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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**19 August 2020 – 10am – 2:30pm**

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

Ministry staff present: Nic Aagaard, Hayley Robertson, Rob McHawk, Courtney Parnell, Lucy Campbell.

Apologies:

1. Welcome, introductions, appointments, update from Secretariat and confirmation of minutes from 8 July 2020

The meeting opened at 10.15am. Members did a round of introductions and greetings.

Confirmation of minutes with minor changes requested as directed by the Committee.

Health Research Council Ethics Committee Institutional Ethics Committee meeting update

The Secretariat updated the Committee on a discussion with the Health Research Council (HRC) Ethics Committee annual meeting, which concentrated on research conduct, particularly in the University setting. COVID-19 resurgence planning was also discussed.

The HRC updated the Ministry on an institutional ethics Committee survey administered by the HRC on the new NEAC standards. The results will be shared with the members following this meeting.

The Secretariat noted that it is almost time for the HDEC annual reports to the HRC, as well as being due for the 3-yearly approval report. The Committee asked if the HRC requires reporting on the number of Māori researchers. The Secretariat responded that the HRC report requires information on whether researchers are conducting Maori consultation, and for all instances where a study is declined for not considering Maori adequately, however data is not requested on number of Maori researchers. The Secretariat noted that they would start recording this data on the new HDEC IT system and would raise this with the HRC for the other institutional ethics committees.

HDEC update

The Secretariat updated the Committee on their development of public training sessions to assist with the transition to the Standards. The training will be informed by the HDEC experience of the Standards. A training workshop for new HDEC members, delayed by COVID-19, is also planned for the end of 2020.

The Secretariat advised the Committee that due to the move to Alert Level 3 in Auckland for COVID-19, the emergency standard operating procedures has been activated for that region only as of the week prior.

The Secretariat advised that an updated template for participant information sheets and consent forms has been provided to researchers that now reflect the new standards data chapter, with a template being drafted around integrated / simplified consent.

The Committee asked the Secretariat about potential gaps in the review process between the HDECs and the institutional ethics committees. The Secretariat reported that it is possible that some applications get reviewed at an HDEC or institutional ethics Committee when it should have gone to the other. There are gaps for ethical review for quality improvement (QI) activities and some research where health is not a primary outcome.

Update on Medical Council Consultation

The Secretariat noted that responses had been submitted as per the prior meeting minutes. The copies of these responses are to be provided by the Secretariat outside of the meeting.

Update on Opt Out Consent – Legal Developments

The Secretariat and Committee discussed legal barriers around modified consent. The discussion was based off a recent study submitted for HDEC review that was declined. The study had been resubmitted multiple times in an attempt to overcome the legal barrier, and was determined by the HDEC to be ethically sound, with legality being the only barrier to its approval. The Secretariat has advised and requested the Committee keep consent modifications as an active work item, and to pursue a discussion with the Minister post-election period. The Committee agreed and requested more information when it is available.

WHO and UNESCO meeting update and the Global Summit of National Bioethics Committees

The Secretariat referred to the concept note provided to NEAC in their agenda and invited NEAC members to attend the APNEC II monthly meeting. The Secretariat also noted that the Global Summit, initially to be held in April 2020 in Portugal, was now to be held on Zoom in September, with the in person Global Summit postponed until 2022.

* **Day 1 – 9 September 2020, 1 pm to 3 pm Geneva time**
Keynote speakers introduce the latest current state of research and response to the pandemic outbreak, ethical issues and social perceptions, followed by open discussion.
* **Day 2 – 11 September 2020, 1 pm to 3 pm Geneva time**
Update from National Ethics Committees on key issues raised by COVID in their respective WHO Regions, followed by open discussion.

CDAO New Zealand - Auckland 4-5 November 2020 | Corinium – NEAC Data Talk

The Secretariat advised the Committee of an upcoming conference in November and asked for the members to express interest in attending.

The topic will be National Ethics Advisory Committee Perspective: Data ethics and contact tracing. The work will be based on the Getting Through Together update. The Secretariat noted that they have a good baseline for this talk due to the literature review and the feedback from the recent consultation.

**Actions**

* Secretariat to amend 8 July 2020 minutes before publishing online.
* Secretariat to provide the members with the feedback on the Standards collected by the HRC survey.
* Secretariat to provide minutes for STH HDEC meeting once published online.
* Members to advise Secretariat of interest in attending in November conference and WHO APNEC meeting(s).
1. Framework for Allocation – Summary of Submissions

The Secretariat gave an overview of the submissions to date, noting the targeted consultations held with various groups.

Members went through the summary of submissions document theme by theme.

The Secretariat provided an overview of proposed suggestions to address the scope of the Framework, and a number of solutions and responses to the feedback received.

The Committee stated that it would like to be upfront about the context that the framework sits in and the current inequitable environment and be clear why this document focuses on equity. They acknowledged that it is challenging to achieve entirely equitable health outcomes in a pandemic because of the history that has led to structural barriers in accessing resources such as ICU. They noted that they should signal to the Minister that more work needs to be done in addressing inequities because they are exacerbated and experienced acutely in a pandemic, noting that a pandemic is not the only time to address determinants of health such as housing. The Committee discussed the scope of the framework and whether social determinants that affect health should be included if the Committee is serious about protecting the most vulnerable during a pandemic.

The Committee noted the principle of tino rangatiratanga and the need to consult more widely to give effect to the Te Tiriti article of sovereignty. It was suggested that further engagement with the National Maori Pandemic Group would support this. Members noted that a lot of feedback was received supporting the Te Tiriti principles but noting that they needed more application throughout the document, and that Te Tiriti articles need to be linked with the principles in the next draft. It was further noted that the framework starts off strong but this does not continue through the document. Key principles and integrating principles for Māori much like the standards was discussed

The Committee noted some feedback suggested that the language of rights is not used strongly enough and suggested to build on human rights view more strongly than the current version. The Committee noted that they would bolster the human rights section but did not believe changing the foundation of the document from an equity based principles approach was required to do so.

The Committee discussed the re-allocation from usual standard care to COVID-19 response and how it had a negative knock-on effect witnessed in the healthcare system, with further impact to be fully realised in future (5 years for cancer rates, for example). It was agreed that now the hospitals have lived experience of these measures that some of the cancellation of usual healthcare services was not necessary. The Committee noted to the Secretariat that a recognition of the impact of an elimination strategy should be added to the document and the importance of still having a working health system emphasized more. The Committee further asked to mention it in the framework that recognises we have learnt from experience. In addition, the learned-experience of how important the allocation of human resources should be added to the document and recognised as a scarce resource in itself.

The Committee discussed and advised the Secretariat to amend the framework to include more information via infographic on the structure of the decision making process to facilitate transparency in times of emergency, however it was agreed that rather than have a specific decision making group in mind, the information should be kept generalizable to avoid locality procedures differing.

The Committee noted that since the geriatric population has high mortality rates, targeted consultation should be directed towards geriatrician specialist groups.

The Committee asked if the concept of a tipping point should be included in the framework. The Committee and Secretariat discussed and agreed that recognising the point being reached where procedures have to change should be built into the scope of the framework.

The Committee noted that the Framework doesn’t recognise all the groups that gave feedback, but that the document could not address every group. The Committee noted that translations of allocation decisions and good communication and transparency were still important, and that decision-making groups must consider and have representatives from their stakeholders.

The Committee proposed that the summary of submissions be completed and sent to the Minister, and following response, published online. The Committee requested that the health report supports and communicates the feedback on the wider equity issues in the health system and notes that while the Framework cannot address all of these, NEAC are committed to ensuring those voices and experiences are heard.

**Actions**

* Secretariat to amend the framework document with changes discussed by the Committee.
* The Committee to receive an overview on the working groups that will work to complete the document.
* Secretariat to send NEAC suggestions for further engagement and peer review of the next draft.
* Secretariat to notify the Minister of the wider issues raised about structural inequities that make it difficult to achieve equity in some areas of pandemic response, and highlight the need to address these wider issues as part of an adequate pandemic preparedness plan.
1. Getting Through Together Update

The Secretariat informed members that as part of the consultation for the Framework, there was a lot of valuable information from submitters about the update of getting through together. This will be developed further once the next draft of the allocation Framework is complete.

1. Meeting review and close

The action points discussed during the meeting were agreed upon.

The Secretariat confirmed that the in-person NEAC meeting would proceed contingent upon alert levels.

The meeting closed at 2pm.