



The accuracy of ethnicity data in primary care and its impact on cardiovascular risk assessment and management—PREDICT CVD-8

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Abstract

Background Accurate ethnicity data are a prerequisite for evidence-based cardiovascular risk assessment and management according to national guidelines.

Aims (i) To investigate the accuracy of ethnicity data in primary care medical records by comparing them with self-identified ethnicity. (ii) To determine the clinical impact of ethnicity misclassification on cardiovascular risk assessment and management.

Methods A random sample of 870 patients from 18 general practices (who had ethnicity collected from their medical record as part of cardiovascular risk assessment using PREDICT, a web-based decision support tool) were sent a postal questionnaire asking their self-identified ethnicity using the 2001 Census ethnicity question.

Results Data were available for 665 people (77% response rate) who completed the postal questionnaire. Ethnicity in the primary care record and self-identified ethnicity from the questionnaire were identical for 68% of respondents at Statistics New Zealand Level 2 coding. Data concordance varied from 9.8% for the non-New Zealand European ethnic group to 90.9% for New Zealand European. The primary care record agreed with self-identified ethnicity for 64.9% of Māori respondents. Fortunately, when the same ethnicity data were categorised using the Statistics New Zealand ethnic group prioritisation rules and applied within PREDICT, which adds a risk weighting for Māori, Pacific, and Indian subcontinent peoples, the impact of misclassification was small. The main reason was that about half of misclassifications occurred between ethnic groups classified in the same high cardiovascular risk category. For about 6% of Māori, Pacific, and Indian subcontinent people in our study this misclassification could potentially have delayed risk assessment and resulted in under-treatment. In contrast, about 1.5% of those with other ethnicities may have undergone a premature risk assessment and been over-treated.

Conclusion The clinical impact of ethnicity misclassification on cardiovascular risk assessment and management in primary care is modest because much of the misclassification does not alter cardiovascular risk classification. Nevertheless, efforts to improve the accuracy of ethnicity classification in primary care need to continue in order to support the sector's ability to monitor health service utilisation, outcomes, and performance related indicators.

The capture of ethnicity data in New Zealand has historically posed a significant challenge to the quality of our health statistics. Primary care is usually the first point of contact with health services and as the healthcare provider patients see most is

ideally placed to collect comprehensive accurate patient data, including ethnicity data.¹ However, prior to the introduction of the Ethnicity Data Protocols for the Health and Disability Sector in 2004² there were no standards for the collection, coding and recording of ethnicity data in primary care.

Ethnicity data, if collected at all, have been recorded in an inconsistent and often idiosyncratic way.³ This has been cause for concern for health researchers who monitor Māori health inequalities in New Zealand.

National guidelines⁴ recommend that people who identify with the ethnic groups Māori, Pacific, and Indian subcontinent* peoples:

- Undergo a cardiovascular risk assessment 10 years earlier than other ethnicities (for example, Māori men at age 35 years; Māori women at age 45 years); and,
- Have their calculated 5-year CVD risk adjusted upward by 5% (for example a 5-year CVD risk of 15% for a Māori man would be adjusted to 20%).

(*Where Indian subcontinent peoples include Indian, Fijian Indian, Afghani, Bangladeshi, Nepalese, Pakistani, Sri Lankan, and Tibetan.)

PREDICT, a web-based clinical decision support programme for cardiovascular disease (CVD)⁵⁻⁸ based on New Zealand guidelines⁴ was implemented in ProCare, a large Auckland PHO, from 2002. Implementation was undertaken progressively over several years.

The ProCare Network (Auckland, Manukau, and Waitemata) comprise approximately 178 general practices and 480 general practitioners; it has the largest enrolled Primary Health Organisation (PHO) population⁹ and the largest enrolled Māori population in New Zealand.¹⁰

In this study we undertook a survey to compare self-identified ethnicity with primary care ethnicity to determine the impact of misclassification on cardiovascular risk assessment and management recommendations.

Methods

General practices—Practices were eligible if they met the following study criteria: belonged to or were affiliated with ProCare; used MedTech patient management system; had performed 20 or more cardiovascular risk assessments using PREDICT in the 12-month period to 30 June 2005; and, had at least one permanent general practitioner or long-term locum. From this group, practices were randomly sampled using MS Excel's random numbers table function.

Patients—Patients were eligible if they had undergone a PREDICT-CVD risk assessment in the 12-month period 1 July 2004–30 June 2005; and if they had sufficient patient details to enable a mail-out of the questionnaire. Where a patient had more than one PREDICT assessment undertaken the most recent record was analysed.

Patient ethnicity data—At the practices, patient ethnicity data were extracted from the PREDICT record retained in the patient management system (PMS). Although ethnicity data, where available, were automatically drawn into PREDICT from the PMS, the practitioner also has the ability to manually enter or change a patient's ethnicity within the PREDICT template.

Patient self-identified ethnicity data were collected via a postal questionnaire. The questionnaire used the ethnicity question recommended by the 2004 Ethnicity Data Protocols for the Health and Disability Sector²—i.e. the 2001 Census ethnicity question that has been rigorously tested by Statistics New Zealand (Appendix 1).

Ethnicity grouping for analysis—Patients were assigned to four ethnic group categories that, according to the national guidelines are at higher risk (Māori, Pacific, and Indian subcontinent ethnic groups) or lower risk ('All other' ethnic groups) of developing CVD.

PREDICT uses the rule set of Statistics New Zealand Level 2 codes (Appendix 2: code 21 for Māori, 30–37 for Pacific, 43 and 44 for Indian subcontinent ethnicities but excluding Japanese and Korean, and codes 10–12, 40–42 and 51–54 for All other ethnic groups).

Sampling and questionnaire process—Sample size calculations suggested that, if 10% of patients were misclassified for ethnicity, a sample of 600 people would have given classification estimates within 2.5% of the true value (with 95% confidence). To allow for non-response we aimed to sample 800 people.

A 20% random sample of eligible patients in each participating practice were sent a combined letter/questionnaire, a participant information sheet and freepost return address envelope. The ethnicity question was the only information requested. A second mail-out was conducted and subsequent telephone follow-up of non-responders undertaken one month following the second mail-out.

Ethical approval—The PREDICT project was approved by the Auckland Ethics Committee (AKY/03/12/314).

Results

Eighteen of the 29 ProCare general practices that met the study eligibility criteria were randomly selected and invited to participate. Two practices declined and two other practices from the remaining 11 eligible practices were randomly selected and consented. The selected practices came from the wider Auckland region representing the ProCare Network. All were group general practices except for one Accident and Medical clinic.

There were a total of 4373 people from the 18 practices with a recorded PREDICT CVD risk assessment in the 12-month period to 30 June 2005. Of these patients, 22 were ineligible (16 deceased, 6 mock or test patients) for the questionnaire mail-out.

A random sample of 20% from each practice (n=870) were sent the postal questionnaire. Of these, 669 returned completed questionnaires (77% response rate); 665 had ethnicity data in their primary care record; and 4 did not have sufficient data for comparative purposes. There were statistically significant differences between questionnaire responders (n=669) and non-responders (n=201) with regard to ethnicity and age.

The European ethnic group had a significantly higher response rate (82.6%) than any other ethnic group. The response rates for the non-European ethnic groups were not significantly different from each other—Indian subcontinent (72.4%), Māori (68.7%), Pacific (66.7%), and Other ethnic groups (64.3%). Responders were older (median age group for responders was 55–64 years compared to median age group of 45–54 years for non-responders).

Table 1 shows a classification of self-identified ethnicity codes against codes recorded in the PREDICT database. For about two-thirds of the sample the primary care ethnicity record agreed with self-identified ethnicity at the Statistics New Zealand Level 2 coding hierarchy. Agreement varied from a low of 0% notably for the ethnic descriptions for which 'Not further defined' applied, to a high of about 90% for New Zealand European. Agreement for Māori was below that of the aggregated sample.

Table 1. Agreement between primary care and self-identified ethnicity, in 665 patients, at Statistics New Zealand Level 2 codes and descriptions

Ethnicity codes	Ethnicity descriptions	N	Agreement* with self-identification n (%)	Disagreement with self-identification n (%)
10	European NFD#	82	0 (0)	82 (100.0)
11	New Zealand European	320	291 (90.9)	29 (9.1)
12	Other European	50	13 (26.0)	37 (74.0)
21	Māori	57	37 (64.9)	20 (35.1)
30	Pacific people NFD#	8	0 (0)	8 (100.0)
31	Samoan	40	34 (85.0)	6 (15.0)
32	Cook Island Māori	16	15 (93.8)	1 (6.2)
33	Tongan	23	20 (87.0)	3 (13.0)
34	Niuean	7	7 (100.0)	0 (0)
35	Tokelauan	0	–	–
36	Fijian	8	3 (37.5)	5 (62.5)
37	Other Pacific peoples	0	–	–
40	Asian NFD#	6	0 (0)	6 (100.0)
41	Southeast Asian	3	3 (100.0)	0 (0)
42	Chinese	14	8 (57.1)	6 (42.9)
43	Indian	17	17 (100.0)	0 (0)
44	Other Asian	6	0 (0)	6 (100.0)
51	Middle Eastern	1	0 (0)	1 (100.0)
52	Latin American/Hispanic	1	1 (100.0)	0 (0)
53	African	3	3 (100.0)	0 (0)
54	Other	3	0 (0)	3 (100.0)
All ethnic groups combined		665	452 (68.0)	213 (32.0)

*Agreement = complete agreement between ethnicity codes and descriptions in MedTech and the self-identified ethnicity/ethnicities at Statistics New Zealand Level 2; #NFD = Not further defined.

Table 2 shows the same data reclassified into four main ethnic categories with respect to the degree of cardiovascular risk for different ethnic groups in the national guidelines.² The process of collapsing down to broad higher risk or lower risk ethnicity groups increased the overall agreement level to 95.8% (Kappa statistic 0.91, good agreement).

Table 2. Primary care ethnicity compared to self-identified ethnicity, in 665 patients, with a PREDICT cardiovascular risk assessment

Ethnicity		Patient questionnaire				
		Māori#	Pacific#	Indian subcontinent	All others	Total
Primary care record	Māori	48	4	0	5*	57
	Pacific	3	95	3	1*	102
	Indian subcontinent	0	0	21	1*	22
	All others	4+	5+	2+	473	484
	Total	55	104	26	480	665

*These patients would be risk assessed 10 years earlier than, and given an absolute 5-year risk 5% more than, recommended by the guidelines; +These patients would be risk assessed 10 years later than, and given an absolute 5-year risk 5% less than, recommended by the national guidelines for cardiovascular risk assessment and management; #Patients reporting Māori ethnicity in addition to any other ethnicity are classified as Māori; patients reporting Pacific ethnicity, except Māori, are classified as Pacific.

In the same table, 87.3% (48/55) of self-identifying Māori were correctly assigned as Māori in their primary care record. For Pacific and Indian subcontinent groups, 91.3% and 80.8% were respectively classified correctly according to their self-identifying ethnicity.

Discussion

This study found the accuracy of ethnicity data in the primary care record was limited when directly compared to self-identified ethnicity at the Statistics New Zealand Level 2 code.

About one-third of Māori in our sample had ethnicity data that did not fully agree with their self-identified ethnicity suggesting ongoing systematic misclassification of Māori in primary care records. In some cases, misclassification was due to the failure of primary care data to capture multiple ethnicities.

Therefore analyses of primary care data using Statistics New Zealand Level 2 ethnicity codes and descriptions may be misleading. This makes the monitoring of ethnic differentials in health status, access to health services, and evaluation of health outcomes (including performance-related indicators and health service development) questionable.

When these data were reclassified, using ethnic group prioritisation rules, into high CVD risk ethnic groupings (i.e. Māori, Pacific, and Indian subcontinent peoples) or 'All others' (lower CVD risk ethnic groups), according to national guidelines for cardiovascular risk assessment and management, the potential clinical impact was less than would be expected given the degree of misclassification.

The reason for this lesser impact was that about half of the misclassifications were between ethnicities within the high CVD risk ethnic groupings. Nevertheless, in this sample a total of 11 people who self-identified as Māori, Pacific, or Indian subcontinent ethnicity would have been misclassified into the lower risk ethnic grouping ('All others'); potentially had their risk assessment undertaken 10 years later

than recommended; their 5-year cardiovascular risk under-estimated by 5%; and, been under-treated as a consequence.

A much smaller proportion—1.5% of ‘All others’—may have had their risk assessment undertaken 10 years early and their risk overestimated because of misclassification into the high-risk ethnicity groups. Although the potential impact of misclassification may appear small it must be considered in the context of stark ethnic inequalities in CVD morbidity and mortality in New Zealand.

Reducing these inequalities requires a broad range of approaches. High quality ethnicity data, and associated improvements in clinical management, will contribute to reducing these inequalities.

This study is one of the first in New Zealand to directly compare the accuracy of primary care records with self-identified ethnicity.

Another study¹¹ recently compared the ethnicity data of children on the National Immunisation Register (where data were collected from parents via a protocol-based informed consent process in the Meningococcal B campaign) with ethnicity data on PHO registers. There was significant ethnic group misclassification in the primary care record for about one-third of Māori, a quarter of Pacific and a fifth of Asian children. There are also discrepancies in ethnicity recording among non-European ethnic groups in New Zealand hospital records compared to self-identified ethnicity.¹² However agreement between two independent databases (PREDICT and the National Health Index) is moderately good.¹³

Other researchers have reported that the coverage of ethnicity data recording in primary care in New Zealand has improved since the establishment of PHO registers.^{1,14-20}

Our study has some limitations. Its generalisability may be limited due to the sample coming from one primary care network, albeit the largest in New Zealand, and the lack of precision due to small numbers in some ethnic groups. There were significant differences between questionnaire responders and non-responders, and even with a response rate of 77%, non-response may have contributed to selection bias. For example, we may still have under-estimated the level of misclassification of Māori in primary care records due to the higher proportion of Māori compared to European non-responders.

Ethnicity data reflect important dimensions of difference and power in New Zealand society.²¹ It is not acceptable that Māori are differentially affected by ethnicity data misclassification. Doctors, nurses, healthcare managers, policymakers, and researchers must be cognisant of this and the limitations of ethnicity data in routinely collected health datasets.

Protocols recommended by the Ministry of Health for the standardised collected of ethnicity data throughout the health sector should be nationally implemented and evaluated. In addition, with the increasing use of electronic registers to identify patients eligible for interventions and the expanding use of electronic decision-support tools, that incorporate ethnicity data from medical records, the accuracy of these data will become more and more clinically important.

PHOs and general practices need to be supported and resourced to overcome the barriers to quality ethnicity data collection and systematic assessment of their at-risk patient populations.

Competing interests: None known.

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Appendix 1. New Zealand 2001 Census ethnicity question and standard ethnicity question for the health sector

Which ethnic group do you belong to?
Mark the space or spaces that apply to you.

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

other (such as DUTCH, JAPANESE, TOKELAUAN). Please state:

Source: Ethnicity Data Protocols for the Health and Disability Sector(2004)²

Appendix 2. Statistics New Zealand ethnic group priority order

Priority order	Level 2 ethnic group code	Ethnic group description
1	21	Māori
2	35	Tokelauan
3	36	Fijian
4	34	Niuean
5	33	Tongan
6	32	Cook Island Māori
7	31	Samoan
8	37	Other Pacific Island
9	30	Pacific Island NFD#
10	41	South East Asian
11	43	Indian
12	42	Chinese
13	44	Other Asian
14	40	Asian NFD#
15	52	Latin American / Hispanic
16	53	African
17	51	Middle Eastern
18	54	Other
19	12	Other European#
20	10	European NFD#
21	11	NZ European

Source: Table adapted from Ethnicity Data Protocols for the Health and Disability Sector²; #NFD = Not further defined