



Kāhui Matatika o te Motu

## National Ethics Advisory Committee

8 May 2025

9:00am – 4pm

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## Attendees

<b>NEAC members:</b>	Dr Lindsey Te Ata o Tū MacDonald (Deputy 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>	National Chief, Quality and Patient Safety, Te Whatu Ora; Māori researcher and Te Tiriti educator; Clinical Ethicist, Sydney Children's Hospitals Network; Director of Pharmacy, Children's Hospital Westmead, Sydney; Project Pharmacist, Sydney Children's Hospitals Network
<b>Apologies</b>	Dr Elizabeth Fenton (Chair)

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

## Declaration of Interests

Members noted the declarations of interests and were asked to notify the Secretariat of any amendments.

No new declarations of interest were raised.

### Action:

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

## Approval of minutes from NEAC's 6 March 2025 meeting

Members approved the minutes from NEAC's meeting on 6 March subject to minor amendments.

### Action:

- Secretariat to place the amended 6 March minutes on NEAC's webpage.

## Actions arising

The actions arising and completed were noted. It was agreed that, moving forward, all new Action Items will be clearly identified as such in the minutes. This is to ensure accurate recording and to provide clarity for both the Committee and the Secretariat on what has been formally agreed.

### Action:

- Secretariat to update actions arising for the next meeting.

## Acting Chair's update

The Acting Chair welcomed the Committee, passed on apologies from the Chair who was unable to attend the meeting, and thanked the Secretariat for their support in preparing for the meeting. The Chair thanked committee members for their contributions between meetings, particularly in relation to Clinical Ethics work.



## Secretariat's Update

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

- The Chair's positive meeting with the Minister of Health
- Introducing the new Principal Advisor, Ethics
- Secretariat resourcing.

## Finding Balance report update

The Acting Chair acknowledged the publication of the NEAC report *Finding Balance: Ethical Principles for Epidemics and Pandemics*. The report was published on the NEAC website on 25 April and emailed to key stakeholders the same day.

The Acting Chair acknowledged the hard work of past and present NEAC members as well as the Secretariat in getting the report published. The ethical framework in the report will be used by those working in public health, in developing future epidemic and pandemic strategies.

## Clinical Ethics guest speaker – National Chief, Quality and Patient Safety, Te Whatu Ora

The guest speaker provided an overview of work underway with Te Whatu Ora to strengthen clinical ethics support nationally, noting current regional variation and funding challenges. A regional model is being developed, alongside several related governance groups. The Committee discussed potential roles for NEAC related to its current clinical ethics project, and expressed interest in staying connected with, and supporting, the evolving clinical ethics structures within Te Whatu Ora.

### Action:

- The Secretariat will follow-up with the National Chief, Quality and Patient Safety, after the meeting to request additional key contacts within Te Whatu Ora.

## Clinical Ethics Working Group Terms of Reference

The Committee discussed and approved the draft *Clinical Ethics Working Group Terms of Reference*.

## Clinical ethics guest speaker – Māori researcher and Te Tiriti educator

The speaker shared reflections on mātauranga Māori, Te Tiriti, and how these can be woven into NEAC's clinical ethics work.

## Standards Review

The Committee discussed the 2025 Standards review, resourcing constraints, and the need to phase work to manage the Secretariat's workload. The Committee highlighted the need to review the *Health data and new technologies* Standards; and agreed to progress work on three key chapters.

### Actions

- The Secretariat will meet with the Chair and agree a strategy to progress work on these three chapters:



- Chapter 13: Health data and new technologies
- Chapter 17: Compensation
- Chapter 18: Quality improvement.
- The Secretariat will develop a plan to continue the Standards review in 2026, to be tabled at the November meeting.

## Clinical ethics – Clinical Ethicist, Sydney Children’s Hospitals Network

The speakers from the Sydney Children’s Hospitals Network presented a clinical ethics decision-making framework they have developed to support a hospital-based steering committee in decision-making regarding high-cost and novel paediatric therapy. The framework, intended for use with medicines, helps guide decision-making in ethically challenging cases. This framework has been valuable in documenting decisions and clarifying reasoning, particularly when communicating with families.

The group discussed implementing challenges, including the need for ongoing feedback and the difficulty in ensuring families fully understand experimental treatments and associated risks.

The Committee discussed equity, especially regarding self-funded care, and the importance of consumer (especially Māori) input in a New Zealand context.

The Committee discussed its potential role in this space, including supporting national guidance and/or engaging with existing clinical ethics structures (e.g. CEAGs).

### **Action:**

- The Secretariat will confirm whether Te Whatu Ora is aware of this project and facilitate contact between Te Whatu Ora and the Sydney Children’s Hospital Network teams if needed.

## Clinical ethics – Working Group update

The Clinical Ethics Working Group updated the Committee about their progress since the last full NEAC meeting, including the timeline to replying to the Minister’s request for advice.

The Working Group acknowledged the guest speakers and noted the high-quality clinical ethics work underway in Australia. One member emphasised the significant investment of time and resources involved in developing the Australian framework and highlighted that NEAC cannot ‘do it all’. Instead, the Committee agreed on the need to work strategically with Te Whatu Ora to achieve the best outcomes within available resources.

Members reiterated their commitment to providing timely, focussed advice to the Minister of Health in response to the original request. As requested, the advice will focus on ethics support for clinical decision-making. Some broader issues, such as access to unapproved medicines within the New Zealand health system, will be recorded and may inform future advice to the Minister, but will not be explored in depth at this stage.

The Committee commended the Working Group on their progress and agreed:

- The new working definition of ‘innovative and experimental interventions’ will include medicines, technologies, behavioural interventions, and preventive interventions.



- Rongoā Māori, complementary and alternative medicine, and clinical trials will be excluded from this work with some exceptions. Although the Working Group will seek expert Māori review to confirm treatment of rongoā.
- The Working Group will progress Part 1 of the project, designed to map the current system clinical ethics support within Aotearoa New Zealand.
- The Working Group will progress Part 2 of the project, designed to explore the key issues of opportunity cost, fairness, and communication.
- The Working Group will progress Part 3 of the project which includes drafting ethical guidelines, a decision-making process, and a decision-making algorithm.
- The Working Group will progress the 'next steps' outlined in the paper, including:
  - Literature review
  - Continuing stakeholder engagements.

**Actions:**

- The working group will seek Māori review of the project to date to ensure language and underlying concepts are culturally appropriate and aligned with a Te Ao Māori worldview.
- Secretariat to share Julia's summary of the legislation around access to unapproved medicines.
- The Working Group and Secretariat will begin work on the literature review.
- The Working Group and Secretariat will complete the Stakeholder Engagement plan and continue engagement with key stakeholders.
- The Working Group will update the Committee on its progress in the July meeting.

## Horizon scanning

The Secretariat provided a summary of the discussion held during the previous meeting, including key issues identified by the Committee and suggested solutions to those issues. The group noted the Horizon Scanning document as an accurate summary of the discussion and accepted the document, and its recommendations, with minor changes.

**Actions:**

- The Secretariat will make minor amendments to the *Horizon Scanning* paper and save with other official NEAC documents.
- For future meetings, the Secretariat will provide a draft agenda to all members two weeks prior to the meeting when possible. This will signal upcoming papers but will not include the papers themselves.
- The Secretariat will support the Roopu to recommence.
- The Chair will continue to proactively engage with the Minister by sending him a follow-up letter to their March meeting.
- The Secretariat will add a discussion about NEAC work triaging processes to the forward agenda.
- The Secretariat will include project timelines as part of project planning for all large projects. The Secretariat will monitor progress and report to members at each full meeting.
- Members will seek to utilise student projects to advance NEAC work where appropriate. These projects will contribute to NEAC priorities but will not be NEAC outputs.
- The Secretariat will produce a summary of emerging ethical issues identified by NEAC each year. This may be included in the Annual Report.
- All requests for NEAC members to work on NEAC matters between meetings (e.g. providing feedback on a document) will be sent with a clear deadline. The Secretariat will send a reminder to all members 2-3 days before a deadline.



### Other business

- The Committee briefly discussed the Health Research Council Ethics Committee's (HRCEC) draft position statement regarding insurance for clinical trials. The draft position statement will be provided to the Committee for discussion in the July meeting.
- The Committee noted the *Forward Agenda* and *Other Papers of Interest*.

**Meeting ended 4:00pm**

**Next meeting: 18 September 2025**