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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

# 06 April 2021

Attendees: Dr Neil Pickering, Mr Gordon Jackman, Ms Liz Richards, Dr Mary-Anne Woodnorth, Dr Dana Wensley, Dr Penny Haworth, Dr Vanessa Jordan, Dr Cindy Towns.

Apologies: Dr Hope Tupara, Dr Wayne Miles, Dr Kahu McClintock.

Ministry staff present: Nic Aagaard, Hayley Robertson, Kirsten Forrest, Lucy Campbell, Hazel Irvine, Zoe Benge.

1. Welcome & introductions

The meeting was held via Zoom and opened at 10.00am.

**Action:**

* The Secretariat to update Dr. Vanessa’s Jordan’s contact email.
1. Declaration of Interests

Dr Cindy Towns declared a conflict of interest in relation to Capital and Coast District Health Board Clinical Ethics Advisory Committee. The Chair did not think it was significant.

1. Minutes of NEAC’s 9 February 2021 meeting for approval

The Committee approved the meeting minutes from its 09 February 2021 meeting.

**Action:**

* Secretariat to publish the 9 February 2021 minutes on NEAC’s webpage.
1. NEAC work programme

The Committee noted that there is no Pasifika representation on NEAC. The Secretariat advised that that Appointments are aware of this and taking it into account in the candidate selection process.

1. Ministry updates
	* 1. Meeting with the Minister of Health on 12 March update

The Chair updated the Committee on the meeting with the Minister of Health on 12 March 2021, noting that the Minister had approved the current work programme. The Minister recognised that NEAC’s limited resources means that achieving one item of the work programme may slow the progress of other items.

The Minister asked NEAC to respond to the recently published Simpson Report which reviewed the health and disability system. The Chair responded by highlighting to the Minister that one of NEAC’s strengths is analysis of equity and where it can be achieved, and advised that this could be a key area of advice to the Minister for the health system review alongside other areas of ethical concern. The Chair clarified with the Committee that the Minister was not expecting a formal response to his question regarding NEAC’s position/advice on the health system review beyond what the Chair had answered in their meeting. NEAC agreed the Committee can provide advice to the Minister if he seeks it. The Chair clarified with the Committee that it is within NEAC’s Terms of Reference (TOR) that the Committee can raise issues of national ethical significance with the Minister.

The Chair invited the Minister to meet the Committee, and the Minister expressed interest in doing so. The Committee agreed to issue an invitation to the Minister to meet with NEAC, giving him a list of meeting dates for the rest of the year to choose from. If he does not respond, NEAC will re-issue the invitation with a specific piece of work to present on, such as the Getting Through Together consultation feedback. If the Minister accepts the invitation, the invite will be extended to the associate Ministers.

**Actions:**

* The Secretariat to provide NEAC with a copy of the Simpson Report and any Ministry summaries that are available.
* Secretariat to draft a letter on behalf of NEAC to invite the Minister to meet with NEAC.
	+ 1. Staffing update – new Principle Advisor starting May 2021

The Secretariat noted that a new, permanent Principal Advisor will be starting in the Ethics team on 10 May 2021. A new Advisor will also be joining the team shortly.

The new temporary Administrator who is working in the HDEC space was also introduced.

The Secretariat noted that with these new recruitments, the Ethics teams will soon be back to full staff, noting that Lucy Campbell and Hazel Irvine’s contracts were expiring at the end of June.

* + 1. Committee Appointments update

The Secretariat noted that lack of Committee appointments is an ongoing issue across the board. It was noted that Minister Little has delegated ethics appointments to Minister Henare. The Secretariat noted that appointment papers are currently before the Cabinet Appointments and Honours Committee (APH) and that NEAC may have new membership by the next Committee meeting.

* + 1. Ethics Modernisation Project update

The Secretariat updated the Committee that the Ministry has signed a contract with Infonetica for a new online portal, ERM, to replace RED. The Secretariat noted that this provides an opportunity to significantly reduce the amount of administration within the HDEC space and will increase oversight and data monitoring. The online portal is currently being built and will go live on 1 September 2021. The Secretariat noted that the Ethics Modernisation project will also involve a review of the HDEC Standard Operating Procedures and Terms of Reference.

* + 1. Chairs Day update

The Secretariat updated the Committee on a recent Chairs Day with the HDEC Chairs, noting that Medicines NZ had attended to discuss a repeal of the ACC exclusion for participants in commercial trials. Medicines NZ have requested to meet with NEAC on this matter.

The Committee agreed in principle to meeting with Medicines NZ but noted that it is not a priority due to the current size of the work programme. The Committee agreed that they would wait for their meeting request before deciding whether to accept or decline, based on the size of the agenda. The Committee noted that Medicines NZ must declare any conflicts prior to meeting with NEAC.

* + 1. Ministry of Health COVID-19 Ethics update

The Secretariat noted a Ministry facing framework based on the 2007 Getting Through Together document has been created to use for a stocktake of the Ministry’s response to COVID-19 from an ethical perspective. The project was commissioned by Dr Ian Town and Keriana Brooking. This will be a Ministry facing document, providing a high-level overview. It is in the final stages of its draft.

The Secretariat updated NEAC on the ICU prioritisation project. It was noted that the ICU working group was reconvened as a Ministry initiative to complete the work started last year during the COVID-19 response. The issue of prioritisation/triaging for ICU care was one of the case study topics in the NEAC resource allocation framework. Feedback indicated that further work was required to enable ethics and equity to be operationalised in a national guideline. Two workstreams have been created; steam one will focus on ethics and equity and stream two will focus on completion of the 1000minds digital decision-making tool, including criteria for social justice. The outcomes of the two groups will be integrated to produce national guidance, of which the tool is one component. Broader indicators of disadvantage are to be part of the overall assessment of pandemic patients and a range of culturally and individually appropriate options. Co-design and partnership have been modelled in the ICU group composition and leadership. Membership has been drawn from ANZICS, DHB CEAGs, Māori, Pacific, consumer and disability sectors. Four national meetings will have been held by 27 June 2021, but longer-term work will be needed to complete the process.

* + 1. Publication of NEAC Ethics Equity Framework update

The Secretariat noted that this has been published on NEAC’s webpage.

* + 1. HDC report and modifications of consent discussion – discussion about next steps

The Secretariat noted that this work has not progressed but will be picked up once additional resourcing and staff are available in the Ethics team. The Secretariat advised that this work is still a priority, and that the sector needs guidance and progression of this work.

* + 1. NEAC Standards for Health and Disability Research and Quality Improvement – consultation for annual review closes 31 May 2021

The Secretariat advised that the consultation closes on the 31 May 2021. The responses will then be collated and reported back to NEAC. It was noted that not many responses have been received so far.

* + 1. Implementation of the End of Life Choice Act

The Secretariat gave members an update on the progression of the implementation of the End of Life Choice Act which comes into force in November 2021.

Earlier in 2021, a survey was sent out to better understand the views of health practitioners. Responses were received from 1980 health practitioners, which represents a relatively low response rate compared with the size of the overall health workforce, and does not, therefore, reflect the views of the workforce more widely. Results will be published on the Ministry of Health’s website and the survey will be repeated throughout the year to assist the development of training services and modules for the implementation of end of life services.

Members also expressed an interest in how end of life services will be funded and available to individuals in the regions.

The Chair noted that NEAC’s role will be to discuss the ethics of *implementation*, rather than the fundamental ethical issues of euthanasia itself. The Secretariat will keep the Committee updated on what is required from them.

1. Consideration/Approval of NEAC’s Annual Report for 2020

Members agreed to send feedback on the Annual Report out of session.

**Action:**

* Secretariat to email members the report as a word document for members to make additions via tracked changes.
1. Agreement of dates for the remainder of 2021

**Action:**

* Committee to agree to meeting dates for the remainder of 2021 via email.
1. Mixed gender wards presentation and discussion

Dr Cindy Towns presented her research on mixed gender wards to NEAC. She noted that the opportunity to present to NEAC was not planned before commencing the research several years ago, but that now is a good opportunity to present her findings to the Committee.

The research addresses the problem of mixed-gender wards in hospital, in which men and women share the same room or bay. She highlighted that this creates a sexual safety risk for patients of all genders, particularly for elderly female patients. It was noted that, regardless of whether the sexual safety risk was actualised or not, this risk increases anxiety and distress for both patients and their whānau. Sexual assault statistics were provided to demonstrate why women especially have reason to feel unsafe when placed in wards with men. Dr Towns made the case that protecting patients from this risk of sexual harm is important in order to uphold the human right of dignity, which appears in the Universal Declaration of Human Rights. She also noted that mixed-gender bedding not only violated the principle of dignity under the NZ Code of Rights, but other rights such as respect, fair treatment and proper standards.

Dr Towns referred to the UK National Health Service, where the elimination of mixed-gender bedding has been committed to**.** She suggested that New Zealand should follow suit, making the elimination of mixed gender bedding a KPI at a National level.

Her study looked at all omissions into medical and surgical wards for prevalence of mixed-gender bedding. The outcomes showed that mixed-gender bedding is common, increasing in prevalence, and disproportionately effects older adults.

The Committee then discussed bed availability, time-based targets and hospital design as factors contributing to this issue. It was mentioned that changes in policy, culture, behaviour and practice will also be required to address it.

It was noted that it is within the Committee’s remit to take action on this under the TORs and that, if there is agreement that this is an issue of National ethical significance, the Committee is in fact obligated to advocate for this issue.

The Committee agreed that this is an issue of National ethical significance and agreed to write a letter to the Minister conveying their concerns on this issue. It was suggested that the letter highlights the fact that many of the solutions to this problem are fiscally neutral.

## Actions:

* Member to draft a letter and send to the Chair, before sending to the wider Committee for review.
* Member and the Chair to amend based on feedback send back to the Committee for final review if required.
* Committee to send to the Minister and Associate Ministers of Health.
1. Project work: update of Getting Through Together - Ethical Guidelines for a Pandemic
	1. Discuss updates to sections on contact tracing and managed isolation and quarantine (MIQ) facilities literature review

The Secretariat outlined the documentation prepared for this section including a project plan that will be updated throughout the project, a literature review covering data and digital, surveillance and contact tracing, quarantine (including lockdown measures), mandatory versus voluntary measures and testing, and an initial write up on contact tracing based on the literature review.

It was noted that a discussion is needed to agree on the Committee’s stance on topics such as mandatory contact tracing, quarantine, mask use and vaccines.

The Committee suggested various content to be considered or included in the updated guidelines:

* A focus on the ethical issues surrounding liberty and autonomy, privacy, mandatory measures and equity.
* Whether the principle of liberty can be included under the principle of autonomy.
* The need to lay out the equity principle in greater clarity to ensure that it is actualized. The principle of treating ‘like cases as alike’ was also discussed in relation to this.
* The need to ensure that the document is not too high level – it needs to be practically applicable and provide detail for how to apply the ethical principles in practice.
* The use of The Nuffield Council of Ethics’ “Intervention Ladder” (included in the literature review) as an intervention-justification matrix.
* The importance of discussing the social determinants of health without diverging too far from health.
* The wider issue of New Zealand’s overwhelmed health and disability system, and that the guidelines should note the need for adequate health infrastructure to cope with increased demand on the system during a pandemic.
* The consideration of geographic location and associated equity issues in resource allocation.
* The desirability of a three-phase approach, placing as much emphasis on *post*-pandemic ethical guidelines as is placed on pre-pandemic and during-pandemic guidelines.
* A pithy outline of the different forms that a pandemic might take and the associated issues, e.g. vector-borne diseases.
* The ethical issues surrounding vaccine and immunity passports, noting that they are distinct from one another.
* The preference for talking about centralised and decentralised contact tracing apps rather than aggregated and identifiable data (which applies more specifically to research).
* The mental health impact of lockdown
	+ Domestic violence;
	+ LGBTQI+ being in non-accepting lockdown environments;
	+ “Our family can be outside of our families”.
* The privacy issue of people manually filling in contact-tracing forms and including identifiable information.

A section or chapter specifically on disability wasagreed. A disability case study was also suggested.

* 1. Agree a work plan for working groups and agree NEAC members to lead sections with Secretariat support

Some members volunteered to lead sections with Secretariat support for topics relating to disability, the data and digital space, the impact of pandemics on refugee and migrant communities, education, information and communication and higher-level pandemic issues such as the elimination approach.

* 1. Discuss and approve the Getting Through Together project plan. This has been developed by the Secretariat to map out key timelines and milestones and will be updated throughout the project.

The Secretariat noted the March 2022 deadline for the GTG review and asked for the Committee to agree or amend the scope, objectives, outcomes and timeframes of the project plan.

The Committee indicated their preference for the working groups to take place after a draft overview has been received and discussed by NEAC, to minimise the risk of doubling up on content. Members also noted that they will need access to this first draft from the Secretariat in advance of the next meeting, so that can review it beforehand for discussion and feedback at the meeting.

However, the Secretariat noted that it is unrealistic for the Secretariat to produce a first draft by June based on the current capacity of Secretariat staff who also manage other committees and projects. The Committee agreed that the 21 June 2021 deadline for a draft document ready for public consultation is not feasible.

The Manager of the Secretariat suggested that resource is available in the NEAC budget to hire a contractor to write the first draft. The Committee agreed to allocate resource from the NEAC budget to contract someone to complete a draft overview.

The Chair advised that it is important that a contracted writer is provided with enough information by NEAC in order to write the draft. It was questioned whether, before the contractor proceeds with the draft, the Committee needs to establish the Committee’s stance on the high-level components and sections that they would like to see in the draft. It was noted that the Secretariat has proposed some sections, but these have not been agreed by the Committee.

It was suggested that the contractor could meet with NEAC to be briefed on the high-level components and sections they would like to see in a first draft before they begin writing.

 The Chair noted the decision to reverse the proposed order of the project plan. Namely, that a draft document will be done by a contractor by June or July 2021. The Committee will then review the draft and before meeting to discuss and give feedback in July or August 2021. The working groups will commence working on specific sections after that.

The Committee agree that the June 2021 meeting will be shorter and focused on the rest of the work programme.

**Actions:**

* The Chair to write a request to the Manager of the Secretariat regarding budget allocation for a contractor to write the initial Getting Through Together update draft.
* The Secretariat to scope out a potential contractor to write the draft.
* Secretariat to organise a meeting between the contractor and NEAC so they can be briefed on the Committee’s expectations for the draft and the high-level components/sections that have been agreed on.

The Chair informed NEAC Dr Kahu McClintock had notified him that she is stepping down from the Committee effective immediately due to time constraints. The Committee noted the importance of the Māori member role and the need for an urgent Māori appointment for this membership position. The Committee agreed the priority of expediting a replacement or seeking to co-opt through the Māori directorate at the Ministry. The Committee sought Ministry permission to recruit a new appointment through their own personal networks, noting that the Māori Health Directorate may have limited capacity to assist NEAC.

**Actions:**

* The Ministry to seek expedited recruitment for a Māori appointment to the Committee.
* The Chair to consider approaching Dr Kahu McClintock asking her to stay on in a temporary advisory role until her replacement is organised.
1. WHO meeting update

NEAC was then updated on the 11 March 2021 APNEC meeting, whereby two members and the Manager of the Secretariat presented on Resource Allocation and COVID-19. The member noted that, although the presentation went well, there were only two questions at the end and sensed that Zoom limited the ability to facilitate discussion. He proposed some suggestions to address this issue and the Committee approved these.

The member also advised the Committee that they have been asked to do a presentation in relation to the NEAC Standards and disability. The presentation will not be made in their capacity as a NEAC member, though it does cover information provided by the Committee. Members supported this presentation and agreed to review and provide feedback to the draft presentation when it is completed.

Another member expressed their interest in assisting with the APNEC meetings too.

**Actions:**

* Member to run suggestions for future APNEC meetings by the Secretariat before sending to the organisers of the APNEC meetings.
* Member to send NEAC their draft presentation on the NEAC standards and disability.
* Secretariat to follow up with member who volunteered to assist with APNEC meetings and connect them to the organisers of these meetings.
1. In committee session

Members then had an in-committee session of which the Secretariat was not present for.

The meeting closed at 4:00pm.