Ethnic monitoring: is health equality possible without it?

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Key messages

1 Collecting and using ethnic group data enables health services to demonstrate a clear and localised understanding of where inequalities exist and hence to take informed measures to address them

2 The lack of mandatory ethnic monitoring across primary care means that there are no systematic data available for ethnic health inequalities

3 Against a backdrop of increasing ethnic diversity, poor compliance with race equality legislation gives particular cause for concern

4 Successful ethnic monitoring requires a strong regulatory framework complemented by proactive, committed leadership

5 Examples of good practice do exist, but failure to use ethnicity data to inform and improve practice has been a persistent barrier to improved collection rates: too few data are recorded and those that are recorded are too little used to inform practice.

Introduction

The collection and use of ethnic group data enables health services to identify and respond to health inequalities as experienced by different social groups in terms of health status, access to health care, experience of health care and health outcomes (CRE, 2002). A powerful rationale for the collection and use of ethnic group data is therefore that of social justice. Equity is a core founding principle of the National Health Service (NHS) (Delamothe, 2008) and this stance is reiterated and expanded in the NHS Constitution (NHS, 2009). The recent White Paper on the long-term future of the NHS, *Equity and Excellence*, explicitly endorses the commitment to equity, envisioning an NHS that *'eliminates discrimination and reduces inequalities in care'* (DH, 2010, p. 8).

Over recent decades, successive governments have issued a series of strategy documents focusing on health inequalities (Black, 1980; Whitehead, 1987; Acheson, 1998; Wanless, 2004), culminating in the recent Marmot Review, *Fair Society, Healthy Lives* (Marmot *et al.*, 2010). However, these documents, with the notable exception of Acheson (1998), have typically relied on socio-economic factors in accounting for health inequalities, largely eschewing the role of ethnicity as an explanatory factor. Indeed, the Marmot Review has taken trenchant criticism for its failure adequately to address the ethnic dimensions of health inequality (see Salway *et al.*, 2010). The recent White Paper, its title notwithstanding, remains open to the same charge – for all its strident emphasis on equality and an information revolution, no reference is made to the need for mandatory ethnic data collection as a prerequisite for either health equality or an enhanced evidence base. This briefing paper charts the evolution of ethnic monitoring of service users (also known as patient profiling) in the NHS and argues the case for a renewed and meaningful commitment to its proper implementation at all levels of the organisation. The paper focuses on the rationale for change rather than on its various practicalities, such as funding, ethnic categorisation, modes of ascription, validation and comparability of data and staff training. Framing the paper is the question of whether health equality is possible without ethnic monitoring.

1 **The role of ethnic monitoring in identifying and responding to health inequalities**

There is a wealth of evidence showing that individuals from black and minority ethnic groups experience poorer health than the overall UK population (DH and SSI, 1998; Aspinall and Jacobson, 2004; Sproston and Mindell, 2006). For example:

- Doctor-diagnosed diabetes is almost four times more prevalent among Bangladeshi men and almost three times more prevalent among Pakistani and Indian men than among men in the general population (Sproston and Mindell, 2006).
- Among African Caribbean and South Asian men, the prevalence of stroke is 70 per cent higher than the average (Race for Health, 2008).

Given what we know about the ethnic dimension of health inequalities, effective ethnic monitoring has a fundamental role to play in identifying and reducing inequalities and ensuring that all social groups benefit equally from the services of the NHS.

The role of ethnic monitoring in addressing health inequalities has four principal components:
- to enable an accurate assessment of service users' needs so that services and service delivery can, as much as possible, be personalised and culturally appropriate;
- to enable effective clinical management of patients given that the prevalence and course of many conditions can vary according to ethnicity;
- to enable comparisons to be made of the uptake of services by different groups, thereby ensuring equitable allocation of resources and the provision of services according to need;
- to enable the NHS to meet the requirements of the Race Relations (Amendment) Act 2000.
(Adapted from DH, 2005a)

Collecting and using ethnic group data enables NHS trusts to demonstrate a clear and localised understanding of where inequalities exist and hence to take informed measures to address them. It follows that the absence of comprehensive ethnic group data means that health service managers are unable either to identify need or to demonstrate impact among minority ethnic groups. It follows also that the absence of effective ethnic monitoring masks and may exacerbate the breadth and depth of ethnic health inequalities (Raleigh, 2008). Essentially, missing or incomplete data means that health service commissioners, providers and practitioners are working with one hand tied behind their back (Jacobson, 2008).

Incomplete collection of ethnic group data in primary care

2

The introduction of ethnic monitoring in the NHS was much resisted (Gill and Johnson, 1995), as have been efforts to improve it (Iqbal *et al.*, 2008). A proposal by the Department of Health that patients' ethnicity be stated in GP referral letters from 1992 was not implemented and, when ethnic monitoring in secondary care was made compulsory from April 1995, the results were unsatisfactory (Sangowawa and Bhopal, 2000). Meanwhile, when the new GP contract was introduced in 2004, the opportunity to include mandatory collection of ethnic group data was missed (Evans, 2007). Similarly, the Department of Health's *Delivering Race Equality in Mental Health Care* report (DH, 2005b), while emphasising the importance of collecting comprehensive, accurate ethnicity data, failed to set out any specific actions for primary care (Aspinall, 2006). Given that over 90 per cent of contacts with the NHS take place in primary care (RCGP, 2004), the ongoing situation gives cause for concern.

Not surprisingly, a consequence of the persistent failure to mandate ethnic monitoring across primary and secondary care is that there are no systematic data available for ethnic health inequalities and those that do exist are *'incomplete and patchy'* (Cabinet Office, 2007, p. 74). As Johnson (2008, p. 2) observes, despite a move towards evidence-based practice in health and social care, *'the evidence base for this has not kept pace with the needs'*. The history of ethnic monitoring in the NHS, especially in primary care, is thus one of incomplete collection and hence limited utility (Szczepura *et al.*, 2008).

There are a number of reasons for the lack of routinely collected ethnicity data, including:
- difficulties in obtaining an accurate classification;
- reluctance to request data for fear of giving offence;
- no meaningful incentive to collect or provide data;
- reluctance on the part of service users to supply data;
- inability to supply data owing to language barriers;
- lack of understanding as to how data can or will be used.
(Adapted from Iqbal *et al.*, 2008)

3   Poor compliance with race equality legislation in a context of increasing ethnic diversity

A principal driver for ethnic monitoring is the Race Relations (Amendment) Act 2000, which requires public bodies, including the NHS, to eliminate unlawful discrimination and promote equality of opportunity and good relations between persons of different racial groups. Organisations must demonstrate how they plan to meet these objectives in a race equality scheme, a public document that should include timetables and a realistic action plan. Clearly, to meet these legal obligations, there is a need to record ethnic group data for service users as they come into contact with NHS services (Race for Health, 2008). While NHS compliance with race equality legislation has improved in recent years, nonetheless it continues to be a problem (Healthcare Commission, 2009). In particular, some trusts are unable to produce robust data regarding patients' access to services; indeed, *'the impression is still one of performance that is generally patchy'* (Healthcare Commission, 2009, p. 33).

This picture is especially concerning in light of the increasing diversity of the UK population as well as the relatively younger age structures of black and minority ethnic populations (Szczepura, 2005). At the same time, the rate of growth of black and minority ethnic populations is fastest in rural areas (POST, 2007), so that minority ethnic groups are becoming more dispersed and hence potentially at greater risk of exclusion and disadvantage in terms of equity and access to health services (Sangowawa and Bhopal, 2000). Britain is now characterised by *'super-diversity'*, suggesting *'a level and kind of complexity surpassing anything the country has previously experienced'* (Vertovec, 2006). With regard to ethnic monitoring, *'[s]uch diversity constitutes a real challenge both for health policy makers and for service commissioners and providers, in terms of service planning and delivery, particularly at a local level'* (Jayaweera, 2010, p. 2).

4   Regulation and the need for leadership

In something of a paradox, a clear recognition of the need for effective ethnic monitoring does exist in policy and commissioning circles and has done for some time. A recent Healthcare Commission report recommended that the Department of Health *'should ensure that data on ethnicity is routinely collected and recorded at every point of contact with health services'* (Healthcare Commission, 2009, p. 40; see also Race for Health, 2008). However, the political will to act on this recognition has so far failed to materialise. Current arrangements for ethnic monitoring in primary care remain optional.

Since April 2006, GP practices can earn no more than a single point (out of an available total of one thousand) in the Quality and Outcomes Framework (QOF) for collecting ethnicity and first language data for all new registrations. This is a mild incentive to say the least, quite apart from the fact that no ethnic group data are collected for patients registered before April 2006. A recent county-wide survey of West Sussex, based on QOF results for 2008/9 (Fulton and Richardson, 2010), found that 37 per cent of GP practices fail to earn the QOF ethnicity point. Moreover, for many practices in West Sussex, ethnic monitoring was the only QOF action or one of the few for which maximum points had not been sought and attained (Fulton and Richardson, 2010). It is this reality, replicated in primary care settings across the UK, which accounts for the paucity of data on ethnic health inequalities.

The experience in secondary care, where ethnicity data collection has been mandated since 1995, has been somewhat different. Collection rates for so-called Hospital Episode Statistics (HES) were historically poor, indeed too poor to be of any use (Aspinall, 2000), with some Government Office Regions still failing to record 47 per cent of ethnicity data seven years after collection was mandated (APHO, 2005). However, compliance has improved over recent years, with trusts in the 2007/8 data year averaging 53 per cent 'not known' or 'not stated' ethnic codes compared to an average of 90 per cent for the 2001/2 HES data year (Health and Social Care Information Centre, 2009, p. 10). Significantly, such improvement, albeit from a low base and with some distance yet to travel, has been encouraged by a strengthening of the regulatory framework (Raleigh, 2008) in combination with *'sustained pressure from the regulator and other organisations'* (Thorlby and Curry, 2007, p. 22).

The importance of leadership is emphasised in the literature on ethnic monitoring (Aspinall, 2000; DH, 2005a; Thorlby and Curry, 2007; Yorkshire and the Humber SHA, 2009):

[r]ace equality in general, and ethnic monitoring in particular, needs drive, ownership and commitment from the top of the organisation … this is true of all NHS bodies and councils and is also true of [the Department of Health]. The role of clinical leaders and senior service managers cannot be emphasised enough as it is their staff in front line practice positions, together with reception staff, who are often best placed to collect and use ethnic group and other personal data on reception or at referral.
(DH, 2005a, p. 27)

However, proactive leadership alone is unlikely to be enough in the continuing absence of any political will either to mandate ethnicity data collection across primary and secondary care or to enforce its collection. While the *Equity and Excellence* White Paper includes plans to establish an NHS Commissioning Board, which will have *'an explicit duty to promote equality and tackle inequalities in access to healthcare'* (DH, 2010, p. 5), it remains to be seen how effectively this duty will be discharged.

Examples of good practice in the collection and use of ethnic monitoring data **5**

Identifying good practice in the collection and use of ethnic monitoring data is not straightforward, given the lack of baseline data from which to measure and evaluate performance (POST, 2007). A recent review, which sought to identify evidence of good practice in the collection and use of ethnic monitoring data, found an *'evidence desert'* (Iqbal *et al.*, 2008, p. ii). The following examples, however, demonstrate how ethnicity data can be used to inform and improve practice.

Sheffield Case Register

This is a longstanding 'cradle to grave' monitoring tool, which includes ethnicity data. Data from the register have been used to develop a Joint Learning Disabilities Service BME Strategy as well as to develop and introduce new BME Link Worker posts.

Ethnic monitoring in Bradford District Care Trust

Ethnic monitoring data and related intelligence are used to inform six-monthly dialogues with staff on the health needs of people from black and minority ethnic communities. The meetings also provide a platform for front-line staff to challenge and engage with equality and diversity policy.

NHS Bradford and Airedale's mortality analysis by ethnicity

Extended analysis of ethnicity data indicated higher mortality rates in the early years for *'South Asians'* but much lower mortality over the age of thirty compared to *'non-South Asians'*. Analysis also highlighted the different causes that contribute to *'potential years of life lost'* (adapted from Yorkshire and the Humber SHA, 2009).

Liverpool Primary Care Trust

Ethnic monitoring is core business for Liverpool Primary Care Trust. Data gathered include ethnicity, religion, spoken and read language and interpreter need. Training and a named contact are in place to support practices with patient profiling. Patient profiling is undertaken across all chronic disease registers, with an ethnicity completion rate in 2010 of 89 per cent for diabetes and 85 per cent for chronic heart disease (Liverpool NHS PCT, 2010). Regular reports based on patient profiling assist commissioning leads by enhancing their understanding of the composition of the local population (DH, 2008).

It is worth noting here that the UK is one of the few European countries to collect ethnicity data in the national census and also to recognise officially the need for ethnicity data for monitoring purposes (Raleigh, 2008). However, there are still too few examples of good practice and, despite improving collection rates, *'the data are worthless unless they are used to target need and reduce inequalities'* (Raleigh, 2008, p. 646). Indeed, in a vicious circle, the failure to use ethnicity data to inform and improve practice has been a persistent barrier to improved collection rates: too few data are recorded and those that are recorded are too little used to inform

practice. Consequently, there exist particular collection 'hotspots' in a general landscape of low or non-existent collection. Until ethnic monitoring is mandated and enforced across primary and secondary care, there is neither any incentive nor, in the absence of enforcement, any real imperative to collect the data. As Aspinall (2006, p. 141) asserts: *'the continuing gaps in the information base justify a stronger emphasis on the processes necessary to bring about change rather than on what ethnic monitoring should provide'.*

Conclusion

The single QOF point available to GP practices for recording ethnic data for new registrations speaks eloquently of the absence of political will to mandate ethnic monitoring in primary care. Continuing low levels of ethnic data collection in primary care testify equally to the disinclination of GP practices to engage in ethnic monitoring. Clearly, the two situations are not unrelated. There is a pressing need to radically improve the collection and use of ethnicity data across primary and secondary care in the UK, and not only for reasons of social justice.

The growing ethnic diversity of the UK population compounds the need for enhanced collection and use. Experience suggests that this will only happen when collection is mandated across primary and secondary care and enforced by a strong regulatory framework. The advent of the Equality Act 2010, not least in its provision for a public sector Equality Duty, implies a need for systematic collection of data on other equality strands, data which to date remain all but non-existent (Cabinet Office, 2007). The ethnic group question in the 1991 census *'laid the foundation for ethnic monitoring and provided a baseline against which all other statistics could be measured'* (Gill and Johnson, 1995, p. 890). The approaching 2011 census offers a similar 'springboard' opportunity to invigorate ethnic monitoring in the UK, but this time backed up by political will. As we have seen, health equality is not possible without ethnic monitoring. It is time for politicians to grasp the nettle.

Resources 1

Websites

Equity and Excellence: Liberating the NHS
www.eoe.nhs.uk/nhs_constitution/downloads/
liberating_the_nhs_white_paper_complete.pdf
This is the government White Paper setting out their long-term plans for the NHS.

The King's Fund
www.kingsfund.org.uk/topics/equitable.html
This web page presents a summary of the results of a seminar held jointly by The King's Fund and the London Health Observatory. The seminar sought to address the challenge of equitable commissioning for ethnically diverse populations and to explore what data and intelligence are needed by commissioners in order to commission well. There are very useful links to the PowerPoint presentations made by the main seminar participants.

The London Health Observatory
www.lho.org.uk/LHO_Topics/National_Lead_Areas/
EHIP/EthnicHealthIntelligenceOverview.aspx
In the network of public health observatories, the London Health Observatory is the national lead for

ethnic health intelligence and also for health inequalities. In addition to a number of useful links, the website provides a comprehensive overview of ethnic health intelligence.

Minority Ethnic Health Discussion Forum
www.jiscmail.ac.uk/cgi-bin/webadmin?A0=MINORITY-
ETHNIC-HEALTH
This is a highly informative and responsive email discussion group that offers direct access to experiences and good practice in minority ethnic health.

The NHS Constitution
www.nhs.uk/choiceintheNHS/Rightsandpledges/NHS
Constitution/Documents/NHS_Constitution_interactive_
9Mar09.pdf
This interactive version of the NHS Constitution incorporates a range of useful explanatory information available by clicking on the relevant icon.

Resources 2

NHS Evidence: Ethnicity and Health
www.library.nhs.uk/ethnicity
This NHS website aims to be a repository for the best
available evidence on managing health care services
for migrant and minority ethnic groups, as well as on
the specific health care needs of these groups. The
extensive database presents search results under the
following headings: guidance and pathways, evidence,
reference, education/continuing professional
development and patient information.

Race for Health
www.raceforhealth.org
Race for Health is an NHS programme which works
with PCTs and trusts to drive forward improvements in
health for people from black and minority ethnic
backgrounds. The programme aims to be pragmatic
and takes as its starting point the proper
implementation of legislation. The website has a wide
range of useful resources, including a database of all
Equality and Diversity Leads with names and contact
details, as well as a good practice database
searchable by key word or topic.

Ethnic monitoring toolkits

*A Practical Guide to Ethnic Monitoring in the NHS
and Social Care*
www.dh.gov.uk/prod_consum_dh/groups/dh_digital
assets/@dh/@en/documents/digitalasset/dh_4116
843.pdf

Ethnic Monitoring: A guide for public authorities
www.equalityhumanrights.com/uploaded_files/PSD/12_
ethnic_monitoring.pdf

Ethnic Monitoring Tool
www.isdscotland.org/isd/files/ETHNIC%20MONITORING
%20TOOL.pdf

*Ethnicity Profiling in Primary Care: The Princes Park
Health Centre model*
www.nwph.net/nwpho/Publications/Ethnic%20
HEALTH%20RE-lay-2.pdf

*HRET Disparities Toolkit: A toolkit for collecting
race, ethnicity, and primary language information for
patients*
www.doh.wa.gov/EHSPHL/hospdata/CHARS_UB04/
HRETDisparitiesToolkit.pdf

*Race, Ethnicity, and Language of Patients. Hospital
practices regarding collection of information to
address disparities in health care*
www.hablamosjuntos.org/resources/pdf/RWJNPHHI
report-2-06.pdf

Publications

*Delivering Effective NHS Services to our Multiethnic
Population: Collection and application of ethnic
monitoring data within primary care*
This is the report of a workshop convened by Yorkshire
and the Humber Strategic Health Authority. It includes
examples of good practice, recommendations and a
useful references and further reading section.

*Ethnic Monitoring in General Practice –
Communicating the benefits*
http://webcache.googleusercontent.com/search?q=
cache:yQbk4L5SdLgJ:www.raceforhealth.org/storage/
files/events/patient_profiling_in_gp_practices__gjs_
180907_final_draft3.doc+ETHNIC+MONITORING+
IN+GENERAL+PRACTICE+COMM&cd=1&hl=en&ct
=clnk&gl=uk

*Improving Ethnic Data Collection for Statistics of
Cancer Incidence, Management, Mortality and
Survival in the UK*
www2.warwick.ac.uk/fac/med/research/csri/ethnicity
health/research/crc.pdf

*No Patient Left Behind: How can we ensure world
class primary care for black and minority ethnic
people?*
www.dh.gov.uk/prod_consum_dh/groups/dh_digital
assets/@dh/@en/documents/digitalasset/dh_084973.pdf

*Race Equality in Health – The key to world class
commissioning*
www.raceforhealth.org/pdf/Race_equality_in_health.pdf

*Tackling the Challenge: Promoting race equality in
the NHS in England*
www.carequalitycommission.org.uk/_db/_documents/
Tackling_the_challenge_Promoting_race_equality_in_
the_NHS_in_England.pdf

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