

12 April 2023

Hon Dr Ayesha Verrall
Minister of Health
a.verrall@ministers.govt.nz

CC: Hon Peeni Henare
Associate Minister of Health
p.henare@ministers.govt.nz

Tēnā koe Minister Verrall

Health and Disability Ethics Committees

I write on behalf of the National Ethics Advisory Committee (NEAC).

Part of NEAC's role is to monitor and review the operation of the Health and Disability Ethics Committees (HDECs). NEAC provides direction, guidance and leadership to ensure the ongoing quality and consistency of the ethical review of research in New Zealand's health and disability sector.

Regarding this aspect of our role, we wish to raise a concern with you about the membership levels and timeliness of appointments for all New Zealand's Ethics Committees, but more specifically the HDECs.

Key concerns

The HDECs are Ministerial committees, established under section 87 of the New Zealand Pae Ora (Healthy Futures) Act. They secure for New Zealand and New Zealanders the benefits of health and disability research by checking that it meets or exceeds established ethical standards. Without a quorum of appropriate members, New Zealand's health and disability research industry cannot function. This would impact the quality and availability of treatments New Zealanders are able to receive.

We have been briefed on membership levels by officials from Manatū Hauora - the Ministry of Health (the Ministry) and believe that there is an unsustainable level of risk in our health and disability sector through the lack of HDEC members across the four HDECs.

In the eight-person committees:

- Northern A HDEC is operating with only five current members with one lay vacancy and two members with expired terms who have agreed to continue but may have to finish at any time.
- Northern B HDEC has eight members but is low on clinical expertise.
- Central HDEC has one vacant position.
- Southern HDEC is operating with other HDEC members covering the Chair's role as the Chair's position is vacant. It also has three expired members who have agreed to continue but may have to finish at any time.

While quorum is five members, the vacancies risk the committees not having adequate expertise in critical specialities (such as clinical knowledge, tikanga Māori or research), and puts additional pressure on existing members. The low membership levels may also affect

the ability of HDECs to suspend research in a timely and appropriate manner, in the unlikely event of unethical actions. This may impact trust and confidence in the health research system.

Overview of risks

Reliable and often long-serving members who consistently attend not only their meetings, but who are also co-opted to other HDECs are becoming increasingly stressed due to being overworked. This affects their desire to continue on the committee and poses great risk to the HDECs overall to be able to retain long-serving members with experience and expertise.

In addition, the burden of work required outside of meetings has resulted in some members covering two committees' worth of work as there is not available members within some committees, creating further pressure among long-standing members.

In 2023 so far, the Secretariat have already had to cancel one HDEC meeting due to lack of quorum, have almost cancelled four more, which only just had quorum and meant that the five attending members had to do the work of eight members to cover the full agenda.

Cancellation of the April 2023 HDEC meeting has already had serious affects, as the high volume of applications has resulted in applications that would have been reviewed in April now having to be reviewed in May.

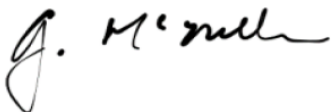
Proposed short term solution

We understand that a recent request for applications from technical experts and members of the public, the Ministry has received a number of potential candidates to appoint to the HDECs but that the approval process has been delayed.

NEAC encourages any existing papers for new members to the HDECs to be prioritised and members formally appointed through the appointments process before the election shut down period, and for additional appointments to be made to the HDECs to ensure the research system can continue functioning through to 2024.

We understand that the HDECs can appoint over 8 members and our advice is to do this to ensure adequate numbers of members and expertise.

Nāku noa, nā



Professor John McMillan
Chair, National Ethics Advisory Committee