

New Zealand's revised Ethnicity Data Protocols must not become a shelved document: a challenge from Hei Āhuru Mōwai

Hei Āhuru Mōwai – National Māori Cancer Leadership Group

Māori New Zealanders suffer substantial inequities in health outcomes compared to non-Māori New Zealanders—and these inequities are perhaps most profound in the context of cancer. Māori are 20% more likely to get cancer than non-Māori, but 80% more likely to die from it.¹ Of the 21 cancer sites investigated in the comprehensive Cancer Trends study, more than 80% (17 cancers) had an excess mortality rate that was at least 10% higher for Māori compared to non-Māori.²

A health system that collects high-quality ethnicity data is able to measure and monitor healthcare and outcomes for ethnic groups within its population, and also to compare between ethnic groups to cast light on health inequities. In September 2017, our Ministry of Health published a revised version of their Ethnicity Data Protocols (hereafter 'Protocols'),³ which updated the original protocols.^{4,5} The 2017 version outlines "*a new set of minimum standards that apply across the health and disability sector to all organisations that collect, record and use ethnicity data*".³

Why is it important for our health system to have a set of protocols around the collection of ethnicity data, and why is it crucial that our district health boards follow-through on its implementation? The general need for ethnicity data has been well-covered by others (see Cormack and McLeod's 2010 report for a summary⁶), but the primary reasons are to ensure a) that ethnicity data is collected as a matter of routine, and b) that the ethnicity data that

is collected is as high-quality as possible. With respect to the latter, markers of quality discussed in the revised Protocols include **accuracy** (ie, the collected ethnicity data accurately captures ethnic affiliations for a given individual), **standardisation** (ie, that ethnicity data is always collected in the same way across the sector), **granularity** (ie, the collected ethnicity data is sufficiently detailed to allow for the reality of ethnic complexity) and **currency** (ie, that new ethnicity data is collected regularly for an individual, rather than once or twice in a lifetime). For the remainder of this letter, we will focus on the guidance provided within the revised Protocols around these factors.

With respect to **accuracy**, the Protocols make it clear that a respondent must identify their own ethnic affiliations: these cannot be inferred or guessed. If an individual is unable to self-identify due to incapacity, death or because they are a newborn/child, ethnicity data should be collected from the next of kin.³ The Protocols also make it clear that there is to be no collection of 'principal ethnicity': this practice further marginalises minority ethnic groups and almost certainly results in an undercounting of Māori. Rather, the Protocols state that an individual must be permitted to declare as many ethnic affiliations as they wish, and that a minimum of six (previously three⁴) of these affiliations must be stored.

With respect to the **standardisation** of ethnicity data collection, the Protocols make it clear that only the 2013 New Zealand

Census ethnicity question should be used to collect ethnicity data. In addition, the Protocols state that if an individual declares an ‘Other’ affiliation—that is, affiliation to an ethnic group that is not one of the options in the 2013 Census question—that the individual must be allowed to state what this ‘Other’ ethnic affiliation is. The absence of this ‘Other’ information undermines our ability to validly capture an individual’s ethnic affiliations—an important consideration, particularly given that many Māori also affiliate with one or more Pacific ethnic groups that may not be explicitly listed as part of the 2013 Census question.

With respect to **granularity**, the Protocols make it clear that ethnicity data must be categorised at Level 4, which is the most detailed classification possible. Previously, the minimum standard was Level 2. While this granularity does not impact on Māori affiliation—which remains a single classification across Levels—it is again important to ensure that our ethnicity data validly captures the ethnic groups that an individual affiliates with.

With respect to **currency**, the Protocols make it clear that new ethnicity data must be collected a minimum of every three years, but preferably as often as possible. The Protocols state that new ethnicity data could be collected at the same time as other personal details are collected, such as contact information. Given this directive, it is unacceptable for those who have contact with patients to rely on existing ethnicity data from a patient management system (or similar), given that this data may be considerably out of date (or based on previous inference). Ethnic affiliation may change

over time: the regular collection of ethnicity data ensures that the recorded information adequately reflects an individual’s ethnic affiliations, and reduces the reliance on historic health datasets, many of which have been shown to undercount Māori.⁷

The inequities in cancer care and outcomes shouldered by Māori New Zealanders are abhorrent and unacceptable. The collection of high-quality ethnicity data is crucial in allowing us to identify and monitor cancer care and outcome inequities, and also to adequately direct and monitor efforts to eliminate them. The new Ethnicity Data Protocols offer guidance on best-practice strategies for achieving these objectives. Hei Āhuru Mōwai considers that high-quality ethnicity data are a crucial cornerstone for improving outcomes for Māori, and we support the key elements contained within the revised Protocols.

Hei Āhuru Mōwai also issues two challenges to the Ministry and wider sector: firstly, we challenge the Ministry to exert the necessary leadership to ensure that these protocols do not become shelved documents, but rather an intrinsic part of business-as-usual across our district health boards and their associated services. If implementation strategies such as recurring training and resource provision are required to make this a reality,⁶ then these strategies must be adequately resourced and implemented. Secondly, we challenge our colleagues in the wider health sector who have the opportunity to influence and improve the quality of ethnicity data collection where they work to do so. We must all commit to collecting ethnicity data accurately, appropriately, and often.

Competing interests:

Nil.

Author information:

Jason K Gurney, Department of Public Health, University of Otago, Wellington;
 Nina Scott, Public Health Physician, Waikato DHB, Hamilton;
 Gary Thompson, Chair: Ngāti Paoa Iwi Trust, Kaiwhakarite Community Waikato,
 Morrinsville; Stephanie Turner, Director of Maori Health MidCentral District Health Board,
 Rangitikei; Jo Anson, Manager of Central Cancer Network, Palmerston North;
 Melissa Cragg, Principal Consultant of Karake Consultancy, Blenheim;
 Joanne Doherty, Independent Health Advisor, Researcher and Evaluator, Wellington;
 Madeleine Wall, Radiologist, Wellington; George Laking, Medical Oncologist, Auckland;
 Terina Moke, General Manager, Learning, Royal NZ College of General Practitioners,
 Wellington; Rawiri Blundell, Maori Health Manager Pinnacle Midlands Health Network,
 Hamilton; Pania Coote, District Manager Maori Health Southern District Health Board, Bluff.

Corresponding author:

Dr Jason K Gurney, Department of Public Health, University of Otago, Wellington.
 jason.gurney@otago.ac.nz

URL:

<http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2018/vol-131-no-1470-23-february-2018/7505>

REFERENCES:

1. Robson B, Purdie G, Cormack D. Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status, 2002–2006. Wellington: Ministry of Health, 2010.
2. Soeberg M, Blakely T, Sarfati D, Tobias M, Costilla R, Carter K, Atkinson J. Cancer Trends: Trends in cancer survival by ethnic and socioeconomic group, New Zealand 1991–2004. Wellington: University of Otago and Ministry of Health, 2012.
3. Health Information Standards Organisation. HISO 10001:2017 Ethnicity Data Protocols. Wellington, New Zealand: Ministry of Health, 2017.
4. Ministry of Health. Ethnicity data protocols for the health and disability sector. Wellington: Ministry of Health, 2004.
5. Ministry of Health. 2004 Ethnicity data protocols for the health and disability sector: Supplementary Notes. Wellington: Ministry of Health, 2009.
6. Cormack D, McLeod M. Improving and maintaining quality in ethnicity data collections in the health and disability sector. Wellington, New Zealand: Te Rōpū Rangahau Hauora a Eru Pōmare, 2010.
7. Cormack D, Robson C. Classification and output of multiple ethnicities: considerations for monitoring Māori health. Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare, University of Otago, Wellington, 2010.