Research paper

Capturing ethnicity data in primary care: challenges and feasibility in a diverse metropolitan population

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ABSTRACT

Lack of ethnicity profiling of patients in primary care in the UK has long impeded the informed development of quality of care and research efforts for ethnically diverse populations. This paper briefly summarises past relevant experience of 'ethnic monitoring', and reports a study to explore models and the practical realities of implementing ethnicity data collection in a metropolitan primary care setting.

A proforma for patient completion was designed to collect information on self-assigned ethnic group, religion and preferred spoken and written language, alongside a template for recording these data on practice computer systems. Eight general practices with varying IT use, serving 43 000 patients in a range of socially and ethnic diverse localities, were recruited and trained to collect data.

All practices chose to begin data collection opportunistically in reception and at new patient registrations, with initial delay due to staff shortage or sickness/absence. Using these methods, six practices made good early progress, experiencing few problems and minimal patient resistance. However, with 15–40% of all registered patients' data recorded after three to four months, data collection then reached a plateau with little additional patient data subsequently captured. Two practices requiring an interpreter to assist patients did not engage this support or implement data collection. Most practices found mailing the proforma to patients was beyond their resources, though mailshots to selected patients achieved some success in two practices.

Findings indicate that collecting data on patient ethnicity in primary care appears a considerable challenge, and the scale of work and costs for practices may be underestimated. In some practices, particularly in deprived areas, the realities of organisational and staff resource constraints may preclude practice-initiated ethnicity data collection, and require external administration. A combination of methods and attendant resource to achieve comprehensive profiling of patient populations in primary care is needed.

Keywords: ethnic monitoring, ethnicity and primary care, patient monitoring

Introduction

Alongside concern to reduce health inequalities (Department of Health, 2000) in the UK, the Race Relations (Amendment) Act 2000 introduced a general duty requiring public authorities, such as the NHS, to promote race equality (Commission for Racial Equality, 2002). Thus the NHS has a duty to provide services that take appropriate account of religious, cultural and linguistic requirements. However, information about these requirements, in terms of individual patients, is not routinely available.

Minority communities form around 9% of the UK population and are younger than the majority population (30% aged under 15 years compared to 19%; Scott *et al*, 2001). For example, 16% of the white

population are aged 65 years and over compared to 10% of the black Caribbean group and 4% of the Pakistani group (National Statistics, 2001). This has implications because of ethnic diversity in patterns of illness and health needs (NHS Health and Social Care Information Centre, 2005). For example, the prevalence of type 2 diabetes is much higher among Indians, Pakistanis and Bangladeshis than in the general population. Diseases such as coronary heart disease and type 2 diabetes are strongly related to age, and so the burden among ethnic minorities is likely to increase.

There remains disagreement about whether and how ethnic groups might be categorised and how useful it is to do this in relation to monitoring health status (Aspinall, 2000a). Within the health service 'ethnic monitoring' of hospital inpatients has been compulsory since 1995 but has not been undertaken in any uniform or consistent way. Information is limited, with no primary care or outpatient data for comparison and so has been little used (Aspinall, 2000b). NHS Direct has included ethnic monitoring as part of callers' demographic information since 2003. However, as over 90% of contacts with the NHS occur in general practice (Royal College of General Practitioners (RCGP), 2004), recording such information in primary care, and sharing this with secondary care where necessary, may make more sense, and reduce duplication of effort.

In order to provide information to develop appropriate and effective services and monitor equity for all patients, ethnicity profiling should include as large a proportion of the population as possible and form a routine part of information gathering in primary care. The absence of ethnicity data in the NHS has also dogged effective health services research and development (Department of Health, 1999). Although better ethnicity data have been available from the 2001 Census at ward/locality level, this has not been sufficiently detailed for individual general practices with relatively small numbers of patients from different ethnic groups. Moreover, patient mobility is high in some practices and census data become out of date too quickly to be used reliably for small areas.

Past experience of collecting ethnicity data in primary care

There have been several pilot schemes of ethnic monitoring in primary care (King's Fund, 2002). However, findings are incomplete or difficult to access, with limited published experience of routine collection in general practice (see Box 1). For example, the Improving Health among Ethnic Minority Populations initiative (Department of Health, 1998) included two

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Box 1 Previous experience of ethnicity profiling in primary care

- *Pringle and Rothera (1996)*: one general practitioner (GP), a practice nurse and receptionist in each of 15 practices each asked 20 consecutive patients attending the practice about their ethnic group. Patients were asked for their views on collecting information about ethnicity in a postal questionnaire. The study concluded that recording ethnicity in general practice was feasible and acceptable to both patients and staff.
- *Sangowawa and Bhopal (2000)*: in two practices, patients attending the surgery were asked by reception staff to complete an ethnic grouping form; 56% of patients were seen in 6 months and data on 75% of these were recorded; that is to say, 42% of all patients on the lists.
- In the *Primary Care Ethnicity Project (Alves* et al, *2000)* staff in 10 practices in London received training in ethnicity profiling. The practices used various methods to collect the data, including new patient registrations, forms given to patients by reception staff and postal surveys either individually or in combination. Data from eight practices showed that information on 34% (range 3–72%) of patients aged over 16 years was recorded.
- *The Princes Park Initiative (Lee* et al, *2000)* in Liverpool used a postal survey of all patients over 16 years to collect information on ethnicity and lifestyle. This achieved a 75% response after two mailings followed by various strategies to target non-responders. These included opportunistic collection by reception staff, high levels of publicity and information through community outreach, support from link workers, telephone calls to patients, home visits to identify incorrect addresses and a third mailshot. Patient profiling has since been extended to other practices in Central Liverpool PCT using two mailshots to patients over 16 years, and is organised centrally. The response rate is 56% (range 46–69%) (Department of Health *et al,* 2005).
- A number of other health authorities and primary care trusts (PCTs) around the country are implementing ethnicity profiling, for example West Midlands, but no published information about these initiatives is available.

projects on collecting ethnicity data in primary care, but the results of only one have been published (Lee *et al*, 2000). Information on how data have been used to benefit patients is even more limited (Department of Health *et al*, 2005; Lee *et al*, 2000).

Various methods have been used but with little consensus about how to standardise data. Some studies (for example, Pringle and Rothera 1996; Sangowawa and Bhopal, 2000) have asked questions about ethnic group alone, but most current ethnicity profiling forms in primary care include questions on ethnicity, religion and spoken and written language, and some have additional questions, for instance about country of origin, cultural needs and carers. The experience of four projects is summarised in Box 1.

Not all data collection has followed recommendations to ask about ethnicity in the same order and format as in the 2001 Census, and this may affect the way people answer the question (Commission for Racial Equality, 2001; Department of Health, 2001). Forms have not been translated as it is not generally known in advance which is the best language for each patient, and the cost of translating forms completed in other languages would be too high. A sentence, in the main languages spoken in the local community, explaining the purpose of the data collection has been included on some forms.

Several studies have enlisted the support of community groups to widen understanding of the purpose of the data collection and so improve response rates (see for example Alves *et al*, 2000; Lee *et al*, 2000). There have been major problems with the lack of appropriate Read codes, and difficulties with recording and extracting data from some older clinical computer systems but the range of Read codes has increased since the 2001 Census (Department of Health *et al*, 2005; Kumarapeli *et al*, 2006).

Children are an additional consideration. It is an important principle of ethnicity profiling that it is self-determined. There is some disagreement over whether information should be collected on children under 16 years, for whom the information **is** often provided by a parent. The Princes Park Initiative collected data on patients aged over 16 years (Lee *et al*, 2000) as does the Central Liverpool PCT patient profiling project (Department of Health *et al*, 2005, p.32). In practices where large numbers of patients are from black and minority ethnic groups, the under 16 years age group may form a sizeable proportion of the total list, as in Birmingham for example (Bower and Patel, 1998). Department of Health guidance (2005) currently recommends that parents should speak on behalf of babies and young children, and older children should be asked their views where possible.

Our experiences of collecting ethnicity data in primary care

The study reported here aimed to explore methods and practical experience of collecting ethnicity data in primary care in practices in Birmingham with a range of populations (see Table 1) and took place in 2001/02.

Methods

Eight practices using the EMIS computer system were recruited from members of MidReC (Midlands Research Practices Consortium). These included practices from areas with differing social and ethnic diversity, and practices with high and low computer use, in order to explore a wide range of issues and problems that could arise in the data collection. Following discussion at a MidReC Practice Managers' Forum, a form was designed for completion by patients to collect information about their ethnic group, religion and preferred written and spoken language (see Appendix). None of the practices sought additional information. Data collection in reception, by mailshot, and at new patient registration was considered. Ethical review was not thought necessary, as local primary care organisations were beginning to promote ethnicity data collection. This pilot study supported the practices in collecting these data as part of local service development.

A template was designed to record the information on the EMIS computer system with the appropriate Read codes. Practice staff were trained in ethnic profiling based on the Department of Health training developed for secondary care (Department of Health, 2001). The practice manager and one or two other staff (receptionists and practice nurses) from five practices joined together for training. Three practices were trained individually, and all administrative staff received training where possible. The practices were set targets of one-third of patients profiled after 6 months and two-thirds after 12 months. Practices were contacted regularly by telephone and practice visits to provide support and advice. Computer searches of the data collected were carried out after 6–12 months of data collection.

Findings

Experience of implementing the data collection

The varied experiences of participating practices are shown as brief case studies in Box 2. Initially practices

Table 1 Practice characteristics

Practice number	1	2	3	4	5	6	7	8	Birmingham
List size	7344	5850	5500	7166	6150	3670	3400	3200	
Number of GPs (assistants/registrars)	4 (3)	4 (1)	3 (1)	5 (2)	4 (2)	1 (1)	1 (1)	1	
Ethnic minorities other than white (%) – practice estimate at start of study	Not stated	5–10	<5	49	5	82	35	20	
Ethnicity 2001 Census[a] (ward):									
% White: British	21.72	82.68	88.97	17.64	81.54	40.16	60.26	68.36	65.64
% White: Irish	2.59	4.20	2.74	3.06	2.89	2.48	4.02	5.67	3.22
% White: Other white	0.71	0.85	1.32	1.37	1.51	0.35	3.29	1.10	1.49
% Mixed (All)	2.62	2.56	3.00	4.58	2.50	3.07	3.19	2.96	2.86
% Asian or Asian British: Indian	4.06	3.43	0.50	5.73	5.85	1.66	6.33	7.04	5.71
% Asian or Asian British: Pakistani	50.58	2.46	0.26	40.49	0.87	41.50	13.95	8.53	10.65
% Asian or Asian British: Bangladeshi	8.69	0.12	0.10	10.35	0.08	3.39	0.82	1.08	2.13
% Asian or Asian British: Other Asian	2.62	0.58	0.14	5.01	0.57	1.64	2.64	0.97	1.03
% Black or black British (All)	5.25	2.81	2.67	9.50	3.45	4.99	4.09	3.65	6.12
% Chinese or other ethnic group (All)	1.17	0.32	0.31	2.28	0.75	0.76	1.41	0.64	1.15
Deprivation (ward):									
Townsend 2001 score[a]	14.2	3.8	5.0	18.6	1.4	11.1	3.5	6.0	
Index of Multiple Deprivation (IMD) 2000 score[a]	67.95	38.98	43.90	75.15	31.06	64.11	31.46	44.83	
Rank of IMD 2000 score (out of 8414)	114	1197	884	33	1871	186	1828	831	

[a]Ethnicity, Townsend 2001 and Index of Multiple Deprivation 2000 data are for the ward where the practice is located.

Box 2 Case studies

- *Practice 1* (4 GPs, list size 7344) withdrew after 6 months without having collected any data, due to staff shortages, difficulties due to the open appointment system which meant that large numbers of patients arrived as the surgery opened, and concerns over confidentiality.
- *Practice 2* (4 GPs, list size 5850) included the form with the letter about flu immunisation sent to patients and asked patients to return it when they attended the flu clinic. The number of patients who had completed the form increased from 15% to 50% of the 65–90 years age group during this period. Other practices showed smaller increases in the amount of data collected at the time of the flu clinics. (Data collected: 26%; over 16s: 31%.)
- *Practice 3* (3 GPs, list size 5500) collected data on over 30% of their patients in 3 months but, as time passed, staff found it unrewarding and collected little additional data ('about two patients per surgery'). The data collection ceased altogether both in reception and for new patients following the resignation of the practice manager. (Data collected: 35%; over 16s: 37%.)
- *Practice 4* (5 GPs, list size 7166) experienced considerable difficulties attempting to implement the data collection; the practice was frequently short staffed, the practice manager was reluctant to ask staff to take on additional tasks, the reception area was surrounded by screens and there was nowhere to leave forms for patients to complete or space for staff to assist patients. After long delays in beginning the data collection and having collected data on fewer than 100 patients, the practice concluded it was not possible to collect the data in reception in this practice. The practice also felt unable to undertake a mailing to patients, due to lack of staff.
- *Practice 5* (4 GPs, list size 6150) used a variety of methods to collect the data, but most of it was collected in reception. A mailshot organised by the practice, at the beginning of the data collection, to patients who had not attended the surgery in the previous 12 months achieved a 45% response rate. Two subsequent mailings to non-attenders had lower response rates of around 35%. When the data collection slowed down, the practice arranged for all appointments booked in advance to be marked with an E on the arrivals screen of their computer system so that the reception staff could target only those patients known not to have already completed a form. This was effective in maintaining the momentum for the data collection with staff. (Data collected: 62%; over 16s: 65%.)
- *Practice 6* (1 GP + locum, list size 3670) has large numbers of patients who are unable to speak English, including refugees and asylum seekers, but bilingual receptionists assisted patients with the form where possible. This was time consuming and often there was insufficient staff time to do this. The practice sometimes asked patients to take the form home to get help to complete it, and gave them an envelope to return it. The practice said they did not wish to do a mailing as they preferred to ask their patients in person. (Data collected: 12%; over 16s: 12%.)
- *Practice 7* (1 GP + locum, list size 3400) collected all their data in reception. (Data collected: 45%.)
- *Practice 8* (1 GP, list size 3200) found it difficult to implement the data collection as the GP went on sick leave and the practice manager was on maternity leave. Data had been collected on 130 patients after 6 months and none had been entered on the computer system.

were confident data collection would be straightforward and targets achievable. However, in several practices there were long delays before this began. These were mainly attributed to staff shortages, particularly in reception. All the practices in this study chose to begin the data collection in reception, thinking that this would be relatively easy to do. This proved to be the case, with only one practice (Practice 6) reporting problems due to large numbers of non-English-speaking patients.

Practices 1, 4 and 6, with large numbers of non-English-speaking patients, were offered an interpreter for one to two sessions per week to assist with data collection. However, two of these practices (1 and 4) did not proceed with this or implement data collection and the third (Practice 6), with bilingual receptionists, preferred to interpret for their patients themselves.

The number of patients refusing to complete a form was low, as most patients who questioned the reasons for the data collection completed the form when given an explanation by staff. Practices were inconsistent about collecting data on young children, and some practices chose not to collect data on babies.

Plateau effect on data collection

After 3 or 4 months, practices reported that data collection slowed when data on around 20–40% of patients had been collected (see Figure 1). Practices reported that they were frequently asking patients to complete a form when they had already done so. Reception staff became demoralised as they felt there was little reward for their effort.

Practice 5 targeted patients who had not completed a form by flagging the 'arrivals screen' on the computer system in advance of the patient's appointment, and this was very effective. However, it also proved time consuming and expensive and was not possible for appointments booked at short notice. Practice managers commented that marking the cover of patients' paper notes to show that they had completed an ethnicity form was less helpful, as many patients' notes already had such coloured codes in abundance.

Consultation data

To explore possible reasons for the observed plateau effect, the number of patients attending practices was estimated. In Practices 2, 5 and 7 the majority of consultations were recorded on the computer system, so an analysis of the consultations with a doctor or a nurse was undertaken. At these three practices, 75–85% of the practice population had had a consultation over the previous 12 months, but the figures were around 50% after only 3 months (see Figure 1).

Although this annual consultation rate was similar to national data (RCGP *et al*, 1995), the high consultation rates over shorter periods of 1–3 months were unexpected, particularly as in two practices this occurred during the summer months when consultation rates are lower than in the winter. Around half the practice populations attended a consultation in a 3-month period, and only an additional 25–35% of patients attended in the following 9 months. This suggested data collection in reception is likely to find many repeat attenders after 3 months.

Using different methods for data collection

Practices were encouraged to use other methods that appeared appropriate for their practice to assist data collection. This included putting a message on the electronic message board in the waiting area inviting patients to complete an ethnicity form, sending forms to nursing homes, and targeting special clinics. One practice sent the ethnicity form with a reminder letter about the flu clinic to all eligible patients and had a good response.

An obvious time to collect data on ethnicity is at new patient registrations when patients are asked to provide a range of personal information to practices. All study practices opted to collect data at new patient registrations, but most failed to use this opportunity fully and only collected data on a small proportion of their new patients (see Table 2). The number of new
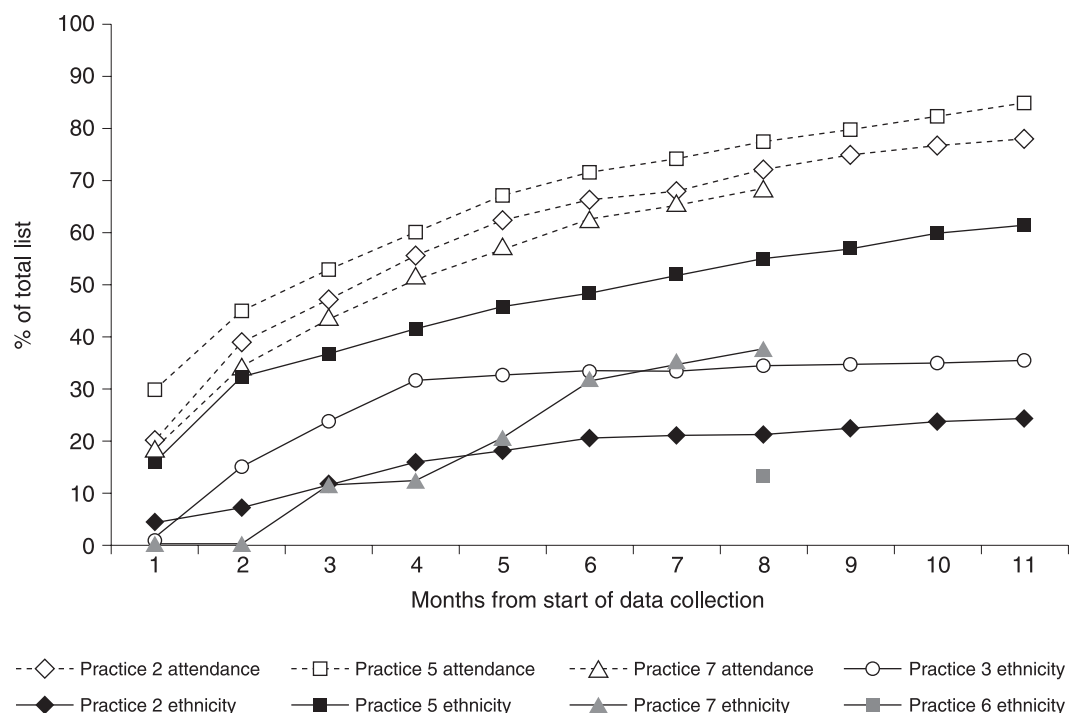

Figure 1 Cumulative monthly attendance and ethnicity recording

Table 2 Data collection

Practice	Training date	Start of data collection	Ethnicity data recorded (% of total list)	New patient registrations 1 April 2001 to 31 March 2002 (%)	New patient registrations with ethnic data (%)
1	Apr 2001	[a]	–	–	–
2	Apr 2001	July 2001	26	6.5	63
3	Apr 2001	June 2001	35	7.4	18
4	Apr 2001	Dec 2001	[b]	–	–
5	Apr 2001	May 2001	62	9.7	78
6	Aug 2001	Sept 2001	12	27.3	3
7	Aug 2001	Sept 2001	45	8.1	50
8	Nov 2001	Mar 2002	5[c]	–	–

[a] Withdrew October 2001.
[b] Collected data on only ∼100 patients; unable to continue data collection.
[c] Practice manager on leave during study.

patients registered in the practices that implemented the data collection was less than 10% (range 6.5–27.3%) of the total patient lists, except in Practice 6 where it was 27%.

Discussion

Our study suggests that common recommendations on ethnicity profiling (Alves *et al*, 2000; Lee *et al*, 2000) are unlikely to be easily translated and incorporated into routine primary care practice without more dedicated resource and organisational support.

This study was undertaken when many PCTs and individual practices were, at best, tentatively planning to collect ethnicity data, and was consistent with thinking at the time. NHS guidance (Department of Health, 2001) referred only to data collection in secondary care, and Read codes for use in primary care were limited. Progress has been made since then. New NHS guidance is now wide-ranging, and advocates data collection in primary and secondary care, NHS Direct, social services, mental health care and local authorities (Department of Health *et al*, 2005).

Following the Race Relations (Amendment) Act 2000, there has been more investment in equality training. Developing patient profiling is becoming a key area of race equality schemes prepared by PCTs. However, progress has been patchy, suggesting that the challenges found in our study continue. For example, in the Heart of Birmingham Teaching PCT (2005),

where 'minority' ethnic communities form the majority population, no systematic programme is currently in place as attempts to introduce a system have faltered. Difficulties with recording data and adapting the data collection to local circumstances remain. For example, Waltham Forest PCT (2005) has reported that only 20% of GPs are collecting information, and the data collection has been delayed by problems with templates for computer systems.

The new Quality and Outcomes Framework within the General Medical Services contract for general practice has been effective at improving the quality of data recording in many areas of primary care (The Information Centre, 2006). From April 2006, this has provided an important new incentive for practices to 'record ethnic origin for 100% of new patient registrations' (NHS Employers, 2006, p.72). This must be welcomed, although, particularly where patient turnover is low, more complete profiles of practice patients will only develop in the long term. Nevertheless, practices may be stimulated to implement procedures to record ethnicity data more routinely.

Recommendations

A range of methods is needed to maximise the data collection. Our findings suggest that the data collection in primary care may be most effective when carried out intensively in reception for 3–4 months followed by a mailshot. After a time, the amount of information collected in reception may not justify staff effort unless

it is targeted at patients known not to have completed a form.

Systems to ensure that information is collected on all new patients at registration will help. However, collection undertaken opportunistically at other consultations or contacts with patients will be needed to maximise data, for example, by including a form with other routine letters sent to patients. Aside from new patient registration, we suggest that for some practices, particularly those in deprived areas, it will not be feasible to collect ethnicity data at other times due to organisational difficulties and limited staff resource. Here a mailshot might be undertaken on behalf of practices, for instance by the PCT, with resource implications, and strategies for non-responders (Department of Health *et al*, 2005, p.32; Race for Health, 2006). To facilitate implementation, concerted measures will be needed to include all practice staff, rather than an interested few, in relevant training that underlines the importance and utility of ethnicity profiling, and enhances ownership of the process.

Conclusion

Changes in the organisation of primary care, and the creation of incentives in relation to monitoring the quality of care, offer vital new opportunities to develop ethnicity profiling and to use the data to benefit patients and their care. Nevertheless, collecting information on ethnicity in primary care remains a considerable challenge. As our experience demonstrates, the amount of wider support and work involved in practices with their associated costs should not be underestimated. A range of methods, appropriately resourced, within and external to practices is needed.

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CONFLICTS OF INTEREST

None.

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Appendix: patient questionnaire

Please write clearly in capitals

Name: ....   Date of Birth: ....

Telephone: ....   Postcode: ....

What is your ethnic group?
Choose ONE section from A to E, then tick the appropriate box to indicate your cultural background

A White
☐ British
☐ Irish
☐ Any other white background
please write in

....

B Mixed
☐ White and black Caribbean
☐ White and black African
☐ White and Asian
☐ Any other mixed background
please write in

....

C Asian or Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Any other Asian background
please write in

....

D Black or black British
☐ Caribbean
☐ African
☐ Any other black background
please write in

....

E Chinese or other ethnic group
☐ Chinese
☐ Any other
please write in

....

What is your religion?
Tick one box only
☐ None
☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
☐ Buddhist
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Any other religion
please write in

....

Do you speak English?
☐ Well
☐ Poorly or not at all

What is your preferred spoken language?

....

Which language do you read?
☐ None
☐ English
☐ Other, *please say which one*

....