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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**08 December 2020**

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

Ministry staff present: Nic Aagaard, Kirsten Forrest, Lucy Campbell, Courtney Parnell, Zoe Benge.

Apologies: Hope Tupara.

1. Welcome, introductions, appointments and confirmation of minutes from 03 November 2020.

The meeting was held via zoom and opened at 09.30am. Members did a round of introductions for the new member of the Secretariat.

The Secretariat advised the members about the new ministerial portfolios, and advised that due to the new COVID-19 portfolio, the COVID-19 work done by the Committee would be signed off by both the COVID-19 Response Minister and the Minister for Health.

The Secretariat updated the members about the Clinical Principal Advisor on secondment to support the Committee in setting up advisory meetings across District Health Boards for the upcoming work on the review of Getting Through Together.

Members approved the meeting minutes from the meeting on 3 November 2020 with minor changes requested.

**Action**

* Secretariat to amend 03 November 2020 minutes and publish on NEAC’s webpage.
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 Secretariat introduced the document and talked members through the initial feedback on the 2007 Getting Through Together that was received as part of the public consultation on resource allocation and equity in mid-2020. The Secretariat asked that the ethical principles, structure of the revised document and section headings were discussed and agreed on to guide the work of the Secretariat for the next few months.

The Committee agreed on an equity focus and to further consider social determinants of health, and what impacts economics and mental health were already occurring and what was hastened by the pandemic. It was suggested that input from a public health professional would be key to the revision of the document and the Secretariat agreed to progress this out of session.

The Committee also discussed the wider implications of economics on health and the importance of ensuring that existing inequities are not further entrenched.

Members also agreed to lead sections with Secretariat support and that a dedicated principle advisor resource to assist with this project is needed.

**Actions**

* Secretariat to begin drafting sections for consideration at the February meeting, starting with contact tracing and use of data.
* Secretariat to make contact with the suggested public health professional.
* Secretariat to progress with organising more resource for this project.
1. HDC report and modifications of consent discussion

The Committee did a round of introductions as they were joined by Dr Martin Than, Dr Mark Marshall, Ron Patterson, Monique Jonas and Lana Lon for this agenda item.

The Committee and guests discussed the lack of flexibility in relation to consent. It was acknowledged that this was experienced by NEAC, HDEC and Researchers. The discussion noted the differences between waiver of consent due to study design, and waiver due to the patient population being studied, noting that there was cross over between the two but also distinct ethical issues.

After discussion of modification of consent and what informed consent means, its role and what a more flexible legal framework might look like, there was an agreement to proceed with the first steps of engaging and identifying further groups that have a stake in these protections. These included consumers, Maori and health researchers. The Committee noted a strong commitment to change after recognising this need, but also firmly recognises the vulnerability of patients that these measures are there to protect. It was noted that patient groups endorsing this and being worked with will facilitate trust, which the Committee agreed.

The discussion concluded in noting that with a new Minister of Health and new HDC Commissioner, it would be important to brief both on the complexities and options from both an ethical and legal standpoint.

**Actions**

* Secretariat to develop material for NEAC to consider, with input from the HRC EC, Maori, HDEC, Consumers and Researchers, which could accompany a letter to the Minister and the HDC Commissioner.
1. End of Life Choice

The Secretariat advised members that with the passing of the End of Life Choice referendum the Ministry of Health was responsible for the implementation of the Bill and will be seeking input from NEAC as this work progresses. Members noted correspondence from an academic regarding expert advisory involvement in the ethical implementation of the Bill.

A member asked the minutes to reflect their involvement in submitting on the consultation on the development of the Bill.

1. Briefing to the incoming Minister of Health (BIM)

The Secretariat presented a draft of the briefing to the Committee for approval. The Committee thanked the Secretariat for preparing a comprehensive overview of NEAC’s functions and work programme. Minor amendments were noted and members approved the briefing for submission to the Minister of Health.

Action:

* Secretariat to organise for the BIM to be sent to the Minister of Health.
1. APNEC report back from meeting on 25 November 2020

The members who attended gave an overview of discussion they were observers for. After discussion, the Committee suggested that NEAC could host a future APNEC meeting.

Meeting finished at 1.20pm.