



Most UK datasets of routinely collected health statistics fail to collect information on ethnicity and religion

Kishwar Sultana¹ • Aziz Sheikh²

¹ General Practitioner, Glasgow

² Professor of Primary Care Research and Development, Division of Community Health Sciences: GP Section, University of Edinburgh, Edinburgh EH8 9DX, UK

Correspondence to: Aziz Sheikh. E-mail: Aziz.Sheikh@ed.ac.uk

DECLARATIONS

Competing interests

None declared

Funding

None

Ethical approval

Not applicable

Guarantor

KS

Contributorship

AS conceived this study and oversaw protocol development, data extraction and analysis. KS undertook data extraction, analysis and drafted the paper

Acknowledgements

Our thanks to the independent reviewer for her constructive comments on an earlier draft of this paper

Introduction

The reduction of ethnic inequalities is a long-declared UK government priority,¹ but despite the moral and increasingly legal imperative to provide equitable healthcare to all sections of the population, there is very limited evidence of progress in achieving this objective. More recently, New Labour has also committed itself to tackling the very considerable religious inequalities in health and social outcomes that have become evident from analysis of data from the 2001 Census.² Similar ethnic and religious inequalities in health outcomes almost certainly exist in many other pluralist societies.

Given the difficulties in reducing health inequalities for certain disorders, the very considerable gaps remaining in our knowledge in relation to minority communities for many other conditions, and the known under-representation of minority groups in research (both in the UK and US),^{3,4} it is important that every effort is made to make use of existing data sources to describe and understand the nature of ethnic- and faith-based variations in health outcomes, and assess progress in tackling these inequalities.

The UK enjoys some of the foremost datasets of routinely collected health statistics, and greater exploitation of these is potentially of considerable importance to shaping policy, prioritizing research and identifying foci for service delivery improvements. In order to investigate the fitness for purpose of these datasets, we sought to interrogate them for evidence of inclusion of ethnicity and faith variables and, where recorded, to see whether there was a consistent approach to recording that would allow comparisons between datasets.

Methods

We interrogated the Directory of Clinical Databases (DoCDat), which is a comprehensive, freely

available UK compilation of 162 local and national health datasets. These datasets contain records of demographic and clinical data from individuals presenting to different health-care providers or participating in academic studies. Such clinical and/or research encounters provide an important opportunity to obtain data that could be used to assess disease profiles, health services' use and clinical outcomes across and between ethnic and faith groupings.

Launched in 1999, DoCDat was developed and has since been maintained by the London School of Hygiene and Tropical Medicine.⁵ A structured questionnaire is used by those compiling and maintaining DoCDat to determine general details about individual datasets relating to, for example, when the dataset was established and what fields it contains. The quality of datasets is also assessed by scrutinizing the validity and reliability of data held against pre-defined criteria.⁵

DoCDat was accessed between May and August 2006 and a table detailing information on all datasets available online was compiled. Each dataset within the Directory was interrogated online by means of detailed searches of questionnaires and webpage information against pre-defined criteria using a standardized approach to ascertain whether or not ethnicity- and faith-related data were collected and, if so, which specific questions were used. If answers were unavailable through online searches, the custodian of the individual datasets was contacted by email in an attempt to obtain this information.

Data were abstracted onto a customized data extraction sheet and descriptive statistics were employed to summarize results.

Results

Online information was available for 95 of 162 datasets. Custodians of the remaining 67 datasets

Table 1**Examples of the types of ways in which ethnic information is being collected**

| <i>Clinical dataset</i> | <i>Ethnicity descriptors</i> |
|--|--|
| Anglia Childhood Diabetes Register | 16 ethnic categories based on UK 2001 Census. |
| Avon Longitudinal Study of Parent and Children | 9 named categories and 14 named religion categories |
| British Association of Head and Neck Oncologists' National Minimum Head and Neck Cancer Data Set | 9 named categories: White; Black Caribbean; Black African; Indian; Pakistani; Bangladeshi; Chinese; Black Other (non-mixed origin); Black Other (mixed); Unknown |
| British Cohort Study 1970 | Ethnic categories based on UK 2001 Census question |
| Confidential Enquiry into Maternal and Child Health – Project 27/28 | Ethnic group of mother |
| Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire | Maternal ethnic group: White; Black; Asian; Mixed; Other |
| Diabetes Audit and Research in Tayside Scotland | Ethnic grouping |
| Glasgow Register of Congenital Anomalies | Racial type of mother and father |
| National Adult Cardiac Surgical Database | White, Black, Asian, Oriental, Other |
| Hospital Episode Statistics | 9 categories initially, but then superseded by 16 ethnic categories based on UK 2001 Census |
| National Cancer Minimum Data Set | Ethnic origin |
| National Chronic Obstructive Pulmonary Disease Audit 2003 | Ethnicity: Mixed; White; Black or Black British; Asian or Asian British; Chinese; Other |
| National Drug Treatment Monitoring System | Ethnic categories: 18 named options given |
| National Spinal Injuries Centre – Medical Research Database | Ethnicity |
| North of England Young Persons' Malignant Disease Registry | Simple classification devised by data group – no details available |
| North West London Chronic Disease Register | Ethnicity |
| North Western Cancer Registry | Birthplace |
| Northern and Yorkshire Cancer Registry and Information Service | Birthplace, 9 named ethnic categories and 9 named religion categories |
| Northern Ireland Cancer Registry | Religion – no code available. |
| Oxford Monitoring System for Attempted Suicide | White, Mixed, Asian, Black, Other |
| Paediatric Intensive Care Audit Network | NHS standard ethnic categories |
| Quality Indicators In Diabetes Services | Ethnic category and religion requested |
| Scottish Renal Registry | Ethnic group (race) – chosen from Registrar General List |
| Trent Arthroplasty Audit Group | Ethnic origin |
| UK Renal Registry | Ethnic group (Read code) |
| West Midlands Congenital Anomaly Register | Ethnic origin of mother |

were emailed to request information on the variables of interest, and 37 responses were obtained. We were therefore able to ascertain whether questions on ethnicity and/or religion were included in 132 of 162 datasets (81%). Of the 132 datasets for which relevant information was available, 62 (46%) contained a question on ethnicity and seven (5%) on religion/faith.

The questions used to determine ethnicity varied widely, as demonstrated in Table 1. Of the 62 datasets collecting ethnicity data:

- 21 used an open question requesting details of ethnic group, ethnicity, ethnic code or ethnic category
- Nine used a question along the lines of the census question of 2001
- Five used a question with nine named categories

- For the remaining 37 datasets it was not possible to ascertain the exact ethnicity question used.

All seven datasets collecting data on religion/faith used a different code, again reflecting a lack of standardization.

The email responses from data custodians revealed two major reasons for these data not being collected: perceived irrelevance of or difficulty in collecting such information; and a failure to appreciate the importance/potential uses of these data (Box 1).

Discussion

Despite ample evidence of persistent ethnic health inequalities, we have found that the majority of UK health datasets still fail to collect *any* data on

Box 1**Examples of email responses from data custodians**

- Perceived lack of importance/difficulty *'Too hard to get reliably to make it worthwhile collecting. And the South is still very white, although becoming less so...'* (R156)
- Failure to appreciate importance *'Neither is included ... it would be very easy to add this information ...'* (R152) *'... but now you have asked the question I will consider whether we will capture this in future'* (R42)

ethnicity; fewer still record data on religious identity. Considering the potential locked within these sources to help understand the nature of inequalities and assess progress on delivering equitable care to all sections of the community, this represents a real wasted opportunity.

It is important to note that our findings are likely to paint an overly optimistic picture. In many datasets, even where there is provision to record ethnicity data – for example Hospital Episode Statistics or primary care datasets, which would have been counted as a positive outcome in our study – recording of ethnicity data is known to be so poor that any meaningful analysis is precluded. This problem is compounded further by the fact that many datasets fail to use standard validated ethnic and religious codes.

While the immediate clinical relevance of collecting information on ethnicity and religion may reasonably be debated by some, the legal imperative on health-care providers to demonstrate equality of service provision would seem to make the importance of having access to such data for research and audit purposes beyond argument. Such data have, for example, been able to demonstrate marked differences in asthma outcomes between UK minority ethnic groups and whites.⁶ Whilst scepticism still exists, it should also be noted that such identity descriptors may also prove useful in planning and delivering clinical care to individuals. For example, in some parts of the UK South Asian babies are selectively offered BCG vaccinations.⁷

Our work corroborates the view that collection of data on ethnicity and religion are in general still not seen as a priority. This is in sharp contrast to the view taken by the Department of Health, which notes in its 'Position Statement' the importance of – and accords 'top priority' to – the need to

collect data on ethnicity; it furthermore urges that this should be consistent with the census categories.⁸ At present, neither routinely occurs: given the Equality and Human Rights Commission's recent insistence that public bodies meet the needs of minority groups, be they ethnic or religious and no matter how small, this reflects a worrying lack of awareness amongst clinicians and academics.⁹

In 2001, the UK Census and Home Office Citizenship Survey clearly demonstrated that it is feasible to collect valid and reliable data on ethnicity and religion, and that these data can be used for extremely important analyses.^{10,11} Years on, it is time that the standard set in these national surveys is much more widely adopted within health-care services.

References

- 1 Department of Health. *Reducing health inequalities: an action report*. London: HMSO; 1999
- 2 Anwar M. Muslims in the West: demographic and socio-economic position. In: Sheikh A, Gatrad AR, (eds) *Caring for Muslim patients*. Oxford: Radcliffe; 2007. p. 7–23
- 3 Sheikh A, Netuveli G, Kai J, Panesar SS. Comparison of reporting of ethnicity in US and European randomised controlled trials. *BMJ* 2004;**329**:87–8
- 4 Sheikh A. Why are ethnic minorities under-represented in US research studies? *PLoS Med* 2006;**3**:e49
- 5 *Directory of Clinical Databases* At: http://www.nchod.nhs.uk/NCHOD/Home.nsf/NCHOD?OpenFrameset&Frame=Frame5&src=/NCHOD/DocDat_2.nsf/1EA0E40B2B425443882571D7001DA884/3A662767DA074F80882571D7001DABFE?OpenDocument/ (last accessed 13/12/2007)
- 6 Netuveli G, Hurwitz B, Levy M, et al. Ethnic variations in UK asthma frequency, morbidity, and health-service use: a systematic review and meta-analysis. *The Lancet* 2005;**365**:312–7
- 7 *NHS immunisation information* At: <http://www.immunisation.org.uk/article.php?id=43> (last accessed 13/12/2007)
- 8 Department of Health. *Census implications for ethnicity*. London: DoH; 2007. At: http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalDevelopment/Developmentinpersonalsocialservices/DH_4016344 (last accessed 11/12/2007)
- 9 Equality and Human Right Commission. At: <http://www.equalityhumanrights.com/pages/eocdrcre.aspx> (last accessed 13/12/2007)
- 10 National Statistics. *Census 2001*. London: TSO; 2002. At: <http://www.statistics.gov.uk/census/> (last accessed 13/12/2007)
- 11 O'Bierne M. *Religion in England and Wales: findings from the 2001 Home Office Citizens Survey*. London: HMSO; 2005