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| **Date** | 24 July 2024 | |
| **Committee meeting** | NEAC meeting | |
| **Location** | Online zoom meeting  Link: <https://mohnz.zoom.us/j/87884021998> | |
| **Meeting time** | 9:00am – 3.00pm | 10.30am morning break  12:00pm lunch break |
| **Attendees** | **NEAC members**  Professor John McMillan (Chair)  Julia Black  Maree Candish  Edmond Carrucan  Dr Lindsey Te Ata o TūMacDonald  Dr Hansa Patel  Associate Professor Vanessa Jordan  Dr Tania Moerenhout  NEAC Secretariat  Manager Ethics  **Apologies**  Shannon Hanrahan (Deputy Chair)  Nora Parore | |
| **Guests** |  | |

**Welcome (9.00am)**

* 1. Karakia
  2. Opening Comments

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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 ngunguru ki te pōhatu**  **E ngunguru ki te rākau**  **tītaha ki tēnei taha**  **tītaha ki tērā taha**  **Tihei mauriora** | Cross over to life in the changing world  in the world of light and understanding  Cross upwards, cross downwards.  Turn to the rock  turn to the tree  leaning to this side  leaning to that side |

## **Apologies**

1. **Approval of the day’s agenda** (presented by the Chair)
2. **Declarations of interest** (opened by the Chair)
   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 11 April 2024 meeting: for committee approval** (opened by the Chair)
   1. Paper 1
6. **Actions arising from the 11 April 2024 meeting: for noting** (opened by the Chair)
   1. Paper 2

## **Secretariat’s Update** (presented by the Manager, Ethics)

* Update on the change process at Manatū Hauora
* Update on appointments
* Update on Finding Balance: finalisation of report and the publication process
* Update on the Review of the National Ethical Standards for Research
* HDEC update on AI form feedback and transparency of approved HDEC applications

## **Chair’s Update** (presented by the Chair)

* Update on April conference attendance

## **Rangatiratanga Roopu Update** (presented by the Secretariat)

* Update on the development of the Terms of Reference

**Short break (10:30am-10:45am)**

1. **Work programme update** (opened by the Secretariat)

* Paper 3
* Appendices included – NEAC's prioritisation framework and six proposed topic outlines for discussion (approx. 15 minutes per topic)

**Lunch break (12.15pm-12.45pm)**

1. **Consultation on Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers’ Rights**

* Paper 4
* Appendices include consultation doc and previous letter from NEAC to the HDC Commissioner

1. **Correspondence**

* Update on recent OIA request
* Copy of NEAC’s submission to the Law Commission’s second consultation in Review of Adult Decision-Making Capacity Law (Paper 5)

## **15. Any other business**

* N/A

**16. Work between meetings**

* NEAC to confirm any in-between meetings or working groups to progress NEAC work programme.
* Karakia (provided at item 1)

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| **Member** | **Declarations of interests** |
| **John McMillan (Chair)** | * 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 |
| **Shannon Hanrahan (Deputy Chair)** | * 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 |
| **Julia Black** | * Member of the Dunedin Colorectal Cohort governance committee (DNCRC). * Discretionary Beneficiary of a Trust, which holds shares in some pharmaceutical and health care companies. No equities held personally. * Co-founder of 'Hope Without Fear’, a charitable organisation with a focus on helping to raise funds for research and development for the early detection of bowel cancer in New Zealand. |
| **Maree Candish** | * Board member of Science for ME, an international forum for the advancement of knowledge of post-infection conditions including ME/CFS (unpaid) * Other unpaid international advocacy work related to post-infection conditions including ME/CFS and Long Covid |
| **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 |
| **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) |
| **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 |
| **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 |
| **Lindsey Te Ata o Tū 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 * Member of Health Research Council * Co-Chair, University of Canterbury Human Research Ethics Committee |
| **Tania Morenhout** | * Lecturer at Bioethics Centre, University of Otago, Ōtepoti Dunedin * Chair of the WONCA (World Organisation of Family Doctors) Working Party on Ethics and Professionalism * Member of the NZTHF Working Group on Research, Audit and Evaluation * GP at Broadway Medical Centre, Ōtepoti Dunedin (employee) * Consultancy work for King Baudouin Foundation Belgium (in position of Lecturer) * Member GP Aotearoa, NZ Women in Medicine, PATHA |
| **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 * Member of the National AI and Algorithm Expert Advisory Group for Te Whatu Ora * Legal and ethical consultant on several projects in the fields of genetics/genomics and digital pathology and Hepatitis C |