



National Ethics Advisory Committee

24 October 2024

9:00am – 2:15pm

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Attendees

NEAC members: Dr Lindsey Te Ata o Tū MacDonald (Acting Chair), Associate Professor Vanessa Jordan, Dr Hansa Patel, Edmond Carrucan, Maree Candish, Julia Black, Dr Tania Moerenhout

Apologies:

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.

One member requested an amendment.

Action:

- Secretariat to amend the recorded declarations of interests.

Approval of minutes from NEAC's 24 July 2024 meeting

Members approved the minutes from NEAC's meeting on 24 July 2024 subject to minor amendments.

Action:

- Secretariat to update the July 2024 minutes and place on NEAC's webpage.

Chair's update

The Chair noted that NEAC would continue to progress their work while being mindful of bringing on board the new Chair and members when they are appointed. The Chair thanked the Secretariat for their ongoing support with NEAC work.

Actions Arising

The actions arising and completed were noted.

Action:

- Secretariat to update actions arising for the next meeting.

Secretariat's Update

The Secretariat provided an update on new members and roles within the Secretariat.

The Secretariat informed the committee of new NEAC member appointments expected in mid- to late November 2024. And raised the possibility of an out-of-cycle meeting if new members are not appointed in time to attend the December meeting.

The Chair thanked the Secretariat and Committee for their ongoing support.

The group engaged in whakawhanaungatanga to introduce the new Secretariat members.



Rangatiratanga Roopu update

The Chair noted that the Terms of Reference are nearly finished. However, delayed due to staff resourcing.

Presentation on proposed ethical guidelines for organ donation after assisted dying

A speaker from New Zealand Blood Service presented the Organ Donation, Assisted Dying (AD), National Strategy for Assisted Dying Organ Donation (ADD) with a focus on the Ethics Framework. They sought feedback from the committee on the principles of the framework and Māori considerations on ADD.

Organ Donation New Zealand has been working with the Ministry of Health, Te Whatu Ora, the transplant teams, GPs, and assisted dying practitioners to develop a national strategy for Assisted Dying Donation (ADD). They are currently iteratively developing an ethics framework for ADD to provide appropriate safeguards and maintain public trust.

The committee thanked the speaker for an interesting and carefully considered presentation and noted the papers they had provided. The committee sought clarification from the speaker on:

- The two-week timeframe for ADD completion.
- Age of consent for ADD, currently 18 in New Zealand.
- While most people undergoing AD choose to do so at home, in New Zealand ADD is currently only available to those dying in hospital. However, tissue donation (e.g. cornea) is available to people undergoing AD at home.

The committee discussed the following:

- Establishing and working with a Tikanga Advisory Group is crucial for this work to uphold Te Tiriti. Ensuring robust tikanga around ADD is crucial and can enable ADD to be a mana enhancing experience. A member of NEAC with expertise in tikanga Māori is available to, with New Zealand Blood service, support the embedding of robust tikanga practices.
- The opportunity to participate in ADD must be balanced with the need to ensure no undue pressure is placed on the dying person to donate. The methods of communication around ADD will impact opportunity for participation.
- The need to ensure genuine opportunity to withdraw from the ADD process at any time, even after entering hospital for the ADD procedure.
- It is crucial for the ADD project team to work with the disability community when developing the Ethical Framework to ensure it meets the needs of this vulnerable population.

Actions:

- Secretariat to draft written feedback from the Chair to the New Zealand Blood Service.
- Secretariat to send a copy of the documentary: Her Last Project by Rosvita Dransfeld to the members.



Finding Balance update

The Secretariat updated the committee on the progress of the Finding Balance report which is expected to be published on the NEAC website in December 2024. Several members noted typos and formatting issues in the document.

Actions:

- Secretariat to ensure the Finding Balance report receives a final proofread before publication.
- Secretariat to publish Finding Balance on the NEAC website and email to key stakeholders in a soft launch.

Introduction to clinical ethics

Mascha Moerenburg presented their work on the availability of clinical ethics support services for healthcare professionals in New Zealand.

The research was a quantitative cross-sectional survey of healthcare professionals carried out in 2021. The questions focussed on ethical issues in clinics, support for dealing with complex ethical issues, frequency of ethical dilemmas, uncertainty of ethical concerns (organisation/legal risks vs ethics), perception and availability of support, and demographics.

The research resulted in seven recommendations:

1. Develop services to support clinicians and align with overseas developments in clinical ethics support services.
2. Clinical ethics support services should be available in every healthcare organisation.
3. Government recommendations and regulations for clinical ethics support – when external bodies require providers follow regulations then there is an uptake of other ethical service availability.
4. Ethics education should be provided regularly.
5. Co-design future research projects and potential new types of clinical ethics support services with Māori.
6. Clinical ethics support services should be seen as part of standard quality improvement and control – this brings clinical ethics in line with research ethics.
7. Funding needs to be made available to remunerate the professionals who fulfil roles in clinical ethics support services.

The Chair thanked the speaker for their informative presentation. The committee discussed:

- The need to include community-based clinicians when considering clinical ethics. Groups that could be considered include counsellors, chiropractors, GPs, disability and age care workers. Next steps for research would be to target clinicians in the community.
- An example of how ethics works in the legal profession. Lawyers can contact a 'panel of friends' who are senior practitioners and are available to anyone in the profession to call for ethical advice. This could be a model to explore.
- Barriers to Māori input in this work. The committee agreed that getting the right people involved is key.
- Moral Case Deliberation and its use within clinical ethical decision-making.



- A need to understand the definition of clinical ethical issues and the distinction from legal and research ethical issues.
- Clinical ethical discussions are often clinician focussed, while some clinical ethics committees have patient representation or consumer representation. There is a need to balance patient input with clinician's ability to speak freely (which can be hindered when the patient or relative is present).
- Lack of Māori representation in this field of work. Members requested ensuring appropriate mātauranga Māori expertise to contribute to their work on clinical ethics.

Clinical ethics support project scoping discussion

The committee agreed the draft letters to the Minister and Health New Zealand can be sent.

The committee discussed key scoping questions for the work:

- Do clinicians need more guidance/policies regarding clinical ethical decision-making?
- Should this project address primary, secondary, and/or tertiary care?
- Should the committee aim to produce general ethical guidelines or focus on answering the Ministers specific questions about unapproved medicine/treatments?

Members recommended having an additional deep dive meeting to discuss the scope of the work. As a next step the Secretariat will develop some scope options for the committee to discuss at the next meeting.

Actions:

- The Secretariat will finalise and send draft letters to the Minister and Health New Zealand.
- The Secretariat will identify and contact key stakeholders. With a focus on clinical and Māori experts.

The Secretariat will develop scope options and explore what is required to undertake each option. The Secretariat will bring this paper to the next meeting to aid scope discussions.

An Associate Professor from the Department of Psychological Medicine, University of Otago presented on the CEAGs role in clinical ethics within New Zealand.

The guest speaker presented CEAGs role in clinical ethics and how it currently operates at a local and national level. They provided an overview of the Chair of CEAGs role: educational upskilling, talking to community groups and other organisations about ethical problems, looking at policies/processes and documents. He noted he is in favour of national clinical ethical guidelines and feels they should be developed in partnership with current clinical ethical support groups/specialists.

The group discussed the details of how the CEAGs operate including:

- Regional variation in the level of awareness of CEAGs across Health New Zealand staff.
- Variation in the function/operations of different CEAGS.
- There is an increase in clinical work that is considered 'experimental' due to the increasing development of new health products and clinicians are making more decisions about unapproved and off-label treatments. This has created a greater need for 'distributive justice' in treatment options.



- The pros and cons of formal vs. informal pathways for clinical ethical advice.

The Chair thanked the guest speaker for facilitating a useful discussion and noted the links between this and the previous presentation. The group is keen to work with the guest speaker on this project going forward and may invite them back to speak at an upcoming NEAC meeting.

The group discussed the scope of the project regarding:

- Health professionals that should be targeted (e.g. primary, secondary, tertiary).
- Maintaining an 'ethics' scope and excluding other issues (e.g. legal).
- Whether the focus should be on experimental and unapproved treatments or whether it should be broader.

The group discussed stakeholders including:

- The difficulty in engaging with Health New Zealand and the likelihood of this continuing as they progress through their restructure.
- That Māori have a different ethical perspective than western medicine so there is a need for solid Māori consultation (or co-design).

The group discussed the idea of having several smaller products instead of one large product at the end of the project and taking an open and iterative approach to drafting.

Actions:

- The Secretariat will expand and share the draft literature review.
- The Secretariat will write a paper to develop the scoping questions and identify key stakeholders to engage with to answer each scoping question.
- The Secretariat will send key document drafts to the Chair and NEAC members where appropriate to ensure transparency of this work as it progresses.

Annual report

The Secretariat presented the 2023-2024 Draft Annual Report to the committee for review (note: the annual reports are being moved from calendar year to financial year reporting, meaning this report covers 18 months (from January 2023 to June 2024).

A member requested minor changes to the Draft Annual Report.

Actions:

- Members to email feedback for the Draft Annual Report to the Secretariat by 2 November.
- The Secretariat will finalise the Draft Annual Report and send to the Chair for approval.

Any other business

Paper 7a was noted.

Meeting closed at 2:15pm