

22 June 2021

Hon Andrew Little Minister of Health andrew.little@ministers.govt.nz

Tēnā koe Honourable Mr Little

Re: 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). We provide direction, guidance and leadership to ensure the ongoing quality and consistency of ethical review in New Zealand's health and disability sector.

Regarding this aspect of our role, we wish to raise a concern with you on the membershiplevels and timeliness of appointments to the HDECs.

Key concern

The HDECs are Ministerial committees, established under section 11 of the New Zealand Public Health and Disability 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 the Ministry of Health and believe that there is an unsustainable level of risk in our health and disability sector through the lack of HDEC members.

In the eight-person committees:

- The Northern A HDEC has two vacancies (including the Chair) and two members with expired terms
- The Northern B HDEC has four vacancies, and one expired member
- The Central HDEC has one vacant position
- The Southern HDEC has three vacancies (including the Chair) and two expired members.

While quorum is five members, the vacancies risk the committees not having adequate expertise in critical specialities (such as legal 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.

We understand that through 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.

Summary and recommendations

In summary, we believe that a lack of timely appointments to the HDECs fundamentally risks a critical failure in the health and disability sector. We ask that the importance of appointing new members to the committees and adequate resourcing is addressed by Ministers immediately. We advise the Minister that this is an urgent concern with considerable risks for health and disability research in New Zealand, and would impact potential treatment outcomes for New Zealanders.

Yours sincerely,

Associate Professor Neil Pickering Chair, National Ethics Advisory Committee