



Iwi (tribal) data collection at a primary health care organisation in Aotearoa

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ABSTRACT

INTRODUCTION: Indigenous peoples' rights include the right to self-determine one's identity. For Māori, this includes self-assignment of ethnicity, and traditional identities such as Iwi (tribe). New Zealand's Ministry of Health requires health services to collect ethnicity data using standard protocols. Iwi data are also collected by some health services; however, with no health-specific protocols, little is known about Iwi data collection and quality. The National Hauora Coalition (NHC) Primary Healthcare Organisation (PHO) sought to understand Iwi data collection across its network of primary care providers.

AIM: To understand Iwi data collection at the NHC PHO; specifically, is it being routinely collected, how is it being collected and what are the results?

METHODS: In 2017, NHC's general practice clinics were invited to submit their enrolment forms, which capture ethnicity and potentially Iwi information, by e-mail to the audit team. Forms were reviewed to determine whether Iwi information was being collected and if so, what question was being used. Iwi numbers were collated from the annual data extract.

RESULTS: Thirty-three of a total of 35 clinics (94%) submitted their enrolment forms to the audit team. Nine of the 33 clinics (27%) sought Iwi name/s with a specific question on their enrolment form. Six different 'Iwi' questions were used by the nine clinics. The data extract revealed that the NHC had Iwi data for 13% (2672/20,814) of its Māori enrolments. Ngāpuhi were the largest Iwi group at the NHC.

DISCUSSION: This is the first study to describe the quantity and quality of Iwi data collection in NZ primary care. Standard procedures for collecting, recording and using Iwi data are being developed by the NHC PHO. These could inform national protocols to optimise the quality of Iwi data.

KEYWORDS: Iwi; Indigenous health data; Primary care; Indigenous data sovereignty; Indigenous identification

Introduction

There are over 300 million Indigenous Peoples living across the world. Indigenous Peoples are custodians, guardians and practitioners of unique

ways of life.¹ Many also experience a shared history of colonisation and violation of human rights. For example, some colonial governments did not even acknowledge Indigenous Peoples as human until

recently,² a clear example of institutionalised racism.³

The Declaration on the Rights of Indigenous Peoples⁴ recognises the right of Indigenous Peoples:

‘to determine their own identity or membership in accordance with their customs and traditions. This does not impair the right of indigenous individuals to obtain citizenship of the States in which they live.’ [Article 33.1]

Self-determined identity as an Indigenous person within a colonised society is an important political statement. It also supports the monitoring of colonising governments and their responsiveness to Indigenous Peoples’ rights.⁵

In Aotearoa Māori, the Indigenous Peoples, are ‘counted’ as a separate ethnic grouping. Ethnicity in this regard is:

‘the ethnic groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation. It is not a measure of race, ancestry, nationality, or citizenship. Ethnicity is self-perceived and people can belong to more than one ethnic group.’⁶

It is worth reiterating that ethnicity is as much an individual’s right to self-identify as it is a measure of external assignment and categorization.⁷

Demographic data, including self-identified ethnicity and Māori descent (ie ancestry, or whakapapa), are collected every 5 years during Aotearoa’s national census. Questions for each are set by NZ Statistics (Figure 1) and these are considered ‘best-practice’. In the 2018 NZ census, 16.5% (775,836) of the total population self-identified as Māori ethnicity⁸, up from 14.9% in 2013, and this proportion is expected to continue to grow.⁸ The 2018 population of Māori descent was 19.1% (896,567) of the total usually resident population⁹, indicating that more Māori claim Māori whakapapa/descent than self-identify as Māori ethnicity.

Ethnicity is just one form of identity available to Māori; Māori identity is also shaped by whakapapa (ancestry/descent) and self-groupings into Iwi (tribes), Hapū (sub-tribe) and whānau (extended family), which are based on whakapapa kinship.¹¹ Iwi are defined by geographical areas and there are

WHAT GAP THIS FILLS

What is already known: Health services in Aotearoa are required to collect ethnicity data using standard protocols. Some health services also collect Iwi data, but with no health-specific protocols. Little is known about Iwi data collection and quality.

What this study adds: This is the first study to describe the quantity and quality of Iwi data collection in NZ primary care.

Figure 1. Ethnicity, ancestry and Iwi questions¹⁰

7.	Which ethnic group do you belong to? <i>Mark the space or spaces which apply to you.</i> New Zealand European Māori Samoan Cook Islands Māori Tongan Niuean Chinese Indian Other (eg Dutch, Japanese, Tokelauan. Please state)
11.	Are you descended from a Māori (that is, did you have a Māori birth parent, grandparent or great-grandparent, etc)? Yes Don't know No
12.	Do you know the name(s) of your Iwi (tribe or tribes)? Yes No
13.	Give the name(s) and region(s) of your Iwi (tribe or tribes): Iwi: Region:

over 100 different Iwi across Aotearoa based on the Iwi Statistical Standard, a list of all known Iwi at a specific time.^{12,13} The list will develop over time with further input from Iwi.¹⁴ Table 1 presents the nine largest Iwi reported in the 2013 census (noting that there were issues with Iwi data in the 2018 census¹⁵). Some Māori belong to more than one Iwi,¹⁶ and this number will increase with inter-marriage and improved access to knowledge of one’s whakapapa.

As highlighted in Table 1, not all people identify with or know their Iwi. As a result, many Iwi, Hapū and Whānau are self-funding surveys and

Table 1. Nine largest Iwi in Aotearoa New Zealand¹⁶

Iwi	2013 census (n)
Ngāpuhi	125,601
Ngāti Porou	71,049
Ngāi Tahu	54,819
Waikato	40,083
Ngāti Tūwharetoa	35,874
Ngāti Maniapoto	35,358
Tūhoe	34,890
Ngāti Kahungunu ki Te Wairoa	21,060
Te Arawa	19,719
Total Māori who identified with an Iwi	535,941
Total Māori ethnicity (2013)	598,605
Total Māori descent (2013)	668,724

census-type activities to identify their own peoples. One example is Ngāi Tahu.¹⁷ These Iwi-led activities are particularly important in light of Waitangi Tribunal¹ claims so that people who identify with a particular Iwi can participate in decision-making, engage with Iwi-led programs and access support such as scholarships for higher education. Differences in the definitions and methods used to collect Iwi data exist between Statistics NZ and Iwi, as well as between Iwi, which has both strengths (such as Iwi-determination) and limitations (in terms of standardisation).

One potential site for Iwi data collection is health services. Ethnicity data are currently routinely collected by health and disability services in Aotearoa. The Ethnicity Data Protocols, describing the standard procedures for collecting, recording and using data on the ethnicity of people by health services, were updated in 2017.^{18,19} Although the collection of ethnicity data is mandatory for health services, the Ministry of Health does not require the collection of Iwi data. Instead, it recommends that 'an iwi response to the ethnicity question is coded to Māori'.¹⁸ However, many health services have recorded Iwi names in the person's patient management system (PMS), although there is little information about the collection methods (including their consistency) or numbers.

The National Hauora Coalition (NHC) Primary Health Organisation (PHO) is a Kaupapa Māori

health organisation that, in 2017, had more than 35 general practice clinics across its Auckland and Waikato networks. The PHO had protocols to standardise the collection of most demographic information, including ethnicity; however, it did not have a protocol to collect Iwi information. With an interest in Indigenous data and its use in practice, we sought to better understand Iwi data in our organisation; specifically, is it being routinely collected, how is it being collected and what are the numbers? This project sought to address these questions with an audit of current practice across the NHC general practice clinics in 2017.

Methods

The audit was undertaken over 4 weeks from 14 September to 12 October 2017.

An email explaining the purpose of the audit and requesting the clinic's current Ethnicity Data Form was sent to the practice managers of NHC's 35 general practice clinics from the Lead for Network Relations Primary Care Networks. The subject heading was 'Enrolment Form – Section Ethnicity Iwi'. The email stated 'We are doing a stock take of all our practices' enrolment forms who are collecting Iwi in their ethnicity section – would you please send me a copy of your current enrolment form. I understand you are very busy but we would greatly appreciate your help. Thank you in advance – please don't hesitate to contact me if you have any questions' and provided the contact details for the Lead Researcher. Practice Managers scanned the forms and sent these by email to the Lead Researcher. When there had been no response within 2 weeks, a follow-up phone call to practice managers was made.

The forms were reviewed for an Iwi-specific question by the audit team of JE, MH and RJ. The audit was supplemented by an extract from each practice of the most recent ethnicity data for their enrolled patients, including Iwi where this was collected. The extract was collated by the NHC for reporting purposes at the end of the fourth quarter of the 2016–17 financial year, which was 30 June 2017.

The project did not require ethical approval as it was an audit, was undertaken by the PHO, and no personal health information was collected.²⁰

Results

Of the 35 NHC clinics at the time of the audit, 33 (94.3%) responded to the audit during the audit period.

Nine (27%) of the 33 responding clinics collected Iwi data on their enrolment forms. These forms are completed in a handwritten format, generally at the time a person enrolls in a clinic. As shown in Table 2, there was variation between the nine clinics in the

Table 2. Six versions of the Iwi questions and number of practices using each version

	Iwi question versions	Number of clinics	Clinics using this version	Percentage Māori enrolled at the clinic
Tahi	3. Ethnicity*: WHICH ETHNIC GROUP DO YOU BELONG TO? (YOU MAY SELECT UP TO THREE ETHNICITIES): NZ European/Pakeha 11 <input type="checkbox"/> Tokelauan 35 <input type="checkbox"/> Not Stated 99 <input type="checkbox"/> Māori (please state Iwi) 21 <input type="checkbox"/> African 53 <input type="checkbox"/> Declined 95 <input type="checkbox"/> Samoan 31 <input type="checkbox"/> Other Pacific 37 <input type="checkbox"/> Latin American/Hispanic 52 <input type="checkbox"/> Cook Island Māori 32 <input type="checkbox"/> Middle Eastern 51 <input type="checkbox"/> Fijian 36 <input type="checkbox"/> Tongan 33 <input type="checkbox"/> South East Asian 41 <input type="checkbox"/> Other European 10 <input type="checkbox"/> Niuean 34 <input type="checkbox"/> Other Asian 44 <input type="checkbox"/> Chinese 42 <input type="checkbox"/> Indian 43 <input type="checkbox"/> Other Ethnicity (please state) 51 <input type="checkbox"/>	2	A	68
			B	80
Rua	Nationality/Ethnicity – Please circle all that apply – 21 MĀORI IWI _____ 33 TONGAN 32 COOK ISLAND MĀORI 31 SAMOAN 11 NZ EUROPEAN 35 TOKELAUAN 36 FIJIAN 34 NIUEAN 37 OTHER PACIFIC ISLAND 30 PACIFIC NOT FURTHER DEFINED 51 MIDDLE EASTERN 53 AFRICAN 41 SOUTH EAST ASIAN 43 INDIAN 42 CHINESE 44 OTHER ASIAN 40 ASIAN NOT FURTHER DEFINED 12 EUROPEAN 10 OTHER EUROPEAN 94 NOT STATED ETHNICITY _____	2	C D	79 20
Toru	Ethnicity Details Which ethnic group(s) do you belong to? Tick the space or spaces which apply to you <input type="checkbox"/> New Zealand European <input type="checkbox"/> Māori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Māori Iwi: <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Other (such as Dutch, Japanese, Tokelauan). Please state _____ _____	2	E F	12 18
Whā	Ethnicity Details Which ethnic group(s) do you belong to? Tick the space or spaces which apply to you <input type="checkbox"/> New Zealand European <input type="checkbox"/> Māori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Māori Name the Iwi you affiliate with: <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Other (such as Dutch, Japanese, Tokelauan). Please state _____ _____	1	G	88

Table 2. Continued

	Iwi question versions	Number of clinics	Clinics using this version	Percentage Māori enrolled at the clinic
Rima	Which ethnic group do you belong to? Please tick which applies to you <div> <div>NZ Māori</div> <div>NZ European/Pakeha</div> <div>IWI</div> <div>Burmese</div> </div> <div> <div>Samoan</div> <div>Middle Eastern</div> <div>African</div> <div>Chinese</div> </div> <div> <div>Latin American</div> <div>Indian</div> <div>Other (please state)</div> </div>	1	H	17
Ono	Ethnicity Details Which ethnic group(s) do you belong to? Tick the space or spaces which apply to you <div> <div>New Zealand European</div> <div>Māori</div> <div>Samoan</div> <div>Cook Island Māori</div> <div>Tongan</div> <div>Niuean</div> <div>Chinese</div> <div>Indian</div> <div>Other (such as Dutch, Japanese, Tokelauan). Please state</div> </div> If Māori – Please state Iwi →	1	I	10
	No Iwi question	25	Not applicable	53
	Did not respond	2	Not applicable	
	TOTAL	35		

Table 3. Ten most common Iwi at NHC in 2017

Order largest to least	Iwi
1.	Ngā Puhi
2.	Ngāti Maniapoto
3.	Tainui
4.	Ngāti Tūwharetoa
5.	Ngāti Porou
6.	Tūhoe
7.	Te Arawa
8.	Te Ati Hau Nui-A-Pāpārangi
9.	Waikato
10.	Ngāti Kahungunu

¹For more information about the Waitangi Tribunal, see: <https://waitangitribunal.govt.nz/claims-process/>.

Iwi data question used, its location on the clinic enrolment form, and the space available to write the names of Iwi (up to four). Version Tahī was used by two practices and therefore made available to 13% of the PHO's Māori enrolments compared to version Rua, used by two practices and available to 17%, and version Toru, used by two practices and available to 9% of Māori. Versions Toru and Whā were the only forms to have room to write the names of up to four Iwi.

Most clinics surveyed (24, 73%) did not collect Iwi data. As a result, 11,054 Māori people, or 53% of the total Māori population at the NHC PHO, were not able to document their Iwi in their primary care record.

A review of Iwi data across NHC's enrolled population revealed further information. At the time of the audit, the NHC had Iwi data for 2672 of the 20,814 (13%) Māori people enrolled. In the auditing process, we found that only one Iwi could be recorded in the electronic Patient Management System (PMS) per person. When questioned about which Iwi was recorded, for people with two or more Iwi listed, administrators advised us that the first on the list was selected. The 10 top Iwi recorded are listed in Table 3. In total, 100 Iwi were recorded.

Importantly, 91 people who did not self-identify as Māori ethnicity had an Iwi recorded in their PMS record (Table 2).

Discussion

An audit at the NHC Primary Health Organisation in 2017 was undertaken to understand Iwi data collection at its 35 general practice clinics. Of 33

respondents, nine general practice clinics formally sought the name/s of a person's Iwi on enrolment forms. There was significant variation with six different 'Iwi' questions used by the nine clinics. Data were collected in handwritten format rather than electronically. When available, there was room for the person to write one or up to four Iwi on the different forms. When administrators transferred this information to the person's electronic patient medical record (PMR), only one Iwi could be listed and administrators chose the first listed. Therefore, Iwi data for some people at NHC practices is not 'self-determined'. Ngāpuhi were the largest Iwi group. The NHC had Iwi data for 13% of Māori enrolments.

The audit identified several issues. The Iwi data collection questions were not consistent, often did not provide room for more than one name, and were completed at enrolment. Appropriate policy and process at the PHO, including distribution of an exemplar Iwi data collection question as shown in Figure 1,¹² in the same way as the PHO provides templates for the collection of ethnicity and other data, would support a standardised approach. In addition, we recommend regular opportunities for people to self-define themselves based on Iwi. Many people find it difficult to integrate both traditional and contemporary identities, thus creating a constant desire for Indigenous Peoples to re-affirm themselves.⁵ A regular check, in line with current protocols for checking ethnicity and other demographic information every 3 years,¹⁸ may help to address this.

At the time of the audit, only one Iwi per person was able to be entered into the PMS record, which is unacceptable. The NHC has taken steps to address this and now all Iwi listed by enrollees are captured in each person's PMS (pers. comm. with Jonathan Murray, 10 February 2020). Despite the fact that only one Iwi was entered for each person providing their Iwi name/s, the 10 most common Iwi for this PHO were mainly consistent with national data. The main difference was Ngāi Tahu, which did not feature in the top 10 of Iwi at the NHC. This is unsurprising, as NHC practices are located in the North Island, whereas Ngāi Tahu is centred in the South Island. The 91 people with an Iwi recorded, despite not having Māori ethnicity, may reflect an error with data entry or a personal choice to assign

non-Māori ethnicity despite being of Māori descent.

Issues with Māori and Iwi data collection and use are well documented,²¹ with calls for Māori data sovereignty, including complete control over the collection, analysis, storage and use of Māori data.²¹ Given its infancy, Iwi data collection in primary care could start with setting safe and sustainable rules and processes based on Indigenous Data Sovereignty recommendations.²¹ Snipp's²² tenets of data de-colonisation (that Indigenous Peoples exercise sovereignty and control of data, the data reflects the interests and priorities of Indigenous communities and they dictate the content of and access to data) provide an excellent foundation for such rules and processes. Further thought to the governance and operationalisation of the collection, analysis, and dissemination of Iwi data into primary care is recommended.

Iwi and primary care services in Aotearoa may wish to look to international models. For example, in the United States, many health services are run by Tribal entities that collect and analyse data by Tribes who have set their own demographic data agendas.²³ The Ysleta del Sur Pueblo (YDSP) and Cheyenne River Sioux (CRS) Tribal peoples in North America are considered the exemplars of providing leadership in this regard.²⁴ Primary care services in Aotearoa could similarly support Iwi in their desire to set and govern their own data programs.²⁵

Most NHC clinics did not collect Iwi data. Iwi data have the potential to provide a level of granularity to Māori data, and supports the rights of people to name themselves in ways that give meaning. It is particularly useful for understanding and tracking outcomes by Iwi, monitoring the responsiveness of health-care services delivered to Iwi, and thereby informing the development of Iwi-specific services.^{11,26} Other uses include supporting opportunities for people to access Iwi-led health programmes. One example is access to private health insurance for people identifying as Ngāti Whātua Iwi.²⁷ Although such benefits are important, there is a risk that those people who do not have access to whakapapa or knowledge about their Iwi (Table 1) may 'miss out'. Although not the remit of health-care services, services that safely connect

Māori to their Iwi are available²⁸ and could be offered to people.

There are several limitations to this research. It was an audit of a small primary care organisation with 35 general practitioner-led primary care clinics. It is therefore not reflective of all primary care services in NZ. We believe that Iwi-led health services (eg Ngāti Porou Hauora, Ngāti Toa, Ngāti Whātua ki Ōrākei) will have more and better-quality data on Iwi. However, as far we are aware, this is the first Iwi data audit in primary care to be published. Another limitation is that the audit was undertaken at the end of 2017. However, we believe the findings are still relevant today, given the current environment of Iwi development, Waitangi claims and Indigenous data sovereignty.

Despite these limitations, this study makes an important contribution to highlighting systematic problems that contribute to continued restrictions to self-determination of Māori peoples in Aotearoa. The audit revealed areas for improvement at NHC. Plans to implement corrective actions are under way and will be monitored. Standard procedures for collecting, recording and using Iwi data are being developed by the NHC PHO. These could be used as the basis for national protocols to optimise the quality of Iwi data.

Competing interests

AA, RMJ and JM are employees of the NHC PHO. The other authors (KB, JE, MH and VS) have no competing interests to declare.

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