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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**09 February 2021**

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

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

Apologies: Dr Kahu McClintock

1. Welcome, introductions, appointments and confirmation of minutes from 08 December 2020.

The meeting was held via zoom and opened at 09.00am. Committee members introduced themselves to, Hazel Irvine who is contracted to the Ministry ethics team as a principal advisor to support the review of Getting Through Together.

The Secretariat advised the Committee that both the COVID-19 Response Minister and the Minister for Health have acknowledged and approved NEAC’s Resource Allocation Framework.

The Committee approved the meeting minutes from its 8 December 2020 meeting with minor changes requested.

**Action**

* Secretariat to amend 8 December 2020 minutes and publish on NEAC’s webpage.
* Secretariat to organise for the Framework to be published and disseminated to stakeholders.

1. Declaration of Interests

Dana Wensley declared a conflict of interest in relation to End of Life Choice at this meeting.

1. Project work: Review of Getting Through Together

The Committee discussed the intended audience, ethical principles, and structure as starting points for the revision and update of this document. Members agreed to contribute to sections of the document and commended the Ministry on the appointment of a dedicated Principal Advisor to assist with this project.

The Secretariat advised of a recent meeting with a Pacific representative from Capital and Coast District Health Board, who utilised the 2007 Getting Through Together document in the COVID-19 response. The representative had found the document useful and shared it with their community, including colleagues within the health sector. Pacific community groups had found the 2007 document easy to use and a helpful resource when training young people within their community. The case-studies were also found to be helpful in outlining practical, community aspects of a pandemic response such as checking up on neighbours and helping neighbours with shopping. Disseminating the updated guidelines in different languages would help to foster clearer communication with New Zealanders who do not have English as a first language.

The Committee agreed to keep an equity focus in the updated document and to further consider the social determinants of health, what economic and mental health impacts are already occurring and what has been hastened by the pandemic. The Committee also discussed the wider implications of economics on health and the importance of ensuring that existing inequities are not further entrenched. It was reiterated that contributions from a public health specialist would be key to revision of the document.

New Zealand’s unique cultural setting, and experience and learnings from COVID-19, provide further rationale for an update of Getting Through Together.

**Audience**

The Committee noted that the audience is arguably wider than health. The importance of ensuring the update reflects New Zealand’s diverse community alongside Pākeha and Māori views was also noted and includes refugee and new migrant populations.

The update could provide advice across all levels of decision-making, from ‘top level’ decision making by the Prime Minister, relevant Ministers and Ministry of Health to healthcare sector and community needs. For example, the impacts on the community of a high-level elimination strategy including disruption of regular primary health care services and access to medication.

The Committee also discussed the possibility of including a statement that highlights the need for a joined-up Government approach (e.g. between relevant Government agencies) led by the Ministry in co-ordination with community leaders, because many communities manage well with their own leadership and resources.

**Values and Principles**

NEAC agreed to apply the principles from the ‘Ethics and Equity’ Framework on resource allocation to pandemics in general. There is a chance that the principles may be further adapted as the content is developed.

It was suggested that the 2007 Getting Through Together values could be presented in a similar way to the NEAC research standards, noting the tauiwi values in the Ethics Standards differ to the values in the 2007 Getting Through Together document.

The Committee re-iterated their desire for an equity focus in the update of Getting Through Together and for recognition of the social determinants of health. NEAC agreed the update should have a strong Te Tiriti focus, including Te Tiriti values as in the NEAC Ethics Standards for Health Research.

**Scope (including topics)**

The Committee discussed inclusion of case studies related to continuity of ‘usual care’ and areas of healthcare that are difficult to transition to Zoom and Telehealth. noting that there are examples of harm caused to people with existing medical conditions through the de-prioritisation of usual care.

Issues related to older New Zealanders and in particular the ethical tensions related to the confinement of older people in hospitals due to concern that they would spread COVID-19 upon return were also noted.

Health worker rights were discussed as a topic and points highlighted were, burnout, access to Personal Protective Equipment and discrimination, as well as ensuring day-to-day care continues. It was noted that health worker rights could be acknowledged upfront in the updated document.

The Committee agreed the ‘Ethics and Equity’ resource allocation framework be adapted and included as a chapter in the update. Resource distribution and how COVID-19 demonstrated the Government’s ability to quickly redistribute resource including housing for the homeless and income support was also discussed.

**Actions:**

* Secretariat to contact NEAC and set up working groups via email. Members to notify secretariat of availability and topic preference
* Secretariat to begin drafting sections for consideration at the April meeting
* Secretariat to organise a NEAC and Ministry led hui for feedback on the response to COVID-19 and Getting Through Together update.

1. Sector engagement: Dr Ruth Cunningham, Public Health Ethics Specialist

Dr Cunningham has been asked to provide public health ethics advice and perspectives for the update of Getting Through Together.

Dr Cunningham is familiar with the 2007 Getting Through Together document, and has provided public opinion in relation to the guidelines including comment on the values and how to use them: <https://blogs.otago.ac.nz/pubhealthexpert/getting-through-together-ethical-values-for-a-pandemic/>

She also wrote an article for the Spinoff: <https://thespinoff.co.nz/science/17-02-2020/as-nz-prepares-for-covid-19-reciprocity-and-respect-must-trump-stigma-and-fear/>

Dr Cunningham’s view is that the 2007 document does have some good content and that it makes sense to incorporate the thinking that has already been done into this update. At the same time, she acknowledged the limitations of the 2007 document for example in relation to its focus on the management phase of a pandemic. It is less ‘fit for purpose’ as New Zealand’s predominant COVID-19 experience has not been in the management phase. The preparedness and recovery stages of a pandemic also need to be updated in this document.

The country’s pandemic planning prepared for an influenza pandemic, which COVID-19 is not. It was noted that this demonstrates the need for a flexible approach to pandemic planning and simple, effective tools to assist with a pandemic response. It is also crucial to ensure strong clinical and public health specialist contributions together.

Dr Cunningham would like to see the learnings from this pandemic response included in the update of Getting Through Together, including learnings from the global experience, vaccination, managed isolation and quarantine (MIQ) and contact tracing.

The importance of understanding the target audience for this updated was discussed and included the need for the update to be accessible for consultation at all decision-making levels, including the political level (e.g. Ministers) to support their decision making.

**Actions:**

* Secretariat to contact Dr Cunningham to further discuss her availability to assist NEAC with the update of Getting Through Together

1. Ministry Update

*Briefing to the Incoming Minister*

The Secretariat advised members that NEAC’s Briefing to the Incoming Minister (BIM) has been signed out by the Director General’s Office at the Ministry. A key action point of the BIM is a request for the new Minister of Health to attend a NEAC meeting.

*Secretariat staffing changes*

A new Principal Advisor with strong clinical ethics capacity has been seconded into the Secretariat for 6 months. Applications have also closed for the Secretariat’s permanent Principal Advisor role and interviews will begin soon. The permanent Principal Advisor role will support all the committees managed by the Secretariat. Further changes within the Secretariat include the resignation of an HDEC Advisor and the return of an Administrator.

*Official Information Act (OIA) Requests*

The ‘Ethics and Equity’ Resource Allocation Framework and accompanying briefing have fallen in scope of two OIA requests. The briefing will be released with minor redactions, but the Framework will not be released because it will soon be publicly available. The Ministry of Business, Innovation and Employment has consulted the Secretariat and the Chair about an OIA they received on commercial clinical trials that captures advice given by NEAC to a previous Minister. The information will be released as it is already publicly available.

*‘Ethics and Equity’: Resource Allocation Framework*

The Resource Allocation Framework will soon be publicly available, and a communications plan is in progress. The secretariat will send the Framework to stakeholders.

*Committee Appointments*

Candidate Selection Papers are in the Minister’s office for approval. If the new Minister approves the new members, they could be joining the Committee in April this year. There will need to be a handover of institutional knowledge to the new members. These appointments will also present an opportunity for NEAC to meet in person to welcome the new members. The Committee then discussed how four other members are due to complete their two terms. The re-appointment process has not begun for these members and the Secretariat advised NEAC that this will take some time e.g. finding and interviewing candidates. The Secretariat advised that these members may be able to extend their time on the Committee for another year and should contact the Manager if interested.

*COVID-19 related ethics work at the Ministry*

This work has included a Secretariat-led presentation to the Ministry’s vaccination sequencing team. The vaccination team indicated their interest in regular ‘real time’ support from NEAC but they currently have ongoing ethics support from Dr Angela Ballantyne. Another aspect of the COVID-ethics work pertains to the Ministry strengthening its leadership in ICU and equity. The Secretariat’s seconded Principal Advisor will assist with convening an advisory group to consider and critique advice for the Health sector. The Secretariat expects that NEAC will be contacted about this.

*Next steps for the Health and Disability Commissioner (HDC) report and modifications of consent*

The need for wider consultation, especially with Māori was noted. as well as a new, high-level letter to the new Minister and Commissioner to ensure that the new Minister is aware of this issue before resourcing it. An update for original stakeholders is also planned.

*NEAC Standards for Health and Disability Research and Quality Improvement (the Standards) annual review.*

NEAC agreed that emailing relevant committees and stakeholders to ask for feedback about the Standards, including suggested amendments, is the most effective approach. This approach allows stakeholders to review the document itself and leave comments and/ or write a cover letter with advised changes. It will also be possible to hold consultations with stakeholders over Zoom where necessary. The Secretariat will provide NEAC with the consultation findings.

*Health and Disability Ethics Committees (HDEC) modernisation project*

The Secretariat is implementing a new online application platform for HDECs and taking the opportunity to update New Zealand’s HDEC system in general. Industry advice that New Zealand is likely to get a ground swell of trials reinforces the need for the modernisation project. An advisory group will be set up and will include NEAC members.

The Secretariat noted that presenting at a WHO APNEC has been delayed but will happen sometime this year.

**Actions:**

* Secretariat to contact the Minister about attending a NEAC meeting if the Minister agrees to it in the BIM
* NEAC members to contact the Manager if interested in extending their NEAC membership another year
* Secretariat to disseminate the ‘Ethics and Equity’ Resource Allocation Framework to stakeholders once it has been signed-off by the Minister.
* Secretariat to update original stakeholders who attended the HDC report and modifications of consent discussion at NEAC’s 9 December 2020 meeting, that this work will be picked up when Principal Advisor in place to resource work
* Secretariat to begin consultation process for review of the Standards
* Secretariat to include NEAC’s previous submissions on clinical trials landscape in next agenda
* Secretariat to organise date for NEAC presentation at WHO APNEC meeting.

1. WHO and APNEC update: meetings on ethics and vaccination and vector borne diseases

A member who had attended both WHO and APNEC meetings gave a broad overview of each meeting. They noted that APNEC is interested in receiving feedback about national ethics committees’ experiences with Government e.g. utilising ethical tools and frameworks.

**Meeting about vector borne diseases**

There are many ethical issues related to vector borne diseases. For example, vector borne diseases driving into new areas because of climate change as a global issue.

The spread of dengue fever in Singapore was an example given. This mosquito-borne disease has required more intensive surveillance methods alongside other preventative methods to control vector environments (in this case, mosquito larvae). Such methods include:

* a system incorporating the population whereby officials ask for consent to inspect peoples’ houses to locate possible sources of standing water that may support the growth of mosquito larvae. If refused permission to enter a person’s premises, there are processes in place to enforce it and protect public health.
* utilising drones to scan for environments likely to encourage the growth of mosquito larvae. Systems have been implemented to show how information is kept, including drone locations and who has access to the information.

Singapore has been relatively successful with controlling the Dengue fever overall. This was attributed in part to the population involvement in the response.

The member also touched on the paper they had included about vector borne diseases in New Zealand. This is an issue New Zealand is likely to face in future because of climate change and the possibility of new vector borne diseases. Furthermore, vector borne diseases may require different response measures – for instance, migrating birds could become a vector for disease transmission and cannot be controlled at the border.

The Committee noted the importance of resilience, and what it takes to resource a population so that it is resilient to a virus. Health systems must be taken into consideration in the process, including guiding values, resourcing and population structure. A well-resourced health system with less limitations is more likely to enhance resilience than one that is not well resourced.

**Meeting about the ethics of vaccine distribution**

Parts of the discussion were highlighted, including:

* the role of education and teachers. Namely, whether teachers should be deemed essential in the same way medical workers are, for vaccine allocation. This is likely to depend on a society’s values and national assessment of these values in relation to vaccine allocation.
* how to encourage public acceptance of allocation decisions, for instance, gaining public support for an equity-based approach.
* discussion about incorporating indigenous peoples in vaccine allocation decisions
* vaccine hesitancy and degrees of coercion, including discussion about incentives to encourage use of a vaccine.

NEAC acknowledged the prioritisation of health workers and MIQ workers vaccinating before vulnerable groups. It was noted that being vulnerable is different to being actively sick (e.g. with underlying conditions) and that vaccinating may not benefit some people, for instance, it may cause more suffering and harm to those who are already sick. These nuances should be considered when prioritising vulnerable groups.

Economic vulnerability was raised because it seemed utilitarian in nature and economic justification for vaccine prioritisation may not be ethically justifiable. Especially from a pandemic sense, where everyone should be protected.

**Action:**

* Member to continue providing in-depth notes from APNEC meetings.

1. Implementation of the End of Life Choice Act

The Ministry is responsible for the implementation of the Act and members of the project team attended the meeting to ask for expert ethical advice from NEAC as a key stakeholder as this implementation work progresses.

The team were interested in hearing NEAC’s views on:

1. the main ethical challenges/tensions with the implementation of the End of Life Choice Act
2. how best the implementation team can work with NEAC to address these ethical challenges/tensions through-out implementation
3. who from NEAC may be interested in joining the newly established advisory group for the implementation of the Act.

This work carries some urgency as the Act must be implemented to ensure a safe and equitable assisted dying service by 7 November 2021.

NEAC provided feedback related to clear implementation of Te Tiriti, including strong Māori representation in the implementation process to especially ensure active protection of Māori. The role of family and whānau was raised as well as ensuring euthanasia is culturally safe for all groups. Members also noted the potential impacts implementation of the Act may have on frontline medical practitioners, palliative care, people with disability and the definition of coercion in relation to the Act’s implementation.

In terms of providing ethics perspectives to this work, the Secretariat can assist by attending the meetings and preparing information for the wider Committee to consider. To ensure views are representative of NEAC as a whole, members volunteered to attend weekly implementation meetings and take notes to share with the wider Committee. The implementation team also suggested updating NEAC at future meetings for feedback.

Actions:

* Secretariat to touch base with End of Life Act implementation team to further discuss a viable method for NEAC’s involvement
* Secretariat to contact members who volunteered to attend and take notes at implementation meetings if method is agreed upon with implementation team
* Secretariat to contact NEAC about proposed method for involvement

1. NEAC work programme

The Secretariat introduced a new document for a rolling agenda item for noting. The document outlines timeframes and the prioritisation of work programme items for NEAC’s discussion and approval. It also provides an opportunity for members to suggest possible items to include on NEAC’s work programme (subject to the Minister’s approval). The ACC ‘two tiered’ health system and vector borne diseases were raised as possible, future work items alongside mixed gender hospital accommodation (mixed gender bedding). Members agreed that this will be a useful document.

**Action:**

* Member to give a presentation about mixed gender bedding at NEAC next meeting in April.