

## **The Collection of Patient Ethnicity Data: A Challenge for General Practice**

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## **Abstract**

**Aim.** To explore issues relating to accurately collecting patient ethnicity data in general practice.

**Method.** A survey of current practice was undertaken in Wellington, New Zealand, followed by a qualitative survey of the knowledge and attitudes of health professionals, patients and users of health data to the collection of ethnicity data.

**Results:** Ethnicity data was routinely collected by only 29% of Wellington general practices. Significant increase in the number of practices routinely collecting ethnicity data will require training practice personnel and education of both practice personnel and patients. Education should focus on explaining ethnicity, how to collect the data and reasons why ethnicity data is important in health.

**Conclusions:** Accurate data on patient ethnicity is urgently needed and general practice is ideally positioned to provide this health information. An opportunity exists to collect patient ethnicity as part of patient registration. Practices need support and training to facilitate accurate data collection.

## Introduction

In New Zealand information from secondary care and other sources suggests that disparities exist between Māori and non-Māori in most indicators of health status.<sup>1,2</sup> Monitoring health status plays an important role in the effort to reduce health disparities between ethnic groups. Accurate recording of patients' ethnicity can provide useful information, about the utilisation of health services, to plan and evaluate public health services and allocate health resources<sup>3,4</sup> and to monitor trends in the health status of people from different ethnic groups.

Recent policy changes in the area of ethnic health statistics have been implemented after investigations by the Ministry of Health in 1991,<sup>5</sup> Statistics New Zealand<sup>6</sup> and an inter-departmental working party. The recording of patient ethnicity in hospitals has been reviewed<sup>7,8,9</sup> and a process for the collection and audit of ethnic data developed for secondary care.<sup>10</sup>

Good data from general practice is also essential. Differences between secondary care and primary care in New Zealand mean that a separate process for ethnicity data collection needs to be developed for primary care. The majority of general practices in New Zealand operate on a fee for service basis and there are opportunity costs involved in the collection of any data for use outside the practice. Nevertheless, general practice, as the first point of contact with the health system and as the provider with an ongoing relationship with the patient, is well placed to collect comprehensive health data, including ethnicity.

There have been attempts to record ethnicity in general practice but in the absence of a standardised process for data collection many practices faced difficulties.<sup>11</sup> Kljakovic described the difficulties general practitioners found in arbitrarily defining ethnic categories. A national survey of 1062 general practitioner members of the Royal New Zealand College of General Practitioners (RNZCGP) found that only 20% of practices collected ethnicity data (unpublished data). A recent study of a sample of 12 South Island practices found ethnicity was recorded for only 5% of patients.<sup>12</sup>

Issues relating to ethnicity data collection in general practice are explored in this paper and strategies to facilitate data collection described. The process for ethnicity data collection focuses on defining ethnicity by cultural affiliation<sup>13</sup> and collecting ethnicity data using the same question as in the New Zealand Census of Population and Dwellings (New Zealand Census) because this definition is already used in the National Minimum Data Set and in the collection of ethnicity data in secondary care<sup>1</sup>. Defining ethnicity by cultural affiliation groups people on the basis of shared culture, language, religion, history or traditions. This definition allows different realities to be captured that would not be captured using a biologically based definition and allows people to change their ethnicity throughout their life and to identify with more than one ethnic group. Standardisation of ethnicity data collection is essential to enable comparisons, both longitudinally and within groups. Issues relating to ethnicity data collection in New Zealand and the monitoring of Māori health are discussed more fully in a paper by Reid et al.<sup>14</sup>

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<sup>1</sup> Copies of this question are available from the website [www.wnmeds.ac.nz/academic/gp/index.html](http://www.wnmeds.ac.nz/academic/gp/index.html)

## Method

The project was undertaken in 1998. It consisted of two stages: a survey of current practice; and a qualitative study of the attitudes of practice personnel, patients and researchers/users of health data. Recommendations for the systematic collection of ethnicity data in general practice were developed.

**Survey of Current Practice:** All sixty-eight general practices and three After Hours Medical Centres, in the greater Wellington area including Porirua, the Hutt Valley and Wainuiomata were surveyed. Practices were identified from the Royal New Zealand College of General Practitioners (RNZCGP) database and from local telephone directory listings. A one-page questionnaire and covering letter were faxed to 65 practices and posted to a further three practices without faxes. Practices were asked about the collection of ethnicity, marital status and occupation data from new patients. Practices that collected ethnicity data were asked about their method of collecting and recording the data, any problems they had experienced collecting ethnicity data and about their attitude toward ethnicity data collection.

**Qualitative Survey of Practice Personnel:** Personnel were interviewed from a sample of practices, drawn from those identified in the current practice survey to include practices with a range of attitudes to ethnicity data collection and to represent a range of different practice types. A profile of personnel interviewed is shown in table two. Interviewing continued until saturation of interview themes was reached. Viewpoints were sought about: how ethnicity could be defined; the relevance and benefits of collecting ethnicity data; how the data should be collected and who should collect the data; attitudes to the collection of ethnicity data and who should have access to the data once collected.

**Qualitative Survey of Patients:** Interviews were conducted with fourteen patients and ethnic group representatives, from a wide range of ethnic groups including Māori and Pacific people, Asian, Indian, Chinese and different European groups, all living in Wellington. Informants were identified from a range of sources. Some were personally known of by the researchers, others were members of ethnic associations. None of the informants had any professional association with general practice. All informants were sufficiently fluent in English to allow them to express their views without the use of an interpreter.

All but two interviews were face to face in the informant's home or place of work. Two informants preferred to be interviewed by telephone. An open ended questionnaire was used to identify attitudes to ethnicity data collection in general practice. Open-ended questions related to the informant's understanding of ethnicity, the value placed on ethnicity, the perceived benefits and disadvantages of ethnicity data collection at a general practice and the process of collection, storage and utilisation of ethnicity data in a general practice. In addition a questionnaire was left in the waiting room at two practices to give a wider range of patients the opportunity to comment. One practice was located in a predominantly Pākeha population and the other in an area with a higher proportion of Māori and Pacific people.

**Qualitative Survey of Researchers/ Users of Ethnicity Data:** Face-to-face interviews were held with representatives from: Statistics New Zealand, The Ministry of Health, New Zealand Health Information Service, Te Puni Kōkiri, Te Rōpū Rangahau Hauora a Eru Pōmare, RNZCGP and the Wellington Independent Practitioners Association.

**Analysis:** Face-to-face discussions were audio-taped and then fully or partially transcribed by either the interviewer or a clerical assistant. When discussions were transcribed by a clerical assistant the interviewer checked the transcription while listening to the audio tape of the interview. Issues raised by each respondent were described. Key themes from the combined data-sets were identified by one researcher by manual analysis of the data. Themes were independently cross-checked by at least one other researcher. Participants in the qualitative survey of patients were sent a summary of their interview and asked to confirm that the summary was a correct account of the interview.

**Ethical Approval:** The study was approved by the Wellington Ethics Committee.

## Results

**Current Practice in Wellington:** Sixty-two of 71 practices (87%) responded to the questionnaire.

**Qualitative Study:** Face-to-face, semi-structured interviews were held with 9 general practitioners, 6 practice managers, 3 practice nurses, 4 receptionists and 1 practice administrator. Personnel interviewed represented 7 fee-for-service practices, 1 Student Health Service, 2 After Hours Medical Centres and 1 Health Care Aotearoa Medical Centre. At least one health professional agreed to be interviewed from each practice approached.

Representatives from all of the government agencies and other users of health data approached agreed to be interviewed.

All patients approached in the qualitative phase were willing to take part in the study except for one person who did not have the time to participate. Sixty-five patients completed questionnaires left in two general practices. Forty-six (71%) were female and 17 (26%) were male. Patients were from a range of ethnic groups; 46% identified as New Zealand European/Pākehā and 16% as New Zealand Māori.

### Current Practice

Approximately half the 62 practices did not collect ethnicity data. In a quarter of practices, ethnicity data was collected from some patients or by some general practitioners. Ethnicity data was routinely collected in 29% of general practices surveyed but different practices used different criteria for collection and only two of these practices could provide ethnicity data meeting the criteria for standardised and complete collection using a nationally defined protocol. None of the practices were able to link morbidity data to ethnicity on the practice computer. Ethnicity data was collected less frequently than data on marital status or occupation (Table One).

### Perceived Benefits and Relevance of Ethnicity Data Collection

Respondents described a continuum of potential benefits of ethnicity data collection, ranging from a focus on the individual patient to benefits to the community.

In this study, there was a tendency for practice personnel to focus on how knowledge of ethnicity could contribute to their delivery of health care to individual patients. This is highlighted by the following comments made by general practitioners. *“There are benefits to patients because you tend to know their culture, their background, their outlook ... you can provide them with a service which is acceptable to them.”* *“I only collect ethnicity data when it is seen as medically relevant to the patient.”* Benefits to individual patients included the ability for general practitioners to be culturally sensitive in their management of patients; the ability to identify patients at particular risk of disease because of their ethnicity and enhanced practice management, for example assistance in completing forms and recruiting personnel.

Patients agreed that cultural sensitivity was an important aspect of the doctor-patient relationship and an example given by a patient was *“it is helpful if they know...there are some things that a doctor may not do to me if it is a man.”* They saw ethnicity data as enabling practices to identify who their clients are and evaluate the accessibility and appropriateness of their service. *“...they should take their ethnicity to see if Māori are using that service, and if they aren’t maybe it is showing them that their service isn’t appropriate, or that Māori can’t access that service.”* Aiding diagnosis was also seen as a potential benefit.

Some patients did not consider ethnicity data relevant to general practice and concerns were raised that the information might lead to prejudices, or perhaps allow existing prejudices to become apparent.

Researchers/data users focused on benefits to the community such as in understanding the utilisation of health services in New Zealand, the ability to identify areas of need and to target health funding accordingly, to aid policy decisions and health initiatives and to meet the obligations of the Treaty of Waitangi.

### **Defining Ethnicity**

The comments of both health professionals and patients indicated that there was a diversity of viewpoints on the meaning of ethnicity. While many people agreed with the definition of ethnicity used by the Ministry of Health that is based on cultural affiliation, there were complex views of what ethnicity is, incorporating nationality, culture and genetic background. Sometimes there was variation in how the importance of each component is weighted.

*“Ethnicity is the root of a person... culture, religion, language... everything.”*

*“What does it matter if I am Chinese or Māori or whatever, I feel I am New Zealander.”*

*“I have a bit of Pākehā... While I have ticked Pākehā I don’t really identify with it.”*

### **Issues Relating to Ethnicity Data Collection for General Practices**

Practice personnel interviewed described a number of ways in which ethnicity data collection could impact on a practice including the additional work generated by collecting ethnicity data and the cost to their practices of collecting, recording, storing and retrieving data about patient ethnicity.

The extent to which the costs associated with ethnicity data collection would affect a decision to collect the data varied. Some practice personnel stated that they would be unwilling to collect ethnicity unless costs were met. Others thought cost was not a big issue when weighed

against the benefits of ethnicity data collection. However, all practices surveyed noted that to systematically collect ethnicity data would involve added costs.

Practice personnel were concerned that some patients would be offended or upset by being asked their ethnicity because *“people feel sensitive about being asked about ethnicity data”* and this could result in *“hassles at the front desk”* which may be time consuming. In particular there was concern by practice personnel that existing patients who had an ongoing relationship with their general practitioner may react negatively to suddenly being asked their ethnicity.

In reality though, most patients would not object to being asked their ethnicity. Fifty-five patients (85%) who completed questionnaires left in waiting rooms said they would not mind being asked their ethnicity at their general practice. Six patients (9%) would object and a further four (6%) while not minding being asked their ethnicity, queried the relevance of being asked.

Similarly most practice personnel interviewed did not object to ethnicity data collection. Others, while they would accept the collection of the data on a *“need to know”* basis where it specifically benefited the patient, also had concerns about making distinctions between ethnic groups.

### **Ownership and Privacy Issues**

Most of the patients interviewed accepted the use of data about their age, sex and ethnicity for statistical purposes as long as the data was not identifiable.

### **Discussion**

Reliable ethnicity data from primary care is badly needed in New Zealand and general practices could provide this data. The current movement in New Zealand toward patient registration provides an opportunity to include ethnicity data collection in the patient registration package but general practices need support to meet the challenge of standardised data collection.

At the time of this survey, there was no support or education about methods of ethnicity data collection for Wellington general practices and not all practices perceived ethnicity as directly relevant to patient care. It was not surprising therefore that a survey of current practice revealed that only 29% of practices surveyed usually collected ethnicity data, a considerable gap between current practice and standardised collection of ethnicity data on a national level. Given adequate support this gap can be closed. In England Pringle and Rothera<sup>15</sup> assessed ethnicity recording in primary care and concluded that recording ethnicity was feasible and acceptable. Overcoming the barriers to the collection of ethnicity data will require a commitment to ethnicity data collection by policymakers and health funding agencies as well as general practices.

In some practices ethnicity data was collected in an ad hoc fashion and only for some patients. The experience from mortality statistics demonstrates that collecting ethnicity information on only some people leads to undercounting. Prior to 1995, identification of ancestry was only required for Māori and Pacific deaths. Missing ancestry data led to major over-reporting of Pakeha mortality rates and under-reporting of Māori and Pacific mortality.<sup>16</sup> The introduction of mandatory collection of ethnicity for all death registrations from September 1995, has greatly improved the accuracy of mortality data for all ethnic groups.<sup>16</sup> For accurate data in general practice, it would be necessary to collect everyone's ethnicity.

In order that ethnicity data be collected consistently and accurately, it is important to address the concerns of practice staff. Information on its benefits to patients, practice and community, its meaning, and training on how to collect the information, is needed. The experience of hospital staff and staff at primary health care centres who gather ethnicity in a systematic way could provide the basis of a training programme. This would include training on how to respond to questions or objections from patients.

Responses to questionnaires in this study, which although non-random were consistent with previous surveys of hospital patients,<sup>17</sup> demonstrated that while the majority of patients would not mind being asked for ethnicity data at their general practitioner's a few patients would object. Using estimates from the patient survey, in an average practice there may be one patient every four or five days during the initial data collection period, where the person collecting the data may need to spend additional time addressing issues raised by the patient. In part these concerns relate to different opinions about what ethnicity is and the benefits and relevance of collecting ethnicity data in primary care.

Public education is needed to help people understand what ethnicity is and may help to minimise the impact of personal objection. Responses of informants in this study demonstrated misunderstanding of ethnicity and confusion between ethnicity, race and nationality, such as New Zealander. An information pack for both patients and practice personnel could be produced at either national or IPA level and may be combined with information about other aspects of patient registration. Information for patients could be displayed in the waiting room as well as being available for the receptionists to give to patients. A brochure on ethnicity data has already been produced for use in hospitals.<sup>18</sup> Combining ethnicity data collection with the collection of other demographic data may help. Ethnicity data could be collected of as part of patient registration for new patients or as part of a check on data held by the practice for existing patients.

A data collection facilitator, modeled on the immunisation facilitators, could be a way to help individual practices to establish a process for collecting ethnicity data and to provide training and support for practice personnel. The facilitator would: support practices to develop systems for recording and storing ethnicity data within the practice; train practice personnel to collect ethnicity data and in strategies to deal with any situations which may arise; liaise with software providers to alter fields in existing software to enable ethnicity data to be recorded accurately; establish a process for reviewing data collection and the accuracy of collected data. They could work with individual practices to develop alternative strategies for collecting data from existing patients, such as a postal collection form if necessary. Employment of a data collection facilitator and training for practice personnel could be part of IPA educational programmes.

The issue of cost to individual practices and responsibility to collect ethnicity data needs to be considered, possibly through IPAs and contractual arrangements with the Health Funding Authority.

In summary, it is feasible to collect good data on patient ethnicity in general practice. The challenges associated with ethnicity data collection could be minimised with appropriate training. Good ethnicity data will have benefits to patients and general practice, as well as provide valuable information to providers, purchasers and policy makers. Practices need to be adequately supported to overcome the barriers to data collection and to establish systematic data collection processes. The establishment of data collection facilitators could provide the necessary support to enable practices to collect ethnicity data well.

Table One:

Comparison of practice policy for the collection of different forms of data.

	<b>Number of responses</b>	<b>Never attempt to collect</b>	<b>Sometimes attempt to collect</b>	<b>Not policy but some GPs collect it</b>	<b>Usually collect</b>
Ethnicity	<b>N=62</b>	<b>29 (46.8%)</b>	<b>11 (17.7%)</b>	<b>4 (6.5%)</b>	<b>18 (29.0%)</b>
Marital Status	N=57	14 (24.6%)	8 (14.0%)	3 (5.3%)	32 (56.1%)
Occupation	N=57	10 (17.5%)	11 (19.3%)	3 (5.3%)	33 (57.9%)

Table Two:  
Practice Personnel Interviewed in the Qualitative Stage.

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**Type of General Practice**

7 fee-for-service general practices ranging in size from solo general practitioners to larger group practices

1 Student Health Service

2 After Hours Medical Centres

1 Health Care Aotearoa Medical Centre

**Practice Personnel Interviewed**

9 General practitioners

6 Practice managers

3 Practice nurses

4 Receptionists

1 Practice administrator

**Gender**

The age and gender of the general practitioners varied. The receptionists, practice nurses and practice managers were all female.

**Ethnicity**

Practice personnel interviewed were asked to complete a questionnaire about their ethnic group, age and gender. The ethnicity question was the same as the New Zealand Census version. Responses to the ethnicity question are presented here as they were reported.

<b><u>Ethnicity</u></b>	<b><u>Number (%)</u></b>	
New Zealand European only	8	35%
New Zealand European and other	1	4%
New Zealand Māori only	0	0%
New Zealand Māori and other	1	4%
Other European	5	22%
Asian only	3	13%
Samoan	2	9%
Samoan and other	1	4%
New Zealander or Kiwi	1	4%
Not stated	1	4%
Total	23	

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