

**National Ethics Advisory Committee**

**23rd November 2023**

**9:00am – 4:30pm**

# **Attendees**

**NEAC members:** Professor John McMillan (Chair), Associate Professor Vanessa Jordan, Nora Parore, Edmond Carrucan, Rochelle Style, Maree Candish, Dr Tania Moerenhout, Julia Black, Lindsey Te Ata o Tū MacDonald.

**Apologies:** Seini Taufa, Dr Hansa Patel, Shannon Hanrahan (Deputy Chair)

# **Declaration of Interests**

Members noted the declarations of interest.

# **Approval of minutes from NEAC’s 21st September 2023**

Members approved the draft minutes with a minor amendment.

*Action*

* Secretariat to amend minutes and upload to NEAC’s webpage.

# **Actions Arising**

The actions arising were noted.

*Action*

* Secretariat to update the actions arising list and work programme streams following the meeting.

# **Secretariat’s update**

*Staffing update*

The Manager of Ethics notified the Committee of several staffing updates in the ethics team and the broader regulatory and monitoring directorate, including the appointment of a new Deputy Director General.

The new Ethics Manager has been recruited and will start in the new year.

*Work programme update*

The Secretariat advised the Committee write a comprehensive Briefing to the Incoming Minister to familiarise them with NEAC’s work programme and potential future work and to offer a meeting to discuss NEAC’s work programme for 2023/24 that had been agreed by the previous Minister of Health.

*Update on Royal Commission Inquiry into Covid-19*

The Secretariat updated members on the Royal Commission of Inquiry’s request to view NEAC’s near final version of Finding Balance prior to publication. The Chair agreed that this could be done in confidence.

*Sector Day Update*

The Ethics Manager notified the Committee that almost all of the ethics committee members will be attending the Ethics Sector Day for a training and relationship building day in early December.

*Actions*

* Secretariat to send the near final iteration of Finding Balance to the Chair of Royal Commission of Inquiry into COVID-19.
* Secretariat to prepare and send a comprehensive Briefing to the new Minister and include an invitation to meet with the Chair and Co-Chair.
* Secretariat to extend an invitation to the new Deputy Director General of Regulation and Monitoring to attend a future Committee meeting.

# **Chair’s update**

*Standards Update*

The Committee discussed the history of the Standard’s work and the importance of the mahi and ensuring that the Standards are both fit for purpose and delivered in a timely manner. It was acknowledged that NEAC’s two key projects, Finding Balance and the review of the Standards are nearing completion.

*Rangatiratanga Roopu Update (presented by the Deputy Chair)*

The Roopu has not met since the last NEAC meeting but are scheduled to meet a number of times before the next NEAC meeting in February 2024. The Deputy Chair noted that the group’s key priorities are developing draft Terms of Reference for the Rangatiratanga Roopu and improving the content in the Finding Balance document. The Roopu will also meet to review chapter three of the Standards.

*Action*

* Secretariat to facilitate a hui with the Principal Advisor and the Deputy Chair to discuss the development and process of Terms of Reference for the Roopu.

**Finding Balance**

Members were sent the draft document in advance of the meeting for review and their suggested changes were discussed at the full meeting.

A member advised the Committee that the document’s definition of disability should be amended, and further content added to the disability section. The member recommended that the committee consult with *Whaikaha | Ministry of Disabled Peoples to* develop relevant ethical principles and ensure correct terminology. Members asked the Secretariat to reach out to Whaikaha and ask for input on the document.

Members noted that a small number of sections could do with further clarification. The Committee agreed that the mental health section needed to be expanded referenced and that the correct terminology is used throughout the document when referring to groups of people.

Members discussed the scope of the document, with a conclusion that it covers both infectious and non-infectious epidemics. It was noted that the document should make the scope clear, were consistent with other pandemic planning documents, and that definitions would be adjusted.

The Committee also discussed post-infection and post-viral long-term effects such as long covid, and directed the Secretariat to review the consequences section.

Members discussed social restrictions and consequences of COVID-19 lockdowns and agreed to acknowledge occupational risks, concerns regarding holding community events and taking part in social activities. The sections on visitation and aged care facilities were also discussed.

The Committee discussed how matauranga Māori was described in the document and whether consultation had occurred with experts in Māori and Pacific health. The Committee agreed that the Roopu could review this, and asked the Secretariat to contact the Pacific team at the Ministry for further review.

It was noted that the document discusses staff welfare after pandemics and the Committee discussed the need for decision makers to be consider whether they should make adequate financial support available.

It was agreed that the document should include some commentary about anti-viral medications and priority populations. It was agreed that a member would draft a paragraph that would be signed off by the Chair and Deputy Chair.

The Committee also noted the recent publication *Te Niwha* publication as a resource for future pandemics.

The committee discussed the importance of acknowledging substantial discussions to provide context for significant actions and recommendations. A member advised that the document could benefit from reference to additional case law, for example recent cases that consider how pandemic ethics interact with the Bill of Rights. The Committee discussed the Hansen v R, the common law case that clarifies the test for applying the Bill of Rights. The Chair asked the Secretariat to seek advice from a legal adviser to ensure the relevant case law is used.

Members suggested that first person perspectives could be included in the document. Members suggested sources for these quotes and asked the Secretariat to review these for appropriate content.

Lastly, the committee also directed the Secretariat to review the legal references in the document.

Members agreed that the Chair and Deputy Chair sign off the final document following amendments.

*Actions*

* Secretariat to facilitate a hui with the Principal Advisor and the Rangatiratanga Roopu to discuss members suggested amendments to Finding Balance.
* Secretariat to work with members to confirm wording for new paragraphs and amendments to the document and review the legal references.
* Secretariat to confirm the final document with the Chair and Deputy Chair and draft supporting information required before publication.

**Review of the National Ethical Standards for Research**

The Committee discussed the near final document and the draft communications plan for undertaking consultation on the revised Standards. The purpose of the discussion was to consult on new material developed between meetings. Members suggested further amendments and asked the Secretariat to update and amend sections of the document to ensure it is fit for purpose.

The Committee asked that further expert review was obtained for the Pacific research chapter in light of the changes that had been made to the chapter on Research and Māori to a more inclusive framing. The Committee asked that statements about whakapapa and individual wishes be included in Standard 2.2 and noted the importance of kinship obligations and internal iwi discussions. The Committee agreed to highlight the potential for harm in community and individual consent, and the context of participating in research against the wishes of others. Members discussed suggested amendments to the Research and Māori chapter and agreed to delegate final sign off to the Roopu.

The Committee discussed the potential overlap Chapter 12 – Health data and Chapter 13 Health data and new technologies. The Secretariat noted that additional expertise was being sought to review these chapters and noting the distinction between Artificial Intelligence in research and its usage in clinical settings. The Committee acknowledged the Standards apply to research and quality improvement, so need to distinguish research ethics and from clinical use and that adequate and timely ethical review of research involving Artificial Intelligence requires a range of different expertise.

The Committee discussed the section on compensation for injury to participants in a clinical trial and the limitations of the current compensation arrangements for commercially sponsored clinical trials. A member presented a revised section on the topic of compensation for commercially sponsored trials, and the Committee agreed these amendments. The Committee thanked the member who redrafted this section and agreed that the draft amendments should be distributed for public consultation.

*Actions*

* Secretariat to continue amending the document and preparing it for public consultation.
* Secretariat to seek external expertise on the *Research with Pacific Peoples* chapter.

**Clinical Ethics**

Work on clinical ethics was agreed as part of the 2023/24 work programme and is due to start in early 2024 once the Finding Balance work is complete. The Chair gave a brief update to the Committee about preliminary discussions and the Committee agreed to begin with a scoping exercise for consideration at the February 2024 meeting.

*Action*

* Secretariat to prepare papers for the first meeting of 2024.

**Correspondence**

The Committee noted a publication of the article “Blowing the whistle on mixed gender hospital rooms in Australia and New Zealand: a human rights issue” by Professor Angela Ballantyne and Dr Cindy Towns on mixed gendered hospital rooms.[[1]](#footnote-2) The Committee wish to acknowledge and congratulate them on their success.

**Any other business**

A member raised the issue of transparency around the approval and decline of research studies. The Secretariat spoke about the challenges in this space and will consider transparency as part of the wider review of HDECs in 2024. This led to a discussion about transparency and accessibility in a user-friendly form that’s useful and also protects privacy. The Committee asked the Secretariat to report on progress of the work by the HDEC team to improve transparency at the first meeting in 2024.

It was noted that the use of equity adjusters within Clinical Priority Assessment Criteria has been reviewed and that this would be shared with the Committee when it is released. The Committee discussed their previous work on prioritisation of elective services and how this review might inform that work.

The Secretariat asked members to agree proposed dates for full committee meetings in 2024. It was confirmed that the first meeting would be held in February and that in person meetings and working group meetings were yet to be confirmed.

Members noted that Roopu meetings are confirmed before the next NEAC meeting and that they will report to the committee in February.

A member asked for a wider discussion at the following meeting in 2024 regarding how the committee gets work done.

The Committee thanked the Manager of Ethics for their mahi and significant contributions across 10 years at the Ministry of Health and supporting across the 7 independent ethics committees. They wished him the best for the future.

*Actions*

* Secretariat to organise NEAC meetings for 2024, upload dates to NEAC website and send calendar invitations.
* Secretariat to report on progress of the work by the HDEC team to improve transparency at the first meeting in 2024.

The meeting finished at 4.30pm.

1. Towns C, Ballantyne A. Blowing the whistle on mixed gender hospital rooms in Australia and New Zealand: a human rights issue. J Med Ethics. 2023 Oct 2:jme-2023-109080. doi: 10.1136/jme-2023-109080. Epub ahead of print. PMID: 37783477. [↑](#footnote-ref-2)