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The Royal Australasian College of Physicians' submission to the Ministry of Health

HISO 10094:2021 Māori Descent and Iwi Affiliations Data Protocols

Whiringa-a-Rangi | November 2021

Introduction

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to submit feedback on the draft Health Information Standard 10094:2021 (the Standard), Māori Descent and Iwi Affiliation Data Protocols.

The RACP works across more than 40 medical specialties to educate, innovate and advocate for excellence in health and medical care. Working with our senior members, the RACP trains the next generation of specialists, while playing a lead role in developing world best practice models of care. We also draw on the skills of our members, to develop policies that promote a healthier society. By working together, our members advance the interest of our profession, our patients and the broader community.

Key points

- A nationally-consistent protocol aligned with Stats NZ is welcomed.
- Māori descent and iwi affiliation data are taonga, as a record of whakapapa. Any and all data provided by tangata whenua is taonga, whether indicating whakapapa, sex or gender, or health status.
- Data are neither neutral nor static, and have been used in ways that have actively harmed tangata whenua.
- Training for collectors in Te Ao Māori, Te Tiriti o Waitangi, cultural competence and cultural safety is foundational, particularly for data collectors working in the field or in communities.
- Greater information regarding the Ministry of Health’s plans for outputs and implementation of a co-governance framework is needed.

Section 1 – Purpose

The RACP supports the intention and purpose of the Standard, and of the consultation document.

Giving active, lived expression to Te Tiriti partnership is fundamental to all aspects of the health system. This includes the data and information provided by people and whānau to support policy, programmes, resource allocation and decision-making.

Data are not neutral entities. Data has been deployed as a tool of governmental and institutional power throughout history, and continues to operate as an organising principle, categorising and classifying information according to accepted, seemingly objective frameworks. As Maggie Walter and Stephanie Russo Carroll note, “Data are created and used by the assumptive determinations of their makers to collect some data and not others, to interrogate some objects over others and to investigate some variable relationships over others”[1].

The rationale for, and context of the consultation and the Standard are evidenced in Māori health outcomes; most starkly the persistent life expectancy gap between Māori and non-Māori. This gap finds Māori dying on average, seven years earlier than non-Māori, and living with chronic health conditions and/or disability from younger ages than non-Māori[2].

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[1] Walter M, Kukutai T, Russo Carroll S, Rodriguez-Lonebear, D, editors. Indigenous Data Sovereignty and Policy. London: Routledge; 2021.

[2] Manatū Hauora. Ministry of Health. Tatau Kahukura: Māori health statistics. Ngā mana hauora tūtohu: Health status indicators: Life expectancy. Available from: https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/life-expectancy. Accessed 4 November 2021.

While the consultation cites the findings and recommendations of the Health and Disability System Review, the Waitangi Tribunal's Wai 2575 inquiry, there have been a litany of commissions, reviews and investigations have shown that the health system has failed to ensure equitable health outcomes for Māori since 1840.

We note that the Ministry continues to work with Māori, including the Data Iwi Leaders Group to understand its "obligations and responsibilities with respect to Māori data sovereignty and governance". The RACP is encouraged by the continued partnership, between the Ministry and the Data Iwi Leaders Group, as it will support a vision and framework centred on Te Tiriti principles.

We strongly support the Ministry and Iwi Data Leaders Group publicly sharing the definition of Indigenous data sovereignty it is applying to this work in the final version of the Standard. This would support organisations within the health sector (including medical colleges) explore how to apply such a definition and framework to the data these entities collect.

The Consultation on the Standard is timely. The Whānau Ora Commissioning Agency is currently seeking Māori health data to support the vaccination rollout through its network of vaccination locations from the Ministry of Health[3]. The data would enable the Agency to implement a highly targeted vaccination programme using a by Māori, for Māori, as Māori framework, informed by te reo me ona tikanga Māori – including principles of Manaakitanga, Whanaungatanga, Kaitiakitanga, and Tino Rangatiratanga.

Although this example is obviously beyond the scope of this consultation, it does raise interconnected issues related to the implementation and application of Indigenous Data Sovereignty in the real world. Further, we note that the Covid-19 vaccination programme is one current Ministry initiative this Standard is being utilised.

Section 2 – Scope

The RACP supports the scope of the Standard as described in the document, especially the consistency with the Stats NZ Iwi Statistical Standard and Classification. This underscores the need for a single, consistent Standard for government, NGO, academic, and community sectors.

Section 3 – Background

3.3 Definition of iwi affiliation

The Ministry of Health's approach to data collection, privacy and storage is through a Western, biomedical science lens – something the consultation document itself acknowledges through its emphasis on self-identification. These conversations are dynamic: data is neither neutral nor static.

Recognising Māori descent and/or iwi affiliation may change over time acknowledges the legacy of colonisation in Aotearoa New Zealand, where people and whānau have become separated and alienated from their whakapapa. The Standard strikes a balance between consistency for reporting across Māori descent and/or multiple iwi affiliations, while leading from an inclusive, self-determining and person-centred position.

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[3] Tahana J. Ministry of Health "reconsidering decision" to not provide Māori vaccine data. [Internet]. RNZ 2 November 2021. Available from: https://www.rnz.co.nz/news/te-manu-korihi/454790/ministry-of-health-reconsidering-decision-to-not-provide-maori-vaccine-data. Accessed 4 November 2021.

Section 4 – Protocols for collection Māori descent and iwi affiliation data

“We have often allowed our ‘histories’ to be told and have then become outsiders as we have heard them being retold”

Linda Tuhiwai Smith[4]

The RACP supports clear protocols for Māori descent and iwi affiliation consistent with Stats NZ. This section identifies is careful to delineate between those likely to be responsible for data entry, and those providing data. How Māori descent and iwi affiliation is recorded has contributed to harm; where this information is held, classified, re-presented and contextualised to support deficit narratives driven by colonisation. This is not a historical phenomenon: in 2020, RNZ revealed the New Zealand Police were stopping and illegally photographing rangatahi Māori on the street, before entering their images into a database as ‘intel notings’[5].

4.3 Process for collecting Māori descent and affiliation data

Data collectors must receive appropriate cultural competency and cultural safety education and training, especially if they are working to support collection of self-identification Māori descent and iwi affiliation data in the field (such as in the Census, or the Covid-19 response)

Section 5 – Protocols for classifying, coding and recording Māori descent and iwi affiliation data

The RACP supports the Standard’s minimum six responses to iwi affiliation questions. This level of guidance is useful as the College reviews its own systems for self-identification of Māori descent and iwi affiliation.

Note that under item 5.3.3 at line 3, it should read as “an iwi and a hapū”.

Section 6 – Output of Māori descent and iwi affiliation data

The RACP notes that this section is still developing and emergent.

Section 7 – Adoption and Implementation

As our submission has noted above, this consultation is timely given the recent High Court case taken by the Whānau Ora Commissioning Agency to compel the Ministry of Health to release data to support a targeted vaccination drive among whānau Māori. While this example considered identifiable and individualised data, rather than higher-level, de-identified data, the principles are broadly similar.

Although Active Protection and Tino Rangatiratanga are identified in the consultation document, all Te Tiriti principles uphold Māori descent and iwi affiliation output data. Perhaps most importantly in relation to data outputs and governance, Partnership should be specifically articulated.

The document describes future states of self-determination and Mana Motuhake and involvement of whānau, hapū and iwi, yet there is no information included as to what a co-governance model with

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[4] Tuhiwai Smith L. Decolonizing Methodologies: Research and Indigenous Peoples. [3rd Ed.]. New York: Zed Books; 2021.

[5] Hurihanganui T. Police use app to photograph innocent youth: “It’s so wrong”. [Internet]. RNZ 26 March 2021. Available from: https://www.rnz.co.nz/news/in-depth/437944/police-using-app-to-photograph-innocent-youth-it-s-so-wrong. Accessed 4 November 2021.

the Ministry as the Te Tiriti Partner will look like; if there is scope for individual iwi to have different agreements as to output data; or a timeline for when a co-governance model will be released.

The RACP recommends the final version of this document includes further information regarding the co-governance model. How data will be governed, and where partnerships will sit within the new health system architecture – the Māori Health Authority, Health NZ, and the Ministry of Health – would also be useful to include.

Overall general comments

Indigenous Data Sovereignty is a global movement, and Aotearoa is fortunate to have several prominent experts working in data sovereignty and governance from a Te Ao Māori perspective. The CARE Principles for Indigenous Data Governance (Collective benefit, Authority to control, Responsibility, Ethics) should inform the overarching frameworks and the outputs section, as well as align with the principles in the Te Mana Raraunga Charter[6] [7].

Conclusion

The RACP thanks the Ministry of Health for the opportunity to provide feedback on this consultation. To discuss this submission further, please contact the NZ Policy and Advocacy Unit at policy@racp.org.nz.

Nā māua noa, nā

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[6] Global Indigenous Data Alliance. CARE Principles for Indigenous Data Governance. 2018. [Internet]. Available from https://www.gida-global.org/care. Accessed 4 November 2021.

[7] Te Mana Rauranga. Māori Data Sovereignty Network. Tūtohinga. Our Charter. [Internet]. Available from: https://www.temanararaunga.maori.nz/tutohinga. Accessed 4 November 2021.