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Research paper

Ethnicity data collection in the UK: the healthcare professional's perspective

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What is known on this subject

- Inequalities in health and access to healthcare among ethnic minority groups have been widely reported. However, ethnicity data collection to date has often been conducted in an ad-hoc manner, resulting in patchy data.
- The need for good-quality and complete ethnicity data has been reinforced by the Equality Act 2010, which places responsibility on authorities to tackle inequalities and target services appropriately.
- Many authors emphasise the need for improved ethnicity data collection and monitoring, but little is known about the barriers that healthcare professionals face when collecting these data.

What this paper adds

- It provides a rare glimpse of the barriers to ethnicity data collection as revealed by healthcare professionals who are not collecting the data, and a better understanding of the problems experienced by those who do collect them.
- The barriers identified here point to areas in which the development of training materials is vital.

ABSTRACT

The collection of ethnicity data has been demonstrated to be important in healthcare. However, despite recent efforts by the UK government, it remains incomplete and unvalidated. In order to be able to assess inequalities and target resources appropriately, it is essential to have complete and accurate data. This paper examines the reasons for the gaps in ethnicity data based on the perceptions

and experiences of the healthcare professionals who are charged with collecting these data.

A questionnaire was used to assess perceptions of ethnicity data collection, including any barriers encountered as well as the perceived importance of collecting these data. Respondents were asked whether routine ethnicity data collection was limited to specific disease areas, and approximately what proportion was

complete in these areas. There were also questions concerning preferred methods of collection (e.g. self-report). The questionnaire was completed by 30 respondents, who included healthcare managers, clinicians, nurses and other staff working in the healthcare setting. The findings confirmed that the collection of patients' ethnicity data is deemed important by the healthcare professionals, but showed that there remains uncertainty and unease as to how best to collect these data or how to explain

to patients how the data will be used. The majority of healthcare professionals agreed that it was important to record patients' ethnicity, but no clear rationale was given to staff about the use of these data, and no training was provided on the best way to collect the data.

Keywords: data collection, ethnicity, healthcare professionals, perspectives

Introduction

The 2001 UK census classified 4.6 million people as belonging to a non-white ethnic group (7.9%), with over 50% of these being Asian or British Asian (Office for National Statistics, 2001). Reports on health inequalities and outcomes by ethnic group emphasise the necessity of overcoming barriers to make way for complete and accurate recording of ethnicity. Some ethnic groups have an increased incidence of specific diseases, such as some cancers, and experience disparities in access to both primary and secondary services (Chinegwundoh *et al*, 2006; Bowen *et al*, 2008; Sproston and Mindell, 2006; Jack *et al*, 2009, 2010, 2011; Farooq and Coleman, 2005; Atkinson *et al*, 2001; Aspinall and Jacobson, 2004). Furthermore, certain ethnic minority groups are associated with risky behaviours. For example, smoking rates are reported to be highest in Bangladeshi males, at 44%, compared with 27% in the general population (White, 2002).

Policies based on inaccurate data may lead to poor targeting of resources and services (White, 2002; London Health Observatory, 2003; Mackintosh, 2005). In this evidence-based era, the reality neatly stated by Johnson is 'that which is measured can be aimed at; that which is left unobserved can be ignored' (Johnson, 2012, pp. 39–40).

UK government policy first required ethnicity data collection for Hospital Episode Statistics (HES) in 1995. However, high levels of missing data and invalid codes in the early years made the data unusable (Aspinall, 2000). Although there has been some improvement, such as the decline of 'not known' or 'not stated' codes in Finished Consultant Episodes from 23.9% in 2004–2005 to 8.6% in 2009–2010, HES data remain incomplete (HESonline, 2009). In 2004, the Quality and Outcomes Framework (QoF) began awarding one point (of a possible 1000 points) to GP practices for the recording of ethnicity for all newly registered patients. The incentive was insubstantial, and uptake was limited and was therefore later abandoned (Johnson, 2012).

In 2005, the Department of Health produced *A Practical Guide to Ethnic Monitoring in the NHS and Social Care* (Department of Health, 2005b). An ethnic monitoring tool developed by NHS Scotland was also released in 2005. The tool offered information on the 'whys' (duty and accountability) and 'hows' of ethnic monitoring (i.e. who is involved and what needs to be put in place). Training materials were available to download and modify alongside 'Training the Trainer' notes and role-play scenarios (NHS Health Scotland, 2005). However, little is known about the practical applicability and uptake of any of these guidelines.

The Equality Act 2010 reinforced the Race Relations Act of 1976 and the subsequent Amendment in 2000. This legislation made public authorities directly responsible for ensuring equity in access to healthcare and for reducing inequalities. Furthermore, public authorities are required to publish data to demonstrate their adherence to the legislation and to set clear objectives for the future. The intention is that compliance with the legislation will lead to a better understanding of the decision-making processes and make public authorities accountable for their performance (Home Office, 2010).

Staff attitudes to ethnicity data collection have been reported to be quite positive (Pringle and Rothera, 1996). For example, a survey of 16 GPs and practice managers reported that they all regarded ethnicity data collection favourably and thought it acceptable, practical and beneficial for service evaluation and targeted health promotion as well as for other purposes (Sangowawa and Bhopal, 2000). Nevertheless, ethnicity data collection is known to be patchy, particularly in primary care, where much of the research has focused upon the acceptability, feasibility, resource implications (including staff time), and limitations of computer systems, categories and coding (Kumarapeli *et al*, 2006; Pringle and Rothera, 1996).

In our first publication about this research we reported findings from a systematic literature review of ethnicity data collection methodology in primary and secondary care (Iqbal *et al*, 2009). 'Barriers to collection' featured as one of seven themes that were

identified, and the evidence revealed healthcare professionals' perceptions to be a major obstacle to the collection of ethnicity data. Fear of causing offence to patients or encountering resistance, together with confusion about ethnicity categories and a lack of understanding of the need for ethnicity data, have also been reported as deterrents by healthcare professionals in two reports from the USA (Hasnain-Wynia *et al.* 2004; Regenstein and Sickler, 2006). Baker *et al.* (2005) reported that administrative staff feared that asking for ethnicity data would alienate patients. Barriers reported by US physicians included the beliefs that collecting ethnicity data would be time consuming, would impinge on privacy and would be uncomfortable for both staff and patients, but the greatest barrier was the belief that the data had no relevance (Wynia *et al.*, 2010).

In our second publication we reported the results of a series of focus groups conducted with healthy South Asian volunteers (Iqbal *et al.*, 2012). The topic guide focused on perspectives and experiences of ethnicity data collection in a healthcare setting. The findings showed a somewhat linear relationship between staff comfort and patient willingness, such that the more comfortable the staff appeared to be about asking the question, the more willing the patients were to provide these data. The participants also felt that staff should be able to offer reasons for collecting the data and explanations of how the data would be used. In a US study, Baker *et al.* trialled four different rationales and found that patient comfort levels were highest when quality monitoring was cited as the reason for collection (Baker *et al.* 2005).

Despite the push towards improving the completeness and reliability of ethnicity data recording, little is known about how healthcare professionals in the UK perceive the collection of these data. The aim of this paper is to explore the likely reasons for gaps in the ethnicity data by evaluating the perceptions and experiences of healthcare professionals who are tasked with collecting this information.

Methods

Cancer Research UK commissioned a project to assess ethnicity data collection for statistics relating to cancer incidence, management, mortality and survival in the UK. Ethical approval was obtained from South Birmingham Research Ethics Committee.

A survey of healthcare professionals was undertaken using a questionnaire based upon one previously developed by the Centre for Evidence in Ethnicity, Health and Diversity (CEEHD), and modified by the project working group. The modified questionnaire consisted of nine items using a mixed

style of questions. Respondents were asked to rate how important they thought the collection of ethnicity data was using Likert-style items, while other questions were posed in either a closed format (no/yes/not known response options) or a tick-box format. Two open-ended questions were included, allowing respondents to provide detailed reasons for not recording ethnicity and to describe any problems encountered. The questionnaire was intended for clinicians, managers, nurses and other staff (e.g. reception staff) involved in collecting or using ethnicity data in a healthcare setting (see Figure 1).

The questionnaire was distributed between March and June 2007 throughout England and Wales, via the Minority-Ethnic-Health and ALLSTAT JISCMail lists (a national academic mailing list service for academic and research communities). Questionnaires were also circulated to the 23 Race for Health primary care trust programme leads, as well as to all registered members of the Race for Health mailing list. The questionnaire was posted on the CEEHD website with a link to this placed on the NHS Evidence – Ethnicity and Health website (formerly the Specialist Library for Ethnicity and Health) and sent to the National Cancer Research Network (NCRN) head office for circulation to the 24 Cancer Networks in England and Wales. A thread was created on NHS and Academic Clinical Oncology and Radiobiology Research Network (ACORRN) discussion forums. Regular weekly bulletins from the NHS forum to its members highlighted new threads. The questionnaire could be completed and returned by either post or email. In total, 14 questionnaires were completed and returned within the 4-week deadline. This was extended for a further 4 weeks (on the website links). Circulation of the questionnaire to the NCRN was repeated, but this time the questionnaire was sent electronically to each network manager, which increased the number of questionnaires returned to 30. There was a special interest in the cancer networks because the project was commissioned by Cancer Research UK.

Results

In total, 30 responses were received, coded, analysed and reported using descriptive statistics. Responses to the open questions *reasons why ethnicity data are not collected* and *problems encountered when collecting these data* are presented as direct quotations. Respondents classified themselves as *clinicians* ($n = 7$), *nurses* ($n = 5$), *managers* ($n = 5$), *information scientists* ($n = 6$) and *other* ($n = 7$), which included two radiographers, a cancer services coordinator, a patient profiling officer, a quality coordinator, a diabetes educator and a diversity manager.

Name of organisation:

Position (circle as appropriate): Clinician/Manager/Nurse/Information Scientist/Other

Job title:

Ethnicity data collection (this includes ethnic group, language, religion, country of origin, country of birth, and racial category)

1. Please rate how important you *personally* think the collection of ethnicity data is on a scale of 1 to 5:

Unimportant					Very important
1	2	3	4	5	

2. Do you attempt to collect any ethnicity data on patients? No/Yes

2a. If ethnicity data are not collected, please give reasons below and go to Question 5:

2b. For which disease areas do you routinely collect ethnicity data (please tick all relevant boxes):

All disease areas Cancer Diabetes Hypertension

Other If other, please state:

2c. For the routine data collection indicated in 2b above, please estimate the overall percentage for which you have recorded ethnicity:

3a. If ethnicity data are collected, please state the methods used:

Patient self-assessment

Assessment by healthcare professional by observation

Other

If other, please give details
(e.g. Indirect assessment using country of origin or name recognition software)

3b. Please comment on any problems you have encountered when collecting ethnicity data:

Figure 1 Ethnicity, Health and Diversity questionnaire

3c. Which indicators of ethnicity do you routinely collect (please circle all relevant responses)?

Census ethnic group	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known	Country of birth	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known
Race	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known	Country of origin	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known
Religion	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known	Language	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known
Patient name (i.e. for use with name recognition software)	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known		
Other	<input type="checkbox"/> No/ <input type="checkbox"/> Yes/ <input type="checkbox"/> Not known		
If other, please give details:	<input type="text"/>		

4. Are you using any name recognition software (e.g. Nam Pehchan or SANGRA)?

No (go to Question 5)

Yes, please state which:

4a. What is your experience (in terms of reliability) of using such software? High/Medium/Low

4b. Have you compared the results of this software with other data sources? No/Yes/Not known

4c. Have you developed a local dictionary to enhance its reliability? No/Yes/Not known

5. If not used in the past, would you be interested in using name recognition software? No/Yes

6. Does your organisation provide any training in ethnic monitoring? No/Yes/Not known

7. Would you be interested in attending an 'ethnic monitoring and its uses in cancer' workshop? No/Yes

8. Please rate the value of collecting ethnicity data *to your organisation*:

Unimportant					Very important
1	2	3	4	5	

9. Any other comments:

Would you be prepared to speak to us about this area? If yes, please provide your contact details below:

Name:

Email:

Tel:

Thank you very much for your patience in completing this questionnaire.

Would you like to receive a copy of the final report: Yes/No

In total, 21 respondents (70%) attempted to routinely collect some form of ethnicity data, two (7%) did not consistently collect ethnicity data, and seven (23%) did not collect any ethnicity data. Respondents who collected ethnicity data (routinely or occasionally) did so for cancer (37%), for all disease areas (32%) or for diabetes and hypertension (5%). The majority used the recommended self-report method ($n = 12$); observer assessment was used less frequently ($n = 4$). Several respondents reported using a combination of methods (e.g. self-report and observer assessment) (see Figure 2).

Respondents who did not collect ethnicity data were asked to give their reasons for this. Their explanations included a lack of resources:

Our data collection is poorly resourced as it is, so we have to stay entirely focused on what is clinically relevant.

(Oncologist)

It is very difficult to record ethnicity data for our cancer records as it is not documented in the patient's case notes, to the best of my knowledge. Due to this, it would take a great deal of time to collect and is, however, not asked for in any reports that are asked of me.

(Cancer professional)

Respondents stated that they were not required to collect or report ethnicity data:

Ethnicity data is not part of the data sets that are collected.

(Information manager)

In some instances, ethnicity data were only collected for specific services or when requested as part of a clinical trial:

Ethnicity data collection currently limited to midwifery as Trust is taking part in the Welsh Assembly Government Patient Equality Monitoring Project and staff are awaiting training in how to collect information.

(Human resources manager)

Only if it is required as part of a research trial and the company require that information. We then only fill it in, but it is very rare. We do not routinely collect this.

(Research nurse)

Collecting ethnicity data could be problematic:

because it involves asking the patient what they want it to be and they are not always available or willing to answer.

(Informatics lead)

Staff collecting ethnicity data might not be aware of the need for self-report, and patients might refuse to answer if the options available did not match their ethnicity. Ethnicity was most commonly recorded based on the categories used in the Census (Office for National Statistics, 2001). Data about religion and language were routinely collected, but data about country of origin, race and country of birth were least likely to be collected (see Figure 3). Data systems were reported to be inadequate, and the ethnicity categories needed to be refreshed:

Existing data collection systems are not made for it. Ethnic categories are not up to date, follow old traditional immigration routes.

(Information analyst)

Collected as part of a large data set, and some items are poorly returned.

(Chair of information network)

The optional nature of ethnicity data collection was an additional factor. Patients could choose not to respond, which meant that ethnicity data would always be incomplete.

Ethnicity data collection was considered:

Time consuming – reception time, patient time, data entry time, also language have used link workers to help patients fill in. Definite resource implications.

(GP)

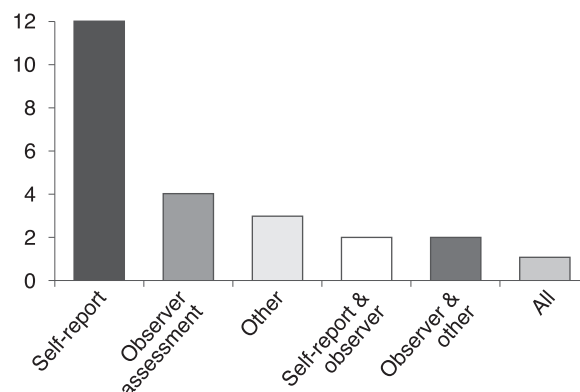


Figure 2 Method of collection.

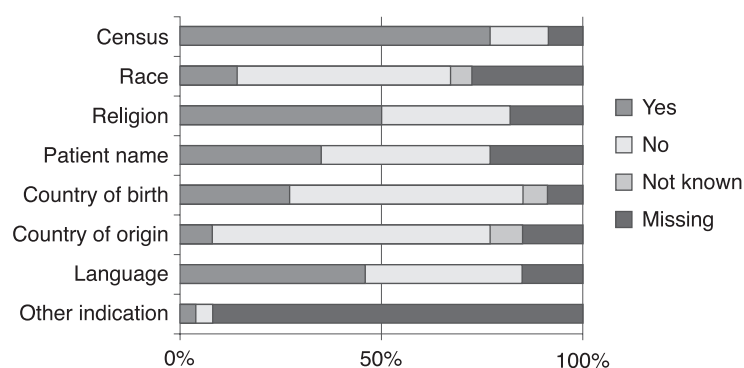


Figure 3 Routinely collected indicators.

Patients and staff did not always understand why it was necessary:

We have been collecting data surrounding ethnicity, etc. for around 7 years. The main issue is the patients' lack of understanding of what ethnicity is. Also practice staff's lack of awareness of why we need to collect this information. On the whole, though, there have been very few problems.

(Patient profiling development officer)

Ease of access to data was also a problem. Ethnicity data were not always recorded in an accessible place, such as the front of the patient's records or on the computer, which could mean that it was necessary to manually search for the information:

Often not recorded on software, so had to retrieve old notes and read through pages of clerking notes. Ethnicity usually recorded by junior doctors + written in. I did not wish to assume ethnicity from name alone.

(Consultant)

Staff feared being challenged by patients who wanted to know the reasons for the collecting of ethnicity data, and the possibility of ensuing hostility, or causing offence:

Patients will ask why you need to know. If they come for anonymous info [they] do not want to be listed. Do not accept that you need to have an idea of ethnic origin so as to be able to review/develop/change service that is provided.

(Information and support services manager)

I feel this is a difficult area due to fear of offending anyone. Most of the younger generation are British, I would have thought.

(Nurse)

Training large workforces was problematic:

We have had difficulty releasing the vast numbers of staff required to attend 'patient equality monitoring' training

sessions. However, this has been made easier by an All-Wales Patient Equality Monitoring Project sponsored by the Welsh Assembly Government and run by the NHS Wales Centre for Equality and Human Rights, who have produced an excellent Train the Trainer pack for patient equality monitoring.

(Manager)

However, the situation had changed following the development of a Train the Trainer pack by the NHS Wales Centre for Equality and Human Rights. Finally, respondents were asked to rate how important they personally thought ethnicity data collection was, and how important they perceived it to be to their organisation. Overall, respondents attached more importance to it at a personal level (69%) than at an organisational level (59%). This may be due to a lack of training provision. Only 28.5% reported that their organisation provided ethnic monitoring training, 28.5% reported that no training was provided, and the remaining 43% were not aware of any training provision. In total, 12 respondents (44%) expressed an interest in attending a workshop on ethnic data monitoring and its uses in cancer.

Discussion

These findings showed that, although individuals regarded ethnicity data collection as important, this did not mean that they went on to actually collect this information. A number of barriers were identified, particularly that of using self-report, which is unanimously agreed to be the ideal method of collection and is recommended by many guidelines as the gold standard (Commission for Racial Equality, 2002; Department of Health, 2005b; Regenstein and Sickler, 2006). However, assessment by observation alone based upon appearance (e.g. skin colour, hair colour and/or type, dress code), despite being discouraged, was the second most commonly utilised method. Reasons given

for using this approach included the avoidance of discomfort and confrontation, accompanied by a fear of causing offence to patients. This is not a new concern. An early experimental project on collecting ethnicity data in the NHS recorded a similar fear of offending patients coupled with a fear of being accused of discrimination, embarrassment when asking the questions, and concern that the questions were too sensitive as the main barriers to ethnicity data collection (Johnson *et al*, 1993). In the modern context, worries emerged about dealing with younger patients who are more likely to be born in the UK and who may wish to identify themselves as British. In addition, one respondent in our survey highlighted the difficulty of obtaining self-reported ethnicity data (as recommended by Department of Health guidelines) in situations where the patient is unwilling or simply chooses not to provide the information (Department of Health, 2005a).

Methods of data collection other than self-report are actively discouraged by the Commission for Racial Equality, and may only be used where self-report is not possible. Results of surveys conducted by the Robert Wood Johnson Foundation (a funding body established in the USA in 1972) revealed that 61% of healthcare professionals used the self-report method, whereas 25% used the observer method. Professionals considered the data to be accurate, given their knowledge of the local population, and believed that this method eliminated discomfort both for themselves and for the patients (Regenstein and Sickler, 2006).

A number of our respondents did not attempt to collect any form of ethnicity data. In many cases this stemmed from their own or their organisation's lack of awareness of the importance of the data, and the belief that it was not relevant to patient care or treatment. However, exceptions occurred if the information was required for participants in a clinical trial or for religious, dietary or communication purposes. Interviews conducted with physicians in the USA revealed that the strongest objection to collecting ethnicity and race data is the belief that it is, or should be, clinically irrelevant. Other barriers that were reported included a lack of resources, concerns about privacy, the legality of collection, and discomfort or resistance on the part of patients and staff (Hasnain-Wynia *et al*, 2010). These findings concur with the earlier results reported by Regenstein and Sickler (2006), who found that the single most important barrier to data collection is staff not knowing why it is important. However, this was not reflected in our sample, where only one participant expressed the view that it was 'not relevant to care or treatment.'

Additional barriers that were reported included difficulty in allowing staff time away from work to attend off-site training courses. However, training packages such as those developed by Lambeth Primary

Care Trust, NHS Health Scotland, and the Health Research and Educational Trust (HRET) in the USA freely offer a wide range of material online, including role-play scenarios which can be used for in-house training (NHS Health Scotland, 2005; Health Research and Educational Trust, 2007; Race for Health, 2006). Weinick *et al.* (2007) have found 'train the trainer' sessions to be a viable alternative to releasing numerous staff for training in Massachusetts in the USA.

Example of good practice

Lambeth Primary Care Trust is an example of good practice where ethnicity monitoring has been relentlessly pursued. Lambeth introduced the 'Individual Patient Registration Profile' programme, which provided substantial cash injections to GP practices as an incentive to collect comprehensive patient profiling data, and also provided 1.5 days of staff training, with the half day being held at the practice. Practices were also assisted with patient profiling data collection for all patients. Mailshots of the profiling questionnaire were posted out to capture data for registered patients with free return envelopes and fully funded data entry upon return. Data were collected prospectively for all new registrations and recorded on dedicated templates provided by the programme. The resulting data have been used in a health equity audit of Stop Smoking Services and a needs assessment exercise undertaken with the Portuguese community (Race for Health, 2006).

Regenstein and Sickler (2006) have provided examples of good practice in the USA, which include the provision of ethnicity data collection training for new hospital employees as part of their induction programme. Furthermore, members of staff working in registration areas are subjected to a quality review. Managers are able to identify individuals who record a large number of 'unknown' ethnic categories or fail to record any ethnicity data, and then provide further training where necessary.

Limitations

This study was limited in terms of time and resources, and we were therefore unable to recruit a large sample or conduct large mailshots, but relied instead on links to the questionnaire posted on websites, forums, newsletters and mailing lists, and a small mailshot to all NCRN network managers. Unfortunately, this means that we are unable to calculate a response rate. In the event, we received only 30 responses despite extending

the deadline for returns. With hindsight, an online questionnaire would have been easier to complete. It would have eliminated the need to print out, post or email the completed questionnaire, and might have resulted in an increased response rate. Targeted mailshots such as that to the NCRN could have been sent to other groups (e.g. individual GP practices or primary care networks), which might have yielded more questionnaire returns than using JISCMail lists. However, given the scarcity of research in this area, the responses that we did receive provide a useful insight into the perceptions and experiences of healthcare professionals today, and identify important areas for further consideration.

Conclusion

Our findings are likely to be irrelevant without a change in local and national policy. Ethnicity data collection needs to be mandated in primary care and improved in terms of quality and completeness in secondary care. Training exercises should include familiarising healthcare professionals with the Equality Act 2010, and raising awareness of the need for ethnicity data collection and how these data will be used. Methods of collection should also be included, and the importance of self-report emphasised, as well as the need for standardising of the rationale, wording of questions, response categories offered, and answers and explanations to frequently asked questions. Training may help to alleviate any anxiety felt by staff who are tasked with obtaining ethnicity data from patients. It should be emphasised that using the data we already have, irrespective of its quality and completeness, will encourage improved collection by highlighting any inadequacies. Unused data are a disincentive to healthcare professionals and patients alike (Iqbal *et al*, 2012; Fulton, 2010).

In conclusion, 'health equality is not possible without ethnic monitoring' (Fulton, 2010, p. 5). Improving ethnicity data collection requires commitment from governing bodies and agreement on what is to be collected and when. Standardised questions should be complemented by sufficiently flexible options to facilitate responses from those who do not quite fit predetermined categories. Patients need to feel assured that these data will be treated confidentially and used appropriately (Johnson, 2012; Fulton, 2010). Ethnicity data are of no value if they are not utilised to target resources and reduce inequalities (Raleigh, 2008).

A few primary care trusts have worked hard to improve ethnicity data collection, and have utilised the resulting data to help to reduce health inequalities (Race for Health, 2006; Public Health Sector, School of

Health and Human Sciences, Liverpool John Moores University, 2000). However, these are isolated examples. What is needed, alongside these efforts, is a consistent message from policy makers and managers to frontline staff that collecting these data matters. Ethnicity data collection should be part of the daily routine at both primary and secondary care levels. Most importantly, we need more reporting of ethnicity data in healthcare in order to improve planning and delivery of services for members of ethnic minority groups.

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CONFLICTS OF INTEREST

None.

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