

## Practicality of recording patient ethnicity in general practice: descriptive intervention study and attitude survey

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### Abstract

**Objective**—To assess the feasibility of recording patient ethnicity in primary care using the Office of Population Censuses and Surveys classification.

**Design**—A descriptive intervention study and attitude survey in random samples of adults and primary care staff in randomly selected practices.

**Setting**—Eight practices in Lincolnshire and seven in Leicester.

**Subjects and methods**—When patients were asked their ethnicity by general practitioners, nurses, or receptionists data were collected for 863 of a possible 880 patients. Of 750 patients sent a questionnaire about their attitudes towards the collection of such data 489 responded. Ninety five primary care staff completed a similar questionnaire.

**Main outcome measures**—Time taken to record a patient's ethnicity; attitudes of patients and staff towards such recording, including who should ask, who can respond for others, and whether data can be shared with secondary care.

**Results**—Recording the data took less than a minute for three quarters of patients, but even this would need an average of a week of receptionist time per general practitioner. 72% of patients and 57% of staff agreed that ethnic data could be shared with secondary care, and 73% of patients and 60% of staff felt that the data should probably be collected in general practice.

**Conclusions**—Ethnicity recording in general practice is feasible and acceptable. Nevertheless, the role of ethnic data in assessing health need in primary care, an adequate recording system, and evidence that recording offers benefits greater than the costs need to be established.

### Introduction

The recording of the ethnicity of patients admitted to hospital has been mandatory since April 1995.<sup>1,2</sup> If ethnic monitoring is beneficial, however, these data would be more logically collected in primary care, being shared from there with other parts of the health service, allowing health needs and equity of provision of health services to be assessed for the whole population.<sup>3,4</sup> Before such recording could occur the role of ethnicity in health care would have to be accepted; the recording would need to be appropriate, accurate, ethical, and acceptable; the benefits should be clear; and resources to undertake the recording and respond to its findings must be available. None of these criteria is uncontroversial.

Nevertheless, a study in New Zealand<sup>5</sup> and anecdotal evidence from the United Kingdom<sup>6,7</sup> suggest that recording of ethnic data in primary care is feasible and acceptable. So, without uncritically accepting the case for ethnic recording in general practice, we designed a

study to look at three specific issues: the feasibility and practicality of such recording and its possible resource implications.

### Methods

We performed the study in two areas, one (Lincolnshire) with a low prevalence of ethnic minorities (0.76% at the 1991 census) and one (Leicester) with a high prevalence (11.11%). Forty practices were randomly identified from the family health services authority register of each area and invited to take part in the study. After letters and visits to those practices expressing an interest in the study eight practices in Lincolnshire and seven in Leicester were recruited; we recruited them sequentially and wanted eight in each area, but one practice in Leicester dropped out.

In each practice two studies were conducted. Firstly, after training, one general practitioner, one practice nurse, and one receptionist each asked 20 consecutive patients about their ethnicity. These patients were first asked to describe their ethnicity in their own terms and were then offered the classification used by the Office of Population Censuses and Surveys (OPCS) and invited to choose one of its nine categories. The patients' age, sex, and postcode were recorded, as was the time taken and how the recorder felt asking the patients their ethnicity (on a five point scale from very comfortable to very uncomfortable).

For the second study 50 adult patients in each practice were randomly selected from those aged 16 or over registered with the practice and sent a questionnaire that asked for their views on the practical issues of recording ethnicity. Their responses to a range of attitudinal statements using a five point scale were elicited, as were their age, sex, postcode, and ethnic group (using the OPCS classification).

The questionnaire was translated by a translating service recommended by the Leicester Family Health Services Authority and printed in English, Hindi, Gujarati, Punjabi, Urdu, Bengali, Polish, and Chinese. The list of all sampled patients was shown to the practice, which used its knowledge and records to identify the most appropriate version for each patient, all of whom received at least the English version. One reminder letter, with a second questionnaire, was sent to non-responders.

In each practice all general practitioners, practice nurses, and receptionists were given a similar questionnaire to that sent to the patients.

### Results

Forty four staff members in the 15 practices (one practice did not have a practice nurse) elicited responses from 863 patients (98.1% response rate) concerning their ethnicity; 360 (41.7%) of these responders were men. When practice staff asked patients to give their ethnic group without any prompting 851 (96.7%)

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**Table 1—Responses of patients, general practitioners, practice nurses, and non-clinical practice staff to the question "Who should ask patients about their ethnic group?" with multiple responses allowed. Results are numbers (and percentages)**

Person who should ask	Patients' responses	General practitioner responses	Practice nurse responses	Practice manager/receptionists' responses
Doctor	263 (54)	16 (64)	12 (57)	31 (63)
Practice nurse	78 (16)	17 (68)	11 (52)	18 (37)
Practice manager	54	10	5	13
Receptionist	53 (11)	12 (48)	4 (19)	11 (23)
Specially trained person	214 (44)	13 (52)	5 (24)	17 (35)
Other	25 (5)	3 (12)	4 (19)	0

offered a response and when prompted with the OPCS classification 855 (97.2%) patients selected a category. In 236 (27.7%) of valid cases this was an exact or very close match to the self reported ethnicity.

The time taken to ask the patient for their ethnicity, then offer the OPCS classification, and record the answers was recorded for 844 (96%) patients. Three quarters of the recording episodes took less than one minute (339/454 (74.7%) in Lincolnshire and 303/390 (77.7%) in Leicester), but in 34 cases (4%) it took more than three minutes. A significant correlation existed between the time taken and the staff member's level of comfort in asking that patient (Pearson  $r=0.38$ ,  $P<0.0001$ ). The staff in Lincolnshire took longer ( $\chi^2=8.6$ ,  $df=3$ ,  $P<0.05$ ) and felt less comfortable ( $\chi^2=44.5$ ,  $df=4$ ,  $P<0.0001$ ) than those in Leicester in asking about ethnicity.

Of the 750 patients sent questionnaires, usable replies were received from 489 (65.2%)—287 (71.8%) in Lincolnshire and 202 (57.7%) in Leicester. Ninety five replies were received from practice staff—62 in Lincolnshire and 33 in Leicester—of whom 25 (26.3%) were general practitioners, 21 (22.1%) nurses, and 49 (51.6%) receptionists.

Both patients and staff were asked their opinion of the factors that determine "ethnicity." Three hundred and four (62%) patients and 68 (72%) staff thought that parentage determined ethnicity, although among patients language and religion were identified more often in Leicester than in Lincolnshire ( $\chi^2 = 4.09$ ,  $df = 1$ ,  $P<0.05$ ). Two hundred and thirty eight (49%) patients and 60 (63%) staff thought that ethnicity never changed.

Table 1 shows opinions about who should ask about ethnicity. The general practitioner was identified as a key questioner by all groups of respondents, but practice nurses, managers, and receptionists were rated suitable more often by practice staff than by patients (for example, for a practice nurse,  $\chi^2=49.79$ ,  $df=1$ ,  $P<0.0001$ ). Responders were asked about the possibility of people other than patients themselves deciding ethnicity. This may be important when one member of a family registers the whole family or when a patient is deemed incompetent to respond. For healthy adults 59 (12%) patients felt that a close relative could assign ethnicity and 87 (18%) that the general practitioner could do so; 30 (32%) practice staff felt that a close relative could do so and 17(18%) that the general practitioner

**Table 2—Responses to the question "Should general practitioners record the ethnic group of their patients?" by patients and practice staff. Results are numbers (and percentages)**

Respondents	Definitely	Possibly	Don't know	Possibly not	Definitely not
Patients	167 (34)	190 (39)	47 (10)	51 (10)	35 (7)
General practitioners	2 (8)	13 (52)	1 (4)	7 (28)	2 (8)
Practice nurses	2 (10)	11 (52)	3 (14)	3 (14)	2 (10)
Managers and receptionists	8 (17)	20 (42)	7 (15)	11 (23)	2 (4)

could do so. For children aged under 16 the picture was clearer, with 384 (79%) patients and 87 (93%) staff thinking that a close relative could assign ethnicity. For those patients with a major health problem, such as dementia, 324 (66%) patients and 80 (85%) staff thought a close relative could decide, while 221 (45%) patients and 37 (39%) staff thought that the general practitioner could also decide.

Patients and staff were asked about their attitudes to ethnicity: 449 (92%) patients and 84 (89%) staff agreed that patients should be told why their ethnicity was being recorded, and 310 (64%) patients and 68 (73%) staff disagreed with the proposition that "ethnicity is far too private and sensitive to be recorded at all." However, 70 (74%) staff agreed that patients had the right to refuse to have their ethnicity recorded.

Patients and staff were asked about the desirability of a practice passing data on ethnicity recorded in primary care on to hospitals without specific permission, and 352 (72%) and 54 (57%) respectively thought this was acceptable (patients *v* staff difference,  $\chi^2=9.57$ ,  $df=2$ ,  $P=0.01$ ).

To the global question "Should general practitioners record the ethnic group of their patients?" 56 (60%) staff thought "definitely" or "possibly" compared with 357 (73%) patients (table 2). While there was no difference between Leicester and Lincolnshire for patient opinion, the staff in Leicester were more positive (67% *v* 56%,  $\chi^2=15.8$ ,  $df=4$ ,  $P=0.003$ ).

## Discussion

The ethnicity of patients living in Britain is associated with variations in health risk. In addition to established genetic risks such as sickle cell anaemia and thalassaemia, the risk of coronary heart disease is higher in people of Asian origin and those from the African Commonwealth<sup>8</sup>; the mortality from strokes and hypertension is higher in Asians and Afro-Caribbeans<sup>9</sup>; diabetes is more prevalent in Asians<sup>9</sup>; diabetic renal failure is greater in Black and Asian groups<sup>10</sup>; and Asian women are at higher risk of osteoporosis.<sup>11</sup> Some supposed differences, however—for example, the high rate of psychoses in Afro-Caribbeans<sup>12</sup>—are apocryphal, and members of the British Asian community would prefer better access and information to special programmes.<sup>13</sup>

If access is the main issue there is evidence of barriers. Language problems, especially among first generation immigrants, may impair communication.<sup>13-15</sup> But differential consulting rates may reflect different attitudes to medicalisation and somatisation.<sup>13-15</sup> For example, Asians have a higher rate of investigation for dyspepsia,<sup>16</sup> but a lower rate of detected abnormalities.<sup>17</sup> The uptake of preventive services, notably cervical cytology, varies between ethnic groups,<sup>18-19</sup> and the use of complementary and alternative therapies can create side effects and interactions. These established links between "ethnicity" and health service need and use<sup>20</sup> might simply reflect social variations—poverty, housing, education, prejudice, and language—rather than ethnicity itself.<sup>21</sup> Nevertheless, there seems to be enough evidence that ethnicity is associated with variations in health need (whatever the cause) and provision for the case to be made for recording.<sup>3,4</sup>

Whether there is an appropriate and acceptable method for recording ethnicity is also debatable, as the classification of ethnicity used by the OPCS is controversial,<sup>22-24</sup> and even the idea of "ethnicity" can be disputed.<sup>13-25-28</sup> It is also too soon to expect clear evidence of beneficial effects from ethnic recording and monitoring, but doubts have already been raised.<sup>29-30</sup> Moreover, until now, the resource implications have not been measured.

Data on ethnicity would have to be recorded in all areas of Britain if it were to be used for health needs

## Key messages

- There is increasing pressure for ethnicity to be recorded in primary care
- Such recording would usually be quick for individuals but adds up to a considerable commitment for practices
- Patients and staff generally find the concept of recording ethnicity in primary care acceptable
- There needs to be clearer evidence of benefit before asking about ethnicity can be recommended as a routine part of general practice care

assessment. Lincolnshire was chosen as one of the areas in the study to test the acceptability of recording ethnicity in an area where benefits might be hard to define. That nearly three quarters of patients and over half the staff in such areas support the recording of ethnicity offers some support for the feasibility of nationwide ethnicity recording in primary care.

If ethnicity is recorded it seems to be generally a quick exercise for individual patients but the scale of the exercise for whole practice populations should not be underestimated. An average of one minute per patient (the highest end of our estimate) is equivalent to one full working week of staff time per general practitioner distributed unpredictably over many months. Additionally, it is not clear how often patients would need to be questioned about their ethnicity. Over half the patients and a third of the staff thought that a person's ethnicity could change. A "white" teenager could marry an "Afro-Caribbean" and in time regard himself as "Afro-Caribbean" by culture. The children could be reported as "Afro-Caribbean" by their parents but may regard themselves as "white" in adult life. The resources for repeated data capture need to be available, as must be the staff, skills, and technology to use the information effectively.

Recording of ethnicity must be within the established concepts of ethnicity. A patient's ethnic group should ideally be determined by that person since indirect assignment of ethnicity can be fallacious.<sup>16 31 32</sup> This was generally understood and agreed by the respondents in our study but it has implications for data capture. A woman, for example, attending to register her family cannot report her husband's ethnicity but may do so for her children aged under 16.

If ethnicity is recorded in general practice patients must be told why it is being recorded, the use of data must be ethical, intended to benefit the patient, and a patient's rights to refuse must be respected. If recording is handled appropriately, however, our study suggests support among patients and general practice staff for sharing data collected in primary care with secondary health care providers.

Doubts still exist about whether the collection of eth-

nicity data in general practice will help reduce variations in health need and access and whether the current OPCS classification is the right one for these purposes. Only when these issues have been resolved should ethnic recording in general practice be considered.

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## MEMORABLE PATIENT

### A recorded message is not good enough

A few years ago, when on call, the telephone rang in the early hours. A man's voice, with the intonation of the profoundly deaf, said, "Doctor, please come at once. My wife is very ill. I am deaf and I cannot hear you." He repeated the message once and rang off. I went immediately and arrived within a few minutes to find that his wife was very ill. I had a portable monitor and defibrillator with me. This showed ventricular fibrillation but, unfortunately, defibrillation and other resuscitation measures were unsuccessful.

The point of this little story is to ask what would have happened if, as is so often the case, this man had been answered by a machine. He would not have known that he had been unable to pass on his message and would have waited in vain for help. At least on this occasion he knew that all that could be done for his wife was done. I know that the use of telephone answering machines is now normal but surely a place remains for a real live human being to answer emergency telephone calls.— REX D LAST is a retired general practitioner in Somerset