



National Ethics Advisory Committee

8 September 2021

9.00am – 4.30pm

Attendees

NEAC members: John McMillan (Chair), Elizabeth (Liz) Richards, Dr Mary-Anne Woodnorth, Dr Dana Wensley, Gordon Jackman, Dr Penny Haworth, Dr Cindy Towns, Dr Vanessa Jordan, Hansa Patel, and Shannon Te Ahu Hanrahan

Ministry staff present: NEAC Secretariat, Nic Aagaard (Manager, Ethics)

Guests: Associate Professor Neil Pickering (former Chair of NEAC) and Alastair Higham-Lee (Programme Manager, Ministry of Health)

Apologies: Dr Hope Tupara and Nora Parore

Getting Through Together

The first draft of the update of the 2007 edition of Getting Through Together, was discussed. Discussions covered the full gamut of the report, including: the already existing pressure on the healthcare system, experience of LGBTQIA+ communities in lockdowns, and wider economic and social impacts of COVID-19. Particular focus was placed on the importance of the first section and overarching principles. A sub-group of members was confirmed to work on the first section between meetings.

Health and disability research with adult participants who are unable to provide informed consent'

The Chair's meeting with the Health and Disability Commissioner was confirmed in November 2021.

End of life

A presentation was given to members on the status of the Ministry of Health's progress in implementing the *End of Life Choice Act* that comes into force on 7 November 2021.

Discussion focussed on:

- Approaches to ensuring that the public understand how they can access the choices the legislation provides for, and the need for transparency around how the end-to-end process and safeguards work.
- Medical professionals are already under pressure and experiencing burnout in navigating the challenges in the health system - particularly for the past 18 months.

The moral and emotional burden in supporting an individual and their whānau through this pathway could add to the work and mental load of health professionals.

- Whānau support throughout the process. It was noted that while the involvement of whānau is strongly encouraged, the decision to proceed or to involve a support system is up to the individual.
- How pandemic-related restrictions may impact on essential healthcare throughout this process.

NEAC noted their interest in hearing from the Support and Consultation for End of Life in New Zealand group at a subsequent meeting.

NEAC ethical standards

A summary of submissions was verbally provided to members. A sub-group of members was confirmed to review the submissions in more detail between meetings.

Monitoring and reporting

A verbal update was provided by the Ethics Manager on Health and Disability Ethics Committees. Concerns were raised by members about the ongoing risks around delays in appointments to these committees.

Correspondence

The Committee acknowledged the response to their letter on the practice of non-gendered wards from Minister Little. It was agreed that the response would be reconsidered following the publishing of New Zealand research on the topic.