



# General meeting information

Date	25 May 2023		
Committee meeting	NEAC meeting		
Location	Online zoom meeting Link: https://mohnz.zoom.us/j/87884021998		
Meeting time	9:00am – 3:30pm	Online meeting with three 10 min comfort breaks and a 30 min lunch break.	
Attendees	NEAC members		
	Professor John McMillan (Chair)		
	Shannon Hanrahan (Deputy Chair)		
	Dr Penny Haworth		
	Associate Professor Vanessa Jorda	n	
	Dr Hansa Patel		
	Nora Parore		
	Rochelle Style		
	Edmond Carrucan		
	Dr Lindsey MacDonald		
	Maree Candish		
	Dr Seini Taufa		
	NEAC Secretariat		
Guests	N/A		



## Table of contents

Genera	al Business 9:00am – 9:10am	3
1.	Welcome	3
2.	Apologies	3
3.	Approval of the day's agenda	3
4.	Declarations of interest	3
5.	Minutes of NEAC's 16 March 2023 meeting: for approval	3
6.	Actions arising from the March 2023 meeting: for noting	3
7.	Secretariat's Update (presented by Ethics Manager)	3
8.	Chair's Update (presented by Chair)	3
Projec	ts 9:30am – 3:00pm	3
9. Imp	Review of the National Ethical Standards for Health and Disability Research and Quality rovement (the Standards)	3
Corres	pondence 2:40pm – 3:00pm	4
	Summary of NEAC and Ethics team meeting with Health and Disability Commissioner's	4
11.	ACART consultation of Human Reproductive Research – NEAC response	4
12.	NEAC letter to Minister Verrall regarding committee appointments	4
13.	Response from Minister Henare regarding committee appointments	4
14.	Response from Minister Verrall regarding moral distress in the workforce	4
Closing	g items 3:00pm – 3:15pm	5
Declar	ations of interests	6



## General Business 9:00am - 9:10am

### 1. Welcome

- a. Karakia
- b. Opening Comments

## Standing Items: 9:10am – 9:30am

#### 2. Apologies

- 3. Approval of the day's agenda (presented by Chair)
- 4. Declarations of interest (opened by Chair)
  - a. Review declarations of interest
  - b. 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 16 March 2023 meeting: for approval (opened by Chair)
  a. Paper one agenda item 5
- Actions arising from the March 2023 meeting: for noting (opened by Chair)
  a. Paper two agenda item 6
- 7. Secretariat's Update (presented by Ethics Manager)
  - a. Staffing Update
  - b. Appointments update
- 8. Chair's Update (presented by Chair)

### Projects 9:30am – 3:00pm

9. Review of the National Ethical Standards for Health and Disability Research and Quality Improvement (the Standards) (opened by Nic Aagaard and Matthew Poulsen) The revised chapters of the Standards are provided for review and approval (Paper 3 – Review of revised Standards). Each chapter is presented in a separate Appendix and the order of consideration is provide below.



Chapter	Review timing
Chapter 9 – Research development and design (Appendix 8)	9:30am – 9:50am
Chapter 10 – Ethical features of studies (Appendix 9)	10:10am – 10:30am
Comfort break	10:40am – 10:50am
Chapter 11 – Research conduct (Appendix 10)	10:30am – 10:50am
Chapter 12 – Health data (Appendix 11)	11:00am – 11:20am
Comfort break	11:20am – 11:30am
Chapter 13 – Health data and new technologies (Appendix 11)	11:30am – 11:50am
Chapter 14 – Human tissue (Appendix 12)	11:50am – 12:10pm
Chapter 15 – Biobanks (Appendix 12)	12:10pm – 12:30pm
Lunch break	12:30pm – 1:00pm
Chapter 17 – Compensation for injury in commercially sponsored intervention studies	1:00pm – 1:20pm
<ul> <li>Chapters with minimal changes: <ul> <li>Chapter 5 – Disability (Appendix 4)</li> <li>Chapter 6 – Ethical Management of vulnerability (Appendix 5)</li> <li>Chapter 7 – Informed consent (Appendix 6)</li> <li>Chapter 8 – Research benefits and harms (Appendix 7)</li> <li>Chapter 16 – Research with stem cells and reprogrammed cells (Appendix 13)</li> <li>Chapter 18 – Quality Improvement (Appendix 14)</li> </ul> </li> </ul>	1:20pm – 1:50pm
Comfort break	1:50pm – 2:00pm
Review Chapters 1 and 2	2:00pm – 2:20pm
Summary and next steps	2:20pm – 2:40pm

### Correspondence 2:40pm – 3:00pm

#### 10. Summary of NEAC and Ethics team meeting with Health and Disability Commissioner's office

a. On 29 March 2023, the Chair and Deputy Chair met with the Health and Disability Commissioner's office to discuss the scope of the upcoming review of the HDC Code of Rights. (A meeting summary is provided in Paper 4).

#### 11. ACART consultation of Human Reproductive Research – NEAC response

a. Following the March NEAC meeting, NEAC submitted their response to the ACART consultation on 31 March 2023. (Paper 5)

#### **12.** NEAC letter to Minister Verrall regarding committee appointments

a. NEAC wrote to the Minister expressing concerns about delays in the appointment processes for the Health and Disability Committees. (Paper 6)

#### **13.** Response from Minister Henare regarding committee appointments

a. Minister Henare responded to NEAC noting the actions being taken to resolve the delay. (Paper 7)

#### 14. Response from Minister Verrall regarding moral distress in the workforce

b. Minister Verrall responded to NEAC noting the concern and welcome a meeting to discuss NEAC's work programme. (Paper 8)



Closing items 3:00pm – 3:15pm

### b. Work between meetings

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



### **Declarations of interests**

Member Declarations of interests	
John McMillan	<ul> <li>Member of the National Screening Advisory Committee</li> <li>Editor in Chief of The Journal of Medical Ethics</li> <li>Professor at the Bioethics Centre, Dunedin School of Medicine, University of Otago</li> </ul>
Vanessa Jordan	<ul> <li>Senior Research Fellow, University of Auckland</li> <li>New Zealand Cochrane Fellow</li> <li>Associate Director Cochrane New Zealand</li> <li>Member Cochrane Council</li> <li>Member and Chair of Cochrane Conflict of Interest Panel</li> <li>Expert reviewer NZ Heart Foundation</li> <li>Director MSDocs Ltd (owns a primary care practice)</li> </ul>
Penny Haworth	<ul> <li>Honorary Research Fellow (Institute of Education, Massey University) – Appointed for 6 years from June 2019</li> <li>Member of TESOLANZ (Teachers of English to Speakers of Other Languages)</li> <li>Volunteer with ELP (English Language Partners), providing English assistance to new migrants and refugees</li> <li>Member of NZ Property Investors</li> </ul>
Hansa Patel	<ul> <li>Research applicant for study approved by HDECs (18/CEN/18)</li> <li>Ministry of Education</li> <li>Visiting Scholar, Victoria University of Wellington</li> <li>Volunteer client interviewer, Citizens Advice Bureau, Lower Hutt</li> </ul>
Shannon Hanrahan	<ul> <li>Member of the New Zealand Health Practitioners Disciplinary Tribunal</li> <li>Member of the Faculty of Public Health (United Kingdom)</li> <li>Director of Praxis Health Limited</li> <li>Chair of KŌ Kollective Trust</li> <li>Chair of Moetangi Land Trusts</li> <li>Member of the New Zealand Mental Health Review Tribunal</li> <li>Member of the Advisory Committee on Assisted Reproductive Technology</li> </ul>
Nora-Jayne Parore	<ul> <li>Research Fellow – Health Services Research Centre, Victoria University of Wellington</li> <li>Health Research Council NZ Clinical Research Training Fellow funded for thesis. Title "He Tono Whakapiki Ora: Whānau and Pharmacists' knowledge exchange"</li> <li>Research Team Member – 'Te Puna Rongoā: Achieving Medicines Access Equity for Māori – Pharmacists' role' (funded by PHARMAC and HRC)</li> <li>Member – Ngā Kaitiaki o Te Puna Rongoā o Aotearoa, The Māori Pharmacists' Assn Inc</li> <li>Member – Inaugural Te Pātaka Whaioranga PHARMAC Māori Advisory Rōpū</li> </ul>
Rochelle Style	<ul> <li>Member of the Artificial Intelligence Governance Group, Waitematā District Health Board (July 2021 – present)</li> <li>Discretionary Beneficiary of a Trust, which holds shares in some pharmaceutical and health care companies. (Further details available on request). No equities held personally</li> </ul>



	<ul> <li>Appointed to a COVID-19 Algorithms Governance Advisory Group for the Ministry of Health/Precision Driven Health, March 2022</li> <li>Member of National AI and Algorithm Expert Advisory Group for Ministry of Health</li> <li>Consultant on several projects in the fields of genetics/genomics and digital pathology</li> </ul>	
Edmond Carrucan	<ul> <li>Former Lecturer in Te Piringa – Faculty of Law at the University of Waikato</li> <li>Former Rōia Rangatahi for Te Hunga Rōia Māori o Aotearoa</li> </ul>	
Lindsey MacDonald	<ul> <li>Research Fellow at Ngāi Tahu Research Centre</li> <li>Senior Lecturer in the Department of Political Science and International Relations at the University of Canterbury</li> <li>Co-Chair of Aotearoa Research Ethics Trust</li> </ul>	
Maree Candish	No declarations	
Seini Taufa	•	