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**National Ethics Advisory Committee**

 **The Thorndon Hotel Wellington by Rydges**

**24 Hawkstone Street, Wellington**

**3 November 2020**

**9am-4pm**

Attendees: Neil Pickering, 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

Ministry staff present: Nic Aagaard, Hayley Robertson, Kirsten Forrest, Lucy Campbell, Courtney Parnell, Rob McHawk (9:40am-9:50am).

Presenters from the Ministry: 1:30pm – 2:45pm: Laura Cleary and Esther Lim (Data and Digital), Emily Black (Health Legal), Ali Ajmal (Pacific Health and resurgence planning).

1. Welcome, declarations of interest and confirmation of minutes from 24 September 2020

The meeting opened at 9am. The Chair welcomed NEAC and thanked members for travelling to Wellington for the in-person meeting.

Declarations of interests were noted as requiring updating. No declarations of interest were declared for the meeting, however the Secretariat agreed to send an email to members to provide an opportunity for members to update their declarations of interest if needed.

The Committee then approved the 24 September 2020 minutes.

**Actions:**

* Secretariat to send committee an email for members to update their declarations of interest
* Secretariat to publish 24 September 2020 meeting agenda and minutes to NEAC’s website.
1. Ministry update

*Briefing for the Incoming Minister*

The Secretariat updated NEAC that preparation on the Briefing for the Incoming Minister (BIM) will begin after the meeting. The new Ministerial appointments were then noted, including the appointments of Associate Ministers for Maori and Pacifica Health. Namely, that Hon Andrew Little has been appointed as the new Minister of Health (the Minister) and Hon Dr Ayesha Verrall has been appointed as an Associate Minister of Health. Lastly, that Hon Chris Hipkins has been appointed to the newly established Minister for COVID-19. The Secretariat noted that an update about where the different health portfolios sit will be sent to the committee in due course.

**Actions:**

* Secretariat to prepare a BIM for NEAC to review at the next meeting and invite the Minister to meet them
* Secretariat to update members on Ministerial portfolios.

*Appointments*

The Committee was then advised that the appointment process for NEAC can continue as the new Government is in place. Members were reminded of the vacancies in the Committee, as well as the election of a new Chair. The Ministry’s appointments team has advised that Cabinet is unlikely to confirm any new members until 2021.

HDEC is also going through the appointment process, with 16 vacancies that need filling. The Secretariat will organise a structured training day once these vacancies are filled and approved by Cabinet. The Secretariat noted that work on a review of the fee structure for the HDECs and ECART is in progress.

The Secretariat advised that Zoom meetings for committees are now standard policy at the Ministry, unless an in-person meeting can be justified for example, new member induction, training days.

The Committee was then advised that the Secretariat team is down 3 FTE with vacancies of an assistant advisor, administrator and manager. These roles are in the process of being advertised and filled. A clinical principal advisor will also be seconded for 6 months to strengthen the Secretariat’s clinical ethics capacity, including assisting the Ministry and the Committee in the response to COVID-19.

*WHO APNEC meeting update*

Gordon and Kahu provided an overview of the recent WHO APNEC meeting they had attended. The meeting had focused on training and education. The members advised that internationally we are working across different environments and capacities which has resulted in different public health outcomes. They noted that New Zealand is not facing the same challenges other countries have been.

*The End of Life Choice Bill*

Rob McHawk then updated the Committee about the End of Life Choice Bill (the Bill). The Committee was advised that the Ministry will have 12 months to setup the service for the first time if the Bill is passed. Development on the work programme has started and the policy team has been asked to ensure that law and ethics are included within these workstreams to connect with NEAC. It is anticipated that NEAC will start receiving public correspondence on the topic. NEAC will be informed of the progression of the work programme as it develops.

*Research without consent update*

NEAC wrote to the Minister in 2019 noting that there are outstanding, serious ethical issues in relation to law and research trials for non-consenting adults and waiver of consent. The Secretariat has attended a number of meetings on the topic. The Secretariat advised that it is an appropriate time to restart this work by writing to the Minister, the new HDC Commissioner, and Health Research Council.

**Action:**

* Secretariat to arrange a meeting with the HRC EC and Researchers to discuss next steps.

*The Standards update*

The Secretariat advised that a review of the NEAC research standards (the Standards) is coming up. The Committee can start designing a survey to seek feedback on how the Standards have worked – possibly leading an update of the document to ensure it is fit for purpose. Sector issues such as ACC injury cover will be looked into when judging whether updates should occur. An upcoming meeting with ACC and Medicines NZ is planned to discuss commercial trial insurance and ACC.

1. Correspondence received

The chair updated members that a letter has been sent on the Committee’s behalf to thank former member Maureen Holdaway for her time and contribution to NEAC.

The Secretariat then updated the Committee about an email request to interview a member about the ethics of pharmaceutical companies profiting from COVID-19. The secretariat had replied to the student on behalf of NEAC and directed them to the draft framework for allocation. The student had since published the article but was still interested in interviewing a member on the subject. The Committee noted that the terms of reference state that only the chair can respond to media inquiries. Members agreed these types of requests should be treated as a media inquiry (rather than brought to the committee for discussion) in the future. The committee agreed to not respond to the request any further.

1. Open session and 2021 meeting dates

The meeting then moved into an open session on the Committee’s work programme and ways of working. The Secretariat advised members that the session provided an opportunity to raise issues they would like the Committee to consider – subject to the Minister’s approval before they can be added officially to the work programme.

The items already on the work programme include:

* Getting Through Together update
* Clinical ethics
* Review of the Standards
* Consent modifications work.

It was noted that the issue of mixed gender hospital wards has previously been raised (and logged) as a possible work item.

The Committee had a conversation about equity of access and the ways in which COVID-19 has exacerbated existing inequities. Members noted that their work programme is heavily focused on equity and discussed whether there is scope to look further into other areas of equity and healthcare. Members discussed the different avenues that are available in the public health system (through ACC, private health or public health) as a ‘three-tier’ system that creates issues in equity and outcomes, and does not provide ACC insurance for cancer. Members agreed that equity of access, and more broadly the ethical implications for health care delivery post Heather Simpson Report could added as a possible work item.

The Committee then discussed ways of working. It was once again agreed that media requests should be treated as media inquiries and responded to by the Secretariat on behalf of NEAC.

Members agreed that full-committee meetings should occur every two months, with shorter working group meetings occurring in-between. It was also agreed that full-committee meetings will occur on the second Tuesday of every second month from February 2021. The shorter working group meetings will be scheduled as needed.

**Action:**

* Secretariat to schedule and send NEAC meeting invites for first half of 2021.
1. Project work: Resource Allocation Framework and implementation plan

The Secretariat updated members about the recent updates made to the Resource Allocation Framework (the Framework). The Secretariat advised the Committee that minor changes agreed at the meeting could be incorporated into the document before it is published. It was also noted that the Framework links into the planned update of ‘Getting Through Together’ and, that this update will provide further opportunity for members to build on Te Tiriti and equity principles from the Framework.

The Committee made final amendments to the Framework and approved for publishing on the provision that the Secretariat would send a final, updated version of the document based on the feedback provided in the meeting for a final review. It was agreed that the Secretariat would also contact members about specific changes they had raised in the meeting to ensure the feedback is accurately captured.

The Secretariat opened the floor to the committee to discuss the Framework implementation strategy for the implementation plan. The Committee was advised that a health report has been prepared and the Ministerial sign-out process for the Framework will occur after final feedback has been received. It was noted that a road show strategy (as used for the Standards) is unlikely to work, and that the focus should be on publication and dissemination of the Framework. Members noted that they were proud of the document and thanked the Secretariat for bringing the material together and consulting in a short timeframe.

**Actions:**

* Secretariat to update the Framework based on feedback from the meeting
* Secretariat to send NEAC the updated version for review. NEAC to provide any final, minor feedback for the final draft
* members to respond if they have any minor, final feedback before the Framework goes through sign-out
* Secretariat to complete the health report HR and start the sign-out process.
1. Presentation: CDAO Data ethics conference report back

A member updated the Committee on a data ethics talk related to contact tracing and data ethics. Slides were provided to NEAC.

Ministry staff then arrived to present about their experience of working on the COVID-19 response.

* Presentation 1: a data and digital perspective on issues related to balancing the public good with other ethical considerations such as individual privacy rights and the potential for individual cases to be identifiable in populations with a small number of COVID-19 cases.
* Presentation 2: gave an overview of legal issues related to the COVID-19 response. Balancing human rights (which are legislatively protected in the New Zealand Bill of Rights) with the COVID-19 response (including related legislation such as the COVID Act) and population health, was a central issue discussed in the presentation.
* Presentation 3: gave an overview of the pacific communities in New Zealand and resurgence planning, including discussion of the recent resurgence which affected New Zealand’s Pacific population. The speaker noted that there is a large Pacific community in South Auckland who face long-term inaccessibility to healthcare. The importance of ensuring equity is central to the COVID-19 response was also discussed.

**Action:**

* Secretariat to send members the PowerPoint slides from the three presentations.
1. Getting Through Together update

The Secretariat gave an overview of the preliminary feedback from the Framework consultation in regards to the update of Getting Through Together.

The floor was opened for discussion and brainstorming how to improve the document and incorporate learnings from the COVID-19 pandemic. Committee members agreed that the equity focus of the Framework should be strengthened even further in the update of Getting Through Together – including more discussion about the social determinants of health. The Committee discussed adapting the Framework as a chapter in the update of Getting Through Together, alongside the importance of including a chapter on data and digital, public health interventions and aged residential care. The Committee proposed a joint-Ministry section around impacts beyond just the COVID-19 virus.

**Actions:**

* Secretariat to develop a template for the update of Getting Through Together and begin populating the document for NEAC’s consideration at their next meeting
* Secretariat to set up a shorter Zoom meeting in December to progress planning for the Getting Through Together update.