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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**24 June 2020**

Attendees: Neil Pickering, Wayne Miles, Gordon Jackman, Liz Richards, Hope Tupara (until 11:00am), Mary-Anne Woodnorth, Dana Wensley, Penny Haworth, Vanessa Jordan, Cindy Towns

Ministry staff present: Nic Aagaard, Hayley Robertson, Kirsten Forrest, Lucy Campbell.

Apologies: Kahu McClintock

1. Welcome, introductions, appointments and confirmation of minutes from 19 May 2020

The meeting opened at 10.00am. The Chair welcomed members and advised a formal letter will be sent to Maureen Holdaway who recently resigned from NEAC to thank her for her years of service. Members did a round of introductions and welcomed new members.

The secretariat updated members about the advertisement of three new roles in the past month. Three papers are going to the Minister this week and decisions regarding these are expected. The secretariat noted that NEAC should therefore be fully staffed in the next few months. A transition plan will be developed to ensure continuity across projects.

Members formally signed off the minutes from 19 May 2020 but advised a couple of changes.

Actions

* Secretariat to amend 19 May 2020 minutes and upload them to NEAC’s web page.

1. Ministry updates

The secretariat advised members that researchers using data have requested assurances from ethical perspective, especially regarding historical use and future use of data. It was then noted that this is still progressing in the background.

**Framework on Allocation – update on consultation**

The secretariat updated NEAC that the draft framework on resource allocation in times of scarcity is now online for public consultation. It was noted that feedback has been wide spread and largely positive, and has included suggestions from a rural health perspective. It was also advised that informal feedback and consultation meetings from the ICU community have occurred both in writing and in person, but that formal written feedback will also be provided by the ICU consultants.

NEAC members then agreed to extend the period of consultation for another week. The public consultation now closes on 15 July 2020. An interim analysis of feedback received so far will be undertaken at the meeting on 8 July 2020 instead. The interim analysis will also include a mix of online submissions and high-level consultations. This will be an opportunity for NEAC members to recommend to the secretariat any other individuals for engagement during consultation.

Members will receive an updated draft with track changes and comments as well as a thematic view of analysis. These are key documents and will be continually updated.

Actions

* NEAC members to advise the secretariat if they know any other people who may be interested in or have interesting views to offer the consultation.
* Secretariat to send a thematic review based on analysis so far for members consideration at the 8 July 2020 meeting.

**ICU Consultation**

An update about the ICU consultation on 23 July 2020 was provided. The two consultants offered perspectives from palliative care and ICU as lead palliative care and co-lead ICU physicians at Wellington hospital, and a NEAC member also provided feedback as a physician with acute medicine and palliative care experience. The discussion revealed ICU allocation to be a particularly complex issue regarding equity. The consultation also clarified the perspectives of both sides (NEAC and ICU clinicians). NEAC was advised by the consultants that this work should occur at a national level and that the triage system developed by a clinical advisory group will be shared with NEAC.

Angela Ballantyne also attended the consultation and sent through a summary of the consultation. The Chair advised that the perspectives in the face to face consultation meetings are very interesting and open to all NEAC members who can attend.

Action:

* The chair to circulate responses written by members able to attend the consultation and Angela Ballantyne’s summary around NEAC.

**Ministry of Health COVID Ethics Project – Manager of the Ethics team Update**

At the request of Dr Ian Town (Chief Science Advisor) and Keriana Brooking (Deputy CEO COVID-19 Health Systems Response) the Ethics Team has been asked to commission a project as part of the overall COVID-19 Health response. This project is to provide an analysis and documentation of the ethical tensions/themes/issues/human rights violations that exist (real or potential) during the development and publication of any advice, guidelines and frameworks and assess how these were managed during the COVID-19 response. This will include advice given from Ministerial Committees across the board and any health-related work from other Government agencies.   
  
This project will include a retrospective stocktake of the advice given so far, as well as setting up guidance for Ministry Staff in providing advice with some ethical framework oversight. Two members of the ethics team will be leading this work.   
  
Although this project is separate from NEAC, there will be ideas and learnings arising from this project that may be useful for NEAC’s current work program. The Minister has been briefed on the project and the Ministry is currently working through the project plan and expected deliverables. The secretariat will keep NEAC informed as this develops.

The secretariat expanded on this update further, stating that this is project is effectively the Government and the Ministry acknowledging that ethics should have been considered in more depth - even though COVID-19 required a quick response, including a range of actions and health measures taken at the time. This project will be useful to NEAC while ‘Getting Through Together’ is updated as there will be cross-over information.

Members commented on the importance of this project and the misconception that NEAC only provides advice related to health and disability research ethics rather than health-related ethical issues generally. The importance of clear communication between the Ministry and NEAC regarding this ethical analysis was discussed. It was suggested that a secretariat representative for NEAC and/ or a member attend these meetings to ensure this project and the update of ‘Getting Through Together’ not occur in isolation given the contextual overlap.

**Diligent Boards Update**

The secretariat informed members that NEAC’s feedback regarding the lack of a consistent platform for agenda development has been addressed by working with the Ministry to procure diligent boards. These diligent boards will act as an online platform for document sharing. It will also allow the secretariat and members to access and work on the same document throughout its development. NEAC members agreed with this approach.

NEAC will be moving to diligent boards between 24 June 2020 and 8 July 2020.

Action

* NEAC members to contact an ethics administrator to sign up for, and attend, diligent boards training before 8 July 2020. Training is on Zoom and will take between 45 minutes and 1.5 hours depending on competency.

**NEAC Annual Reports (2017-2019)**

The secretariat advised members that three outstanding annual reports will be sent to the Minister of Health following this meeting. The large amount of work completed last year, including public consultations and road shows, was also acknowledged and noted as having prevented the completion of these reports last year.

Actions

* Members to contact the secretariat if they have any other final amendments to make.

**Letter to Minister – HDC report on research with adults who cannot provide informed consent**

The secretariat updated NEAC that the health report is with the Minister and awaiting approval.

**NEAC work programme update**

* Annual Survey of users of NEAC Ethical Standards for Research and QI
* Review of Getting Through Together

There was a discussion about the annual review of the NEAC ethical standards for research and QI (the standards). The standards are in line with what was presented in the implementation roadshow. December 2020 will mark the standards one-year anniversary. The secretariat recommended surveying researchers and any other relevant stakeholders about possible changes/ improvements for the research standards near the end of 2020 in October or early 2021. A member expressed concern about issues with IT capabilities and forms distorting feedback on the standards themselves.

The overhaul of the health and disability ethics committees IT system will be resumed as a key work item. This includes creating application forms for HDEC studies based on the new standards. The secretariat recommended that a couple of members should be involved in the working group as representatives of NEAC. After some members expressed concerns about the operational nature of this work and queried the necessity of the committee’s involvement, the secretariat confirmed the committee should be involved as the work item is based on NEAC standards. However, members may determine the level of involvement NEAC has, for instance, providing feedback once the system has been developed. A member then volunteered to represent NEAC when the project is restarted.

The secretariat will attend a meeting with Ministry IT staff who will design and implement the system.

Members discussed the wider work programme and other items on the work programme. The Health and Disability System Review was identified as a key piece of work with major implications for the wider health sector. Members discussed the role of NEAC as a national ethics committee and making a submission. Members agreed it is important for NEAC to have some input in the report. Some members expressed a desire to work on shorter term ethical issues such as bedding in hospitals as well as larger projects. The role of NEAC was then clarified as a committee independent of the Ministry but accountable to the Minister of Health. Any feedback provided by NEAC must come from NEAC as a whole rather than subcommittees.

The secretariat also recommended members look at the 2013 terms of reference as these will be reviewed in 2021.

1. Revision of Getting Through Together – Ethical Values for a Pandemic

**Project Overview**

The secretariat updated members about the revision of Getting Through Together. Namely, that a literature review of 30 documents has been completed, with an additional 30 documents still to be reviewed at the time of meeting. Members were advised of its preparation for the 8 July 2020 agenda for a list of themes, topics and headings. Structure and formatting of the document will be discussed at a future meeting.

The secretariat proposed implementing three working groups for different pandemic-related ethical issues. These groups would then present their work at more substantial NEAC meetings for feedback. Members agreed to this approach and recommended that specialists be brought in as a crucial aspect of these subgroups. NEAC can suggest possible candidates and the secretariat will check the selected individuals have the right expertise for review. The secretariat noted that the ethics budget has been further reduced but it is possible for some of it to be allocated for expert review. The secretariat aims to have a draft ready for consultation in early October 2020.

It was requested that NEAC check and confirm a number of meeting dates sent by the secretariat. Most meetings will be held on Zoom but a few in-person meetings are possible. Shorter, more regular meetings were also suggested as an alternative to the current system. Though the secretariat is open to figuring out an approach that suits both NEAC and the secretariat (including frequency and duration of meetings), the documentation prepared by the secretariat before a meeting must also be taken into consideration. Though open to shorter, more frequent meetings, members noted they need to be issue-specific because a general agenda may not work with less time at hand.

Action

* Members to discuss and agree work plan and process for updating the document.

1. Next steps

The secretariat advised that key documents related to the Resource Allocation Framework and the revision of Getting Through Together will be sent to members before the meeting on 8 July 2020 for discussion. This will include a summary of submissions for an interim analysis of consultation responses.