



Missing Record:

The Case for Recording Ethnicity at Birth and Death Registration

Executive Summary July 2003



Foreword

Those concerned with the health of the public have been interested in ethnic differences in health and disease for two principal reasons: as a guide to understanding, and a guide to improving health for all sub-groups of the population.

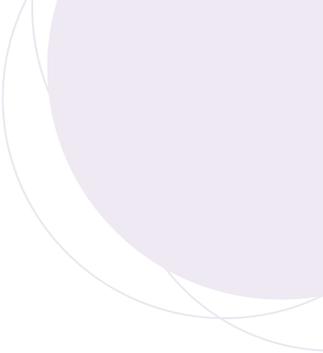
There has been intense debate as to whether 'ethnic group' conveys something more than a measure of socio-economic position. It might.

Social status confers privileges to those at the high end and disadvantages at the other end. Membership of an ethnic group may not only be related to where one is on the social scale but may cut across it. Discrimination on the basis of ethnicity is not identical to being of low social status. There are examples of minority ethnic groups who have better health than others with the same socio-economic classification, and examples where health is worse. Without routine measurement of ethnic group, it will be difficult for these problems to come to light. The Acheson Report on inequalities in health recommended 'that the needs of minority ethnic groups are specifically considered in the development and implementation of policies aimed at reducing socio-economic inequalities' in health.

Having data on ethnic groups in our health statistics will be an invaluable aid to researchers who are investigating the issues of differences in health, and to those responsible nation-wide for developing and implementing appropriate policies.

Professor Sir Michael Marmot

Director of the International Centre for Health and Society
University College London



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A Summary of the Evidence

Preface

The Government's new consultation on what information should be recorded at birth, marriage and death registration provides an unprecedented opportunity for us to correct a key omission in what is currently recorded. At present neither birth nor death registration requires any information on ethnicity to be recorded. We summarise below the evidence the London Health Observatory (LHO) has reviewed in support of the case for the recording of ethnicity at birth and death. Without this information we cannot understand the health and health care needs of minority ethnic communities, and neither can we plan for appropriate public services such as schools, housing and transport that underpin good health. With this summary we are issuing a call for action from the LHO and London Health Commission for all agencies who are committed to tackling ethnic inequalities in health to submit their own evidence - alongside ours - to the government, to correct this omission for the future. We hope this document provides you with the information you need to submit your own perspective based on our evidence.

This action will not only help to make visible the health needs of our growing, diverse communities, but will also ensure that the way is paved for a more equal Britain.

Judith Hunt OBE
Chair, London Health Observatory

Len Duvall OBE
Chair, London Health Commission

Recommendations to Government

At birth registration the ethnicity of the baby should be recorded – using the 2001 Census classification – as defined by the parent(s)

At death registration the ethnicity of the deceased should be recorded – using the 2001 Census classification – as defined by the person registering the death.

1 Why take action now?

The Registrar General is currently part-way through a plan to modernise civil registration, that is, the process of recording of births, marriages and deaths. The first phase of the consultation was issued in 1999 by the Registrar General on behalf of England and Wales and resulted in a white paper “Civil Registration: Vital Change” published in January 2002. (<http://www.statistics.gov.uk/registration/whitepaper/default.asp>). This will result in more choice for how and where births, marriages and deaths are registered in future, and will introduce new technology to allow people to register births and deaths electronically.

The next phase of the consultation process concerns the information content collected for civil registration and provides a unique opportunity for both the public and public sector bodies to respond with their views. The consultation starts in July and will continue until the end of October. Any changes to the content of civil registration will need to be made via the new Regulatory Reform Act (RRA) 2001, and will need to be scrutinised by both houses of parliament before any proposals can be agreed. This is a long and complex process. The implementation of any changes to civil registration will not begin before 2005.

2 What does this summary cover?

This booklet summarises the reasons why it is vital for ethnicity to be recorded at birth and death certification in England if we are to be able to open the route to tackling ethnic inequalities in health and health care. The full report of our evidence is available on the LHO's website (<http://www.lho.org.uk/hil/civilreg.htm>). This booklet provides a summary of the evidence in relation to the issues that need to be weighed up by government before making any changes to information that is currently collected. These are:

- What benefits will the collection of such data bring?
- Will it impose an unreasonable burden on citizens?
- Can the information be satisfactorily collected from elsewhere?
- What are the benefits/risks of putting such information on the public Vital Statistics record?
- Will it place unacceptable extra costs on government?

This summary covers the following arguments:

- Public health benefits
- Race equality requirements
- Feasibility
- Technical issues - including why existing data collections are inadequate
- Ethical issues

3 The importance of ethnicity recording for health and health care

It is widely known that many major diseases, for example diabetes, high blood pressure, stroke and heart disease, and the consequent disability

and premature death, are more common in one or more ethnic groups than in the overall population. Research has also shown that there are unacceptable inequities in health outcomes and access to effective health interventions between ethnic groups. Yet we also know that many such inequalities are not inevitable. At present we are unable to monitor such differences routinely because ethnicity information at key points in people's lives is either not collected or collected incompletely. The record of the NHS in such data collection has been poor across hospital, general practice, cancer registration and disease registers. Even in the area of hospital episode statistics, where collection of ethnicity information has been mandatory for 8 years, the completeness and quality of information on ethnicity has shown little overall improvement, with about 38% of hospital episodes in London still recording ethnicity as "unknown" between 1997/8 and 2000.

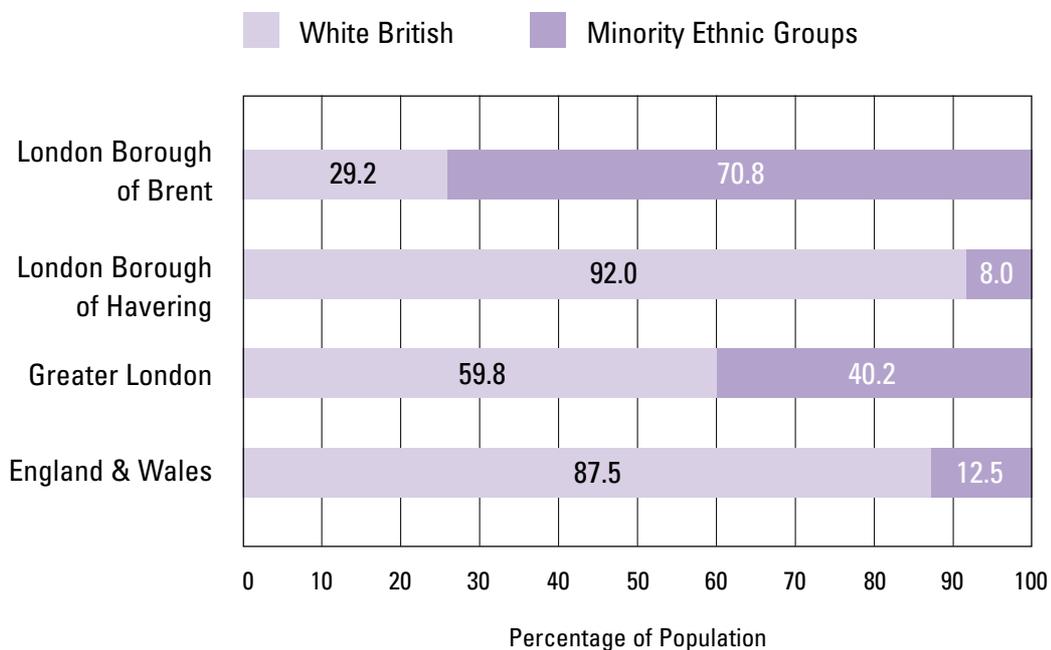
A more comprehensive means of monitoring such differences would help build the evidence we need to facilitate timely action to prevent ill health and improve access to effective and culturally appropriate services for those who most need it. The comprehensive collection of ethnicity information at birth and death is probably the single action that could most improve the evidence base for addressing ethnic inequalities in health and health care.

4 Why it is important for race equality in our modern society?

In order to achieve improvements in race equality in a modern and diverse Britain, The Race Relations (Amendment) Act 2000 places a general duty on all public authorities, including the England & Wales and Scotland NHS, to promote race equality and eliminate unlawful racial discrimination. This duty covers all aspects of an organisation's activities, policy and service delivery, as well as employment practice. In everything they do all public bodies must aim to eliminate unlawful racial discrimination, promote equality of opportunity, and promote good relations between people of different racial groups. It follows that service providers such as the NHS and local authorities need relevant knowledge about the ethnic composition of their service users in order to deliver an appropriate service.

5 The particular importance of ethnicity recording in the UK

Minority ethnic communities in England & Wales, i.e. all ethnic categories other than White British, as defined in the 2001 Census, have increased substantially since 1991. The latest Census in 2001 indicated that they comprised 12.5% of the population in England & Wales and 40.2% in Greater London. London's ethnic diversity means the issue of ethnicity recording is particularly important. More than 30% of London's school children speak a language other than English, with a total of more than 300 languages being spoken by all such children at home. Not only has the total minority ethnic population grown as a proportion of the total population, but the increasing diversity of cultures and communities living in Great Britain today underline the importance of knowing our communities better. The diagram below shows the significant size of ethnic minority communities both in England and Wales as a whole, and in London.



Note (1): Minority Ethnic Groups includes all categories, except White British, listed in the text box in Section 6 below ("The 16 ethnic categories in the 2001 Census").

6 Why current methods of collecting ethnicity data are inadequate

The ability to define the overall size and ethnic mix of a population accurately and how it changes over time is fundamental to the production of an accurate description of the health of a community. All key planning and resource allocation decisions are based on such estimates. Inaccurate estimates lead to built-in unfairness.

In 1991 ethnic group was for the first time collected in a decennial census and a new/revised question set on ethnicity/culture in the 2001 Census provides information on ethnic group/cultural background and religion across Great Britain and on ethnic group/religion in Northern Ireland. The 16 ethnic categories defined in the new census for England and Wales are set out in the box below:

The 16 Ethnic Categories in the 2001 Census (England and Wales)

<p>White: British White: Irish White: Other*</p>
<p>Mixed: White and Black Caribbean Mixed: White and Black African Mixed: White and Asian Mixed: Other Mixed*</p>
<p>Asian or Asian British: Indian Asian or Asian British: Pakistani Asian or Asian British: Bangladeshi Asian or Asian British: Other Asian*</p>
<p>Black or Black British: Caribbean Black or Black British: African Black or Black British: Other Black*</p>
<p>Chinese or Other: Chinese Chinese or Other: Other*</p>

*Note** These were open response categories on the Census form.



These categories are also those required in most public sector information collections. While this offers a good baseline for work around the time of the census at the beginning of each new decade (for example, for use as a 'denominator' in the calculation of rates and ratios), it becomes increasingly inaccurate as the data ages. This makes it difficult to project the future size of ethnic minority communities. As a result, the planning of many public services vital for good health has been based on inaccurate assumptions.

7 Why information on country of birth as a proxy for ethnicity at birth and death is inadequate

Information on country of birth is currently collected at death registration, and information on the country of birth of mother and father is recorded at birth registration. Country of birth has been used in the past as a "proxy" for ethnicity but this is unacceptable for two reasons:

- Some of the ethnic categories introduced in the 2001 Census show a large number of people born in the UK but recording their ethnicity as mixed. This cannot be reflected using country of birth;
- Country of birth is a very poor indicator of ethnicity today because many people from ethnic minorities were born in the UK - and thus key aspects of health inequalities remain invisible if this measure is used. The 2001 Census shows that in London 95.9% of White British people were born in the UK, but so were 90.2% of Mixed: White and Black Caribbeans.

Census figures show that people born outside the UK are now a minority in many minority ethnic groups. Clearly, country of birth statistics provide information only on the first generation and tell us nothing about the large and growing second and subsequent generations that now form an overall majority of the minority ethnic group population in this country.

8 Why the NHS Birth Notification will not be a good enough alternative

The NHS started collecting information on babies' ethnicity at birth - as defined by the mother - in October 2002, through the new Birth Notification Data Set. Even if this information should be more complete than other sources of hospital information the ethnic group is not passed on to registrars so that totals can be checked and corrected.

9 There is no alternative to ethnicity recording of deaths

There are strong arguments for collecting ethnic group at death registration (using the 2001 Census classification) as there are no clear alternative options. Populating of central administrative registers/records with ethnic group, whether derived through hospital episodes statistics or eventual collection in primary care, is likely to take two or more decades to yield data that is of sufficient quality and completeness.

10 Why Civil Registration of births and deaths is the best way of recording ethnicity

Registration is an administrative task that is performed by necessity at birth and death, normally by a close relative of the subject. It is performed in virtually 100% of cases and is characterised by a high standard of quality in recording and completeness. It thus offers the best opportunity to collect an essential data item both quickly and efficiently.

11 The evidence on the feasibility of collecting such data from other comparable countries

Ethnic group/race is collected on birth and death registrations in the United States, Australia, New Zealand, and Canada (6 of the 12 provinces).

There is no evidence that completeness of registration is compromised by including ethnicity information, demonstrating the feasibility of such collection in civil registration processes.

12 Will the recording of ethnicity through civil registration have an adverse effect on the current high level of registration and the quality and completeness of other data currently collected?

Ethnic group data has been collected in two national censuses in the UK and there is no evidence that the addition of ethnic group has had a detrimental effect on overall response to the census. Moreover the recent addition of a voluntary question on religion resulted in a 91.3% completion rate in London and 92.3% in England and Wales. There is also no evidence of a detrimental effect on response rates by adding an ethnic group question in social surveys. Further, the use of ethnicity/race questions in vital statistics collections in North America, Australia, and New Zealand does not appear to have had any detrimental effect on the level of registrations of births and deaths.

13 The proxy reporting of ethnic group on birth and death certificates: does it matter?

In most events during a person's life that need to involve knowledge of their ethnicity, such as employment monitoring and most hospital episodes, this is self-assessed, i.e. chosen by the individual from a list of available options. Clearly, at birth or death ethnic group can only be proxy-reported, by parent(s) or defined operationally using ethnic group of father and mother for birth certificates, and by the person registering the death. In neither case would this detract from the validity or quality of the data. Ethnic ascertainment/self-identity does, of course, change through the life course. However, the information would be collected specifically to address the need for ethnic information at birth and at death rather than as a measure of ethnicity throughout life.

Given that Census data is needed as 'denominators', the method of data collection at births and deaths needs to be compatible with Census definitions. With respect to births the Census "form-filler" in families with young dependent children is likely to be a parent who would similarly "proxy report" the ethnic group of the baby. The differences in assignment with respect to deaths are unlikely to be large.

14 Modern Government requires a modern registration system

The Government locates its proposed changes to civil registration processes in the context of the needs of society and the modernisation required to reflect those needs. Modernisation in today's society must recognise the contribution diverse groups make and the importance of planning to meet such communities' needs.

15 Will the collection of such data through the Civil Registration process be cost-effective?

Whilst there is scant evidence on the time and cost of asking about ethnicity in any settings, it should be acknowledged there will be a cost for asking this additional item. There is evidence that in primary care settings, three-quarters of the recording episodes for the collection of ethnic group took less than one minute. However, in 2% of patients the staff member felt uncomfortable asking about ethnicity, a significant correlation existing between the time taken to ask the patient (over 3 minutes in 4.3% of patients) and level of discomfort. These costs may need to encompass training for registration officers in how to collect the data. However, the registration process is already in place and the costs of adding a small number of additional items (including ethnicity) may be offset by cost savings in new methods of registration, such as the Internet. There may be other savings with respect to current expenditure on the estimation of ethnic fertility and mortality rates from other sources of data. Moreover, these costs should be seen in the context of the costs that will not need to be incurred in ensuring that public services

such as the NHS and local authorities meet their duties under the terms of the Race Relations Amendment Act.

16 Implications for civil liberties and other legal matters

There is no evidence from Censuses and government social surveys that the public object to answering questions about their ethnicity using census classifications. This issue was extensively tested in preparation for the last two censuses. The level of refusals to provide such information is extremely low. Careful consideration will also need to be given to whether this item is made available to the public (on the public record) or treated as confidential (on the statistical record). Given its treatment in NHS collections (with respect to the published (“Caldicott”) Guidelines on data confidentiality), it may be necessary to make ‘ethnic group’ at birth and death registration a restricted item not available to the public.

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London Health Observatory

The London Health Observatory (LHO) was set up in 2001 following the Government White Paper: "Saving Lives Our Healthier Nation" (DoH, 1999). The LHO brings together the information and know-how needed to analyse and research health in the capital. It also has a role to help all those working to improve the health of Londoners to make better use of health and health-related information. The LHO is part of a national network of Public Health Observatories and has a lead role on health inequalities, social exclusion and regeneration.

www.lho.org.uk



London Health Commission

The London Health Commission (LHC) is a high level partnership that works to reduce health inequalities in the capital and to improve the health and well-being of all Londoners. The LHC recognises that this requires coordinated action to improve the determinants of health across London.

The London Health Observatory is one of the key partner organisations of the LHC.

The LHC promotes this action by:

- building partnerships across sectors and organisations
- influencing key stakeholders and policy makers
- providing practical support for local activities.

www.londonshealth.gov.uk