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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**24 September 2020 – 9am – 4:30pm**

Attendees: Neil Pickering, Wayne Miles, Gordon Jackman, Liz Richards, Hope Tupara, Mary-Anne Woodnorth, Dana Wensley, Penny Haworth, Vanessa Jordan, Cindy Towns, Kahu McClintock.

Ministry staff present: Nic Aagaard, Courtney Parnell, Lucy Campbell.

1. Welcome, introductions, appointments, update from secretariat and confirmation of minutes from 19 August 2020

The meeting opened at 9am. The chair welcomed the members and secretariat, acknowledging that the meeting was initially intended to be face-to-face, but had not been possible due to COVID-19 risk factors. The secretariat noted that Frances Anderson from the Human Rights Commission was no longer able to attend the meeting and members acknowledged the change in agenda.

The secretariat updated the committee on the status of the annual reports and re-accreditation of the HDECs with the Health Research Council (HRC). They noted that a significant amount of work had been undertaken with the deadline approaching soon. It was advised that feedback from the HRC will be provided to the committee afterwards.

The secretariat gave an overview of how the HDECs have responded to COVID-19, including notification of the HRC and Ministry releasing substantial research funding, developing eSOPs in response to prioritize COVID-19 applications and manage unrelated work. The eSOPs also accommodated amendments made to studies in response to COVID-19. The secretariat advised the committee that the eSOPs will be stood down once Auckland is in Level 1. It was noted that the eSOPs were followed in conjunction with other standards and there was no weakening of the conduct of research, even under emergency scenarios.

The secretariat gave an overview on the impact COVID-19 has had on the secretariat and HDECs, including any technology issues (which the Ministry provided support for) and increased workload. The secretariat commented that the increase in workload has subsided and they are returning to a normal amount.

The secretariat gave an update about data research involving Māori in response to the committee’s request to investigate this on the 19 August 2020 meeting. As part of the work undertaken for the annual reports for HDEC, the secretariat was able to obtain the prevalence of declines due to cultural issues such as lack of consultation. While it was found to account for a small percentage of declines, consistent issues related to lack of consultation and citing the Treaty of Waitangi as a health benefit were identified.

The secretariat updated the committee about ERM and stated that the contracts are almost signed, and the secretariat will be swiftly building and implementing the new system as soon as possible.

The committee asked the secretariat to identify potential information on Māori applicants and identify any hurdles they experience in comparison to non-Māori applicants.

The secretariat notified the committee that Rob McHawk has been seconded to help manage and setup a new team within the working group. Principal Advisor Nic Aagaard is acting Manager. They noted that the committee’s work will be spread between other members of the secretariat and there is a possibility the role of Principal Advisor may change to become more broader across all committees managed by the Ethics team.

The secretariat advised the committee that a full update on the Global Summit will be provided once received. It was also noted that international circles are having more discussions about equity and are looking to New Zealand to lead this.

The committee was advised that a member is invited to give a talk on ethical consideration for elective surgery during COVID-19 and members discussed their interest.

NEAC approved the minutes from the 19 August 2020 meeting, subject to proof-reading and minor changes requested by the committee.

**Actions**

* secretariat to amend 19 August 2020 minutes before publishing
* secretariat to investigate if Māori applicants to HDEC are experiencing more difficulty than non-Māori
* secretariat to provide summary of Global Summit once it has been received
* secretariat to confirm in-person meeting date.

2. Euthanasia Bill correspondence

The committee discussed a letter received from a member of the public regarding the End of Life Choice referendum. The committee acknowledged that this is not something the committee is currenting being asked to give advice on but stated that there are some issues not adequately explained for all subgroups. The committee expressed an interest in this work if it comes to them in future.

**Action**

* secretariat to acknowledge letter but note this is not something the committee is currently giving advice on.

3. Framework for Allocation

The committee discussed the changes made by the secretariat since feedback was last given. The secretariat updated the committee that the Summary of Submissions had been finalised, including a completed review of all the comments. It was noted that the human rights lens and Treaty of Waitangi references were strengthened since the last meeting. The committee commended the secretariat’s work and provided further feedback that included critique about the Framework for Allocation being cautious to not over-reach, minimising infection and advice about seeking further advice from Urutā. It was agreed that the committee would provide any other feedback post-meeting via email or Diligent boards.

4. Clinical Ethics Meeting/Getting Through Together Discussion

The CCDHB Clinical Ethics Advisory Group (CCDHB CEAG) gave a presentation that outlined the nature of their work; namely, giving advice or information in direct patient care cases alongside support they provide to health professionals handling difficult ethical dilemmas. Recent cases the CCDHB CEAG had assisted with were included in the presentation to further illustrate the work they do.

5. Framework for Allocation Submitters Discussion

Representatives from the New Zealand Nurses Organization joined the committee for discussion of the framework. They noted nurses’ concerns over equity of access due to differing guidelines across District Health Boards, stating the framework was valuable for addressing these differing guidelines for consistency nationally. They stated that resources and scarcity covers a lot of circumstances and could be broader in application than just COVID-19. The committee was asked to consider circulating information for healthcare consumers for the implementation Framework for Allocation.

The meeting closed at 3.45pm.