



Kāhui Matatika o te Motu

## National Ethics Advisory Committee

6 March 2025

9:00am – 4:00pm

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## Attendees

<b>NEAC members:</b>	Dr Elizabeth Fenton (Chair), Julia Black, Maree Candish, Edmond Carrucan, Assoc. Prof. Vanessa Jordan, Dr Filipo Katavake-McGrath, Dr Fiona Miles, Dr Tania Moerenhout, Dr Hansa Patel, Dr Karaitiana Taiuru
<b>Guests:</b>	Prof. Dame Helen Stokes-Lampard, National Chief Medical Officer, Health New Zealand   Te Whatu Ora
<b>Apologies</b>	Dr Lindsey Te Ata o Tū MacDonald (Deputy Chair)

The meeting was opened with a karakia and members approved the agenda.

## Declaration of Interests

Members noted declarations of interests and updated the Committee and Secretariat with changes to their declarations of interests.

### Action:

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

## Approval of minutes from NEAC's 18 December 2024 meeting

Members approved the minutes from NEAC's meeting on 18 December 2024.

### Action:

- Secretariat to place the 18 December 2024 minutes on NEAC's webpage.

## Actions arising

The Actions Arising and completed were noted and one minor revision was requested.

### Action:

- Secretariat to update actions arising for the next meeting.

## Whanaungatanga exercise

The group engaged in a short whanaungatanga exercise.

## Chair's update

The Chair signalled her upcoming meeting with Minister Brown to introduce the Minister to NEAC and discuss NEAC's current work programme.

## Secretariat's Update

The Secretariat provided an update on NEAC work since the December 2024 meeting, including:

- Chair's upcoming meeting with the Minister
- Secretariat resourcing.



## Review of Standards

The Committee discussed the usability and accessibility of the Standards, including their current use by researchers and overall effectiveness.

The Secretariat highlighted that the original scope of the review was broad, and progress has been delayed due to Secretariat resourcing constraints. The Secretariat recommended breaking the project into smaller deliverables and carefully prioritising these to ensure the work delivered creates maximum impact. The Committee agreed there is a need to prioritise the Standards review alongside the Clinical Ethics work, but that both must be phased to ensure a manageable workload.

One member suggested re-naming the website heading from 'National Ethical Standards' to include the word 'research' in the title. This would more clearly distinguish the Standards from any clinical standards NEAC may produce in the future.

### 2025 Review

The Committee discussed the Chair's proposal to prioritise chapters focused on health data and new technologies, compensation, and quality improvement (QI). One member highlighted the importance of balancing ease of publication with safeguarding of patients in QI.

The Committee agreed to the proposed purpose and scope for a focused review of the Standards in 2025, focussing on:

- Chapter 13: Health data and new technologies
- Chapter 17: Compensation
- Chapter 18: Quality improvement.

The Committee agreed to the proposed process and timeline for the 2025 review and to pause work on other priority chapters until the 2025 review is complete.

The Committee discussed the possible outputs of the 2025 review. These may include changes to the Standards and/or advice to ethics committee chairs.

### Post 2025 review

The Committee noted that the hoped-for public consultation in 2025 had been cancelled due to limited Secretariat resource. Members considered the need to balance regular Standards review with addressing emerging issues related to the Standards (and associated risks) in a timely manner. Members expressed a desire for regular review when resources allow. While current resourcing constraints prevent the Secretariat from planning regular reviews for now, NEAC will continue to consider when reviews of the Standards should be conducted in the future. In addition, the Secretariat will continue to analyse and triage issues raised by Standards users (including through engaging with HDEC chairs).

Members noted that a lot of work has been done on the review of the Standards to date, and that some chapters may have progressed to the point that they are ready for public consultation. The Secretariat will summarise work completed to date for each chapter of the Standards to support the committee's prioritisation of them for future review and, will identify chapters where changes proposed in previous reviews have been completed.

The Committee discussed stakeholder engagement and public consultation and the reasons and thresholds for each. How to consult appropriately with the public, and in particular Māori, is



something that should be considered further and the Committee has the expertise to do this effectively.

The group signalled their intent for a review of the full document, subject to Secretariat resourcing, to begin when the 2025 review is complete. Members raised concerns about repetition, style, and usability of the Standards. The Committee agreed the Secretariat would procure a professional editor to improve the usability of the Standards when resources allow.

Members suggested the Standards would benefit from an overarching review to ensure they are in line with Te Tiriti and current international ethical standards. Any proposed changes to the Standards that resulted from the review could be progressed as part of a larger Standards review.

The Committee agreed to prioritise the following areas of work after the 2025 review is complete (subject to resourcing).

- Review the standards from a Te Ao Māori perspective to ensure they meet NEAC's Treaty obligations.
- Review the Standards against the Declaration of Helsinki (updated October 2024).
- Improve overall usability of the Standards.

The Committee discussed the difficulty in committing to regular updating of the Standards into the future without knowing what the resourcing or work programme will look like.. The Committee discussed recommending a regular Standards update to be prioritised alongside other work at the time of implementation.

### **Actions**

- Secretariat to investigate updating the heading of 'National Ethical Standards' on the website to include 'research and QI'.
- Secretariat to collate feedback from key stakeholders (HDEC and IEC Chairs) and present at the May NEAC meeting.
- The Secretariat will summarise the progress of reviews done to date on each chapter of the Standards.

## **Clinical Ethics**

The Chair opened the item and proposed a two-phased approach to the work.

- Phase 1: narrow focus designed to respond directly to the Minister's request for advice.
- Phase 2: advice to the Minister regarding further work identified during Phase 1 (if needed).

The Chair introduced the Clinical Ethics Working Group (Working Group). The Working group is made up of three members: Fiona Miles, Julia Black, and Tania Moerenhout.

The Working Group introduced their work and gave an update on their first meeting, held on 5 March 2025. They have agreed their purpose, responsibilities, and communication channels with the wider Committee and the Secretariat. The Working Group will develop a project plan, including a proposed timeline, and present it at the May meeting.



The Working Group has started in-depth discussion about their final product. They propose this will comprise two main parts:

- a. overarching principals/aims
- b. process/guidelines.

Fiona Miles gave a presentation introducing NEAC to the topic of clinical ethics. The presentation included key themes for clinical ethics in Aotearoa New Zealand, what's working and not working in the current system, and the role of mediation in clinical practice.

Julia Black presented on clinical ethics from a patient and whānau family perspective.

#### **Action**

- The Secretariat will email Fiona Miles' slides to the Committee.

### **Clinical ethics guest speaker: Prof. Dame Helen Stokes-Lampard**

The Chair welcomed Dame Helen and the group introduced themselves.

- Dame Helen has varied experience with ethics including in her previous roles as Clinical Director of research trials, Professor of Medical Education, and as a practising clinician in general practice.

Clinical ethics work is currently carried out within several different parts of Health New Zealand (HNZ) and there is a programme of work in place to centralise and streamline clinical infrastructure, including clinical ethics.

Dame Helen suggested NEAC engage with Sarah Jackson, Clinical Chief, Quality and Patient Safety who sits on the National Quality Advisory Board. This group is developing:

- clinical governance pathways and processes
- systems for consent and clinical auditing.

Dame Helen identified areas for further development within the New Zealand clinical ethics system, including:

- timely ethical advice for clinicians on the frontline
- consistent access to clinical ethical support by region.

Dame Helen spoke about her experience with clinical ethics in NZ and the UK.

#### **Actions**

- Secretariat to contact Sarah Jackson and other members of HNZ involved in clinical governance to speak at a future NEAC meeting.
- The Secretariat to contact Dame Helen again in late April to confirm whether she can provide additional contacts for NEAC.

### **Clinical ethics – scoping decisions**

The Committee agreed to the process and timelines outlined in the paper subject to Secretariat resourcing.



The Committee discussed the definition of ‘treatment’ and the need to widen the project scope to ‘interventions’ to include technologies, techniques, and behavioural interventions, which may also require careful clinical ethical decision-making.

The Committee agreed the scope of the project will include innovative and experimental ‘interventions’ and that the working definition of innovative and experimental interventions includes:

- a. innovative or experimental use of unapproved medicines
- b. innovative or experimental use of approved medicines in ‘off label’ uses.

The Committee discussed groups that the work should apply to. Members identified the importance of including primary care practitioners, since many clinical ethical decisions are made in primary care, including use of unapproved or off-label medications.

Members expressed the view that including family in this work, as well as patients, was important given the Aotearoa New Zealand context, and the role family play in treatment planning. The Committee agreed that the advice should apply to clinicians, patients, and family members.

### **Actions**

- The Secretariat will draft a TOR document for the Working Group and present at the May meeting.
- The Working group will provide an update to the wider Committee at the May meeting.

## **Horizon scanning**

The Committee worked in small groups to consider the following:

- Roles and responsibilities of NEAC members
- Current challenges for the Committee and potential solutions
- How the committee could balance existing work commitments with emerging issues
- What’s working well, and what could be improved, in the Secretariat’s support for NEAC.

### **Actions**

- A representative from the HRC Ethics Committee will attend a NEAC meeting annually to present an overview of operation and outcomes of the HDECs and IECs for the previous year.
- NEAC will input into the Ministry of Health’s review of the NEAC TOR.
- The Secretariat will add *Emerging ethical issues* as a standing agenda item to seek input from members.
- The Secretariat will maintain an up-to-date ‘parking lot’ list of *Emerging ethical issues* which it will provide to the Committee for discussion once a year.
- The Committee will undertake a work prioritisation exercise once a year as part of deliberations on its work programme.
- The Secretariat will summarise the outputs from the horizon scanning small group discussions and present the summary at the May meeting.



## Other business

The committee approved the ongoing inclusion of the *Forward agenda and upcoming conferences* and *Other papers of interest*.

### **Actions**

- The Secretariat will add NEAC's *Forward Agenda and upcoming conferences* as a standing paper to each meeting.
- Secretariat to email members three weeks before the meeting to request material for the *Other papers of interest* as a standing paper to each meeting.

**Meeting ended 4:00pm**