



Ethnicity data and primary care in New Zealand: lessons from the Health Utilisation Research Alliance (HURA) study

Health Utilisation Research Alliance (HURA)

Abstract

Aims To explore issues in the collection and analysis of ethnicity data in primary care, and discuss the implications of this for health services research.

Methods Data routinely collected by 25 Wellington Independent Practice Association (WIPA) general practices in 2001.

Results Practices varied in the level of ethnicity data coverage achieved, ranging from less than 10% to greater than 90% of patients. Combining practice data with National Health Index (NHI) ethnicity data increased coverage to at least 70% for registered patients at 23 of 25 practices. There were differences between the data collected in general practices and ethnicity recorded on NHI. However, with the exception of the 'Other' category, this disagreement was not systematic. Practices had lower proportions of patients with ethnicity recorded as 'Other' (not further specified) than NHI ethnicity records.

Conclusions The study demonstrated that it is possible to collect quality ethnicity data in general practices, although there are challenges. Merging practice-collected ethnicity data with NHI ethnicity data increases coverage. However, there is some mismatch between data sources. The findings support the need for standardised, consistent approaches to ethnicity data collection and analysis, as well as systems and policies that facilitate the collection of high quality data.

In New Zealand, there is strong evidence of an association between ethnicity and health exposures, experiences, and outcomes. This is reflected in differential access to healthcare and significant disparities in health status.¹⁻⁶ It is also consistent with substantial international literature on the relationships between ethnicity and health.^{7,8}

Comprehensive, high-quality ethnicity data are essential to the mapping of health trends by ethnicity; the development of effective policies and strategies; and the measurement, monitoring, and elimination of ethnic disparities in New Zealand.

Inconsistencies in approaches to the definition of ethnicity and the collection of ethnicity data have resulted in inaccuracies in New Zealand ethnicity statistics. In health, for example, this has been reflected in the under-reporting of both morbidity and mortality for certain ethnic groups.⁹ Issues with the consistency and quality of data sets within the health sector have been noted, including an historical lack of standardisation across the health sector and missing data.¹⁰

In addition, gaps in ethnicity data and in the availability of ethnic breakdowns of health data, have contributed to an incomplete picture of ethnic trends and disparities. Information on health utilisation patterns by ethnicity in New Zealand is not yet comprehensive. A standardised approach to the collection of ethnicity data for

hospitalisations and self-identification of up to three ethnic groups in line with the Census definition of ethnicity has been the official policy since 1 July 1996.¹⁰

Until recently, ethnicity data have not been routinely collected in primary care (or in other areas such as disability and aged care services). It has therefore been difficult to have an understanding of trends by ethnicity in the primary care sector, as available data tend to be from surveys of self-report such as the New Zealand Health Survey, the Commonwealth Fund Survey, and from point-in-time studies such as *WaiMedCa* and *NatMedCa*.^{11–13}

Recent changes in funding primary healthcare in New Zealand increased incentives for the collection of ethnicity data in primary care (as ethnicity was included as a variable in two of the funding formulas for Primary Health Organisations [PHOs] and as a non-formula criterion in a third) alongside other population-level variables such as socioeconomic deprivation and age. Accurate and comprehensive ethnicity data are also a necessary component in meeting high-level strategic and policy goals of reducing inequalities in health. However, issues remain in regard to the consistency and quality of ethnicity data within the health sector.

The Health Utilisation Research Alliance (HURA) project was a study of general practice services undertaken to explore the relationship between ethnicity, socioeconomic deprivation, and utilisation of primary care using routinely collected data for a 12-month period (1 January to 31 December 2001). A significant part of the study was working with a sample of general practices to increase ethnicity data coverage and support standardised data collection.

This paper outlines the methods used to increase ethnicity data coverage in the dataset for analysis (i.e. the merging of practice collected and NHI ethnicity), issues encountered in the study, and the implications of these for New Zealand health services research.

Methods

General practices—This study involved data routinely collected by 25 of 37 general practice members of the Wellington Independent Practice Association Limited (WIPA) using electronic patient management software. In 2001–2002, when the data collection was undertaken, WIPA general practices were distributed around Wellington and Porirua Cities and on the Kapiti Coast (up to and including Waikanae) in the lower North Island of New Zealand and included most general practices in the locality.

At that time, all WIPA practices (like most New Zealand general practices) operated under a fee-for-service system with a mixture of patient payment for consultations and partial government subsidy for low-income patients. Patients registered with a general practice for their care but there were no restrictions or funding implications if patients also consulted or registered elsewhere.

All WIPA practices were invited to take part in the study (with the exception of one practice not providing primary healthcare to a general population); 25 practices participated. Over the study period, one practice split into two and both practices continued to participate. Of the nine practices declining, there was no systematic difference in practice size and locality compared to participating practices.

Data collection—Raw data were extracted from practice computing systems using custom-written programmes. After extraction, data were transferred to the WIPA computer system. Data were combined and edited, and small-area deprivation (NZDep2001) codes were added. Individuals' National Health Index (NHI) numbers were encrypted and any unique identifying information removed before analysis.

Ethnicity data—The 25 practices participating in the HURA study undertook to add ethnicity data to their patient registers (five practices were already collecting patient ethnicity data prior to their involvement in the HURA study).

As ethnicity was not routinely collected by WIPA general practices at the time of the study, researchers met with practices once they had agreed to participate in the HURA study to establish their baseline ethnicity coverage, discuss ethnicity data collection, and support the development of appropriate methods for individual practices.

Ethnicity data collection was standardised as much as possible by supporting practice personnel to collect self-reported data using the ethnicity question in the 2001 New Zealand Census of Population and Dwellings. The research team also supported practices by developing resources (including a patient pamphlet and a staff card), assisting in setting up alerts on practice software, and providing individualised feedback on progress. This support was ongoing throughout the study.

Ethnicity data was extracted alongside other demographic variables in 2002, for the 2001 calendar year. Prior to analysis, missing ethnicity data were supplemented with data from the National Minimum Data Set linked by NHI number. Ethnic groups were combined into broad aggregate categories for analysis. People who identified with more than one ethnic group were assigned a single ethnicity using a prioritisation process used by Statistics New Zealand at the time of the study.

In prioritised grouping, any patients identifying as Māori were defined as Māori, whether or not they also identified with another ethnic group. Priority was given secondly to Pacific, then to Asian, other ethnic groups, and finally to European.

As NHI data included a grouping defined as 'Other', people defined in this category were divided into those where a specific ethnicity was identified other than Māori, Pacific, Asian, or European (specified other) and those where there was no further definition (unspecified other).

Analysis—Databases for managing the data were constructed and edited in Microsoft Access software and data transferred to SAS software for analysis. Comparison of ethnicity data collected by general practices in the study with that held on the National Minimum Data Set (NMDS) were based on 216,132 patient records from 25 practices for whom a date of birth and NHI number were available. As it was possible for patients to be recorded at more than one practice, this number does not reflect individuals.

Ethics approval—The Wellington Ethics Committee approved the study.

Results

The coverage of ethnicity data achieved varied by practice, ranging from below 10% to over 90% of all patients (Table 1). Data collection processes were developed by practices to suit their individual requirements, as practice management software and registration procedures differed. All practices increased their coverage during the study period. Practices that were already collecting ethnicity data prior to joining the study were more likely to achieve higher coverage by the end of the study period, as were smaller practices.

In general, ethnicity data coverage (as for coverage of other demographic data) was higher at practices for patients registered with the practice than for non-registered patients. Ethnicity was also more likely to be recorded for registered patients who had consulted during the study period, with ethnicity data missing for 67.2% of registered patients who did not consult in 2001 (Table 2). (This is consistent with the ethnicity data collection method of self-identification.)

To conduct analyses on service utilisation (published elsewhere),¹⁴ data from practice records and NZHIS (giving priority to practice collected ethnicity) were combined to increase coverage to the extent that 23 of the 25 practices in the study (92%) had ethnicity data for at least 70% of registered patients. The proportions of different ethnic groups in the data collected by the practices and from NZHIS are compared in Table 2.

Table 1. Ethnicity data coverage at 25 individual general practices throughout New Zealand

% coverage	Practice ethnicity data				Merged ethnicity data			
	All patients		Registered patients		All patients		Registered patients	
	Number of practices	% of practices	Number of practices	% of practices	Number of practices	Cumulative % of practices	Number of practices	Cumulative % of practices
90–100	1	4%	1	4%	2	8%	8	32%
80–89.9	1	4%	2	8%	8	40%	11	76%
70–79.9	3	12%	5	20%	7	68%	4	92%
60–69.9	3	12%	5	20%	5	80%	2	100%
50–59.9	4	16%	3	12%	3	100%	–	–
40–49.9	3	12%	3	12%	–	–	–	–
30–39.9	4	16%	2	8%	–	–	–	–
20–29.9	3	12%	2	8%	–	–	–	–
10–19.9	1	4%	1	4%	–	–	–	–
0–9.9	2	8%	1	4%	–	–	–	–

Table 2. Ethnicity profile of listed patients sourced from practices, NZHIS, and merged data

Ethnicity	Total practice		Practice data				NZHIS data		Merged data*	
	Number	%	Number	%	Number	%	Number	%	Number	%
Registered patients										
Māori	7,097	5.2%	5,033	6.3%	2,064	3.5%	8,139	5.9%	10,760	7.8%
Pacific	6,042	4.4%	4,405	5.5%	1,637	2.8%	6,698	4.9%	8,706	6.3%
Asian	4,721	3.4%	3,432	4.3%	1,289	2.2%	4,027	2.9%	6,551	4.8%
Other	1,421	1.0%	1,065	1.3%	356	0.6%	28,966	21.0%	15,487	11.2%
- Specified	496	0.4%	371	0.5%	125	0.2%	328	0.2%	597	0.4%
- Not specified	925	0.7%	694	0.9%	231	0.4%	28,638	20.8%	14,888	10.8%
European	47,720	34.6%	33,988	42.7%	13,732	23.6%	51,284	37.2%	72,633	52.7%
Missing	70,821	51.4%	31,689	39.8%	39,132	67.2%	38,708	28.1%	23,685	17.2%
Total	137,822		79,612		58,210		137,822		137,822	
Non-registered patients										
Māori	1,835	2.3%	740	4.5%	1,095	1.8%	2,422	3.1%	3,482	4.4%
Pacific	1,184	1.5%	480	2.9%	704	1.1%	1,272	1.6%	2,005	2.6%
Asian	1,193	1.5%	526	3.2%	667	1.1%	896	1.1%	1,773	2.3%
Other	222	0.3%	110	0.7%	112	0.2%	6,012	7.7%	4,230	5.4%
- Specified	87	0.1%	46	0.3%	41	0.1%	69	0.1%	134	0.2%
- Not specified	135	0.2%	64	0.4%	71	0.1%	5,943	7.6%	4,095	5.2%
European	13,949	17.8%	4,956	30.2%	8,993	14.5%	14,533	18.6%	24,196	30.9%
Missing	59,927	76.5%	9,624	58.6%	50,303	81.3%	53,175	67.9%	42,624	54.4%
Total	78,310		16,436		61,874		78,310		78,310	

*Priority given to practice collected data where ethnicity differed unless practice data was not stated or other no further defined and NZHIS ethnicity data provided a specific code; †consultation data available for 22 practices

Table 3. Comparison between ethnicity data collected by general practices and corresponding NZHIS ethnicity categories for 216,132 records (including missing data)

Practice collected data	Māori		Pacific		Asian		Other		European		Missing		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Māori	4,269	47.8%	221	2.5%	8	0.1%	1,124	12.6%	1,106	12.4%	2,204	24.7%	8,932	100%
Pacific	257	3.6%	3,929	54.4%	39	0.5%	843	11.7%	335	4.6%	1,823	25.2%	7,226	100%
Asian	12	0.2%	116	2.0%	2,327	39.3%	957	16.2%	328	5.5%	2,177	36.8%	5,917	100%
Other	16	1.0%	29	1.8%	42	2.6%	738	44.9%	452	27.5%	366	22.3%	1,643	100%
European	778	1.3%	245	0.4%	146	0.2%	12,710	20.6%	28,709	46.6%	19,082	30.9%	61,670	100%
Ethnicity missing	5,229	4.0%	3,430	2.6%	2,358	1.8%	18,606	14.2%	34,889	26.7%	66,232	50.7%	130,744	100%
Total	10,561	4.9%	7,970	3.7%	4,920	2.3%	34,978	16.2%	65,819	30.5%	91,884	42.5%	216,132	100.0%

Bold text highlights the number of records where ethnicity data is coded the same on both sources.

The most noteworthy differences in comparing practice collected ethnicity with NZHIS data were differences in the proportion of people recorded as 'Other', with a lower proportion of patients in the unspecified 'Other' category in general practices. While only 1% of registered patients and 0.3% of non-registered patients were coded as 'Other' by practices, 21% of registered and 7.7% of non-registered patients were coded as 'Other' on NZHIS data.

To understand the implications of combining data from two different sources, ethnicity data collected by general practices were compared with corresponding ethnicity data from the NHI at an aggregate ethnic group level (e.g. Māori, Pacific, Asian, Other, European). The comparison showed that there was a level of disagreement between ethnicity data collected at the practice and that from the NZHIS (Table 3).

Of those records where there was no ethnicity data recorded at the practice, approximately 50% had an ethnicity coded on the corresponding NHI record. Of those records where ethnicity data was available from the practice (85,391), there was 47% agreement overall with the ethnicity coded on the corresponding NHI (47.8% for Māori, 54.4% for Pacific, 39.3% for Asian, 44.9% for Other, and 46.6% for European). NHI ethnicity data was missing for a further 30% of records overall where ethnicity data was available from the practice. The remaining 23% of records were coded as a different ethnic group on the corresponding NHI record.

Discussion

At the end of the study period there was considerable variation in the coverage achieved at different practices. Although based on the standardised process recommended by the HURA study, data collection processes varied between practices as a result of differences in practice management software and registration procedures.

For many participating practices there was limited baseline ethnicity data already available on practice registers. Most practices therefore had to collect this data for the majority of their patients, and this provided challenges for some practices (including software issues, time costs, and competing priorities). Ethnicity data were more likely to be collected for patients who consulted, as the recommended method of ethnicity data collection is self-identification. It thus requires some form of contact between patient and practice.

The study period coincided with significant changes to the way in which primary healthcare was funded and organised, including the introduction of funding formulas for which ethnicity was a variable. While this provided a new incentive for the collection of ethnicity data in primary care, these changes were also associated with other impacts on practice workloads.

The study also found a divergence between ethnicity recorded on the NHI (often collected in hospitals) and that collected in general practice. When compared to NHI ethnicity data, practices were more likely to have ethnicity data missing in general. However, where data were present, it was more likely to be more specific than that on the NHI. Practices did not tend to have a large 'Other' (not elsewhere specified) group, but were more likely than NHI to have recorded a specific ethnicity within the 'Other' category. The size of the 'Other' category on the NHI data for this study

(21%) was substantially higher than that of the total population as reflected by census data.

The proportion of people in the 'Other' category in the last census was 0.69%.¹⁵ When restricted to records with ethnicity data available from both sources, we found that over 75% of those coded as 'Other' on NHI were coded as European by the practice. A 1999 study of ethnicity data in Wellington Hospital also found a higher than would be expected proportion of admissions coded as 'Other' (no further defined).¹⁶ The likely over-representation of the 'Other' category will need to be taken into account when interpreting NHI ethnicity data.

It is important to note that NHI data is likely to be historical and could have been collected continuously over several years prior to corresponding practice-collected data. Although the collection of self-identified ethnicity data on the NHI has been official policy since 1996, there have been problems with the consistency and quality of the data. For example, the New Zealand Census Mortality Study (NZCMS) found a 30–40% undercount of Māori, Pacific, and Asian ethnicities on the NHI when compared with census ethnicity data.¹⁷

When restricted to patients with ethnicity data available from both sources (practice-collected and NZHIS), we found similar patterns although not as extreme. After the merging of NHI ethnicity data with practice data (where ethnicity was missing in the practice data), the residual misclassification within NHI data will remain, specifically a likely undercount of Māori, Pacific, and Asian ethnic groups, and overcount of the 'Other' ethnic groups.

It is difficult to establish the extent to which the disagreement between practice-collected and NZHIS ethnicity data is due to miscoding, issues with data collection, or a true difference in response to the question. Indeed, there will always be some level of disagreement between ethnicity data collected at different times and within different contexts, even where a standardised process is in place. This is because it is possible for ethnicity to change over time and/or for people to respond to the ethnicity question differently within different contexts. However, a standardised approach to data collection will reduce the variation that is due to inconsistent data collection approaches.

Since the study was undertaken, the Ministry of Health has launched Ethnicity Data Protocols for the standardised collection of ethnicity data throughout the health sector. If these protocols are implemented consistently and comprehensively, they may address some of the issues in divergences between practice collected and NZHIS ethnicity data. In addition, there will need to be ongoing monitoring and auditing of the accuracy of ethnicity data within the health sector.

High quality ethnicity data is a valuable public health resource in terms of monitoring health status and health indicators, and is essential for the measurement of ethnic disparities in health. General practices need to be supported in their collection of consistent, appropriate, quality ethnicity data for their practice populations.

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