

# **Making Difference Count: Ethnic Monitoring in Health (and Social Care)**

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## **1. Summary**

The collection of data about 'race' or ethnic origin is in itself contentious, but an essential tool for statisticians concerned to combat inequality. This article reviews some of the history of the introduction of this policy tool and discusses associated problems and advantages alongside some examples of its application. Tools and guidance for implementing ethnic monitoring or 'patient profiling' are indicated and the future development of 'equalities monitoring' is discussed. It is concluded that 'if you are not measuring it you cannot be shown to be doing it' and the implications for this are considered.

## **2. Introduction**

For many years, or so it seemed to those of us working in the field of 'race relations', there was a struggle to establish the facts of racialised inequality, especially in relation to health care and health outcomes (Johnson 1998). Indeed, it was often argued that health care professionals would be morally incapable of discriminating on grounds of race, and asserted that 'we treat everyone the same'. Further, the case was made that asking for, or recording 'ethnic origin' data was in itself potentially discriminatory and reprehensible – while at the same time recognised that if you were not measuring something, it could not be shown that it was happening (Drew 1980)! There were also heated debates about precisely what was to be measured, and whether 'ethnic group' was a legitimate or intellectually coherent category (Royal Statistical Society 1983; Burchard et al 2003). Eventually, after a false start in 1981 when the question was dropped at the last moment from the UK Census form, the Office of Population Census and Statistics incorporated a composite question into the 1991 census. It then

became possible to refer to a robust denominator, and to use survey data from studies such as the series conducted by the Policy Studies Institute (Modood et al 1997) to make estimates of national and local levels of need (Bardsley & Lowdell 1999).

### **3. Monitoring and Health Inequality**

The existence of ethnic or racial inequalities in health, both in health status and outcomes, and in the delivery or enjoyment of health care, is now well-established and has been the theme of many studies conducted by ‘*Radical Statisticians*’ and others (Alexander 2000; Acheson 1998; Nazroo 1997). More recently, the move towards a more active policy to tackle health inequalities and promote the health of minority and migrant peoples, both at a UK and a European level, has been supported by political and policy changes, coupled with a move towards ‘evidence-based’ practice in medicine and social care. However, the evidence base for this has not kept pace with the needs. Indeed, there is a sense in which the health data available now are worse than was the case when the first volumes of statistical analyses of racial inequality were published by the Radical Statistics collective (1980; second edition Bhat et al 1988), drawing on the epidemiological data available then from death registrations and birthplace data (cf Marmot et al 1984). Since that time, the linkage between place of birth and presumed ethnic origin has deteriorated even further – dubious as it might have been in relation to the 10% or so of ‘Indian-born’ people (in 1981) who were of White British origin but had been born in the ‘days of the Raj’! In 21<sup>st</sup> Century Britain, over half of the ‘minority ethnic’ population of the UK were born in Britain, and for many the same was also true of their parents. However, the interest in issues such as place of birth and other evidence of the social standing and situation of individuals remains important for public health and epidemiology as well as service design, as indeed it was when the first Registrar—General created a system for recording data on births and deaths, and classifying social class. As far as tackling health inequalities, indeed, the need for such data and for detailed understanding of the influence of ethnicity and other aspects of social identity on health, has if anything increased since then (Johnson & Gill 1995).

Jones, in an essay in this volume (Jones 2008) provides an illustration of the utility of these data drawing on the well-regarded

development of ethnic monitoring practice in the short-lived Parkside Health Authority in London. This organisation was one of those which took a lead during the funding and support offered in the 1990s by the NHS 'Ethnic Health Unit' and did manage to create a useful guide to ethnic monitoring as well as reports based on that data, although few were formally published. Jones' paper shows how the approach can be applied to staffing and governance as well as to service delivery, and illustrates the differences in patterns of use and uptake between ethnic groups revealed by such data. Such information can of course also show that a service such as physiotherapy or occupational therapy (Johnson et al 1996) or coronary revascularisation (Fitzpatrick et al 2007) is not actually discriminating, but may be operating in a different way for specific groups of clients. Similarly, the data can be used, as they have been in Liverpool (Public Health Sector Group 2000), to develop services and ensure that investment is appropriately targeted to meet the real needs of patients, including recognising when new demographic changes are having an impact on a catchment area. Other examples of good practice in the use of ethnicity-based monitoring statistics can be located, and also there are reports where attempts have been made to use alternative sources of data (Bardsley et al 2000). A recent publication by the European Commission summarises the alternatives and gives guidance on how to obtain at least some estimates of need (Makkonen 2007). It is clear from these that while some estimates can be made of morbidity or mortality from hospital admission and vital events (birth and death) statistics, these are inadequate and increasingly inaccurate guides to need. Indeed, the experience of the London public health sector has been that there are enormous variations in the level of accuracy and completeness of 'ethnic group' data across London's hospitals and trusts. These cannot be explained in terms of local perceptions of need – there is no relation between the levels of completeness of collection and the proportions of the local population belonging to minority ethnic groups (as shown by the Census) or indeed, by comparison with known levels of activity or policy relating to improving the health of such groups! The same indeed is true at a national level, with considerable variation in completeness of monitoring not only between regions, but also across different health datasets, with the best recording being found in the centrally collected data on the medical and dental workforce, and the worst in hospital activity statistics (Fitzpatrick et al 2007). Furthermore, that review found some datasets and

areas were using out-of-date or non-standard classifications of ethnicity, making comparisons impossible.

## **4. Problems of Implementation**

It is therefore necessary to revisit the underlying policy debate regarding the question of the legitimacy and practicality of implementing ethnicity monitoring, in order to move forward. The collection of statistics about people described or defined in terms of their 'ethnic origin', 'ethnic group' and/or other racial, national, skin-colour or similar descriptors, has always been controversial. Indeed, it is still in some European states illegal, although in those at least the use of the term 'migrant' and often (but not always) collection of data on religion or birthplace provides some alternative ways of estimating the situation of minority groups (Johnson 2001). Another possible objection that has been made is the problem of data protection. The European Data Protection Directive (Directive 95/46/EC 24.10.1995) regulations state quite clearly, and for good reason based on the experiences of 1939-45 and more recent 'ethnic cleansing' events, that 'personal data must (only) be collected for specified, explicit and legitimate purposes', and furthermore in Article 8, that

*“Member states shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership and ... data concerning health or sex life”.*

However, further sub-sections within this go on to explain that data may be collected when the data subject gives 'his explicit consent', or where such data are necessary to ensure compliance with employment law, and when public interest (such as public health concerns) dictates that such data are necessary and that the rights and safety of the individual can be safeguarded. Indeed, there is growing recognition across Europe that there is a need for such data. Increasingly, it is being recognised, and has been most recently demonstrated in the context of Article 13 of the Amsterdam Treaty (<http://europa.eu/scadplus/leg/en/lvb/a10000.htm>), that in order to work towards the equality targets and agenda of the EU, such data will need to be collected not only in relation to employment, but also in service delivery. To support this, the UK agencies

responsible (both in England and Wales, and Scotland: see Fischbacher C 2005; DH 2005 or via [www.library.nhs.uk/ethnicity](http://www.library.nhs.uk/ethnicity) using the 'search' tool for 'monitoring') have provided detailed and supportive guidance on implementing such systems.

One of the key themes in discussing the implementation and use of ethnic monitoring is the need for a consistent set of terms or categories, and for a set of 'baseline' data against which results can be compared. It is agreed that since 'ethnic group' membership is at best a personal identity rather than an objective and verifiable fact, 'self-identification' is to be preferred (Makkonen 2007 : 40). The alternative of observer classification has been shown to be fraught with risks, and to underestimate numbers of minority users of services, while creating confusion between minority groups based on stereotypical views. However, there are clear risks that every individual might wish to create or self-define their own identity, and thus it is preferable to ask people to pick from a selection of well-tested categories, with the option of opting for an 'other' (self-defined, and written-in) category. In Britain, since the introduction of an 'ethnic question' in the 1991 census, the default and the recommended best practice has been the set of terms used in the national census. This is far from perfect, as is generally acknowledged, and (with the support of the Commission for Racial Equality and the Department of Health) many local or health authorities have added selected additional codes. This permits local variations – such as recognising the presence of significant numbers of people from particular areas (e.g. Somali refugees, or Kashmiri/Mirpuri people who may feel that they form a distinctive community in Birmingham) to be identified and their specific needs met. In 2001, the original defined groups developed by the census were revised, and a two-stage classification was adopted which has subsequently been largely used across most public sector bodies.

In 2011, a new set of categories based on these is likely to be preferred, and a final test of this new question will be performed in 2009 before seeking parliamentary approval. It is to be hoped that local data collection will take account of this, and move to start using the new classification as soon as it is known, so that data can be compared with the new Census baseline when it becomes available, rather than (as has happened in the past) a delay occurring before the new classification is widely used. It does however, appear that the new classification will be generally

compatible with that used in 2001, with the same structure. However, a new question on 'national identity' has been suggested, as well as one on 'what languages can you understand, speak or write', which might be of value in planning services. Both of these may not be included in the final form. The main change which is likely to be adopted is the addition of two new 'other ethnic group' sub-categories: Arab and Gypsy/ Romany/ Traveller, recognising two of the larger ethnic groups of interest to many health and social care workers – although not providing a specific identity group for people of Turkish, Kurdish, Somali or European background, as might be required in some larger cities (and indeed, rural areas) where migrants of these backgrounds now form significant populations.

A conference on public health and migration held as part of the Portuguese Presidency of the European Commission in 2007 concluded that migrants are an important resource for Europe who make a significant contribution to demographic and economic growth. However, they (as migrants and as minority ethnic people) experience increased health risks which threaten these benefits. In order to combat these challenges, there was a consensus, which is expected to be reflected in future EU policy and guidance, that there is a clear need for more data and knowledge on migrant health in the EU. Specifically, it was felt important to conduct more research, and to implement more systematic and coherent data collection across vital statistics and health and social care monitoring systems.

<http://www.hmelisbon2007.com/site.asp?ID=6&IDIOMA=2>  
accessed 8 Jan 2008)

## **5. Conclusion**

While it was possible that early opposition to the introduction of ethnic monitoring was a fear of what the data might show in terms of discrimination, and a belief that 'if we don't measure it we can't be doing it', the situation has now changed. Another argument against ethnic monitoring that was put forward at the time, was that the data so collected might be misused (as had been indeed the case during Hitler's Germany) to identify members of minorities and thus to abuse or damage them. This was countered at the time as being irrelevant in respect of 'visible' minorities who could simply be 'spotted' on the basis of their skin colour. It has also

been shown subsequently to be unnecessary since there are plenty of ways of locating and identifying members of minorities – as in Ruanda/Burundi and the former Yugoslav Republic, where neighbours or other informants were more than capable of pointing out members of targeted religious or ethnic groups for attack. The existence of data files was irrelevant in such cases. Indeed the whole debate about what is kept in welfare service and demographic administrative files has been rather overtaken by the growth of databases freely (or involuntarily) entered into by the vast majority of the population for a diversity of purposes including retail, taxation and security purposes. Furthermore, the onus now in terms of policy and legislation has become one of needing to demonstrate not that one is *not* discriminating, but that, as required by the Race Relations Amendment Act or the new Equality Directives of the European Commission, one *is* actively taking steps to combat disadvantage and inequality and promote community cohesion. Increasingly it seems likely that a similar approach will be required in relation to the ‘other equalities’ (age, disability, gender, religious and sexual orientation), and it will be assumed that if one is not measuring it (action to reduce inequality) then one isn’t doing it.

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