



Kāhui Matatika o te Motu

National Ethics Advisory Committee

18 September 2025

9.00am – 1.00pm

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Attendees

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| NEAC members: | Dr Elizabeth Fenton (Chair), Julia Black, Maree Candish, Edmond Carrucan, Assoc. Prof. Vanessa Jordan, Dr Filipo Katavake-McGrath, Dr Fiona Miles, Hansa Patel, Dr Dr Karaitiana Taiuru |
| Apologies: | Dr Tania Moerenhout |
| Guest: | Ministry of Health intern |



Welcome

1. The meeting was opened with a karakia.
2. Opening comments were provided. Shorter agenda for the day was noted. But still a significant amount of work for discussion.
3. Apologies were noted.
4. The agenda was approved.

Chair's update

5. The Chair welcomed the Committee and thanked them for their ongoing work.
6. The Chair acknowledged the resignation of Dr Lindsey Te Ata o Tū MacDonald from the NEAC, effective 31 August 2025. The Chair, on behalf of the Committee, expressed sincere appreciation for Dr MacDonald's contribution, expertise, and commitment during their tenure. The Committee noted that that Dr MacDonald's insights have significantly supported the committee's work and extended best wishes for his future endeavours.
7. The floor was opened for committee members' reflections. Members spoke warmly of Dr MacDonald's kindness and presence, as well as his extensive knowledge and mentorship for new members. There was appreciation for the opportunity to work alongside him on NEAC, and committee members again wished Dr MacDonald well for the future.
8. The Chair noted NEAC attendance at the HRC roundtable discussion on clinical trial insurance compensation and provided details of the roundtable discussion for the Committee (the matter of insurance compensation in relation to the Standards review is discussed later in the meeting).
9. The Chair relayed that she gave a presentation on the role of NEAC and the National Ethical Standards at the HRC joint HDEC and institutional ethics committee training day.
10. The Chair noted her attendance at a meeting of the national advisory group for use of routinely collected data for research. The Chair described the relevance of the group's discussion for the Standards review and highlighted the concepts of data harm and data justice that were raised in the discussion. The Committee engaged in a discussion on different aspects of data harm and data justice. It was noted that one of the committee members potentially has a summer student project, which could investigate the topic of data justice and would be of interest to NEAC.

Declarations of interest

11. Members noted the declarations of interests and were asked to notify the Secretariat of any amendments.
12. A member noted they have recently been appointed to the Oranga Tamariki Disability Advisory Group (DAG) until December 2025 and is currently a reviewer on the Independent Human Ethics Research Committee (IHREC).
13. All disclosures were noted by the Committee, and no further action was deemed necessary at this time.



Action

- Secretariat to update members' recorded declarations of interests if needed before the next meeting.

Approval of minutes from NEAC's 17 July 2025 meeting

14. Members approved the minutes from NEAC's meeting on 17 July subject to minor amendment.

Action

- Secretariat to place the amended 17 July minutes on the NEAC webpage.

Actions arising

15. The actions arising and their new format separating Standard Operating Procedure actions from General Business actions were discussed and noted.

Action

- Secretariat to update Actions Arising for the next meeting.

Secretariat's update

16. The Manager, Ethics updated the Committee on Secretariat resourcing and staff changes for NEAC.

17. The Manager, Ethics provided an update on NEAC member appointments and noted that the Ministry's Appointments Team is likely to support getting new members early in 2026. In discussing NEAC representation, the Committee stressed the significance of diverse voices, including the representation of wāhine Māori.

18. The Manager, Ethics outlined for the Committee steps being taken to improve HDEC activities, such as changes to the HDEC scope and trialling AI for administrative tasks, and opportunities for the ethics system. It was noted that the Secretariat will consult further with NEAC as these activities progress.

19. The Manager, Ethics described ongoing Secretariat engagement with Health NZ and updates to processes relevant to ethical review, including compensation/indemnity for clinical trials, locality assessments, and the establishment of a research ethics committee to provide review over non-HDEC research. The Secretariat recommended representatives from Health NZ attend the November NEAC meeting to elaborate further on these updates.

Action

- Invite Health NZ to present on process updates at the 27 November meeting.



Clinical Ethics – Working group update

20. The Chair and Working Group acknowledged the hard work that has been done to draft the clinical ethics discussion paper and engage with a wide range of stakeholders, including clinicians and Māori perspectives. The next step is to develop ministerial advice and recommendations from the discussion paper, drawing on the literature review and further feedback.
21. The working group noted changes to the paper following advice from the NEAC Roopu. The working group and committee members discussed potential recommendations, including developing practical clinical ethics guidelines, noting regional variability in the availability of ethics advisory services.
22. Committee members deliberated the use of the term “guidelines”, suggesting alternatives, such as “recommendations” or “points of consideration” to avoid confusion with guidelines for evidence-based medical practice. There was also a discussion on the utility of flow charts for clinicians, with some members advocating these to aid rapid decision-making, while others preferred written guidance. The consensus leaned towards combining both formats for clarity and usability.
23. The Committee highlighted the importance of ethics support infrastructure, especially in smaller settings lacking established ethics committees.
24. Proposed recommendations included endorsing formal support for Health NZ’s planned clinical ethics infrastructure with regional ethics committees, and developing clinical ethics guidance aligned with NEAC’s mandate to determine nationally consistent ethical standards across the health sector.
25. The working group aimed to respond to the Minister’s advice request by the end of 2025 (phase one) and then consider further guidance development after ministerial approval (phase two).
26. Additional discussion points included recognising resource constraints in clinical ethics support, the need for clarity on clinicians’ duties, and the importance of ethical decision-making tools like checklists and decision trees to reduce cognitive load under pressure. The committee also discussed the need for further consultation, with a preference to prioritise the ministerial advice before broader stakeholder engagement, including with patients and general practitioners.

Action

- Draft Phase 1 ministerial advice formatted for review at the November meeting.

Standards review – Health data and new technologies

27. The Chair introduced the Standards review, focusing on chapters 12 and 13, noting to the need to update the content and integrate AI considerations into data governance and health data discussions. Committee members suggested considering genetics data and biotechnology, and the importance of including relevant topics when combining chapters.
28. There was agreement on the need to engage with Health NZ and the commercial sector to provide insights on AI applications and data use in health research. Members discussed inviting expert speakers to future meetings to provide insights on AI applications and frontline



experiences. Data on AI-related applications from HDECs may also be available for NEAC to consider.

29. The Chair commented on Standards review progress and discussed the importance of maintaining the profile of the Standards. The Committee discussed the target audience for the Standards, their relevance alongside international frameworks like the Declaration of Helsinki and Good Clinical Practice (GCP), and the need for the Standards to reflect the New Zealand context. Suggestions included usability and formatting improvements, renaming the Standards, and enhancing website accessibility, potentially using AI tools to link related content.
30. Consultation approaches were discussed, with a focus on balancing workload implications for stakeholders and testing committee thinking. The idea of making the Standards a living document was revisited, although challenges exist around maintaining user certainty. The Chair emphasised continuing background work on chapters 12 and 13 and preparing for targeted consultations.

Actions

- Secretariat to compile a list of potential speakers on AI applications and data use in health research and schedule 1-2 speakers for November.
- NEAC to continue working with the Secretariat on targeted updates and improved accessibility of the Standards, and appropriate stakeholder engagement for the ongoing review.

Standards review – Next steps – Chapter 17: Compensation and Chapter 18 – Quality Improvement

31. The Chair noted NEAC's letter to the Health Research Council Ethics Committee (HRCEC) providing feedback on HRCEC's draft independent comment on compensation for injury in research. Members discussed next steps for review of the Standards chapter on compensation.
32. Members agreed to invite Health NZ representatives to discuss changes in policy related to indemnity and compensation, including insurance requirements and clinical research gaps.
33. The Committee discussed the merits of subgroups versus full committee involvement for progressing the Standards review, recognizing the value of diverse perspectives.

Action

- Invite representatives of Health NZ to the November NEAC meeting to outline changes to insurance compensation and indemnity policy.

Ministry of Health Intern interim report – Comparing NEAC Standards to the Declaration of Helsinki and ICH Good Clinical Practice - Scientific guideline

34. An intern from Victoria University gave a presentation on her project comparing the NEAC Standards with the Declaration of Helsinki, updated in 2024, and ICH Good Clinical Practice guidelines. The presentation and its accompanying report were well received and commended for their clarity and comparative insights. The presentation reinforced the importance of



including Mātauranga Māori perspectives and the relevance of New Zealand-specific ethics standards.

35. Committee members also reflected that culture underpins all major standards (including the Declaration of Helsinki and GCP) and that many of the standards centre individuals rather than groups. Members welcomed the presentation's up-front AI declaration and the use of whakataukī to frame ethics as knowledge-sharing and requested that the presentation be circulated to the Committee.

Action

- Circulate the presentation and final paper to NEAC members.

Other correspondence

36. The Committee noted the email from Dr Anna Adcock, welcoming discussion with NEAC. The Chair proposed to meet with Dr Adcock and colleagues.

Action

- The Secretariat to arrange an initial meeting on behalf of the Chair with Dr Adcock and colleagues.

Any other business

37. The Committee noted the Forward Agenda, Proposed 2026 meeting dates, for a decision in November, and Other Papers of Interest.
38. There was discussion of whether the first NEAC meeting in 2026 would be an in-person meeting (as had taken place in 2025).

Actions

- Committee to finalise 2026 meeting dates in November 2025.
- The Secretariat to confirm whether it is possible to have an in-person NEAC meeting in February 2026.

Closing

39. The Chair thanked everyone for their contributions to the day's meeting.

Karakia to close

Meeting ended 1:00pm

Next meeting scheduled for 27 November 2025