

**National Ethics Advisory Committee**

 **29th February 2024**

**9:00am – 1:00pm**

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# **Attendees**

**NEAC members:** Professor John McMillan (Chair), Associate Professor Vanessa Jordan, Shannon Hanrahan, Nora Parore, Hansa Patel, Rochelle Style, Maree Candish

**Apologies:** Edmond Carrucan, Dr Lindsey Te Ata o Tū MacDonald, Dr Seini Taufa, Tania Moerenhout

The meeting was opened with a karakia and members approved the agenda. An item of business for the end of the meeting regarding transparency was added by the Secretariat.

# **Declaration of Interest**

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

**Action**

* Members to advise the Secretariat of any changes to the recorded declarations of interests.

# **Approval of minutes from NEAC’s 23 November 2023 meeting**

Members approved the minutes from NEAC’s meeting on 23 November 2023 with minor amendments. The committee discussed the level of detail in the minutes, and the balance between brevity, discussion context, and decisions. The committee acknowledged ethe need to include substantive detail of discussion by providing context for actions and recommendations.

**Action**

* Secretariat to update November 2023 minutes and place on NEAC’s webpage.

# **Chair’s update**

The Chair welcomed the new Manager of Ethics and the Committee introduced themselves.

Other staffing changes include the resignation of a valued member of the Secretariat. The Chair and committee expressed thanks for their service and their work done to support several significant NEAC projects.

# **Deputy Chair’s update**

**Rangatiratanga Roopu Update**

The Deputy Chair informed the committee that the Roopu plan to hold a hui in early March to discuss and draft the proposed terms of reference for the Rangatiratanga Roopu.

**Action**

* Secretariat to invite a Principal Advisor from the Māori Health Directorate | Te Pou Hauora Māori at the Ministry of Health to assist with drafting the terms of reference.

# **Actions Arising**

The actions arising and completed were noted. Members discussed the items on the actions arising worksheet. There was a discussion about some outstanding actions and agreement to add all minor outstanding items to the worksheet to make it more comprehensive of the mahi that NEAC has on at any one time.

**Action**

* The Secretariat will update the actions arising for the next meeting.

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

The Manager of Ethics introduced a discussion regarding NEAC’s work programme to identify the committee’s focus in light of the changing Government priorities. The committee agreed that their focus on clinical ethics as their next workstream was a high priority item. Members discussed their statutory functions under the Pae Ora Act and the Chair asked the Secretariat to circulate the prioritisation framework developed in 2022 to committee members before the April meeting to support further discussions about work programme priorities and resource.

The Manager of Ethics spoke about the change of government and expenditure cuts expected of the Ministry of Health. The committee agreed that the cuts were a key consideration when briefing the Minister of Health on NEAC’s work programme and key priorities. The Secretariat noted that the briefing to the Minister would be drafted prior to the next meeting and agreed with the Chair’s, and members asked that a request for the Minister to attend a meeting be included.

 **Actions**

* Secretariat to circulate the prioritisation framework to members via email.
* Members to send proposed summaries to the Secretariat prior to the April meeting to inform the discussion of priorities in respect of the work programme.
* Secretariat to draft a briefing to the Minister of Health to introduce NEACs functions and current work programme.

# **Standards update**

The Secretariat gave members an update on the changes and proposed consultation process for the review of the National Ethical Standards for Health and Disability Research and Quality Improvement.

At NEAC’s last meeting in November 2023, members agreed to publicly consult on proposed changes to the Standards. Members agreed that changes that would create additional duties to researchers or affect study conduct under the current Standards would be consulted on. The proposed enhancements to the presentation of the Standards document, its use of language, minor wording changes and the structure of the document will be incorporated in the 2024 update were not proposed to be consulted on.

The Secretariat proposed developing targeted questions for the consultation on the acceptability on proposed changes that would affect study conduct. The original and revised text of individual standards will be provided with the reasoning for the change with appropriate questions seeking feedback. NEAC agreed that the consultation plan and suggested targeted questions will be considered by members at the 11 April meeting.

The Secretariat took members through the status of work on remaining chapters and advised that it will be completed from February to April 2024. Members discussed resourcing constraints within the Ministry of Health and advised the importance of options that did not delay the public consultation and ultimately the Standard’s publication.

 A member raised the need to publish the consultation in an accessible way so that the contents could be understood by all participating parties. NEAC requested that the Secretariat involve a communications advisor in the design and communication options for the public consultation. A member offered to review the consultation material and suggest edits once its contents were finalised.

**Actions**

* Secretariat to continue finalising the outstanding chapters of the Standards.
* Secretariat to continue engaging with the communications team for the development of the public consultation in preparation for the April meeting.

# **Finding Balance update**

Following the November 2023 NEAC meeting, committee members were asked to submit final amendments to the Secretariat who would amend the document. These changes have been made and those who made comments have received feedback on how their comments were implemented.

The Chair and Deputy Chair have also received the feedback, along with the final draft. As agreed at the November 2023 meeting, the Chairs are reviewing the document and will approve it for publication once satisfied. It is the intention that the document will be finalised as soon as possible, so that it can proceed through the publication process.

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

# **Any other business**

The committee discussed the importance of transparency in the ethical approval of research and the options to improve the information provided to the public about types of research approved by HDECs.

The Secretariat advised that the HDEC Secretariat has noted the concerns from the Committee about transparency and has agreed to start publishing quarterly reports of what research is approved by the HDECs through their full and expedited pathways, including sponsor information and a lay summary of the research producing by the researchers. The Secretariat noted the intention is to add extra categories (as budget and systems allow) for other information that could be included. The information might allow NEAC to identify themes and areas of importance, for example of an influx of studies around the same issue.

The committee noted the proposed approach and that they supported it.

**Action**

* Secretariat to notify the committee when the first quarterly report is available.

Meeting closed at 1pm.