

**National Ethics Advisory Committee**

**11th April 2024**

**9:00am – 2:10pm**

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# **Attendees**

**NEAC members:** Professor John McMillan (Chair), Shannon Hanrahan, Nora Parore, Hansa Patel, Rochelle Style, Maree Candish, Edmond Carrucan, Dr Lindsey Te Ata o Tū MacDonald

**Apologies:** Dr Seini Taufa, Tania Moerenhout, Associate Professor Vanessa Jordan

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

# **Declaration of Interest**

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

Two members each requested an amendment.

**Action**

* Secretariat to amend the recorded declarations of interests.

# **Approval of minutes from NEAC’s 29 February 2024 meeting**

Members approved the minutes from NEAC’s meeting on 29 February 2024 with a minor amendment.

**Action**

* Secretariat to update the February 2024 minutes and place on NEAC’s webpage.

# **Chair’s update**

The Chair updated members that the Chair and Deputy Chair have finished their review of Finding Balance with minor amendments suggested to the glossary. The Committee were reminded that the next stage is for the document to undergo formatting and editing as part of the publishing process.

There was a discussion about how best to build relationships that persist across networks, in the interests of keeping those important connections for NEACs work that transcend reforms and changes of members on the committee in order for NEAC to discharge its statutory functions and progress work in partnership. Members noted other similar independent Ministerial committees, such as the Hauora Māori Advisory Committee, and suggested it might be helpful to link up and discuss different ways of operating.

There was a discussion about whether submissions NEAC makes to organisations and consultations are made publicly available on NEACs website in the interests of transparency and the Secretariat agreed to look into this.

**Action**

* Secretariat to follow up recent consultations that could be published and made publicly available on NEACs web page.

# **Deputy Chair’s update**

**Rangatiratanga Roopu Update**

The Deputy Chair informed the committee that the Roopu held a hui in March to discuss and draft the proposed terms of reference for the Rangatiratanga Roopu. The hui was attended by a Principal Advisor from the Ministry of Health | Manatū Hauora (the Ministry) to assist in drafting the Terms of Reference. At NEAC’s February meeting, it was suggested that it would be helpful to have them attend NEAC to introduce the draft Terms of Reference and speak of the specific policy context in which they will be developed in, however, they have now left the Ministry. The Roopu intends to give an update at the June meeting regarding the development of the Terms of Reference.

**Secretariat update**

The Manager of Ethics attended and informed the Committee of the change process underway at the Ministry and across the public sector. It was noted that significant impacts are proposed across the organisation and that the proposed changes are currently being consulted on. Final decisions are expected to be communicated in June with the changes implemented by August. The Manager acknowledged that this change directly affects members of the team and will have impacts for NEAC. Members acknowledged the uncertainty faced by the Secretariat and the public sector as a whole, and the effect that has on workflow and wellbeing.

The Manager of Ethics spoke about the change of Government and expenditure cuts expected of the Ministry. There was a discussion about what the changes mean for the Committee’s future work and the Manager noted that it is unclear at this stage if there are changes to NEAC or the Ethics operating budget that could impact the work programme.

It was noted that NEAC’s work programme would be discussed later in the meeting. The Manager also noted that it is unclear what the impact will be of the of the changes will be for NEAC and to consider things like workflow, meeting frequency and bringing on new members as part of this discussion.

# **Actions Arising**

The actions arising and completed were noted. Members discussed the items in the actions arising paper. There was a discussion about the status of NEAC’s briefing to the new Minister to introduce their statutory role, purpose and current work programme. The Secretariat advised that this briefing has been actioned and is currently tracking through the Ministry’s internal sign out process.

**Action**

* Secretariat to update the actions arising for the next meeting.

# **NEAC’s Work Programme and Committee priorities**

At the February meeting, the Secretariat asked members to consider the prioritisation framework developed in 2022 and develop summaries of proposed priority work programme items and challenges in the health sector to the Secretariat prior to the April meeting.

The Manager of Ethics highlighted the expenditure cuts expected of the Ministry and the uncertainty of their impact on NEAC. Noting that the budget will be set internally, the Secretariat expressed an interest in NEACs perspective about where resource should be directed, the importance of in-person meetings, of seeking external expertise to inform NEACs work and amount of Secretariat support needed.

Members sent in topics for the work programme which were added to the previous list, identifying 22 possible areas where NEAC could add value. The Committee discussed and ranked the top six priorities to scoped for possible work streams to be presented and discussed at NEAC’s June meeting.

Members noted that there were linkages and overlaps between the proposed topics and discussed the impact that they could make. Members agreed that the following topics should be scoped and ranked using the prioritisation tool:

1. National approach to clinical ethics - the role of ethics in clinical practice and clinical ethics support services
2. Access to Healthcare – prioritisation, access to primary care and health education.
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 is getting quality health and disability services.

A member stressed the importance of partnership in light of the reforms to the health system and potential resource cuts. It was also noted that in deciding where NEAC could best add value, it is helpful to think about areas where NEAC is best placed to look into specific workstreams and areas for improvement so as not to overlap with what other agencies or committees are working on. NEAC also discussed areas where suggested workstreams overlap with the Government’s priority objectives.

A member also suggested adding in an item to define the scope and nature of NEAC’s statutory role to provide scrutiny for national health research and services (s92 Pae Ora (Healthy Futures) Act 2022. It was agreed that the Secretariat will seek advice on behalf of NEAC from Health Legal to seek clarity on the definition of scrutiny.

Following on from this discussion, work between meetings was discussed and members agreed to input into the scoped items to assist the discussion at the June meeting.

**Actions**

* Secretariat to seek advice from Health Legal about the interpretation of scrutiny in s92 Pae Ora (Healthy Futures) Act 2022.
* Secretariat to scope six possible topics for discussion at the June meeting.
* Members to signal via email which workstreams they would like to assist in drafting via email between meetings.

# **Standards update**

The Secretariat gave members an update on the review of the National Ethical Standards for Health and Disability Research and Quality Improvement, including the proposed consultation. It was agreed at the last NEAC meeting that the consultation would focus on proposed changes to the Standards that create additional duties to researchers or affect study conduct.

The Secretariat were not able to provide draft questions due to resource constraints in the Secretariat. It was agreed that the data, health technologies and Pacific Peoples chapters will not be included in the current round of public consultation, but should be considered in later phases or, possibly, as projects within NEAC’s work programme.

A member questioned delaying review of the AI chapter as this was a rapidly changing field and noted that it was important to have appropriate Te Ao Māori expertise to input into this work. The Secretariat noted that this would need to be balanced against other NEAC work and that it could delay the consultation on the Standards. Noting the discussion of the work programme and the need for external expertise it was agreed that this work would be scoped, including the resources required and the costs.

Members also discussed the frequency the Standards should be updated, and possible thresholds to trigger review in the interim. Also noted was the importance of the reach of the Secretariats stakeholder list and members sharing the consultation with their networks and that a question box could be added to the consultation to seek feedback on what else could be improved in the Standards. The Secretariat noted that in advance of the consultation the Secretariat, will engage with the HDECs and IECs on the proposed changes.

It was agreed that the Secretariat will prepare the consultation questions to be signed off by the Chair and Deputy Chair and then work with the communications team to upload these to the appropriate consultation platform. The Secretariat will then analyse the responses to the consultation and bring a summary back to a future meeting of NEAC.

**Actions**

* Secretariat to prepare the consultation questions to be signed off by the Chair and Deputy Chair and take the document through the publishing process.
* Secretariat to work with the communications team on the consultation.
* Secretariat to develop a summary of submissions for discussion at a future meeting.

# **Finding Balance update**

The Secretariat updated members that the final draft of the report has now been reviewed by the Chair and Deputy Chair with minor amendments requested to the glossary section of the report. The next steps are for the Secretariat to take the report through the publication process so it can be published and distributed.

Members were advised that the Minister would receive a copy of the final report before publishing and requested a copy of the report once it has been professionally formatted and edited.

The Chair thanked the Secretariat and the Committee on their progress regarding this work item.

# **Any other business**

The Secretariat shared an OIA request for a large amount of information regarding the development, rationale and expenditure for updating the Finding Balance report.

A member requested an update on the Modernisation of Ethics project from the Secretariat. The Secretariat outlined that the Modernisation of Ethics project had almost been completed according to the original project plan, but a significant number of additional possible activities had been identified through the project. These are being taken forward into another project that is planned for this year following a series of prioritisation exercises in 2023. The size and scope of this project will be contingent on the available resourcing in the Secretariat.

Meeting closed at 2.10pm.