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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**8 July 2020**

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

Apologies – Neil Pickering

Ministry staff present: Nic Aagaard, Rob McHawk, Kirsten Forrest, Lucy Campbell, Courtney Parnell.

1. Welcome, introductions, appointments, confirmation of minutes from 8 July 2020 and general business

The meeting opened at 12.30pm. The Secretariat welcomed members and members then did a round of introductions.

The Secretariat updated members about NEAC appointments, and appointments for all HDEC committees. It is unlikely these will be confirmed before the blackout election period. The Secretariat then went over the NEAC code of conduct.

Members formally signed off the minutes from 24 June 2020 with minor changes.

The set up of diligent boards was then discussed. A member advised that NEAC and the Secretariat should make sure updated documents are uploaded separately, instead of on the same document, so amendments and comments on each draft are not lost in the process.

The Secretariat informed NEAC of the HDECs workload statistics, including older studies on record. The delay in completion of these statistics was due in part to the COVID-19 lockdown.

The initial close date for NEAC’s Resource Allocation Framework consultation had been the date of this meeting. The Secretariat reiterated an interim analysis of consultation feedback would be done at this meeting given that the due date for responses has been formally extended to 15 July 2020. NEAC also agreed to accept late submissions for two consultations near the end of July 2020.

**Actions**

* Secretariat to amend 24 June 2020 minutes and upload them to NEAC’s web page.
* Secretariat to follow up with contact person regarding diligent board account set up for NEAC members and arrange training.
* Secretariat to arrange early diligent boards training for, and send hard copies of information to, a member who will be away during the training period.

**WHO and UNESCO Update**

The Secretariat updated NEAC on global ethics developments. WHO and UNESCO collaborated to establish a working group comprising members of the APNEC network to enhance the role of NECs in national and regional COVID-19 response efforts. Noting that the objectives of the Working Group are broadly to share information and strengthen the network, we propose to develop a capacity-building framework to directly address ethics issues that countries are facing.

* **Networking and experience sharing:** continue with the monthly APNEC COVID-19 working group meetings, with a particular technical topic the focus of presentation and discussion. Rotate the chair responsibility among APNEC members in turn, with members given the opportunity to present on their own country/context each time they hold the chair duties.
* **Training and development:** development of an online training platform to promote the sustainable capacity building of ethics focal points, NEC and development partners through a focus on (1) NEC and systems governance; and (2) relevant technical areas to be determined by APNEC members (e.g. resource allocation; end-of-life issues; access to health services for migrants; biotechnology and AI etc..)
* **Advocacy and application:** networking, experience sharing and capacity building will not be effective if governments and development partners (including WHO, UNESCO etc) are actively advocating for the application of ethics in their relevant day-to-day operations. Taking a practical approach, APNEC members will be supported to advocate and build awareness of the essential nature of ethics in the work of government and development partners, both within and beyond the health sector.
1. Framework for Allocation – Interim Analyses

Members were updated about the submissions so far. The Secretariat noted that feedback has been generally favourable and has come from a cross-section of New Zealand society, including from Māori, disability, clinical and academic stakeholders. The same template used for the summary of submissions from the consultation of the NEAC research standards submissions has been used for this consultation. ICU consultants have also sent a clinical assessment tool they have developed to the Chair and the Secretariat for informal ethical advice. This will be discussed at the next NEAC meeting. NEAC should consider how national consistency regarding resource allocation and triage will be achieved and what its role in this is.

The Secretariat discussed themes that have been identified from the package of submissions analysed before the meeting:

* ICU allocation has been recognised as a particularly complex area related to resource allocation. Clinical accuracy and feasibility of the current Resource Allocation Framework analysis for the ICU context has been queried.
* Patient autonomy as an important aspect to consider. Namely, that patients should have input into decisions made about their care, particularly in the ICU context.
* Clinicians have indicated a need for ethical guidance for possible situations where patients have a similar likelihood of survival clinically, but there is an insufficient number of ICU beds.
* Funding as a resource. This is not discussed in the current framework and affects rural communities especially. It is an important equity-based perspective to consider.

NEAC discussed equity and the ICU context further, focusing on the tension between equity and clinical perspectives, and application. It is an issue that requires further discussion and will likely entail additional consultation from experts. The determinants of health are important to consider as measures that can prevent an individual eventually requiring ICU admission or palliative care. A member advised how measures such as primary care facilities are especially important for Māori who are unlikely to access and benefit from ICU in the first place. More transparency about why this is happening, such as the role of co-morbidities, might assist Māori, as well as identifying other stages of health (before ICU and palliative care) where funding can be allocated to help mitigate this issue. In a pandemic context, preventative measures such as distribution of PPE may also be more effective. Systemic inequities that affect vulnerable groups and the ‘bigger picture’ of health in New Zealand are also relevant to consider alongside COVID-19 and pandemics in general.

NEAC agreed after further discussion that the Resource Allocation Framework should remain COVID-19 focused given the consultations and literature review have been specific to it. This framework can be adapted so that it corresponds to pandemics in general for the update of Getting Through Together.

**Actions**

* Secretariat to adapt master document and develop summary of submissions and send to NEAC for 19 August meeting.
1. Revision of Getting Through Together – Ethical Values for a Pandemic

The Secretariat gave an overview of how the literature review provided to NEAC was prepared and what its findings were.

The importance of the Treaty of Waitangi was discussed, and it was highlighted that due to a significant response from Asian and Pacific stakeholders for the Resource Allocation Framework, more emphasis on these communities should also be included in the document as well as the update of NEAC’s pandemic guidelines, Getting Through Together.

The Secretariat asked members about what elements of the original 2007 document they would like to retain. Members agreed that while some content is relevant, changes to the structure and examples are necessary to be more current and in line with the country’s recent experiences of COVID-19. It was agreed that the Treaty of Waitangi should be more explicitly woven into the document than it is presently, and that Māori bioethical principles should be included to apply to various pandemic related ethical issues. A possible method to achieve this could be to adapt the eight Māori and bioethics principles from the NEAC Standards. Members discussed that doing this would also ensure continuity across the documents. Overall, the New Zealand context is unique - including the response to COVID-19 - and this must be taken into consideration.

It was noted that there is no ‘one size fits all’ for pandemics, so while it is useful to use learnings and examples from COVID-19, the updated pandemic plan should be adaptable to the unique context of possible, future pandemics too. A member advised that it would also be helpful to cast a human rights lens over content in the update of Getting Through Together. In terms of structure, initially the approach had been to make the document ‘short and snappy’ to ensure accessibility to stakeholders, but the question of whether more depth should be added was raised. For instance, some feedback from the Resource Allocation Framework consultation suggested examining a Utilitarian approach in more depth and discussing why an equity-based approach is more effective, to further justify the use of an equity lens. A member suggested putting the updated version of Getting Through Together online so that various parts can be easily accessed. The use of infographics was also raised as a possibility.

**Actions**

* Secretariat to arrange meetings for topic grouping/working groups.
* Next agenda to include relevant literature papers
* Secretariat to provide literature from the literature review on diligent boards
1. Medical Council of New Zealand Consultations

**Proposed changes to Telehealth statement**

NEAC discussed the Medical Council of New Zealand's Telehealth statement in relation to medicine prescription shifting from (primarily) in-person consultations to virtual consultations. It was agreed there is a role for in-person consultation. Members discussed that telehealth does not work for all populations such as geriatrics, where physical assessment in-person is important. Equity disparities related to access were also highlighted; some groups may lack the technological proficiency required for Telehealth and, those on or below the poverty line may face economic barriers. A member advised that during COVID-19, Māori had preferred a blended approach of telehealth and in-person consultations. Members agreed that an initial in-person consultation is preferable before moving to alternative options such as telehealth.

The benefits of telehealth were also considered. Members noted that virtual consultations are appropriate for situations where it can mitigate patient discomfort or health risk. This was especially prominent during COVID-19 lockdown where patients felt at risk going to consultations in person. Telehealth consultations have also made healthcare more accessible to some groups; local feedback has indicated telehealth is cheaper for instance. However, such benefits do not negate the advantage of in-person consultations whereby a clinician can better gage the ‘wider picture’ of a patient’s health. For example, it is often useful for Mid-wives to visit an individual’s home as it provides insight into their home life and other factors that might not have been apparent but inform the individual’s medical needs.

The privatisation of telehealth was also noted. Members raised further concerns related to the lack of regulation in the private health sector. Though this is an issue for the private health sector in general, it may further impact the healthcare provided via telehealth if there are cases where profit is prioritised over best-care. This could have further equity impacts as disadvantaged groups are often more likely to be affected in these instances.

NEAC were in favour of the telehealth statement outlining that replacing an in-person consultation should ordinarily be only when there are risk factors that outweigh face-to-face consultations.

**Draft discussion paper on when Artificial Intelligence (AI) is involved in the care of patients**

NEAC agreed that it is important for the Committee to provide feedback to the Medical Council of New Zealand on the draft paper. This prompted discussion regarding concerns about the limitations caused by AI dependence on its algorithm. For example, a human clinician will be mindful of impacts such as gender, age and ethnic disparities, and take these factors into account when assessing a patient, whereas an AI might lack this individualisation. This is because an AI is dependent on, and limited to, data collected to inform the algorithm. If the data is extensive, for instance one group is overly represented, the AI will go on to make medical assessments using this information predominantly and may therefore mis-diagnose the spectrum of individuals who do not fit into this group. As such, members expressed concerns that Māori, Women, disabled and older people are groups that have not been considered or acknowledged in the draft. This reinforced apprehensions about the limits of AI algorithms and potential harm it might cause for these groups especially. An important question to consider is whether AI can ultimately make ethical judgements.

Members also advised that the risk of harm has not been emphasized enough in the draft paper, including potential conflicts of interest such as profit. Another point of consideration is whether using AI can be equitable in terms of outcomes.

The deadline for feedback is 7 August 2020.

**Actions**

* Secretariat to draft letter summarising the committee’s comments to send to Medical Council of New Zealand regarding the proposed changes to Telehealth
* Secretariat to prepare NEAC response to AI discussion paper
1. Next Steps
* The Secretariat will analyse the consultation submissions and put together a ‘new draft’ of the Resource Allocation Framework so that there are no comments or track changes on the document. This will include all relevant feedback aside from the late submissions.
* The Secretariat will develop the summary of submissions document that will accompany the new draft of the Framework.
* The Secretariat will go through the principles from the Standards and discuss with the Chair as to whether they can be adapted for Getting Through Together.
* The Secretariat will put together documents related to the update of Getting Through Together. However, the focus of the next meeting on 19 August 2020 will be on finalising the Resource Allocation Framework.