

**General meeting information**

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| **Date** | 16 March 2023 |
| **Committee meeting** | NEAC meeting |
| **Location** | In person – **Rydges Wellington Airport** 28 Stewart Duff Drive, Rongotai, Wellington 6022 Zoom - <https://mohnz.zoom.us/j/87884021998> |
| **Meeting time** | 9:00am – 4:00pm  | Tea/Coffee/Water upon arrival from 8.30amMorning tea: approx. 10:15 amLunch: approx. 12:15pmAfternoon tea: approx. 2.15pm |
| **Attendees**  | **NEAC members**Professor John McMillan (Chair)Shannon Hanrahan (Deputy Chair)Dr Penny HaworthDr Cindy TownsAssociate Professor Vanessa JordanDr Hansa PatelNora ParoreRochelle StyleEdmond CarrucanDr Lindsey MacDonaldMaree CandishDr Seini TaufaNEAC Secretariat |
| **Apologies** | N/A |
| **Guests** | Nic Aagaard, Manager, EthicsCarly Cummins, Long Term Insights Briefing teamAlex Williams, Long Term Insights Briefing team |

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# **General Business 09:00am – 09:30am**

## **Welcome**

* 1. Karakia:
	2. Opening Comments: Name
	3. Round the room

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| **KARAKIA** |  |
| **He Karakia Whakatuwheratia** **Whiti ora ki te whai ao****ki te ao mārama.****Whiti ki runga, whiti ki raro.****E ngungu ki te pōhatu****E ngungu ki te rākau****tītaha ki tēnei taha****tītaha ki tērā taha****Tihei mauriora** | Cross over to life in the changing worldin the world of light and understandingCross upwards, cross downwards.Turn to the rockturn to the treeleaning to this sideleaning to that side |

**Standing Items: 09:30am – 10:15am**

## **Apologies**

* 1. None received in advanced
1. **Approval of the day’s agenda**
2. **Declarations of interest**
	1. Review declarations of interest
	2. Declare any conflicts of interest/role regarding the agenda and determine how to manage any conflict

***Conflict of interest section from NEAC Terms of Reference***

1. 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.
2. 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.
3. 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.
4. The Chairperson will ask members to declare any actual or perceived interests at the start of each meeting.
5. **Minutes of NEAC’s November meeting: for approval**
	1. Paper 1 – November 2022 NEAC meeting
6. **Actions arising from the November meeting: for noting**
	1. Paper 2 – Actions Arising

## **Secretariat’s Update**

* 1. Long-term Insights Briefing on Precision Health – NEAC submission
	Carly Cummins and Alex Williams to present – (Paper 3 – LTIB ppt, Paper 3a – NEAC’s Response)
	2. WHO Summit of National Bioethics Committees March 2024
	3. Staffing Update
	4. Appointments update

## **Chair’s Update**

# **Projects 10:15am – 2:25pm**

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| *Morning Tea (10:15am – 10:45am)* |
| **Ministry operations and New Minister of Health** Paper 4 – New MinisterPaper 4a – draft BIM  | Discussing how NEAC can structure their work for greatest impact and reviewing and approving the Briefing for the Incoming Minister (BIM) from NEAC | 10:45am – 11:15am |
| **NEAC work programme** Paper 5 – NEAC work programme  | Agreeing continuation of current work programme | 11:15am – 11:30am |
| **Standards Review update**Paper 6 – Update on Standards consultation Paper 6a – International scan paper  | Update from the secretariat  | 11:30am – 12:15pm |
| *Lunch (12:15pm - 1:15pm)* |
| **EGAP submission analysis** Paper 7 – EGAP consultation analysisPaper 7a – draft EGAP consultation analysis report  | Review of submission analysis report and approval of next steps to finalise outputs | 1:15pm – 1:45pm |
| **NEAC response to ACART Human Reproductive Research consultation** Paper 8 – ACART consultation Paper 8a – NEAC draft response | Review and approve draft response  | 1:45pm – 2:15pm |
| *Afternoon Tea (2:15pm – 2:45pm)* |

# **Monitoring and Reporting 2:45pm – 3:15pm**

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| **Modernisation of Ethics update** | Update on Modernisation of Ethics and the work programme for 2023  | 2:45pm – 3:15pm |

# **Correspondence 3:15pm – 3:45pm**

## **Clinical Ethics**

1. At the November 2022 meeting NEAC requested a letter to the Minister from NEAC about the ethical issues raised by the current difficulties in the health system, especially the moral distress being experienced by health professionals. This letter was sent to the Minister on 8 March 2023.

Paper 9 – Letter to Minister Verrall from NEAC – 8 March 2023

## **Health and Disability Commissioner**

1. Paper 10 provides an overview of the historical work of NEAC with the HDC and this item is an opportunity to raise topics or issues which NEAC wishes to raise in the meeting with the HDC on March 2023
Paper 10 – HDC – agenda item 16
Paper 10a - Appendix 1: Letter to Professor John McMillan NEAC Chair July 2022
Paper 10b - Appendix 2: Response to HDC from John McMillan November 2022
Paper 10c - Appendix 3: Letter to HDC from NEAC following HDC submission on Consultation on Draft Ethical Standards (2019)
Paper 10d - Appendix 4: Research with adults who cannot consent and general waiver advice – historical paper from the Secretariat following publication of HDC 2019 report, and reissued in 2020 to meet new HDC Commissioner (2019/20)
Paper 10e - Appendix 5: Letter to Minister Salesa on the need to progress law reform for research with adults who cannot provide their own informed consent (2020)
Paper 10f - Appendix 6: International Ethical Guidance on Modifications to Consent (optional context reading)

# **Closing items 3:45pm – 4:00pm**

## **Work between meetings**

1. NEAC to confirm any in-between meetings or working groups to progress NEAC work programme.
2. Karakia

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# **Declarations of interests**

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| **Member** | **Declarations of interests** |
| **John McMillan** | * Member of the National Screening Advisory Committee
* Editor in Chief of The Journal of Medical Ethics
* Professor at the Bioethics Centre, Dunedin School of Medicine, University of Otago
 |
| **Vanessa Jordan** | * Senior Research Fellow, University of Auckland
* New Zealand Cochrane Fellow
* Associate Director Cochrane New Zealand
* Member Cochrane Council
* Member and Chair of Cochrane Conflict of Interest Panel
* Expert reviewer NZ Heart Foundation
* Director MSDocs Ltd (owns a primary care practice)
 |
| **Cindy Towns** | * General Physician and Geriatrician, Capital and Coast District Health Board
* Senior Clinical Lecturer, Wellington School of Medicine
* Honorary Senior Lecturer, Bioethics Centre, University of Otago
* Member Ethics Committee, Royal College of Physicians
* Member Medical Advisory Board, Australia Porphyria Association
* Clinical Ethics Advisor, Capital and Coast District Health Board
* Prevocational Education Supervisor, Medical Council of New Zealand
 |
| **Penny Haworth**  | * Honorary Research Fellow (Institute of Education, Massey University) – Appointed for 3 years from June 2019
* Member of TESOLANZ (Teachers of English to Speakers of Other Languages)
* Volunteer with ELP (English Language Partners), providing English assistance to new migrants and refugees
* Member of NZ Property Investors
 |
| **Hansa Patel** | * Research applicant for study approved by HDECs (18/CEN/18)
* Ministry of Education
* Visiting Scholar, Victoria University of Wellington
* Volunteer client interviewer, Citizens Advice Bureau, Lower Hutt
 |
| **Shannon Hanrahan** | * Member of the New Zealand Health Practitioners Disciplinary Tribunal
* Member of the Faculty of Public Health (United Kingdom)
* Director of Praxis Health Limited
* Chair of KŌ Kollective Trust
* Chair of Moetangi Land Trusts
* Member of the New Zealand Mental Health Review Tribunal
* Member of the Advisory Committee on Assisted Reproductive Technology
 |
| **Nora-Jayne Parore** | * Research Fellow – Health Services Research Centre, Victoria University of Wellington
* Health Research Council NZ Clinical Research Training Fellow funded for thesis. Title “He Tono Whakapiki Ora: Whānau and Pharmacists’ knowledge exchange”
* Research Team Member – ‘Te Puna Rongoā: Achieving Medicines Access Equity for Māori – Pharmacists' role’ (funded by PHARMAC and HRC)
* Member – Ngā Kaitiaki o Te Puna Rongoā o Aotearoa, The Māori Pharmacists’ Assn Inc
* Member – Inaugural Te Pātaka Whaioranga PHARMAC Māori Advisory Rōpū
 |
| **Rochelle Style** | * Member of the Artificial Intelligence Governance Group, Waitematā District Health Board (July 2021 – present)
* Discretionary Beneficiary of a Trust, which holds shares in some pharmaceutical and health care companies. (Further details available on request). No equities held personally
* Appointed to a COVID-19 Algorithms Governance Advisory Group for the Ministry of Health/Precision Driven Health, March 2022
* Consultant on several projects in the fields of genetics/genomics and digital pathology
 |
| **Edmond Carrucan** | * Former Lecturer in Te Piringa – Faculty of Law at the University of Waikato
* Former Rōia Rangatahi for Te Hunga Rōia Māori o Aotearoa
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| **Lindsey MacDonald** | * + Research Fellow at Ngāi Tahu Research Centre
	+ Senior Lecturer in the Department of Political Science and International Relations at the University of Canterbury
	+ Co-Chair of Aotearoa Research Ethics Trust
 |
| **Maree Candish** | N/A |
| **Seini Taufa** | Requested |