John is a professor at the Bioethics Centre at the University of Otago. He has served on several ethics, policy and advisory groups in the United Kingdom, Australia and Aotearoa New Zealand, including the Nuffield Council on Bioethics, helping complete the report *Dementia: Ethical Issues*<sup>3</sup>.

His academic interests include research ethics, the methods of ethics and mental health ethics. He is co-author of *Assessment of Mental Capacity*.<sup>4</sup> His most recent monograph is *The Methods of Bioethics*.<sup>5</sup>

He is also 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.

## Mr Shannon Te Ahu Hanrahan – Deputy Chair, te ao Māori perspectives

Shannon returned to Aotearoa New Zealand from the United Kingdom in 2020. In the United Kingdom, he had run his own public health consultancy business, providing policy advice and commissioning support to clients in government, the National Health Service, health providers, 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 Collective Trust in Ōpōtiki. The Trust aims to ensure 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 these institutions serve.

Shannon was appointed to NEAC in August 2021.

## Ms 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

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<sup>3</sup> Nuffield Council on Bioethics. 2009. *Dementia: Ethical issues: a guide to the report*. London: Nuffield Council on Bioethics. URL: [www.nuffieldbioethics.org/assets/pdfs/Nuffield-Dementia-short-guide.pdf](http://www.nuffieldbioethics.org/assets/pdfs/Nuffield-Dementia-short-guide.pdf) (accessed 9 August 2024).

<sup>4</sup> Douglass A, Young G, McMillan J. 2020. *Assessment of Mental Capacity: A New Zealand Guide for Doctors and Lawyers*. Wellington: Victoria University of Wellington Press.

<sup>5</sup> McMillan J. 2018. *The Methods of Bioethics: An essay in meta-bioethics*. Oxford University Press.

sustainable land use. She has lived and worked around the world, with a focus on Australasia and Southeast Asia. She has a BSc (first-class Hons), an MSc (Oxford) and an MBA (Melbourne).

In 2013, she and her son became sick with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS); they have remained disabled since then. 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.

### **Mr Edmond Carrucan – Legal perspectives**

Edmond has whakapapa links to Ngāti Hako, Tainui and Ngāti Porou.

Edmond is an emerging Māori legal academic and has expertise in tikanga Māori. He 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) and the board of the Massey University College of Humanities and Social Sciences (the latter 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. She was lead researcher in an early childhood service Centre of Innovation, a decile 1 kindergarten in partnership with a Samoan upu amata teacher (early childhood teaching focused on the needs of Samoan children and families). She has published extensively in Aotearoa 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 Inc. Supported Employment.

Penny was appointed to NEAC in May 2020.

### **Dr Gordon Jackman – Disability perspectives**

Gordon Jackman is Chief Executive of the Duncan Foundation, an organisation that supports people with neuromuscular conditions. He is on the board of The Supported Lifestyle Hauraki Trust and the Thames Public Art Trust. He 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.

Gordon had polio when he was 10 months old and has been active in the disability sector most of his life.

Gordon was appointed to NEAC in June 2019.

## **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. She is academic coordinator for the post-graduate paper on systematic review methodology run at the university's 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 Cochrane New Zealand 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, Vanessa 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, who has whakapapa links to Ngāi Tahu, is a senior lecturer in political philosophy and a research associate of Kā Waimaero | Ngāi Tahu Centre | Office of Treaty Partnership at the University of Canterbury. His early career was in Aotearoa 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 Political Science and International Relations Department 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 from 2017 to 2019. That committee is now the Aotearoa Research Ethics Committee, and Lindsey is co-chair of their management trust.

Lindsay was appointed to NEAC in December 2021.

## **Ms Nora Parore – Health researcher**

Nora has whakapapa links to Ngāti Whātua, Ngāpuhi, Ngāti Wai, Te Roroa and Ngāti Kahu ki Whangaroa. She 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 a committed member and past Vice President of the Māori Pharmacists' Association, Nora is able to share her varied work experience in the health and disability 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. She also provides coordination duties for a family-run paediatric health service. After living and working around the world, Hansa settled in Aotearoa 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.

### **Ms 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 health care.

Rochelle was previously a partner at law firm Bell Gully and worked closely with the Pharmaceutical Management Agency Ltd (Pharmac), the Ministry and other government organisations. 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. She was also a member of the expert working party convened to update the National Ethical Standards for Health and Disability Research and Quality Improvement.

More recently Rochelle has consulted on the legal and ethical issues raised by genetics and genomics research and digital pathology. Her most recent appointment is as a member of the AI and Algorithm Expert Advisory Group for Health New Zealand | Te Whatu Ora.

Rochelle was appointed to NEAC in December 2021.

### **Dr Seini Taufa – Pacific perspectives**

Seini 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, of which she is a part owner and founding member. She is also the Pacific theme lead for Growing up in New Zealand, the largest longitudinal study in Aotearoa New Zealand.

Seini was previously based at the University of Auckland, where she taught for over 10 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 and social theories, including unconscious bias, racism, and intersectionality.

Seini was appointed to NEAC in November 2022.

### **Dr Cindy Towns – Ethicist**

Cindy graduated from the intercalated MBChB PhD program at the University of Otago and hold a BSc with high honours from Idaho State University. She is a senior lecturer in the Bioethics Centre, Department of Medicine, University of Otago and works as an Internal Medicine physician and Geriatrician at Wellington Hospital.

Cindy has also been a member of the Specialist Advisory Committee for Geriatrics, Royal Australasian College of Physicians.

Cindy was appointed to NEAC in May 2020.

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

Mary-Anne originally trained to be a biomedical researcher at the University of Otago and has a PhD in neuroscience. She has worked in a variety of research settings, including industry (Neuren Pharmaceuticals, Australia) and research funding (Health Research Council of New Zealand). She has led the Research Office of Auckland District Health Board, Aotearoa New Zealand's largest clinical research facility, since 2010.

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

Mary-Anne was appointed to NEAC in June 2019.

## Member Attendance at NEAC Meetings in 2022

Meeting attendance in 2022	24 March 2022	26 May 2022	28 July 2022	22 September 2022	24 November 2022
Prof John McMillan (Chair)	✓	✓	Apol	Apol	✓
Mr Shannon Te Ahu Hanrahan (Deputy Chair)	✓	✓	✓	✓	✓
Ms Maree Candish	NA	NA	NA	NA	✓
Mr Edmond Carrucan	✓	✓	✓	✓	✓
Dr Penny Haworth	✓	✓	✓	✓	✓
Mr Gordon Jackman	✓	✓	✓	✓	✓
Assoc Prof Vanessa Jordan	✓	✓	Apol	✓	✓
Dr Lindsey Te Ata o Tū MacDonald	✓	✓	✓	✓	✓
Ms Nora Parore	✓	Apol	✓	✓	Apol
Dr Hansa Patel	✓	✓	✓	✓	✓
Ms Rochelle Style	✓	✓	✓	✓	✓
Ms Seini Taufa	NA	NA	NA	NA	Apol
Dr Cindy Towns	✓	Apol	Apol	Apol	✓
Dr Mary-Anne Woodnorth	✓	✓	✓	✓	✓
<b>Total members present</b>	<b>12</b>	<b>10</b>	<b>9</b>	<b>10</b>	<b>11</b>

✓ = Present Apol = Apologies NA = Not applicable

### Notes:

Professor John McMillan took a three-month professorship during 2022 and was unable to attend NEAC meetings over this period.

Maree Candish and Seini Taufa's membership began in November 2022.

Mr Gordon Jackman and Dr Mary-Anne Woodnorth's membership ended in November 2022.

Mr Gordon Jackman attended as a guest for the meeting of 24 November 2022.

## **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.

## Contact Details for the National Ethics Advisory Committee

Contact details for NEAC are as follows:

<b>Email</b>	neac@health.govt.nz
<b>Postal Address</b>	PO Box 5013, Wellington 6145
<b>Website</b>	<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.