

**National Ethics Advisory Committee**

**Kāhui Matatika o te Motu**

**Annual Report 2021**

**Twentieth 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 2021 and summarises its advice on matters referred to it in that year under section 16 of the New Zealand Public Health and Disability Act 2000.

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 mandate involves identifying what matters, explaining how the health and disability sector can act and encouraging ethical decision-making across the sector.

NEAC's main focus in 2021 centred around responding to the challenges created and exacerbated in the health and disability system by COVID-19. NEAC developed an ethics framework for resource allocation to help decision-makers work through the ethical implications of resource allocation and prioritisation during the COVID-19 response<sup>1</sup> and began a review of its 2007 document, *Getting Through Together: Ethical values for a pandemic*<sup>2</sup>.

A primary aim of the review of *Getting Through Together* is to provide ethical guidance for future pandemics in Aotearoa New Zealand and build on the lessons from the COVID-19 pandemic.

The committee also began an update of the National Ethical Standards for Health and Disability Research and Quality Improvement to ensure they are fit for purpose and provide details on current best practice and guidance on emerging ethical issues.

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

This year, we farewellled Dr Kahu McClintock, Dr Wayne Miles and Dr Hope Tupara, as well as the Chair Neil Pickering, who made significant contributions to NEAC's work programme and

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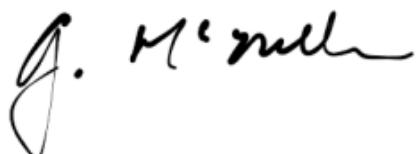
<sup>1</sup> NEAC. 2021. *Ethics and Equity: Resource allocation and COVID-19*. Wellington: Ministry of Health. URL: <https://neac.health.govt.nz/publications-and-resources/neac-publications/ethics-and-equity-resource-allocation-and-covid-19> (accessed 7 August 2024).

<sup>2</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).

governance over many years. I was very pleased to join the committee and we also welcome three new members: Shannon Te Ahu Hanrahan, Dr Hansa Patel and Nora Parore. At the end of 2021, three new members were appointed to NEAC who will join the committee in 2022 and we farewelled Liz Richards and Dr Dana Wensley. The new members are Rochelle Style, Edmond Carrucan and Dr Lindsey Te Ata o Tū MacDonald.

We have continued to be exceptionally well supported by the Secretariat at the Ministry of Health.

On behalf of NEAC, I am pleased to present this annual report for 2021.

A handwritten signature in black ink, appearing to read 'J. McMillan', with a stylized, flowing script.

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 Ethics Advisory Committee on Health and Disability Support Services | Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health (the Minister). Its statutory functions, under section 16 of the New Zealand Public Health and Disability Act 2000 (the Act), are to:

- advise the Minister on ethical issues of national significance in respect of health and disability matters (including research and health 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 16(6) of the Act requires that NEAC 'at least once a year, deliver to the Minister a report setting out its activities and summarising its advice on the matters referred to it under this section'.

## Membership of the National Ethics Advisory Committee in 2021

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 2021

## NEAC Research Ethics Standards

### Progress in 2021

Since 2015, NEAC's main focus has been completing a comprehensive review of its 2012 Ethical Guidelines for Intervention Studies and Ethical Guidelines for Observational Studies. The main objectives of the review were to update and expand both sets of guidelines and bring the two together into a single document. The updates aimed to address ethical issues associated with developments in research methods and emerging topics. National Ethical Standards for Health and Disability Research and Quality Improvement (the Standards) were published in December 2019. They were to be reviewed regularly to ensure they remained fit for purpose.

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 check health research in Aotearoa New Zealand is meeting or exceeding the Standards.

In 2021, NEAC engaged with key stakeholders and experts to update the Standards to ensure they remain fit for purpose. NEAC sought feedback on the Standards' content and whether there are gaps in guidance or issues around applying the Standards that need to be addressed.

Feedback indicated that the Standards are generally fit for purpose and supported by the research sector. Suggestions for improvements 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>3</sup>, significantly revising the chapter on quality improvement activities and making minor updates throughout the Standards.

A summary of the main responses and suggestions for improvement were collated for the committee's consideration, followed by agreement to begin on the next iteration of the draft Standards.

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<sup>3</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).



## Ethical guidelines for a pandemic

### Progress in 2021

In 2007, NEAC published *Getting Through Together: Ethical values for a pandemic*, which emphasised using shared values so people can care for themselves, their whānau and their neighbours and make decisions during a pandemic.

In 2019, NEAC agreed to update this publication but drafting in 2020 was halted by the COVID-19 pandemic. Instead, NEAC shifted its focus and published *Ethics and Equity: Resource allocation and COVID-19* in 2021.

In 2021, NEAC was able to resume updating *Getting Through Together* and began drafting the publication, *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. The draft EGAP publication was seen as an important and challenging piece of work due to the complex issues presented by the COVID-19 pandemic.

The development of EGAP focused on drafting chapters and revisions, with a key emphasis on learning from the COVID-19 pandemic. These changes evolved into basic drafts and a project plan in 2021. The draft publication was provided to the Minister in December 2021, and it received a positive initial response.

### NEAC's resource allocation framework

In response to the COVID-19 pandemic, NEAC committed to developing an ethical framework for resource allocation that addresses equity in prioritisation.

NEAC's resource allocation framework (the '*Framework*') is a high-level guidance document for the health and disability sector that aims to help health workers and policy makers apply ethical principles when deciding how to allocate resources. The Framework sets out ethical and Te Tiriti principles that medical staff, service planners and policy makers should consider when responding to pandemics. In February 2021, the Framework was published and disseminated to stakeholders.

The Framework adds an equity lens to decision-making and assesses how equity sits alongside other ethical principles and Te Tiriti. Equity is a concept that acknowledges different people have different levels of advantage and so require different approaches and resources to achieve equitable health outcomes.

In a resource allocation setting, this means that health workers and policy makers should consider how resources can be allocated to mitigate the adverse consequences of pandemic response measures while at the same time avoiding or minimising growth in inequity from those measures.

NEAC recognises the Framework only addresses a small part of pandemic ethics and is focused on the COVID-19 pandemic.

## **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.

## **Health and Disability Ethics Committees modernisation project**

### **Progress in 2021**

NEAC were informed of the implementation of a new online application system by the Health and Disability Ethics Committees (HDECs).

In April 2021, a new online portal was confirmed for the HDECs. This portal provided an opportunity to significantly reduce the amount of administration work for the HDEC Secretariat and to increase oversight and data monitoring. The online portal went live on 1 September 2021.

In November 2021, NEAC met with the Kate O'Connor, Chair of the Northern B Health and Disability Ethics Committee, who described the recent experiences of the HDECs. Kate noted that the rollout and implementation of the new information technology system, the Ethics Review Manager (ERM), has been a huge success.

# Services Ethics Work in 2021

## Implementation of the End of Life Choice Act 2019

Although the Ministry of Health (the Ministry) is responsible for implementing the End of Life Choice Act 2019, members of the project team sought expert ethical advice from NEAC as a key stakeholder while the implementation work progressed. NEAC was specifically interested in the main ethical challenges and tensions with implementing the Act and how best to address these challenges and tensions.

### Non-gendered wards

In June 2021, NEAC wrote to the Minister to raise concerns about the practice Aotearoa New Zealand of placing male and female hospital patients in the same room.

NEAC advised that it considers it unethical to place female patients in situations that can cause distress and compromise their safety and may violate the Code of Patient Rights, leading to potential legal challenges to the practice. NEAC noted that the United Kingdom National Health Service has prohibited mixed-gender bedding since 2010, and hospitals are now required to report on the practice routinely and publicly.

NEAC advised the Minister to adopt a nationally consistent policy to prohibit this practice and begin routine public reporting. The Minister acknowledged NEAC's concerns. NEAC noted that it looks forward to the publication of the Aotearoa New Zealand research on the topic.

## Other Work in 2021

### Progress in 2021

NEAC members and Secretariat staff were involved in a range of events in 2021, including:

- attending the Australasian Association of Bioethics and Health Law Conference, November 2021
- meeting with the Minister, 12 March 2021
- meeting with the Health and Disability Commissioner to discuss research that involves adult participants who are unable to provide informed consent, November 2021
- attending the Asian Bioethics meeting in Singapore, June 2021 (online attendance)
- representatives attending international World Health Organization (WHO) and the regional internet registry Asia Pacific Network Information Centre (APNIC) steering group meetings throughout the year.

## National Ethics Advisory Committee Members

### **Associate Professor Neil Pickering – Chair (until August 2021), Health Research Council of New Zealand nominee**

Neil is a senior lecturer in the Bioethics Centre at the University of Otago. He has published on a range of ethical issues and has been a member of several research projects both in Aotearoa New Zealand and in his previous job in the United Kingdom. His primary area of research is philosophy of mental health, and his book *The Metaphor of Mental Illness* was published by Oxford University Press in 2006 in their International Perspectives in Philosophy and Psychiatry series.

He was a member of the University of Otago Human Research Ethics Committee from 1999 to 2005. He was also on the Health Research Council of New Zealand Ethics Committee from 2005 to 2010 and was Acting Chair from 2007 to 2008. He is currently a member of the editorial board of the *Journal of Bioethical Inquiry* and a member of the committee of the Australasian Association of Bioethics and Health Law.

Neil was appointed to NEAC in April 2013 and reappointed in July 2016. He was appointed Deputy Chair in September 2016 and Chair from October 2016 to August 2021.

### **Professor John McMillan – Chair (from August 2021), 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>4</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>5</sup> His most recent monograph was *The Methods of Bioethics*.<sup>6</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 as the Chair of NEAC.

### **Mr Shannon Te Ahu Hanrahan – 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

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<sup>4</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>5</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>6</sup> McMillan J. 2018. *The Methods of Bioethics: An essay in meta-bioethics*. Oxford University Press.

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 Kollektive 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.

## **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 is Chief Executive of the Duncan Foundation, an organisation that supports people with neuromuscular conditions. He is on the board of The Supported Life Style 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 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 Kahu McClintock – Māori member**

Kahu (Waikato/Maniapoto, Ngāti Mutunga and Ngāti Porou) is Manager Research at Te Rau Matatini. Kahu has worked in the health and disability sector for over 20 years, with a special focus on Māori health research and child and adolescent mental health. Kahu holds a Dip Nursing (Psychiatric), Higher Dip Teaching, B Ed, M Phil (Māori), D Phil (Psychiatry).

Kahu was a member of the Māori Health Committee, Health Research Council of New Zealand from 2008 to 2014 and Chair of Ngā Kanohi Kitea Community Research Committee, Health Research Council of New Zealand during that time. She is the lead for Te Rā o Te Waka Hourua.

Kahu was appointed to NEAC in July 2015.

## **Dr Wayne Miles – Health professional**

Wayne is Director of Awhina Research and Knowledge, Waitemata District Health Board and a clinical associate professor at the Department of Psychological Medicine, University of Auckland. He has had extensive experience as a psychiatrist, a clinical leader and a clinical researcher.

Wayne has been a Health and Disability Ethics Committee member for seven years and is a member of the Health Research Council of New Zealand College of Experts. Past roles have included President of The Royal Australian and New Zealand College of Psychiatrists and Chair of the Council of Medical Colleges New Zealand.

Wayne was reappointed to NEAC in March 2016.

## **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 the current 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 Whangārei.

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 Liz Richards – Community/consumer perspectives**

Liz is an independent director and trustee for the Tasman Bays Heritage Trust. Previous roles include Chair of the Top of the South Health Alliance, Chair of the Upper South A Health and Disability Ethics Committee and Deputy Chair of the Canterbury Community Trust and the Nelson Marlborough District Health Board. She has also been active in governance roles for several community organisations in the Nelson region.

Liz has worked in health promotion and public sector housing management as well as lecturing in housing studies at University of Salford, Manchester, United Kingdom. She has a professional qualification from the Chartered Institute of Housing and an MA in Housing from the University of Central England in Birmingham.

Liz was appointed to NEAC in October 2015.

## **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 Hope Tupara – Health Professional**

Hope works from home, mostly in private contract research and as a practising midwife. She has a MA Midwifery and a PhD Public Health. She has published papers in the *New Zealand College of Midwives Journal*, the *Cambridge Quarterly of Healthcare Ethics* and *The American Journal of Bioethics*.

Hope has a special interest in iwi development, the Māori Women's Welfare League and Whānau Ora.

Hope was appointed to NEAC in October 2015.

## **Dr Dana Wensley – Lawyer**

Dana has an LLB (Hons) from the University of Auckland and a PhD (Medical Law and Ethics) from King's College London, United Kingdom. She is interested in issues that transcend the traditional boundaries between law, medicine and ethics, specialising in regulatory responses to emerging genetic technologies. She has held posts as a research fellow on the University of Otago Human Genome Research Project and as an assistant editor of the *Bulletin of Medical Ethics* (United Kingdom). She currently serves as consumer representative on the Hospital Advisory Committee of the Nelson Marlborough District Health Board.

Dana was appointed to NEAC in October 2015.

## **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 2021

Member	9 February 2021	6 April 2021	8 June 2021	8 September 2021	11 November 2021
Assoc Prof Neil Pickering (Chair/Deputy Chair)	✓	✓	✓	✓	✓
Prof John McMillan (Chair)	NA	NA	NA	✓	✓
Mr Shannon Te Ahu Hanrahan	NA	NA	NA	✓	✓
Dr Penny Haworth	✓	✓	✓	✓	✓
Dr Gordon Jackman	✓	✓	✓	✓	✓
Assoc Prof Vanessa Jordan	✓	✓	✓	✓	✓
Dr Kahu McClintock	Apol	Apol	NA	NA	NA
Dr Wayne Miles	✓	Apol	✓	✓	NA
Ms Nora Parore	NA	NA	NA	Apol	✓
Dr Hansa Patel	NA	NA	NA	✓	✓
Ms Liz Richards	✓	✓	✓	✓	✓
Dr Cindy Towns	✓	✓	✓	✓	Apol
Dr Hope Tupara	✓	Apol	Apol	Apol	NA
Dr Dana Wensley	✓	✓	✓	✓	✓
Dr Mary-Anne Woodnorth	✓	✓	✓	✓	✓
<b>Total members present</b>	<b>10</b>	<b>8</b>	<b>9</b>	<b>11</b>	<b>10</b>

✓ = Present    Apol = Apologies    NA = Not applicable

### Notes:

Nora Parore, Hansa Patel, Shannon Te Ahu Hanrahan and John McMillan's memberships began in August 2021.

Kahu McClintock resigned from NEAC in April 2021.

Wayne Miles resigned from NEAC in October 2021.

Neil Pickering's membership ended in August 2021. He attended as a guest for the September and November meetings.

Hope Tupara's membership ended in October 2021.

Liz Richards and Dr Dana Wensley's membership ended in December 2021.

## **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 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.