



Kāhui Matatika o te Motu

National Ethics Advisory Committee

24th July 2024

9:00am – 3:00pm

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Attendees

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

Apologies: Shannon Hanrahan (Deputy Chair), Nora Parore

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

Declaration of Interests

The Committee reviewed its declarations of interest policy, and it was noted that members are required to declare any actual or perceived interests to the full Committee.

Declarations of interest in relation to today's agenda were noted and the Committee agreed they were not significant enough to preclude members from the discussion and that regardless, members would send the declarations to the Secretariat to update the Committee record.

Action: Secretariat to update members' recorded declarations of interests once received.

Approval of minutes from NEAC's 11 April 2024 meeting

Members approved the minutes from NEAC's meeting on 11 April 2024 subject to minor corrections.

Action: Secretariat to update the April 2024 minutes and place on NEAC's webpage.

Chair's update

The Chair thanked the Committee for all its work between meetings on NEAC's work programme and noted that Dr Lindsey Te Ata o Tū MacDonald would chair the Committee's discussion of the work programme for today's meeting.

The resignation of NEAC member Rochelle Style was acknowledged.

The Committee acknowledged the importance of building and fostering trust-based relationships between NEAC and research ethics committees that would ultimately assist NEAC being able to advise the Minister of Health about pressures in the system. NEAC can play a valuable role in facilitating discussions between other bodies in the ethics review system and can take the learnings from these conversations to the Minister of Health.

The Chair provided an update on the Global Summit of National Ethics Committees that he recently attended, there was a particular interest in ethics and climate change policy. The Chair talked about the NEAC Finding Balance principles and how they might be applied. The Global Summit is an



important meeting and a unique way in which NEAC engage with and learn from the issues and challenges facing other national committees.

Actions:

- Secretariat to invite HRCEC Co-Chairs and Secretariat to meet with NEAC Chair and Secretariat to talk about how to build the relationships between the different ethics committees.
- Secretariat to arrange for the incoming NEAC Chair to attend an HDEC Chairs meeting in the future to talk about what the HDECs consider would be useful to support their role.

Actions Arising

The actions arising were noted. Members discussed the items in the actions arising paper. There was discussion about: the timeline for annual reporting with the Secretariat advising it will continue to update NEAC; data transparency within the research field which the Committee agreed NEAC might not have a role to comment on because it is not a national ethics question; and the work with the Roopu to develop the terms of reference work.

Action: Secretariat to update actions arising for the next meeting.

Secretariat's Update

The Secretariat updated the Committee on the change process happening at the Ministry of Health | Manatū Hauora (the Ministry). The Secretariat remains low on capacity due to awaiting recruitment. There is some ability to move people around to support urgent priority work for NEAC, if necessary. The lack of a NEAC committee lead in the Secretariat and the uncertainty of when the new Chair will be appointed may mean the August NEAC meeting needs to be cancelled.

[NB. Subsequent to the July meeting, the August meeting was cancelled, and the committee will next meet in October.]

NEAC's Finding Balance document is in the publication process and will be released in the coming months. The review of the National Ethical Standards for Research and Quality Improvement are on hold until the team has resource. The Secretariat will continue to update NEAC on progress via the actions arising.

As members of NEAC had provided input, the Secretariat updated on the work of the HDECs to develop an AI form for HDEC applications. The HDEC Chairs' feedback has been positive about the forms providing the right information to support review by the HDEC members. NEAC acknowledged those on NEAC who had helped and that this was a development that they supported.

The NEAC Chair's term will end in August but he agreed to attend the next meeting for a formal farewell and handover.

Rangatiratanga Roopu update

An update on the development of the Roopu's Terms of Reference was provided. They are still in development and the Roopu have received some helpful advice from a principal advisor from the Ministry's Hauora Māori team. A meeting is planned for early August to progress the work.



Work programme update

NEAC members have worked on six proposed topic outlines for discussion, and the Committee considered how it might refine these further to a short list of topics that might have the most impact.

The following topics were discussed:

1. National approach to clinical ethics - the role of ethics in clinical practice and clinical ethics support services.
2. Access to Healthcare – including prioritisation, health education and ill-health prevention targeted to young people, transparency of publicly reported data, availability of medical specialists, public versus private healthcare services, the two-tiered medical system created by ACC, and opportunities to improve access to healthcare provided by Telehealth.
3. Ethical use of health data in data driven technologies – the use of health data, especially in the development and use of data driven tech e.g. apps, AI products.
4. Health care professionals and conflicts of interest – a review of whether there is sufficient transparency and accountability when healthcare professionals have conflicts of interest.
5. Ethical use of precision medicine and genome editing - the ethical issues raised by these technologies in a New Zealand context.
6. Complaints process in health – whether they are fair, transparent, and equitable in supporting consumers in getting quality health and disability services.

Each topic was presented by a member of the committee and the ethical issues discussed, this was then followed by a discussion of potential areas where NEAC could do a project and where the most value would be generated.

Clinical ethics was selected for further development at this time. Further background will be provided about the Ministry's current work on topics of health data and data driven technologies and precision medicine and genome editing at the next NEAC meeting.

The remaining topics were agreed to be kept on a longlist. An alternative topic was proposed under access to healthcare of intergenerational equity which was agreed to be added to the longlist.

Actions:

- Secretariat to bring a paper to the next NEAC meeting on a potential project on Clinical ethics.
- Secretariat to invite appropriate Ministry staff to discuss the Ministry's work on health data and data driven technologies and precision medicine and genome editing to the next meeting.
- Chair to write to Singapore Bioethics Advisory Committee to request a contact for their work on AI.
- Secretariat to complete a short review of the policy and legislation available in other countries on conflicts of interest.
- Secretariat to re-circulate the Ministry's long-term-insights briefing on Precision Health and paper on the previous work of NEAC.



Consultation on Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights

The Committee considered the HDC consultation document and agreed that it would submit a response.

Actions:

- Secretariat to circulate updated letter to the Committee for review and comment.
- Secretariat to finalise the letter with the Chair and then submit it.

Correspondence

The following were noted:

- The Secretariat updated the Committee on a recent OIA request.
- The Chair noted that NEAC's submission to the Law Commission's second consultation in Review of Adult Decision-Making Capacity Law has been submitted and a copy was provided to the committee for information.

Work between meetings

The only work between meetings was the planned Roopu meeting for early August.