New Zealand National Ethics Advisory Committee (NEAC)

Asian Bioethics Network Meeting – 4 September 2023

John McMillan and Shannon Hanrahan, National Ethics Advisory Committee

Te Kāwanatanga o Aotearoa
New Zealand Government

MANATŪ HAUORA
MINISTRY OF HEALTH

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New Zealand
NATIONAL ETHICS ADVISORY COMMITTEE

- **The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health in New Zealand**

- **We advise on ethical issues of national significance and set ethical standards for the health and disability sector.**

- **The Ministry of Health provides Secretariat staff and other resources to support NEAC but the Committee remains independent of the Ministry and its work.**

Aotearoa New Zealand

Our unique population and global position mean we are well placed to influence and lead the development and application of new and digital health technologies both here and overseas. We support ongoing innovation, research and evaluation leading to high-quality care.

This includes enhanced use of data and digital technologies and approaches to health care that are sustainable, equitable and centred on the individual and their whānau. It is important to:

- Be cautious in adopting new technologies to ensure they will be used equitably and do not displace other interventions that may be more effective and economical.

- Work in partnership with Māori to honour Te Tiriti o Waitangi.

- Work to achieve pae ora | healthy futures for all New Zealanders.

Māori data sovereignty

- Data sovereignty is a critical part of data governance for Māori and will require careful consideration as precision health technologies emerge that increasingly involve the collection, storage, use and sharing of data, including human tissue and genetic material.

- Indigenous data sovereignty recognises the rights and interests that indigenous populations have over their own data and the need for structures to enable control over how these data are used. Māori data sovereignty recognises that Māori data should be subject to Māori governance that supports tribal sovereignty and the realisation of Māori and iwi aspirations. The rapid development of Aotearoa New Zealand's health data and emerging technologies presents opportunities and challenges for Māori needs, aspirations and outcomes within our health system.

- The advancement and application of technologies must include ensuring Māori needs and aspirations are being met (for example, protecting taonga such as human tissue, which incorporates DNA, whakapapa, and data).

- **Te Mana Raraunga – Māori data sovereignty committee**

This committee has been established to enable Māori Data Sovereignty and advance Māori aspirations for collective and individual wellbeing.

Recent changes

- Modernising our ethics system

- Increasing demand for research ethics review

- Increasing complexity of research

- An increased focus on precision health, use of algorithms, genomics and artificial intelligence

- Updating our Research Ethics Standards

Research Ethics Standards and digitalisation

Our standards review includes the following aims:

- Weave principles of Te Ara Tika Guidelines for Māori Research Ethics throughout document and strengthen Te Ao Māori lens

- Include guidance and standards on emerging technologies and developments since 2019 e.g. AI and large language models

- Include updated health data and new technologies chapters

- Include updated diagram on life cycle of data. Includes further work on retention of data, cleaning/preparation after collection and before storage and disposal

- Include additional guidance on AI, machine learning, large language models, algorithms

- Include additional guidance on human-machine interaction, training of staff in using these technologies

Digitisation and big data in Aotearoa New Zealand

- Have electronic patient records, series of disease registries, research databases and trusted research environment for some administrative data (IDI).

- New national health agency for healthcare delivery – Te Whatu Ora | Health New Zealand.

- Developing a national system called Hira will include personal health records, platform for healthcare providers to access information and secure ecosystem for app development.

- Duty as kaitiaki (guardian) of the data.

Development and use of AI and algorithms in healthcare in Aotearoa New Zealand

- Have governance, processes and infrastructure for assessing AI or algorithmic products to be developed or used in healthcare system.
- Small but growing use and interest in using AI in healthcare.

Resources

- Algorithm Charter

- Guidance on use of generative AI and LLMs

- Principles for the Safe and Effective Use of Data and Analytics

- Government Use of Artificial Intelligence in New Zealand

- Trustworthy AI in Aotearoa – AI Principles