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**National Ethics Advisory Committee**

**Ministry of Health - ZOOM**

**19 May 2020**

Attendees: Neil Pickering, Maureen Holdaway, Wayne Miles, Gordon Jackman, Kahu McClintock, Liz Richards, Hope Tupara, Mary-Anne Woodnorth, Dana Wensley.

Ministry staff present: Nic Aagaard, Rob McHawk, Hayley Robertson.

1. Welcome and Ministry update:

The meeting opened at 10.00am. The Chair welcomed members and thanked Angela Ballantyne for joining the dialogue and for her ongoing work on the Resource Allocation Framework.

The Secretariat updated members that new roles have been appointed by Cabinet to cover three vacant NEAC positions. These are:

- community/consumer representative.

- a member with expertise in ethics.

- a member with expertise in epidemiology.

The Secretariat advised that three Annual Reports have been drafted for the years 2017, 2018 and 2019 and are currently undergoing professional editing and formatting through the Ministry of Health. The Secretariat will seek full committee approval on the content of these reports before agreement of the House is sought to publish them on NEAC's webpage.

Actions:

* Secretariat to send out minutes from NEAC’s previous meeting on 29 April 2020 for full committee approval.
* Secretariat to send out correspondence that we've sent in response to councils.
1. Ministry update on Equity Framework for Resource Allocation progress:

There has been a direction from the Ministry of Health for a wider and less urgent consultation given the move to alert level 2. There may be significant public interest in resource allocation and a public consultation would be beneficial to all involved. The Secretariat advised members that a comprehensive consultation list has been drafted. NEAC members suggested names and agencies who might be interested in submitting their thoughts on the Resource Allocation Framework.

1. Resource Allocation Framework:

A member noted that a range of services in hospitals were put on hold during the beginning of the pandemic. Members expressed concern and noted that decisions made in the preparedness of the Covid-19 pandemic have had an impact on non Covid-19 patients. Members reflected about what impacts they have seen on people needing health services during this time and had a discussion about the deprioritising and discussed the repurposing of resources. For example, a range of allied health services were put on hold in preparedness for an influx of patients to ensure that the health system was not overwhelmed. It was acknowledged that the shutdown of medical resources was to minimise contact to lower the spread of Covid-19 not about resource allocation of scare resource.

It was agreed to also include a paragraph acknowledging compromises in times of scarcity in the decision-making section of the Resource Allocation Framework.

Members had a discussion about the scope of the work and were careful not to widen it too much for the Framework document. It was noted that there are a lot of issues that would sit better in the review of the 2007 pandemic guidelines but that the issues should be flagged in the Resource Allocation Framework. Members discussed the current iteration of the framework and the importance of including guidance on the need to review the de-prioritisation of specialist appointments in an emergency situation sooner. It was agreed to include this in the substantial review of the 2007 pandemic planning guidelines.

Members thanked the Secretariat and noted that overall, they are happy with the document and support the release of the Resource Allocation Framework as soon as possible.

A member noted that wording around vaccine allocation should be softened, referring to the overseas global debate about obligations to be vaccinated and acknowledging that not all individuals consider vaccines to be desirable. Members had a discussion about how there will need to be further consideration about communications during the roll out of vaccines when they are available.

Action:

* Members agreed to send the Secretariat suggested questions for submitters to respond to in the public consultation.
1. B4School Check – Data Ethics Advice Request:

Attendees:

Anna Mcdowell - Stats NZ

Barry Milne - University of Auckland

Sheree Gibb - University of Otago

Nick Bowden - University of Otago

Fiona Thomson - Social Wellbeing Agency

Charles Sullivan - Social Wellbeing Agency

Justine Mecchia - Well Child Tamariki Ora

Simon Ross - Data Governance MOH

Laura Clearly - Data services at MOH

Ellish Reilly - Family and community Team MOH

Mary-Anne Woodnorth was not present for this conversation due to a conflict of interest with the before school check data.

Members were joined by the agencies above to progress the discussion and seek clarification on outstanding issues raised in NEAC’s last meeting on 29 April. The attendees presented an overview of the issue of explicit consent obtained at the B4 school check where the data won’t be used for research (but currently is). They noted that while the written information was explicit, the verbal discussion was thought to be broader, and explained the benefits of the continued use of that data set for research and other purposes.

The Secretariat noted that ordinarily when the issue of a lack of specific consent for data is raised with HDEC's, there is a clear pathway for review and an option in the Research Standards for consideration of a waiver of consent for use of data. HDEC’s see a lot of similar applications and have accepted ethical justifications made for use of identifiable B4School check information in the past. This was discussed as an option for researchers in using the B4School check data.

Members were informed about the unique data obtained in the B4School check with it being a national level data set, collected face to face in primary care, and highly valuable from a research perspective for setting the scene for evidence-based policy. The B4School check data is also noted to be a key determinate of health outcomes later in life, identifying inequities and can be used as a measure to flag early whether there may be areas where children need extra assistance. For example, it is the only source of childhood obesity data, and flags difficulties for future long-term consequences in learning, dental issues. NEAC accept that potential uses for research may result in benefit, but cautioned against a blanket view that all research with the data would cause benefit, citing historical cases of research on Māori that did not benefit Māori.

It was noted that the B4School check data was always intended to be used for research, but the consent form did not reflect that intent, and also that the consent form also does not reflect the conversations that individuals undertaking the B4School check are having with children and their parents. NEAC wanted it to be clear that any solution to using past data for research purposes needs to maintain the public’s trust, particularly in the workforce with those living in small communities.

A member of NEAC asked the researchers to consider data sovereignty for Māori and queried how this would be protected. It was noted that through the HDEC pathway the appropriate cultural considerations and review could be undertaken before the data is used in research. NEAC suggested that consultation with Iwi Chairs and the Disability sector be undertaken. NEAC also noted that the consideration of disability perspectives had not been considered in the addressing of the consent and use issue yet.

The Ministry is establishing a group to help adapt and adopt process with Māori governance and data sovereignty. NEAC noted that the B4School check team need to engage with this group, and that early engagement is preferable.

The options proposed by the attendees to address the prior and continued use of the historical data collected under the specific consent wording were:

1. Contact all those signed the consent from and discuss the use. Feasibility was a concern as 56,000 in the last year were in the data set. This goes back 10 years and a concern that details would be incorrect. This option was not considered feasible.
2. Make a public statement on the issue. Clarify the uses of the data and note the statement of use was not accurate. NEAC supported this action.
3. Deliberative engagement process such as citizens jury, where a sample of people are given information and asked questions to determine views that may be representative of the wider group. NEAC supported this, and noted that it should be conducted with Māori, disabled people and if possible, children who are now able to consent for themselves, whose data may have been used.
4. The attendees also asked whether the HDEC could be called upon to review future research proposals that used the historical data. The Secretariat noted this is not possible as it is outside of the scope of HDEC review, due to the data being de-identified, and would breach natural justice requirements. However, the Secretariat noted that the Ministry or, Statistics New Zealand could set up a data governance body that considered future data use. NEAC noted that the new Standards outline data ethics clearly and apply to use of data for research irrespective of HDEC review.

In summary, NEAC believe a combination of the options above should be undertaken, as well as updating the consent for future data collection. NEAC note that collection of data for one purpose when it is fully known it will be used for another purpose without further consent or ethical review is unethical. NEAC thanked the attendees, acknowledging that they were trying to do the right thing and address the ethical issues. NEAC was happy to be involved in future guidance and feedback, and noted that NEACs view was that the above actions should be undertaken in order to maintain public trust in health research and data collection.

1. Next steps:

The Secretariat advised members that the Resource Allocation Framework will be taken through sign out through the Ministry of Health and the document will also be professionally edited and formatted before public consultation.