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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**29 April 2020**

1. Ministry update on Equity Framework for Resource Allocation progress:

Members discussed the current iteration of the framework and the importance of putting it into the New Zealand context in terms of building in Te Tiriti, disability rights and a strong equity focus into resource allocation decisions. Dana volunteered to assist developing this section drawing on the Ministry’s cancer action plan framework.

The Secretariat took members through the document section by section and explained the framework, structure and how the sections were developed. It was noted that work has been moving fast and all of the guiding principles were developed through working groups since NEAC met to give guidance a week prior. The framework was agreed to be structured as a high-level and concise document for decision makers.

The four guiding principles agreed on are:

1. all people are equally deserving of care
2. get the most from resources
3. prioritise those in need
4. equity.

There was a discussion about the principle of getting the most from resources and how this principle aims to drill down into the concept of utility. It was noted that this document does not have a generally accepted view of utility and the document recognises that there could be a number of interpretations for utility depending on the clinical region and setting.

The Secretariat is in the process of developing four corresponding Māori principles to sit alongside the principles which is the approach taken in the recently released National Ethics Standards for Health and Disability Research but applying them to a public health context. The Secretariat sought NEAC’s approval of the development of these.

The Secretariat took members through the newly developed support services section and noted that it is an innovative section in a framework like this as it does not have a basis in other countries National Frameworks. This section deals specifically with issues like financial support following recovery, visitation rights and PPE. This section was worked through with the office of the Disability Commissioner.

Members talked about how it needs to be clear that this is a document that should only be drawn on for guidance in an emergency setting. This led to a discussion about providing guidance on how resources are distributed during an emergency. For example, should standards of care change during a pandemic? Patients receiving the best care shouldn’t change, but the definition of ‘best’ might change (eg: follow up at home instead of in the hospital setting because this might be more practicable and safer.

The Secretariat then took members through the draft case studies. The aim was to use the three case studies to cover a lot of ground to show the way that decisions could be made based on the proposed principles.

This led to a discussion that it is clear that medical professionals don’t receive adequate communication during emergencies. This is evidenced in the lack of transparent allocation of PPE, what situations it should be used in and how. NEAC agreed to include a statement about supporting clinicians on the frontline in the obligations section.

A member suggested whether other costs of emergencies, such as lost opportunities for learning for children and increased domestic violence should be included in this document.

**Action:**

* members to work with the Secretariat to develop a section on Tr Tiriti principles.

1. Right 7(4) update from HDC and discussion on moving forward:

* Cordelia Thomas and Rose Wall – Office of the Health and Disability Commissioner attended
* Monique Jonas and Lana Lon – Health Research Council attended

The purpose of this meeting was to link up the HRC, NEAC and the Ministry of health and discuss the release of the HDC’s recent report on Right 7(4). The Secretariat discussed the Commissioners raft of recommendations and changes to the HDC Code, and NEAC’s potential involvement in updating the research Standards and the Ministry in updating the wider ethical review structure.

The HDC noted that the Commissioner considered public views about non consensual research and provided recommendations. If a person is not able to consent to treatment, a provider may consent on their behalf after assessing their best interests. All agreed that the current test does not work well in research, as there is no way of telling if something is in an individual’s best interests. The HDC outlined what changes would need to be made to provide a better test for research but noted that agreement and commencement for this work was not a political priority. It was also noted that the current HDC Commissioners team ends this year and a new Commissioner would need to agree to progress work in this area.

NEAC agreed to write to the minister on the need to address the report and directed the Secretariat to draft this for review. NEAC’s opinion is that no change to the Code represents failure and risk. NEAC also noted that the Chair is meeting with Hon Jenny Salesa via zoom on 28 May 2020. The Secretariat will put together a briefing for both the Minister and the Chair of NEAC to support the meeting.

Members talked about the value and opportunity of research given the aging population and having the best care available for all. This led to a discussion about the definition of minimal risk in research. The report suggests that further work needs to be done to define this definition and a group would need to be established to guide this. All agreed that moving away from the idea of best interests to a different risk threshold would permit more ethical research. NEAC indicated an interest to add this to their work programme.

All agreed to an approach of open communication as the different parties grapple with this idea, discussing the kinds of beneficial research that are not currently able to be approved under the current test. Members noted that DHB’s could provide data on research that never gets through to the review stage.

**Actions:**

* Secretariat to organise a briefing for both the Minister and the Chair of NEAC to support their meeting in May.

1. Correspondence received:

NEAC has received a few letters of correspondence from clinical groups seeking clarity on the distribution of scarce resources and advising that the current Covid-19 pandemic has contributed to a lot of professional vulnerability in the sector where people have been put in situations where they lack the requisite training.

Members agreed that clinical ethics should be an item on the committees work programme and agreed the importance of an avenue for clinicians to bring complex issues to a committee.

1. Next steps:

Members agreed to small working group meetings in May to progress the resource allocation framework.

Members agreed to send suggested names to feed into the Secretariat’s consultation list for public consultation on the draft Resource Allocation Framework.