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**MISSING RECORD:**

**THE CASE FOR RECORDING ETHNICITY AT BIRTH AND  
DEATH REGISTRATION**

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**On behalf of the London Health Observatory's  
Ethnic Health Intelligence Programme**

**July 2003**

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PJA, BJ, & GMP

July 2003

## **Preface**

We have carried out this review as part of the London Health Observatory's Ethnic Health Intelligence Programme "Diversity Counts" which has been launched to identify and make the best possible use of health-related information containing ethnic components. This has been identified as a top priority by health-related agencies time and again with numerous studies, articles, methodologies and publications dedicated to the subject over the last dozen years in particular. In covering and attempting to establish an evidence base from what is, at best, incomplete information, these efforts have added to our understanding of issues of ethnic inequalities and their determinants and will serve as a useful springboard for further developmental work if and when new, better quality, and more complete data becomes available for use.

Information on the ethnicity of local populations – with implications for the determinants of its health and health needs, and on the ethnicity of its service users - is an essential component of public health information. But an assessment of the ethnic inequalities in health requires the ability to analyse ethnic differences in mortality as well as morbidity/service use. For London with the biggest and most diverse proportion of minority ethnic residents of any Region in the UK, it is a serious omission not to be able to pursue such analyses.

A key part of the “Diversity Counts” Programme is to provide evidence to support a campaign to develop a more complete picture of ethnic health differentials. Consequently, the consultation process on the modernisation of civil registration of births, marriages and deaths - following publication of the White Paper 'Civil Registration: Vital Change' - provides an exceptional and timely opportunity for us to provide evidence to support strategic change, a chance to influence data collection for the future not to be missed. In particular there is the possibility of formulating the case for the introduction of ethnicity as part of the registration process.

This report reviews the evidence for including ethnicity at birth and death registration in England and Wales and addresses five key areas: (1) An overview of the evidence base on why vital statistics are essential for monitoring public health (in addition to other ethnic monitoring data), the problems of an inadequate information base (based on country of birth), and the data needed

to allow a proper analysis of ethnic differentials. This includes examples of work from London in particular and how inadequate information prevents a proper analysis. (2) An overview of international activity in registration methods, with particular attention being paid to ethnic coding and data quality issues. (3) An analysis of present data collections for individual items. (4) An appraisal of the alternative methods there might be of collecting the information (such as electronic databases like Electronic Health Records) and conclusions on which might be the most cost-effective. (5) A review of existing data items collected at registrations of births and deaths and whether there is scope for substitution with respect to adding ethnicity.

The findings will be fed into a wider consultation by the Government in July 2003 that addresses matters arising out of the White Paper <http://www.statistics.gov.uk/registration/whitepaper/default.asp>. A simple summary version of this evidence is also available on the LHO website – <http://www.lho.org.uk>.

PJA, BJ & GMP

July 2003



## OVERVIEW

### **The case for recording ethnic group at birth and death registration**

#### **1. *The importance of ethnicity recording for health***

When stratified by ethnic group the burdens (incidence, prevalence, and mortality) of many diseases are known to vary. There are well documented inequities in access to preventative, treatment, and palliative health and social care services based on ethnic group. There are, too, reported differences in the quality of services received across the different ethnic groups and of outcomes of treatment and care. Many of these inequities are amenable to change. However, in order to address them they must, first of all, be comprehensively defined and documented. Mainstreaming ethnic monitoring/data collection is a vital step in the process. The history of such data collection in the NHS is poor, whichever of the key datasets is examined: hospital episode statistics, general practitioner data, cancer registrations, and disease registers. While steps are now being taken to remedy some of these deficiencies, the continued non-availability of ethnic monitoring data and in some cases of compatible ethnically-coded denominator data remains a problem. In particular the lack of ethnic group in births and deaths data has been the subject of widespread comment by specialists in demography and public health and is probably the single action that could most improve the evidence based for addressing ethnic/racial inequalities in health and health care.

#### **2. *The particular importance of such recording in London***

The minority ethnic population of Great Britain has increased substantially since the 1991 Census. The 2001 Census shows that this segment (excluding White minority groups) comprises 8.7% in England and Wales and 28.9% in Greater London, the latter a proportion similar to continental USA. London's ethnic diversity means the issue of ethnicity recording is particularly acute. According to the 2001 Census, London's black and minority ethnic group population varies at borough level from 4.8% (Havering) to 61.0% (Newham) and is over 40% in four others. More than 30% of London's schoolchildren speak a language other than English, with a total of more than 300 languages being spoken by all such children at home.

### ***3. Why current methods of collecting ethnicity data are inadequate***

Ethnicity recording on the core demographic and health datasets in both London and nationally is very poor with, for example, the ethnic group variable on 37-39% of hospital finished consultant episodes in London being coded not known in the period 1997/98-2000-01. Ethnicity at present is not recorded on either birth or death certificates in the United Kingdom. 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 is providing information on ethnic group/cultural background and religion across Great Britain and on ethnic group/religion in Northern Ireland. While this offers a good baseline for work around the censal period (for example, for use as a 'denominator' in the calculation of rates and ratios), it quickly loses relevance as the data ages. A method for calculating population projections by ethnic group exists for London and a few other authorities; however, the difficulty of accurately estimating fertility and mortality rates by ethnic group is a key methodological difficulty in deriving such projections.

### ***4. 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, is characterised by a high standard of quality in recording and completeness, and offers the best opportunity to collect an essential data item both quickly and efficiently. Many of the alternative methods for collecting such data for these vital events would involve incremental accrual of the data and problems of quality and completeness.

### ***5. 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), demonstrating the feasibility of such collection in civil registration processes. In Europe (the EUROSTAT countries) there are different traditions of collecting population statistics, including those based on capture via automated municipal population registers. However, many countries collect information on nationality and a small number on ethnicity.

#### ***6. The inadequacy of the country of birth item as a proxy for ethnicity for birth and death events***

Country of birth is no longer a good proxy for the minority ethnic group population. In 2001 50.0% of the minority ethnic group population in England and Wales was born outside the United Kingdom (that is, they were migrants). 79.3% of persons in the Mixed group and over half the Black Caribbean group (57.9%) and the Pakistani group (54.8%) were born in the United Kingdom. The small Other Black group (79.2%) also had more than half its population born in the United Kingdom. Bangladeshi (46.5%) and Indian (45.9%) groups are coming close to having equal proportions of their population born in and outside the United Kingdom. However, in the Chinese group only 28.3% were born in the United Kingdom and 67.6% born in the Far East. 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 around half of the minority ethnic group population.

#### ***7. The inadequacy of other sources of information on the ethnicity of births and deaths***

The widely used cohort component method for population projections requires information on fertility, mortality, and migration. None of the existing sources of information on fertility - decennial censuses, General Household Survey, Labour Force Survey, Hospital Episode Statistics and maternity collections - provides the means to derive robust measures of fertility across the different ethnic groups and for sub-national (local) estimates and time series analysis. Once the 2001 Census data is incorporated into the ONS Longitudinal Study (LS), accurate estimates nationally will be available for the different ethnic groups but the LS will not satisfy the need for sub-national estimates of fertility or specific segments of the population such as teenagers. The Birth Notification Data Set - which contains a data item on the ethnic category of the baby as defined by the mother using the 2001 Census classification - may prove to be a viable alternative to the collection of ethnic group at birth registration. However, it is too soon to assess whether this new collection will result in the accrual of data that is complete and of quality. 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 collection in primary care, is likely to take two or more decades to yield data that is of sufficient quality and completeness to address issues of inequity.

#### ***8. The wider benefits of, and uses for, the collection of such data at registration***

With the increasing ethnic/cultural diversity of the population of Britain, it is important to be able to respond appropriately in the delivery of services and in understanding the different health needs of the various groups, including access and inclusion issues. Ethnically-coded data is needed to identify these inequalities and health issues. For example, the Child Health Informatics Consortium's Essential Core Dataset for Child Health includes ethnic group of the child as determined by the parents, consistent with 2001 Census categories. The Key Indicators of Child Health include low/very low birthweight and the number of births >24 weeks gestation in the resident population, broken down by ethnicity.

Further, 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. Moreover, the Race Relations (Amendment) Act 2000 reinforces the duty of organisations to provide for their population and lays on them the onus of ensuring populations are not discriminated against on grounds of ethnicity. One of the prerequisites to satisfy the legislation is the necessity to know the ethnicity of the population served. The Act also places a new, enforceable duty on public authorities to promote racial equality.

#### ***9. The likely effect of recording of ethnicity through civil registration upon the current high level of registration and the quality and completeness of other data items currently collected***

Ethnic group data has been collected in two national censuses and there is no evidence that the addition of ethnic group has had a detrimental effect on overall response to the census. Even the recent addition of a voluntary question on religion was judged not likely to affect overall completion rates of the census. Item non-response for religion in the 1997 Census Test was no different from that for ethnic group or country of birth. There is also no evidence of a detrimental effect on response rates of 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 a detrimental effect on the level of registrations of births and deaths, although item non-response to the ethnic/race questions is variable.

#### ***10. Achieving the recording of births and deaths from a technical perspective***

The most viable method of recording ethnic group at birth registration would be a data item on the ethnic group of the baby using the 2001 census classification, as ascertained by the parent(s). This would then provide information compatible with the ethnic group item in the birth notification dataset (and a means of cross-validation) and the ethnic group of newborns in the decennial Census. Collection of data on the ethnic group of the mother and father at birth registration (to impute the baby's ethnic group) raises complex issues of classification and might incur respondent and administrative burden. Using the mother's ethnic group to define that of the child would be likely to give poorer quality data than by ascertaining the ethnic group of the child directly (for example, with respect to mixed parentage children). However, fertility rates for the different ethnic groups would be easier to estimate from data on the ethnic group of mother than from ethnic group of child. Also, consideration would need to be given to the ethics of parental ascertainment of the baby's ethnic group if that method was chosen, although it is used in the Birth Notification Data Set and in some other collections (e.g. New Zealand birth registrations).

The recording of ethnic group at death registration raises less complex issues than collecting the information at birth. Again, it is recommended that the 2001 Census should be used to record the ethnic group of the deceased and that the person registering the death should be the informant. The recording of this information by funeral directors in the United States has been shown to result in poor quality data.

#### ***11. The proxy reporting of ethnic group on birth and death certificates: Does it matter?***

Clearly, on birth and death certificates ethnic group can *only* be proxy-reported, by parent(s) or defined operationally using ethnic group of father and mother for births 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 for use in a longitudinal context. If central administrative registers were populated with 'ethnic group' obtained by self assignment (for example, via Hospital Episode Statistics), then clearly deaths could be stratified by a self-assigned measure of ethnic group. However, it is unlikely that sufficient data would accrue via such means (or via primary care if that was the point of access), except in the very long term; there would also be problems of

incompleteness associated with non-users of such services and of administrative failures to collect the data.

Given that Census data is needed as 'denominators', the method of data collection at births and deaths needs to be reasonably compatible with Census procedures. 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 child. The differences in assignment with respect to deaths and a Census denominator (age group) is unlikely to be critical given the fairly broad Census categories. Comparisons of ethnic group at birth and death in infancy for the same persons would provide an opportunity to check consistency in recording of ethnic group.

#### ***12. The cost-effectiveness of collection.***

Formal trials are needed to estimate the time/cost of asking ethnic group (by all methods) at birth and death registration. There will be a cost for asking this additional item, although in primary care settings a trial found that in three-quarters of the recording episodes the collection of ethnic group took less than one minute. However, in two per cent 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 per cent 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 registrars will already be receiving the ethnic item in the birth notification dataset by electronic transfer from child health departments. The costs of adding a small number of additional items (including ethnic group) 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 such sources as the Labour Force Survey and LS.

#### ***13. 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. The level of refusals to provide such information is extremely low. However, formal evaluation of the civil liberties implications may be required. Careful consideration will also need to be given to whether this item is made available to the public or treated as confidential.

Given its treatment in NHS collections (with respect to the 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.

## Appraisal of Options and Recommendations

### (i) Births.

Criteria	Options <sup>1</sup>				
	<i>Ethnic group of both parents</i>  (1)	<i>Mother's ethnic group</i>  (2)	<i>Child's ethnic group (ascertained by parents)</i>  (3)	<i>Both (1) and (3)</i>	<i>None</i>
<i>Compatibility with Census denominator data on child's ethnic group</i>	None	None	Good	Good	None (only country of birth of mother)
<i>Compatibility with Birth Notification Dataset</i>	None	None	Good	Good	
<i>Respondent burden</i>	High	Low	Low	Very high	
<i>Administrative burden re: child's ethnic group</i>	Very high (would need very complex algorithms)	Low (read across)	Low (no adjustment)	Very high	
<i>Accuracy of assignment re: child's ethnic group</i>	High (operational definition)	Low	High (direct assignment)	Very high	Would leave dependency on birth notification dataset (not validated v. ascertainment at birth registration)
<i>Utility for fertility estimation</i>	High	High	Medium (but possible through back projection or ratio method)	High	Would leave dependency on very crude data
<i>Utility for child health</i>	High	Low	High	High	Would leave dependency on birth notification dataset
<i>Utility for maternal health</i>	High	High	Low (but some availability on HES record)	High	Would leave dependency on HES/voluntary collections
<i>Likely quality/completeness</i>	Low (for father)	High	(Probably) high	Low re: (1)	

Notes:

1. Ethnic group of 'father only' omitted; known to be unreliable.

CONCLUSIONS:

1. The ethnic group of the child on all cases *OR*
2. Validate Birth Notification Dataset entry & supply missing data (**STRONG**)
3. Ethnic group of both parents (**MEDIUM**)



**(ii) Deaths.**

Addition of ethnic group to death registration as no alternative viable option exists, ethnic group to be assigned by the informant, usually a close relative.

**Recommendations:**

**Births**

- 1. At birth registration the ethnicity of the baby should be recorded – using the 2001 Census classification – as defined by the parent(s).**
- 2. The Birth Notification Dataset should be electronically linked to Civil Registration so that ethnicity records of the baby can be validated.**

**Deaths**

- 3. At death registration the ethnicity of the deceased should be recorded – using the 2001 Census classification – as defined by the person registering the death.**
- 4. New information to be held on Statistical Record.**

## **Chapter 1: The Civil Registration White Paper**

In September 1999, the Registrar General for England and Wales published a consultation paper '*Registration: Modernising a vital service*'. This sought views on defining and providing a civil registration service responsive to the needs of individuals and capable of adapting and evolving to meet changing needs. It aimed specifically at pinpointing possible improvements in service delivery for the registration of births, marriages and deaths; potential new services; responding better to individual's, government's and society's needs.

Delivering potentially radical changes highlighted the need for better organisational arrangements, wider use of information technology and consideration of funding issues. There were almost 1,000 responses to the consultation. The majority were from individual members of the public, notably genealogists or from Registration Officers. The remainder came from a wide range of organisations, including Local Authorities, Medical organisations, Family History Groups/Archivists, Religious groups, Statistical, Voluntary/Community Groups and Central Government.

Drawing on the public consultation, a white paper: *Civil Registration: Vital Change (Cm 5355)* was published on the 22nd January 2002. This sets out the agenda for a modern, effective and high quality registration service in keeping with the principles of 'Modernising Government' including greater use of technology. It also recognises and promotes the development of the wider role of the registration service proposed by Supporting Families. It is essential that civil registration continues to record high quality information and to play its part in protecting human life and in upholding the rights of individuals on access to information.

The paper set out many of the issues now being addressed in this modernisation programme and the responses from stakeholders were used in the formulation of the framework in the White Paper. Updating the legislation should be completed in 2004, implementation of the changes will be phased, and many should be in place by the end of 2005. The changes to civil registration will be made using the order making powers of the Regulatory Reform Act 2001 (RRA). The Act contains a wide power, matched by tough safeguards, for the reform of burdensome legislation. Regulatory Reform orders enable the Government to reform entire regulatory regimes. They may reform one or more Acts, together with their subordinate legislation. The next stage of the process

to change civil legislation is the production of a detailed public consultation document. Following this, committees in each House of Parliament simultaneously subject the proposal to two-stage scrutiny before approval for Regulatory Reform Act Orders can be made. The process for orders made under the Regulatory Reform Act, relating to Civil Registration in England and Wales, will start this year.

The civil registration White Paper proposes a number of changes to registration processes in England and Wales in recognition of dramatic changes in society and the need for the registration service to respond to these changes. Amongst the most important of these changes, in future individuals will be able to register births and deaths on-line, by phone or in person. Local authorities will be responsible for the local service and will be expected to provide these registration services in innovative ways. Respondents to the consultation paper supported a more responsive service with more choice in ways to register, the provision of additional services and with increased availability and use of electronic information. The White Paper also gives recognition to the importance in policy making of the statistical information derived from civil registration, including that from death registration for monitoring the health of the nation.

With respect to *birth registration*, the White Paper retains the legal obligation to register which rests primarily with parents. It emphasises that there must be no disincentive to register or disadvantage to those upon whom the duty falls. The increase in choice in ways to register a birth (including the use of information technology) is accorded importance, although it is recognised that self-completion of the record does have risks for the quality of the information. The Government makes clear that these changes are part of a proposal to create a central database for recording life events.

The relationship between the birth registration process and NHS birth notification procedures is emphasised:

'A vital component of birth registration is the notification of the event from the NHS. The notification provides the evidence that a birth has taken place and helps in verifying that all births are registered, thus guarding against fraudulent registrations and avoiding duplicate registrations. To deliver electronic registration of these births, these notifications will need to be provided by the Health Authority where the birth occurred. Information contained in a notification, including the child's NHS number, will form a 'marker' record and be matched against information given by

the parent(s) when registering the birth and naming the child. A key strand of the NHS Information Strategy is the development of a single administrative register for NHS patients. The civil registration system will be designed to enable it to take the notifications from this NHS administrative register'.

The centralised receipt of NHS birth notifications will enable a birth to be registered from any part of the country. Information will be entered directly on to the central database and will be matched with the 'marker' record. To help ensure all births are registered and to help prevent the registrations of fictitious births, there will be follow-up of births which are notified by the NHS and not registered and vice versa.

The White Paper also addresses the issue of births outside marriage. Each year about 40% of births in England and Wales (almost a quarter of a million children) are to parents who are not married to each other. 50,000 of these children (around a fifth) are registered without their father's details. Where a child's parents are not married to each other, the father's particulars may only be recorded provided both he and the child's mother or a court acknowledge his paternity. The Adoption and Children Bill will give parental responsibility to unmarried fathers who register the birth of their child with the mother. Under new procedures it will be possible for a mother and father to give information independently if they so wish, although if they do this and the parents cannot agree about particular aspects, they may have to go to the local service provider.

With respect to the *registration of deaths*, this will remain primarily the duty of a close relative and the Government will preserve the current obligation to register. As with birth registration, there must be no disincentive to register. The Government proposes to create a central database of deaths, with electronic data exchange between doctors, coroners and registrars. When this is in place, the Government will introduce the option of registering a death by telephone or using the internet. Until then, the proposed central database would allow relatives to register the death at any local office, though the informant must have the medical certificate of cause of death. The same information in the register will be recorded for men and women. This will include, for example, the inclusion of marital status and the name and occupation of the deceased's spouse for all persons. The Government intends to make the registration of a still-birth similar to that for a death so that medical investigations can be carried out in appropriate cases. At present a still-birth cannot be registered later than three months from the date it occurred. The Government will change this restriction so that a still-birth may be registered up to one year after it occurred.

Finally, the White Paper addresses the issue of statistical information for monitoring the size and composition of the population, making projections of the health and circumstances of people's lives, and allocating resources to central and local government and to the NHS. One of the key points is concern about the overall burden on the public and the collection of information which does not seem relevant to the actual registration itself. Civil registration must ensure the civil status of the individual is safeguarded, so the questions asked and the overall process must be sufficiently acceptable to the public to ensure all births and deaths are registered and contain high quality information.

The Government takes the view that legislation should enable full testing of potential questions to ensure sufficient public acceptability both of individual questions and the overall package and that the results are of sufficient quality. Through consultation the Government will seek to balance the needs of users of the information with public acceptability and reliability of the information. With respect to the burden on the public of collecting information, the White Paper suggests that enabling individuals to agree to the reuse of information provided already or to provide it at a more convenient time would reduce this burden. In the only mention of ethnicity, the White Paper states: 'This could mean, for example, using information provided to or available from the Health Service (e.g. ethnic origin, birth weight and gestational age of the baby)'.

*Pointers in the White Paper with respect to strategies for introducing data elements on ethnicity.*

The White Paper suggests some constraints on what information can be collected through civil registration and the following points in particular have been identified as of importance in preparing a strategy.

1. Self-completion of the record through a variety of media (including internet and telephone as well as in person) will require an assessment of the impact of different modes of collection on the obtaining of ethnic group at birth and death registration, suggesting the need for straightforward and easy to complete data items.

2. Given that there should be no disincentive to registration, it may be necessary to privilege simple approaches to ethnic ascertainment over more complex schema that might impose respondent burden.
3. The recognised relationship between centralised receipt of NHS birth notifications and civil registration would require consideration of the former as a source of ethnic information at birth registration or as a way of validating new data collected.
4. The high proportion of births outside marriage and the significant proportion that are solely registered by the mother would require substantial proxy reporting of the father's ethnic group if ethnic information on both parents was collected.
5. The registration service in England and Wales has a good reputation for completeness, accuracy and integrity of the records it creates and maintains. This may be a reason to argue for the collection of information on ethnic group at registration in the light of the likely deficiencies in other methods such as NHS birth notifications.
6. Concern about acceptability to the public and the overall burden on the public needs to be explicitly addressed in any case for adding new ethnicity data items. The Government will need to be reassured that the addition of ethnic group to the data items collected at registration will not jeopardise the current high levels of registration.
7. In this context a decision will need to be made in this review about whether 'ethnic group' as a data item should be included in those contents of the current register entry which will remain publicly available or whether access will be restricted for this data item. Issues of access to the ethnic group data items for statistical and research purposes will also need to be addressed.

On 10th July 2003, The Government published its Regulatory Reform Order consultation document on the reform of the civil registration service in England and Wales, and is inviting feedback on the content of future birth, death and marriage registration. The consultation document can be accessed electronically at [www.statistics.gov.uk/registration/whitepaper/](http://www.statistics.gov.uk/registration/whitepaper/).

## **Chapter 2: Information currently collected in the recording of births and deaths in the United Kingdom**

Different data items are currently collected in birth and death registrations in different parts of the United Kingdom. On birth certificates, for example, only Scotland collects a separate item indicating whether the child is a foundling, and the marital status of the child's mother (but not of the father's). Occupation of the child's mother has only been collected in Northern Ireland for the past six years. Birthweight is only collected in England & Wales. Full details and a list of items currently collected are available in Appendix A, Table 1.

Currently, the only ethnic/cultural background information collected at birth registration is proxy in nature, that is, the place of birth of mother and father (see Appendix A, Table 1). The scope for substitution or removal of one data item to allow for the additional collection appears limited, the data items on place of birth of mother and father being needed for legal reasons.

For deaths (Appendix A, Table 2), only England and Wales collect information on the duration of illness, the date the deceased was last seen alive, the date of birth of surviving spouse, and whether employment contributed to death. Items collected in Scotland only include whether found dead, the number of spouses, the names and occupations of spouses, and the industry and employment status of last or only spouse. In Northern Ireland occupation is not recorded if the deceased was a married female or a widow, aged 16 or over. If the deceased was a child aged under 16 the name, occupation and industry/employment status of the mother are only recorded if child is illegitimate.

Again, only proxy information on the ethnic/cultural background of the deceased is available, that is, the place of birth of the deceased.

## Chapter 3: The case for change

### 3.1 Introduction

The lack of ethnic data collection at birth and death registration in the United Kingdom has been the subject of growing critical comment within and outside Government as the proportion of the ethnic minority population born in England and Wales has increased in size to an extent that it is now a half (2001 Census). A number of written questions in parliament have asked about the availability of ethnically-coded births and deaths data and the Office for National Statistics has had to confirm that such information is not available:

(see, for example, *HC Hansard*, June 2002 [re: percentage of children living in one parent families, the number of live births per 1,000 teenage women, and the percentage of children born outside marriage broken down by 'race']; *HC Hansard* February 2002 [re: annual figures from 1970 for overall number of births outside marriage for teenagers of ethnic minority groups as percentage of overall number of ethnic minority teenage births in the UK]; *HC Hansard* November 2001 [re: suicide statistics by ethnic group] ).

The strongest lobby for the collection of the data has come from the Department of Health, including the former NHS Executive. The Department's Public Health Information Strategy (Department of Health, 1993) emphasised the importance that this information be collected and its recent *Strategic Review of Business Information Needs (RoBIN) Race Equality Review* (Stroud 2000) reiterated this need. The deficiencies of country of birth on birth and death certificates as a proxy for ethnic group - and the need to redress these through the collection of ethnicity data - have also been articulated by the community of public health and demography specialists (for example, Aspinall 1999, 2000; Bell, Rankin *et al.*, 2001; Bhopal 1997, Harding & Balarajan 2002; Hoffman & Higginson 2000; Balarajan 1991; Marmot *et al.*, 1984; Modood, Berthoud *et al.*, 1997; Nazroo 1997; & Sporton & White 2002). In a recent review of inequalities, the Institute of Public Health in Ireland recently recommended that in mortality collections of Northern Ireland and the Republic 'the common set of data items should include...other items such as ethnicity or country of origin' (Balanda & Wilde 2001). The former Health of Londoner's Project (Bardsley *et al.*, 2000; Bardsley & Lowdell 1999) and the London Health Observatory (Barer *et al.*, 2002) have been vocal in identifying the drawbacks of country of birth in examining

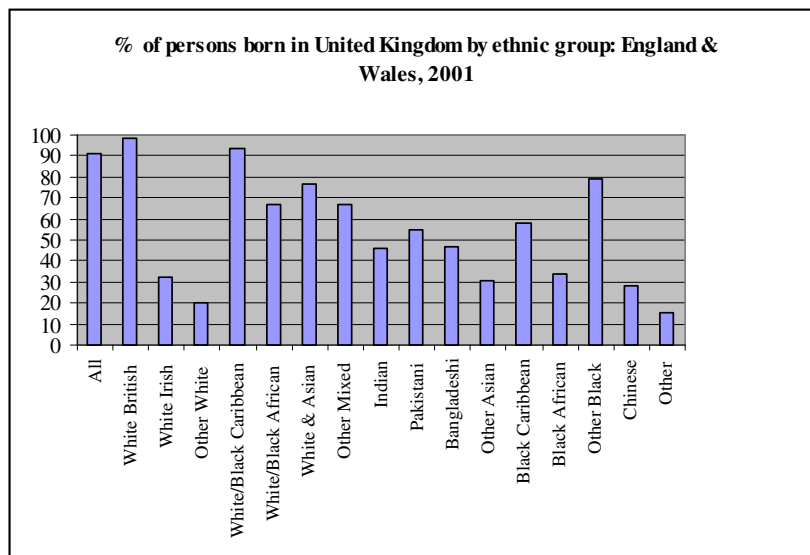


differences in mortality rates across the different ethnic groups in London and also with respect to life expectancy and infant mortality (see Annex, Table AN4). Similarly, the Northern and Yorkshire Public Health Observatory has referred to data on mother’s and father’s country of birth as ‘increasingly irrelevant to understanding established ethnic minority groups’ (Bell, Rankin *et al.*, 2001).

### 3.2 The demographic arguments

The demographic and related public health arguments for adding ethnic group to birth and death registration records are compelling (Fig. 1). Country of birth is no longer a useful proxy for ethnicity in examining mortality differentials by ethnicity. Moreover, amongst the ethnic minority population, migrant women contribute only a small proportion of the total fertility in this population.

Fig. 1. Percentage of persons resident in England and Wales born in the United Kingdom by ethnic group, 2001 Census



Source: 2001 Census.

The 2001 Census for England and Wales has revealed that migrants (persons born outside the United Kingdom) now comprise only half of all persons in minority ethnic groups. Around 79% of persons in the Mixed group and the small Other Black group were born in the United Kingdom, as were over half the Black Caribbean group (57.9%) and the Pakistani group (54.5%). Bangladeshi (46.5%) and Indian (45.9%) groups are coming close to having equal proportions of their population born in and outside the United Kingdom. However, in the Chinese group only 28.3% were born in the United Kingdom and 67.6% were born in the Far East.

### ***3.3 The need for change***

The need for change arises from both 'demographic account' arguments (relating to population projection modelling using the cohort component method) and epidemiological/public health arguments.

#### ***3.3.1 Demographic account arguments***

One of the strongest arguments for including ethnic group at birth and death registration is to enable accurate projections of the size and composition of the ethnic minority population to be made. The widely used, conventional, and tested method of producing population projections - the cohort component method (often developed into a multistage model that allows the population to move between different states) - requires information on fertility, mortality, and migration.

#### *Fertility*

With respect to such population projections, Haskey (2002) suggests that ethnic fertility is 'arguably *the* critical assumption in ethnic projections, given that most of the minority ethnic populations have a much younger age profile than that of the White population'. Sporton and White (2002) have presented a full discussion of the difficulties in projecting fertility by ethnicity, including reliance on births by mother's country of birth. They examine the available data sources for estimating ethnic fertility: the 1991 Census; the ONS Longitudinal Study; the General Household Survey; the Labour Force Survey; Hospital Episode Statistics (HES), including maternities data from NHS Trusts; and birth registrations. None of these data sources provides

comprehensive information on ethnic fertility rates. For example, the investigators compare the 1991 total period fertility rates (TPFRs) estimated by ethnic group - using birth registration data and the 1991 Census - with an alternative set derived from the Labour Force Survey. The marked differences between these two sources for some ethnic groups demonstrates the short-comings of current data sources and the need for comprehensive data that will enable accurate differentials in fertility to be compiled for use in population projection models.

Two particular needs that would be substantially met by adding ethnic group to birth registrations are high-lighted by the investigators. They address the geography of ethnic fertility, suggesting that national estimates of ethnic fertility may conceal important local variations. Geographical variations might be expected, they argue, since cultural norms, attitudes and behaviour are more likely to be preserved where minority ethnic groups have settled in concentrated numbers. Some evidence for such an effect is offered for London, leading the investigators to conclude that ethnic fertility assumptions should take account of local variation.

Secondly, in addition to the need for comprehensive sources of information on current levels of fertility, both nationally and at a sub-national/local level, there is an urgent need for time-series data on ethnic fertility to gauge the likelihood of future changes. The method that has been used - the conversion of TPFRs by mother's country of birth (available since 1981) to those by ethnic group based on various assumptions is not an accurate way of estimating trends.

While Sporton & White consider that the ONS Longitudinal Study (LS) will - once the 2001 Census data is linked in - provide a sufficient sample from which to estimate fertility by ethnic group and country of birth, it will clearly not be adequate to provide such information at the sub-national level (e.g. at the level of individual London boroughs).

Berthoud (2001) has made total period fertility rate estimates by ethnic group using the Labour Force Survey (LFS). He has highlighted data deficiencies arising from the non-recording of ethnic group on birth and marriage registration statistics, especially with respect to the analysis of age-specific fertility rates by ethnic group and of child-bearing by women below the age of 20. Berthoud had to estimate such rates from the dates of birth of mothers and children in the LFS.

The data needed to estimate ethnic fertility could be either ethnic group of mother *or* ethnic group of child. However, given the problem of children's ethnicity in relation to that of their parents,

especially children of mixed ethnicity, it is likely to be easier to estimate fertility from the ethnic group of mother. If the ethnic group of the child was chosen for birth registration, conditional probabilities of the mother's ethnicity based on the child's ethnic group could be obtained from the 2001 SARs (Samples of Anonymised Records).

### *Mortality*

While ethnic fertility is of primary importance in population projection modelling, mortality is still an important component. Mortality represents more of a difficulty than fertility with respect to data sources for such modelling. Unlike fertility (where the birth notification dataset might provide an alternative to collecting ethnic group at birth registration), there is no obvious alternative with respect to deaths.

There are a number of well-documented drawbacks to using country of birth as a proxy for ethnic group in modelling population projections for ethnic groups.

- Deaths by country of birth (as a proxy for ethnicity) exclude deaths among second and later generation members of minority ethnic groups. The size of the latter group is growing with the passage of time, rendering country of birth increasingly unsatisfactory as a proxy measure.

• One of the difficulties frequently mentioned is that of return migration and the extent to which it biases mortality rates (Harding & Balarajan 2002; Rees 2002).

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• There are a number of sources of error arising from ethnic misclassification when mortality data from death registration is combined (unlinked at the individual level) with census country of birth data (Harding & Balarajan 2002). For example, a number of studies have identified the misclassification at death of older people who were recorded as having been born in India but who were born in what is now Pakistan. Further, while Caribbean-born people are usually assumed to be of African origin, a small proportion are of Indian ancestry.

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• Not all persons born in the Indian subcontinent are of Indian ethnic group. A small but significant proportion are the children of British expatriates.

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Many of these difficulties (but not all, for example, the problem of return migration) would be resolved by collecting ethnic group at death registration. Moreover, there is no ready alternative data collection that could serve as a substitute if the latter proved impractical. As Haskey (2002) has concluded: 'The formulation of mortality assumptions by ethnic group will therefore at best be based upon very crude evidence'.

One of the few options available that might enable mortality for the different ethnic groups to be explored is the ONS Longitudinal Study (LS), a record linkage study that began with a 1 per cent sample of the population of England and Wales in 1971 and has linked into vital registration data and census schedules (including 1991 Census data on ethnic group and such data from the 2001 Census in 2003) for the cohort members. However, sample numbers are currently too small for many kinds of analysis. However, in the future this source will increasingly be able to yield the necessary data for national population projection modelling for ethnic groups.

In a local context (for example, in minority ethnic population projects in Bradford, where the largest such groups are South Asian), use can be made of country of birth and name origin of deceased. In Bradford Simpson (1997) used this approach to derive SMRs for males and females aged 35-74 for the Indian, Pakistani, Bangladeshi, and all other groups.

### **3.3.2 Epidemiological/public health arguments**

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The lack of ethnically-coded births and deaths data has been widely criticised by public health practitioners from the perspective of epidemiological research. Bhopal (1997) points out the harm from some of the research on ethnicity and health, including the perception that ethnic minorities are unhealthy. He includes amongst the factors giving rise to this perception the omission of those members of minority ethnic groups born in Britain in standardised mortality ratios. He cites Marmot and colleagues' analysis of mortality in migrants for the period 1970-78 that attempted to analyse ethnicity because country of birth was too crude (Marmot *et al.*, 1984) but notes that an update using mortality data for 1980-2 did not even though there were by then substantially more British born people in ethnic minority groups (Balarajan *et al.*, 1984).

There are epidemiological arguments to support collection of ethnic group at both birth and death.

### *Births*

The collection at birth of ethnic group of mother and father meets somewhat different needs to that of ethnic group of child in the context of epidemiological research. The former would enable many of the maternal risk factors and their outcomes that are currently analysed by country of birth (for example, in the ONS monitor series) to be tabulated by ethnic group (to give full account of births by ethnic group rather than the small subset captured by country of birth of mother). However, ethnic group of child (which could also be defined operationally in terms of the ethnic group of father and mother) would enable the health of the infant to be monitored by ethnic group. For example, infant mortality rates are currently tabulated by country of birth of mother. Such rates are known to be much higher in children whose mothers were born in Pakistan. Having data on the full size of the ethnic group would enable the poorer health of Pakistani children to be more fully investigated, including the high incidence of congenital abnormalities and generational differences (Davey Smith *et al.*, 2000).

### *Deaths*

The public health literature widely reports the previously documented drawbacks of country of birth as a proxy for ethnicity, mainly in the context of studies in migrant mortality (all cause and for selected causes) that use country of birth as a proxy for ethnicity. A number of major studies have been undertaken around the time of the decennial censuses: 1971 Census, 1970-78 data (Marmot *et al.*, 1984); 1981 Census, 1979-83 data (Balarajan *et al.*, 1984); and the 1991 Census, 1991-93 data (Harding and Maxwell, 1997; Wild and McKeigue, 1997).

Again, the same problems that impede the use of migrant mortality in the 'demographical account' context are barriers to interpretation in the epidemiological context. By using country of birth as a proxy for ethnic group/origin, analyses exclude second generation populations born in England and Wales. Country of birth includes foreign-born people of European extraction (since, however, they tend to be older than the age-range covered in many analyses [ $\leq 64$  years], their effect on mortality tends to be small). Problems of country of birth being recorded differently on census forms compared to death certificates for those born in India, Pakistan, and Bangladesh and also for those born in Northern Ireland and the Republic of Ireland limits analysis. Harding & Maxwell (1997) report that special tabulations from the Longitudinal Study suggest the continuation of such problems.

Adding ethnic group to birth and death registrations would provide a count of the 'full size' of the different ethnic groups and standardisation of classifications used would yield compatible numerator and denominator data. Further, these data deficiencies prevent the compilation of statistics on life expectancy by ethnic group (Aspinall 1999; Barer *et al.* 2002), a barrier that would be removed by collection at death registration.

### **3.4 *The Statutory Arguments***

The Race Relations (Amendment) Act 2000 came into force on 2 April 2001, as part of the Government's legislative response to the Commission for Racial Equality's Third Review of the Race Relations 1976 Act.

It reinforces the duty of organisations to provide for their population, and lays on them the onus of ensuring populations are not discriminated against on grounds of ethnicity. One of the prerequisites to satisfy the legislation is the necessity to know the ethnicity of the population served: such an item needs of course to be collected. The possible application of the Act to the services provided by the Registration Service are obvious: in order to ensure the service is not discriminating the data collection needs to take place and the data item needs to be kept to enable future analysis, comparative and over time if necessary. The Office for National Statistics by extension could also be said to be covered, the collection of ethnicity being a prerequisite of ensuring that its work is carried on in a non-discriminatory framework.

In addition, Article 13 of the Treaty of the European Community, which provides a legal base for Community action to combat discrimination on the grounds of racial or ethnic origin, has been revised and was published on 25<sup>th</sup> November 1999. The Directive implements the principle of equal treatment between persons irrespective of racial or ethnic origin, and was agreed unanimously at the European Social Affairs Council on 6<sup>th</sup> June 2000 and published in the official *Journal of the European Communities* on 19 July 2000 as directive no. 2000/43/EC. It must be implemented in member states within 3 years of its publication i.e. by 19 July 2003. Most of UK legislation already complies with the Directive; however, some further amendment of the Race Relations Act will be required. This will take place following further future consultation.

### ***3.5 The Modernisation Arguments***

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. They are explicitly presented as part of the Government's modernisation programme. Elsewhere in the White Paper we are informed that 'the information collected and recorded will reflect our society' and that the changes are '...in keeping with the principles of 'Modernising Government''. It cannot be modern in today's society to ignore the contribution diverse groups make to today's society and to be unable to plan to meet such communities' needs.



## **Chapter 4: The collection of ethnicity/race data at birth and death registrations in other countries**

Practice is variable across European countries. However, the USA, Canada (selected Provinces/Territories), Australia, and New Zealand do record ethnic group/race as part of their registration procedures and utilise this information for public health and other purposes.

### ***4.1 United States***

In the United States most states use US Standard Certificates of Live Birth and Death and closely conform to standard certification procedures (National Center for Health Statistics 1987a). Birth registration instructions indicate that personal information should be elicited from mothers, fathers, or other knowledgeable persons at the time of birth; death registration instructions indicate that personal information should be elicited from next of kin (National Center for Health Statistics 1987b). On birth and death certificates, race and Hispanic ethnicity are treated as separate items. Persons filing certificates are asked to record both items. The race item on birth and death certificates provides a brief list of races as examples ("American Indian, Black, White, etc."); persons recording race are asked to write in the race of both parents (on birth certificates) or of the decedent (on death certificates). The Hispanic ethnicity item on birth and death certificates asks if the father and mother or decedent is of Hispanic origin, and, if so, which Hispanic origin ("Cuban, Mexican, Puerto Rico, etc.").

#### Birth certificates

Up to 1989 the race of an infant was determined by an algorithm incorporating information on the race of the infant's parents as reported on birth certificates. The algorithm was changed for published vital statistics beginning in 1989. In the pre-1989 algorithm the following rules were observed:

- (i) if both parents were white, the child was white;
- (ii) if one parent was Hawaiian, the child was Hawaiian;
- (iii) if only one parent was white, the child was assigned the race of its other-than-white parent; and

- (iv) if both parents were of races other than white, the child was assigned its father's race.
- (v) If data on race were missing for either parent, the infant was assigned the race of the parent for whom information was available.
- (vi) If there was no information on the race of either parent (<0.1% of births in 1983 and <0.2% of births in 1984 and 1985) (Hahn *et al.*, 1992), the infant was assigned the race of the infant in the preceding record in the NCHS computer file.

Since 1989 NCHS has had a new birth registration system which, in effect, includes detailed racial and ethnic information about both parents. As of 1989, the infant's race in NCHS's official published, tabulated statistics is uniformly determined by the mother's race (although a public-use data tape is still available for assessment of the infant's race by the pre-1989 algorithm). However, in research studies the NCHS has also used the race and ethnicity information for both parents in the birth data to impute the race of the child. Classification and coding instructions for the Hispanic Origin and Race items have been contained in periodically revised publications: *Instruction Manual, part 3a: Classification and Coding Instructions for Birth Records* (latest version 1999-2001) (NCHS 1999). Further details are given in Appendix B.

Pre-1989, parental Hispanic origin was reported on the birth certificates of 23 states and Washington, DC. (Hahn *et al.*, 1992). In published tabulations, infants were assigned the Hispanic origin of their mothers. Thus, the 1989 revision of race coding did not affect the coding of Hispanic origin. Birth certificates also give birthplace of mother and father.

The format of the questions on the US Standard Birth Certificate 1989 was:

Qn. 25.a. Of Hispanic Origin (Mother)?

Qn. 25.b. Of Hispanic Origin (Father)?

(Specify No or Yes - If yes specify Cuban, Mexican, Puerto Rico, etc.).

No       Yes (Specify)\_\_\_\_\_

Qn. 26.a. Race (Mother)

Qn. 26.b. Race (Father)

American Indian, Black, White, etc.

(Specify below)

During 1998-2001 the Panel to Evaluate the US Standard Certificates for births, deaths, and foetal deaths (to prepare for new standard certificates in 2003) took evidence and reported (NCHS, 2001). The draft revised US Standard Certificate of Live Birth (as at 11/09/2001), to be implemented in 2003, asks for information on Hispanic Origin and Race:

(Qn. 21. MOTHER OF HISPANIC ORIGIN?; Qn. 24. FATHER OF HISPANIC ORIGIN?)

MOTHER(/FATHER) OF HISPANIC ORIGIN? (Check the box that best describes whether the mother (/father) is Spanish/Hispanic/Latina. Check the "No" box if mother (/father) is not Spanish/Hispanic/Latino)

- No, not Spanish/Hispanic/Latino
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latina

(Specify) \_\_\_\_\_

The report states that these items 'will make it possible to compare variations in child-bearing patterns and birth outcomes of Hispanics. The information is also important for population estimates and projections'.

(Qn. 22. MOTHER'S RACE; Qn. 25 FATHER'S RACE)

MOTHER's (/FATHER's) RACE (Check one or more races to indicate what the mother (/father) considers herself to be)

- White
- Black or African American
- American Indian or Alaska Native

(Name of the enrolled or principal tribe) \_\_\_\_\_

- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian (Specify) \_\_\_\_\_

- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander (Specify) \_\_\_\_\_
- Other (Specify) \_\_\_\_\_

According to the report the race items are used 'to study racial variations in childbearing, access to health care, and variations in pregnancy and birth outcome. This information is also critical for population estimates and projections'. An optional 'Secondary Data Item' on the birth certificate was agreed: As a follow-up to the Race Item, ask, 'Which of these groups would you say best describes your race?'. This information was regarded as important in bridging information between single and multiple race data collection and is consistent with the way the National Health Interview Survey collects data.

*Race/Hispanic origin of child*

The US Census Bureau and the Office of Management and Budget (OMB) suggested that the Panel to Evaluate the US Standard Certificates add a "race of child" category to the birth certificates on the ground that it would aid the agencies in collecting the most accurate population estimates data. Additionally, the race of the child category would allow the parents to identify the child's race rather than tasking the Bureau with doing so, a process of imputing race which would necessarily be done on a standard basis. The item could also be useful for data linkage, e.g. with immunization registries. The Panel's Birth Subgroup discussed the issue of the child's race at great length and decided not to recommend that this item be added to the birth certificate, noting that there were ethical issues of deciding what a child's race is at infant status. The Subgroup felt that it was not appropriate for the child's race to be assigned - even by the parents - and that the child should decide the race for himself/herself. Some subgroup members pointed out that parents may not agree on the child's race and also that the hospital clerk may make a determination of the child's race in these circumstances. In addition, the Subgroup noted, the mother's/father's race can be combined to use as a surrogate for race of child, so the race of child item would not be needed. For its final recommendation, the Panel decided that the race of the mother and father would be collected on the birth certificate.

*Other options considered*

The US Census Bureau considered an all-inclusive tabulation option, whereby persons of more than one race are included in all applicable race categories. For example, a person who is both black and white could be counted as black or African American in combination with one or more other races, or as white in combination with one or more other races. The identified problem with such an approach is that people are counted more than once (in this case twice). Consequently, when the number of people from each race alone or in combination are added up, the sum of the people in the various major race groups exceed the total number of people who are reported. The all-inclusive approach was seen as useful in that the data would reveal the maximum number of people who identify in some way with being a certain race alone or in combination.

The US Census Bureau also assessed the use of check boxes versus open-ended questions - particularly as they relate to issues of race and ethnicity. The Bureau tested nine race categories and found that check boxes yielded more responses and were the best format to get better reporting for those opting to select more than one race on the Census form.

Death certificates

On death certificates, racial identification of the decedent as reported by next of kin to funeral directors (or medical examiners or coroners) is cited as the determinant of a decedent's race. However, with unknown frequency, certifiers make independent assessments of race. In the absence of death certificate information on race (approximately 0.2% of all death certificates from 1983 through 1985), the decedent is assigned white race if the race of the preceding decedent in the NCHS mortality computer file is white; otherwise, black race is assigned. Infant mortality rates were based on the fact that infants were assigned the Hispanic origin of their mothers. Infant mortality rates by Hispanic origin met NCHS criteria for tabulated publication (i.e., reporting  $\geq 90\%$ ) in 15 states in 1984 and 17 states and Washington, DC, in 1985.

The data collected on the US Standard Death Certificate 1989 was:

Qn. 14. Was Decedent of Hispanic Origin?

(Specify No or Yes - If yes specify Cuban, Mexican, Puerto Rico, etc.)

No       Yes (Specify)\_\_\_\_\_

Qn. 15. Race

American Indian, Black, White, etc.

(Specify).

Classification and coding of the Hispanic Origin and Race items was the same as for birth certificates (NCHS, 1999b).

Changes were made to both questions in the Proposed US Standard Death Certificate 2003 with items on Hispanic Origin and Race to be collected by the Funeral Director according to the evaluation report.

DECEDENT OF HISPANIC ORIGIN?

Check the box that best describes whether the decedent is Spanish/Hispanic/Latino. Check the "No" box if decedent is not Spanish/Hispanic/Latino.

- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino -  
specify\_\_\_\_\_

The wording and response categories for these items were changed to comply with OMB guidelines and year 2000 Census questions. The evaluation report states that 'this information is important for population estimates and projections'.

DECEDENT'S RACE

(Check one or more races to indicate what the decedent considered himself or herself to be.)

- White
- Black or African American
- American Indian or Alaska Native  
(Name of the enrolled or principal tribe)\_\_\_\_\_
- Asian Indian
- Chinese
- Filipino

- Japanese
- Korean
- Vietnamese
- Other Asian - specify \_\_\_\_\_
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander - specify \_\_\_\_\_
- Other - specify \_\_\_\_\_

Again, the wording and response categories for these items were changed to comply with OMB guidelines and year 2000 Census questions. The information on race is said to be 'critical for population estimates and projections'.

'Country of Decedent's Parents' Birth' was considered by the Panel but rejected. Currently four states collect this item but it was not considered useful for legal purposes or registration processing. Also, there were questions raised by some members of the Subgroup regarding the quality of data for this item. Additionally, there was a recommendation to add a descriptive field for ethnic origin and modify Race to include "mixed" as a prompt. The Subgroup decided against these recommendations.

#### *Foetal death*

Changes were made to the registration of foetal death in the 9/18/2002 Draft. The questions on Father of Hispanic Origin? and Father's Race (identical to the questions on the birth registration form) were both dropped (but questions on Mother of Hispanic Origin? and Mother's Race retained) because of concerns voiced by the states about the reporting burden on hospitals and states for collecting this information.

#### **4.2 Canada**

The twelve separate provincial and territorial governments in Canada undertake data collection. Whilst the data collected for birth and death registrations is very similar, it is not identical, the systems of registration being specific to each province. There is no standardised reporting of

ethnicity data to Statistics Canada and around only a half of provinces/territories currently collect the data.

4.2.1 *Manitoba* does not collect information on ethnicity other than the identification of First Nation's individuals. Manitoba's Chief Operating Officer reports that some other western provinces also collect data on aboriginal individuals, but the questions asked are not consistent between the provinces and the data would not necessarily be comparable. The Eastern provinces do not collect data on aboriginal status. All of the provinces collect data on an individual's place of birth and that could be used as a proxy to categorise individuals into ethnic groups. Manitoba does not collect any other ethnic identifiers and there are no plans to collect that data in the future. With the introduction of new privacy legislation at all levels of government, data collection must be justified and the Chief Operating Officer for Manitoba reports that this data is not necessary for the registration process. Manitoba Vital Statistics will not be pursuing any additional data on ethnicity.

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Locations on registration are coded in Manitoba to the Census Sub-Division level. Events outside of Manitoba are coded to the province and events outside of Canada are coded to a country level.

Manitoba's Chief Operating Officer observes that '... most Canadians would not know how to answer a question on ethnicity. They would confuse it with citizenship. In the United States questions on ethnicity are on vital statistics forms and their citizens are familiar with answering the question and it would appear feel comfortable with providing the data. I do not see any movement in Canada to expand data collection to include questions on ethnicity. Our three northern territories ask questions on ethnic origin aimed at status Indians, Inuit, other native peoples. The three territories would make up a very small percentage of Canadian registrations and that data series would only be for those northern areas'.

4.2.2 In *Alberta* the content and wording of forms has changed over the last 150 or so years. As far back as 1890, depending on the years, the Racial Origin/Nationality/Citizenship/Native Country of the mother and father of a child was recorded on registration. The practice continued until 1972. This information was recorded on the form itself but not in any database. When the form was revised, origin



was no longer captured. Vital statistics for Alberta have always captured on registration forms the Province/Country birthplaces of the mother and father of a child born in Alberta, and birthplace of deceased. A standard set of Province/Country codes are used that are able to record almost any country in the world. On occasion statistical reporting is undertaken using these codes.

- 4.2.3 However, *Yukon* does collect ethnic group on its birth and death registrations and also for stillbirth registrations. Yukon Vital Statistics started collecting this information on birth registrations (ethnicity and place of birth) in 1930 and has continued the practice of asking ethnic group to date. Ethnic group on death registrations also started in 1930 and continues to date. The Deputy Registrar for Vital Statistics, Yukon, reports that most Caucasians do not fill in the space for ethnic group, although most other ethnic groups do so. Ethnic group on death certificates is completed more often than on birth registrations. The information on ethnic group is used to compile health statistics. The wording of the item takes the following formats:

#### Registration of Live Birth

Ethnic Group. Father. Qn. 19. First Nation (registry number), Inuit, Caucasian, other (specify). Mother. Qn. 24. First Nation (registry number), Inuit, Caucasian, other (specify).

Information is also collected on Birthplace of Father & Mother: City, town or other place (by name) and territory or province (or country if outside Canada).

#### Registration of Stillbirth

Ethnic Group. Father. Qn. 17. First Nation (registry number), Inuit, Caucasian, other (specify). Mother. Qn. 22. First Nation (registry number), Inuit, Caucasian, other (specify).

Information is also collected on Birthplace of Father & Mother: City or other place; province (or country).

#### Registration of Death

Birthplace qn. 10 City or place, territory, province (or country) of birth

Ethnic group qn. 11. First Nation (Registry number), Inuit, Caucasian, other (specify)

Father: qn. 13. Birthplace - City, town or place                      Territory, province (or country)

Mother: qn. 13. Birthplace - City, town or place                      Territory, province (or country)

Note: questions 10 and 11 relate to the deceased

4.2.4 In *New Brunswick*, from 1920 to 1972, a parent's *racial origin* and *citizenship* was collected on the original copy (hard copy) of the New Brunswick birth and death registrations. However, these data were not used at the provincial level to produce any statistical reports or for the purposes of auditing. When the Vital Statistics Office was automated in 1984, key information such as name, date of birth, place of birth and parents' name were collected in the online database for the purposes of issuing certificates. However, racial origin and citizenship were not data items that were required statistically or for the purpose of producing a birth or death certificate and were therefore dropped at the time of automation. Changes to the birth and death registration forms in 1973 involved the discontinuation of racial origin and citizenship as data elements.

In 1995 legislation was put in place to permit the registration of a birth and death either using a traditional name or electing to use a name according to the person's cultural, ethnic or religious heritage. No statistics are currently collected regarding this data. Additional changes to the birth and death registration forms in 2000 resulted in the implementation of *first nation* and *band registration number* as data elements. On the death registration, these are collected on the deceased and on the birth registration, they are collected on the birth parents. New Brunswick also implemented *level of education of parents* as data items on the birth registration form. First nation, band registration number and level of education are not required fields that must be supplied by the informant but may be provided on a voluntary basis. The collection of these data elements is not currently being used for audit purposes or for statistical reporting but may be used in future at the provincial level. The wording of the items takes the following formats:

Registration of Birth

Qn. 1. Child's surname                      Child's given name(s)                      OR Name (according to cultural, ethnic or religious heritage)

*Details of father:*

Qn. 18. Surname, Given Name(s) OR Name (according to cultural, ethnic or religious heritage)

Qn. 20. Birthplace (Community and Province/State or Country)

Qn. 22. First Nation? Yes → Registration No. \_\_\_\_\_ No

*Details of mother:*

Qn. 23. Maiden Surname, Given Name(s) OR Name (according to cultural, ethnic or religious heritage)

Qn. 26. Birthplace (Community and Province/State or Country)

Qn. 28. First Nation? Yes → Registration No. \_\_\_\_\_ No

Registration of death

Qn. 1. Surname, Given Name(s) OR Name (according to cultural, ethnic or religious heritage)

Qn. 3. First Nation? Yes → Registration No. \_\_\_\_\_ No

Qn. 18. Birthplace of father (Community and Province/State or Country)

Qn. 20. Birthplace of mother (Community and Province/State or Country)

4.2.5 Cultural information collected by *Saskatchewan* Vital Statistics is limited to North American/Canadian Indian status (that is, Registered Indian, Métis and Inuit). The registration of birth form asks for both Mother and Father (questions 18 and 27): 'Are you (*optional*) Indian  Metis  Inuit '. On death registration forms a similar question asks 'Was deceased (*optional*) .... This information has been collected since the early 1990s and is recorded on a statistical database for statistical reporting at both national and provincial level. Questions are also asked on Place of birth (Province, state or country) of Mother and Father on both birth and death certificates and this has been collected since the early 1900s, province/country of birth being retained on Saskatchewan VS's database.

4.2.6 *Nova Scotia* VS reports that it does not collect information on ethnicity on birth and death registrations.

4.2.7 *British Columbia* collects the following information on its registration of death form: Aboriginal Status ? (yes or no) & Registration (free text); Birthplace (City or Place, Province/State[country]) of Father. ...of Mother. On the registration of live birth form the following information is collected for mother & father: province/state of birth & country of birth; Aboriginal? (Yes or No), Do you live on reserve (Yes or No).

4.2.8 The Government of *Newfoundland and Labrador* (Department of Government Services & Lands) reported that race/ethnicity is not collected on their birth and death registration forms at present and that there is no plan to collect that information in the near future. Birth Place of Mother and of Father (*Province/Territory/Outside Canada* - free text field) is collected in the live birth notification. On the registration of a stillborn and registration of death forms the birthplace of the father and mother is collected (City or place\_\_\_\_ & Province (*or country*) of birth\_\_\_\_\_).

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4.2.9 In *Quebec* the Live Birth Registration (*Bulletin de naissance vivante*) collects father's birth place, mother tongue of mother & father, and mother's birth place, and language spoken at home. The Death Registration (*Bulletin de décès*) contains birth place of deceased & language spoken at home.

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4.2.10 In *Ontario* the Office of the Registrar General does not ask for ethnic origin on birth and death registrations. That field was on birth registration forms from 1930 through 1958 for the racial origin of each parent. It was on death forms from 1932 through 1960, asking for racial origin of the deceased, but was removed from the 1961 version of the form. Mother's place of birth and father's place of birth have always been - and still are - collected at birth registration, as are parents' places of birth at death registration. The place names are assigned internationally standardized country codes upon data entry.

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4.2.11 In *Prince Edward Island* mother's place of birth and father's place of birth are collected at birth registration. Parents' places of birth are collected at death registration.

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4.2.12 In the *Northwest Territories* the major elements collected on birth registrations include Place & Date of Birth (City, Town, Province or Country) of mother and father and Ethnic Origin (Optional) of mother and father, the four options being: 'Treaty Indian', 'Metis', 'Inuit', and 'Other (Specify)'. Death Registrations also collect parents' places of birth and ethnic origin of deceased.

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### **4.3 Australia**

Information is collected on indigenous status on birth and death registrations. Jurisdictions started to ask about indigenous status on their death registration forms in the 1980s. The exception was Queensland, which began in 1996. All States and Territories now include on their death notification forms a question about the indigenous status of the deceased person (Australian Bureau of Statistics & Australian Institute of Health & Welfare, 1999). Most jurisdictions are now using the ABS standard question, or a slight variation (Cunningham & Paradies 2000):

*Was the deceased of Aboriginal or Torres Strait Islander origin?*

*(If of both Aboriginal and Torres Strait Islander origin, tick*

*both 'yes' boxes).*

- No*
- Yes, Aboriginal origin*
- Yes, Torres Strait Islander origin*

Although the question is on the forms, the recording of indigenous status in the death records of some states and Territories is currently incomplete (i.e. some indigenous people are not identified as such on their death records). This means that the number of deaths registered is an underestimate of the number of deaths that actually occurs among indigenous people. At present the Australian Bureau of Statistics can only publish indigenous death statistics for three States and Territories: South Australia, Western Australia, and the Northern Territory. Only these jurisdictions are deemed to have adequate identification of indigenous people. Some jurisdictions, such as the Northern Territory, are widely believed to be good at identifying indigenous deaths, while others are perceived to be less successful. In 1995-97 about 64% of all deaths recorded as indigenous were of people from Western Australia, South Australia or the Northern Territory, but only 34% of Australia's indigenous people lived in these three jurisdictions at this time. Thus, it is not possible to say how well the experience of these areas represents what occurs in the rest of Australia. Using Preston-Hill analysis, Dunstan & Dunstan (2000) have estimated that only 39.1% of indigenous male deaths occurring in Australia between the 1991 and 1996 Censuses and 39.5% of indigenous female deaths were registered as such.

The coverage of birth registrations is better than the coverage of death registrations. The total number of indigenous births registered in Australia in 1998 was around 90% of the number of births projected in the 1996-base experimental indigenous population projections; by comparison, only about 61% of indigenous deaths were registered in Australia in 1998 compared with the same population projection.

#### ***4.4. New Zealand***

Ethnic group is recorded on birth and death registrations in New Zealand. Changes were made to the ethnicity question on the birth and death registration forms in September 1995. Prior to that, only the degree of Māori or Pacific Islands blood was sought. For statistical purposes, all children with half or more degree of blood were classed as Māori or Pacific Islands (as the case may be). No information was available separately for other ethnic groups. The new ethnicity question on the birth registration form means that births can now be tabulated by ethnic group and ancestry, of both the mother and the child. The introduction of these new questions and the resultant conceptual differences (biological versus self-identification) mean that the new birth data by ethnicity is not directly compatible with the old series.

The number of live births for the year ended December 1997, for the four main ethnic groups, classified separately according to the ethnicity of the mother and the ethnicity of the child were: New Zealand Māori (13,176 Māori mothers and 16,301 Māori children), Pacific Islands (5,966 mothers and 7,596 children), Asian (3,975 mothers and 4,286 children), European (39,452 mothers and 40,980 children) and other (391 mothers and 509 children).

In a number of cases the mother or child may belong to more than one ethnic group. For example, a baby who has both Māori and Pacific Islands ethnicity would be recorded in both ethnic groups. As a result the ethnic group totals (above) will not agree with the New Zealand total. In 1997, there were 46,466 births where the child belonged to only one ethnic group, 9,935 births where the child belonged to two ethnic groups and 1,112 births where the child belonged to three ethnic groups. Significantly fewer mothers (5,252) identified with more than one ethnic group. The increase in inter-ethnic unions has meant that an increasing number of multi-ethnic children are being born to mothers of one ethnicity only.

Following the introduction of the new ethnic question on the death registration form in September 1995, deaths can now be tabulated for all ethnic groups rather than just for the Māori and Pacific Islands groups as was the case previously. Again, because of the conceptual differences between the two series (biological versus self-identification), the new death data by ethnicity is not directly comparable with the past series.

A breakdown of total deaths registered in 1997 (27,471) into broad ethnic groupings revealed that 26,485 deceased people belonged to one ethnic group, 321 belonged to two ethnic groups, and 16 belonged to three ethnic groups. The small proportion of multi-ethnic deaths (compared with births) reflects the ethnic structure of the older population, which is made up largely of Europeans and people who only belong to one ethnic group. In 1997, 356 deaths were assigned to the Asian ethnic group and 23,440 to the European ethnic group.

In addition to the collection of ethnic group on birth and death registrations, the New Zealand Health Information Service's Maternity and Newborn Information System collects information on mother's ethnic group (New Zealand Health Information Service, 2002). The data dictionary states that ethnic group should be self-identified wherever possible and multiple reporting is permitted. Coding for reporting purposes is based on a priority system, e.g. 1, NZ Maori, 2, Tokelauan, 3, Fijian,.....19, Other European, 20, European not defined further, and 21, Other European.

#### ***4.5. European countries***

A survey was undertaken of demographic contacts in all 36 countries under EUROSTAT responsibility to obtain information on items such as ethnicity and nationality collected at birth and death registration.

- On the forms for 'Birth of a live infant' & 'Declaration of death of an infant less than a year or still born' in *Belgium*, information is collected on the 'country of nationality before marriage' of the father and mother, the response options being 'Belgium' and 'Other (specify)'. On death certificates information is collected on 'Country of nationality of deceased' (with the same response options).

- The *Estonian* Medical Birth Registry was established in 1991, bringing about comprehensive birth registration in Estonia from 1992, which involves routine collection of socio-demographic data, including 'nationality'. The data, used in studies of low birthweight and pre-term births, enables mothers of Estonian, Russian, Ukrainian, Belorussian, and other nationalities to be identified and is of good quality (Koupilova *et al.*, 2000). Of 84,604 singleton live born infants in Estonia, 1992-1997, only 137 (0.16%) were recorded nationality 'Not known'. A new medical death certificate was introduced in 1994 which records demographic data about the person (in the 1980s such data came from the death register entry and was added to the person's file at the Statistical Office of Estonia but was not recorded on the medical death certificate) (Lang 2000). This includes 'Citizenship' and 'Nationality' ('for children under 16 years, mother's nationality'), both being free text fields. Data about 'Nationality', education and marital status are recorded on the medical death certificate at the Civil Registration Office. In the case of missing data, 'not known' must be entered.
- In *Finland* information on ethnicity/race is not collected at civil registration. However, country of birth, citizenship, and mother tongue is recorded. The Population Register Centre is responsible for the gathering of this information which is sent to Statistics Finland for statistical purposes.
- In *Greece* the only information collected in the birth report is date of parents' birth and literacy of parents and, on medical certificates of death, the place of birth of the deceased.
- *Ireland* records no information on ethnicity at birth & death registration, nor do these forms record country of birth of mother and father.
- In *Latvia* the importance accorded to ethnicity in civil registration has been documented by Uldis Usackis, Head of Demographic Statistics Division, CSB: 'Taking into account the great interest of the general public and governmental institutions about the problems of ethnic composition of the population of Latvia - the % of the ethnic Latvians in the total population equalled only 58.2% at the beginning of 2002 - the CSB for a rather long time collects and compiles this indicator in demographic and migration statistics. This indicator has been included in all legal documents that have been filled in for every vital event (marriage, birth, and death). Ethnicity of person has been presented also in the Residents' Register of Latvia. If the person wishes the data on ethnicity could be written in the passport of the citizen or



resident of Latvia. Ethnicity for a new-born child is given according to the ethnicity of parents. If the child's mother and father belong to different ethnicity, we give preference to mother's ethnicity in demographic statistics. According to the national legislation in such cases a person who has reached 16 years of age has the right to choose his/her own ethnicity according to the ethnicity of his/her mother or father when receiving the passport. We use the local country Classification of Ethnicities that has been elaborated by the experts of the CSB of Latvia in co-operation with representatives from other interested parties and adopted by the CSB. The legal documents on registration of vital events the CSB of Latvia receives monthly from the Registry Offices under the Ministry of Justice. Surveys showed that these Offices ensure high quality and completeness of information'.

- In *Luxembourg*, a representative of STATEC gave the following information: 'In Luxembourg, we only dispose of data about the nationality of people. In some years however a central population register will be operational and by that time we will also dispose of data according to the country of birth'.
- In the *Netherlands*, the enumeration card for a live birth records nationality of the child and municipality in which the child is entered in the population register (if the child born belongs to the population of another country the name of that country should be mentioned). Also collected for the mother & father is municipality where entered in population register and municipality of birth. For deaths only municipality of death is collected.
- In *Romania*, the following information was provided: 'In Romania the ethnic characteristics are registered since 1965 in three types of documents on birth and death: medical certificate, civil certificate, and demographic statistical report. The sanitary units or the family physician transmit medical certificates (for birth and death) to civil registration offices. The registrar draws up the civil certificates, the verbal statement, and the identity card of the declaring person. At the same time the registrar draws up a demographical statistical report (according to the law on civil certificates No. 119/1996). The demographic statistical reports are sent by registrar to Regional Statistical Offices where reports are checked, coded, and then sent in electronic forms to the central level at the National Institute for Statistics (NIS). The medical and civil certificates are not processed in the health or civil registration systems. Data on birth and death (including ethnicity) are produced only by NIS. Data are used only for demographic purposes. The population structure by ethnic groups is used only from the

Population Census. Ethnicity is coded on the basis of the list of codes established by NIS (the same is used for the Population Census). Considerations I think you have to take into account on ethnicity data quality - ethnicity is registered on the basis of the verbal statement of the declaring person (no act exists to prove the apart (sic) ethnicity); - the statement can be changed in time'.

- In *Slovenia*, the Notification of Birth form includes Mother's Place of Birth, Mother's Nationality, and Mother's Citizenship and Father's Place of Birth, Father's Nationality, and Father's Citizenship. The Notification of Birth form includes a note: 'According to the Article 61 of the Constitution of the RS the person doesn't have to answer the question on ethnic affiliation if she/he doesn't want to'. The explanation for the inclusion of this on some forms (DEM-ROJ, DEM-POR, DEM-RAZ) is that it relates to the question on nationality (and, implicitly, ethnic affiliation). The note is not included if there's no question on nationality on the form ('We would be more precise if we would put on the questionnaire beside the question on nationality ethnicity as well... both are included in the question on nationality'). The question on citizenship is not treated in the same way. Notification of Death includes only Citizenship of Deceased.
- *Sweden* has had a well functioning fully computerised Civil Registration System for several years. All official vital and stock population estimates are based on information from the Civil Registration System (Total population Register System of Statistics Sweden, or Bakgrundsfakta till Befolknings- och välfärdsstatistik). The Head of the Population Register observes: 'For integrity reasons and because of the public opinion it has this far not been politically possible to collect data on race and ethnicity in Sweden, neither in the Civil Registration System nor in the Population and Housing Censuses. Therefore there are no statistics on the subject'. However, data on country of birth and citizenship of the individuals and their parents are included in the Civil Registration System as well as country of departure of persons who have migrated (Statistics Sweden 2002; National Tax Board, 2000).
- In *Switzerland* no collection of ethnicity data takes place on birth and death certificates. The following 'cultural' data are recorded on civil registration documents:

a) births

- nationality (citizenship at the time of registration) of the mother

- nationality (citizenship at the time of registration) of the father (if the mother is married)
- religion of the mother

b) deaths

- nationality (citizenship at the time of registration) of the deceased
- religion of the deceased.

#### **4.6 Other countries**

In *Singapore* information has been collected on ethnic group on registration of births and deaths since 1981 (Singapore Registry of Births and Deaths, 1981-).

#### **4.7 Conclusions**

The USA, Australia, New Zealand collect ethnicity information at civil registration and 6 of the 12 provinces of Canada collect some information on ethnic group/race at birth and death registrations. New Zealand collects information at birth registration on *both* ethnic origin of child and mother. A number of the EUROSTAT countries surveyed collect ethnicity information via local population registers. Slovenia records ethnicity through the civil registration process.

## Chapter 5: Current collections of ethnically-coded births and deaths data

Three types of collection may be distinguished: Formally/compulsorily collected data (mandated under, for example, NHS Executive Letters); national datasets owned and managed under the auspices of the Office for National Statistics or other official agencies that meet the specific research/monitoring needs of Government and other bodies (e.g. ONS Longitudinal Study); and informal datasets collected because of clinical/research/local commitment.

### *Informal datasets for births*

There are a number of collections of data on ethnic group at birth by individual former Health Authority maternity and child health administrative systems or as consolidated databases for health regions (involving a number of Health Authorities). No survey data is available on the extent of such collections but examples reported in the literature include:

- Most of the obstetric units in the North West Thames region have since 1988 used a common maternity information system (the St Mary's Maternity Information System, SMMIS) and have thus created a large database that has been available to researchers for examination. One study (Steer *et al.*, 1995) reported that for the period 1988-91 the total dataset comprised 157,996 pregnancies resulting in a registrable birth (24 or more weeks' gestation and including live and stillbirths). Ethnic origin was available for 153,6092 and missing for 4394 cases (2.8%). Of the former 115,262 were classified by Steer *et al.* as White (73%), 22,206 as Indo-Pakistani (14%), 4,570 as Afro-Caribbean (2.9%), 3,905 as Black African (2.5%), 2,642 as Mediterranean (1.7%), 2,351 as Oriental (1.5%), and 2,666 as other ethnic group (1.7%) (these are aggregations of the codes used on the SMMIS system). There is no simple reading across of these codes to the 2001 Census codes but they may have utility for other purposes that the census codes lack, for example, for risk assessment in antenatal haemoglobinopathy screening settings.

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Steer *et al.* report that coding of ethnic group was done at booking by the midwife after consideration of the woman's family history and appearance and taking into account the woman's own views. Thus, this retrospective analysis of pregnancies by ethnic group was based on maternal ethnic group and not the ethnic group/origin of the baby.

- Similarly, Seed *et al.* (2000) exploited a database for the former SE Thames Regional Health Authority: 49,787 live births between 1 October 1992 and 31 August 1993, to identify ethnic differences in the growth of low-birthweight infants.

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- Bradford's former Health authority maternity and child health administrative system produces birth records to yield birth counts by ethnic group and sex and by age and parity of the mother (Simpson 2002b). A time series of birth counts with these details has, in fact, been maintained since 1971, derived since 1978 from the database of individual live birth records held by the Health Authority. Categories of ethnic group of the child and administrative arrangements for the database have changed over time. Since 1995 the same database of births has recorded ethnic group of both mother and child for births within the city area of the Bradford district.

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#### *National datasets of birth information for monitoring and research*

The collections that fall into this category are CESDI (national in scope) and the ONS Longitudinal Study (LS) (representative of England and Wales as a whole). The Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) was established in 1992 to improve understanding of how the risks of death in late foetal life and infancy, from 20 weeks of pregnancy to one year after birth, might be reduced. CESDI attempts to identify risks which can be attributed to suboptimal clinical care. In 1991 the Department of Health (UK) directed that the fourteen 'Regions' of England should undertake Perinatal Mortality Surveys. CESDI was subsequently organised on this regional basis with separate arrangements for Wales and Northern Ireland. Each region is autonomous and has a full-time coordinator together with varying numbers of support staff. The network of CESDI has remained despite organisational changes in the NHS during 1994-95 and 1998-99 but is now the responsibility of NICE. Linked to CESDI is the Maternity Care Data Project (now a collaboration with the NHS Information Authority). The national Maternity Care Data Project commenced in December 1998. The overall aim of the project was: 'By April 2003, to have standardised and consistent recording of data relating to maternity and childbirth, for women and infants, within Electronic Patient Record systems in all affected NHS organisations'. The Maternity Care Data Dictionary (Version 3.0; Report Version 1.0) reports for Ethnic Group the definition 'The ethnicity of the person receiving care as defined by the mother. Required for monitoring service delivery' and the Category values of the 2001

Census (and a 'Z' Not Stated category). Not all regions have used this standard. For example, the NHS West Midlands Perinatal Institute reported in 1999:

“Following a previous, successful pilot on the use of a 'minimum maternity dataset', the Institute has developed software which is ready for installation in interested maternity units. This project could be run for the modest cost of 60 k per year for the whole region. The collection of routine data would facilitate local and regional audit, and help in understanding social and ethnic causes and trends in perinatal mortality in the West Midlands. The Regional Levies Executive Board is supportive of this project but has so far been unable to fund it”.

Where the MCDP provides a source of ethnic information on the numerator, CESDI has drawn attention to the lack of suitable denominator data. For example, in one of CESDI's studies - a pilot (case control) study of the underlying causes of antepartum term stillbirths (the unexpected loss of a baby at term or weighing above 2.5kg prior to labour, accounting for nearly an eighth of all foetal deaths), the cases had an increased frequency of suboptimal care. An important finding was the greater proportion of mothers of what the report terms "non-white origin" (Odds Ratio 2.6 95% CI 1.4 - 4.9). The report states: 'Ethnic origin has only been recorded routinely in hospital records since April 1995 and there have been substantial technical problems in collecting the data (Hospital Episode Statistics system). Consequently, no appropriate denominator data exist. However, these and other findings have suggested significant differences in death rates' (CESDI 1998).

Other datasets that fall into this genre have already been mentioned: the ONS Longitudinal Study (LS).

#### *Informal datasets for deaths*

No datasets akin to those for births (managed by Health Authorities and Health Regions) have been found for deaths.

#### *National Datasets of deaths information for Monitoring and Research*

As with births, only the Longitudinal Study (LS) and CESDI (for deaths in infancy) contain data on ethnic group. On some local datasets ethnicity for some groups (particularly South Asians) has been assigned using computerised naming algorithms (such as NAM PEHCHAN and SANGRA).

## Chapter 6: Appraisal of options for collecting ethnic group information on births

### 1. *Obtaining ethnic group through Hospital Episode Statistics (HES)*

Currently, the only way this can be undertaken is through the mother's ethnicity, as her ethnic group should be recorded in relation to her maternity admission. The mother's ethnicity can be linked to her birth(s) in the HES record. However, the poor levels of completeness of the *ethnos* field in the HES dataset rules out this possibility at least until completeness of collection substantially improves. Even then, the baby's ethnicity would be defined as that of the mother and babies of mixed heritage/descent would not be identifiable as such.

[Ethnicity recording on the core health datasets in both London and nationally is currently incomplete and often of a poor quality. It is a mandatory requirement for all provider units/hospitals in the NHS to collect and record ethnicity of patients for inclusion in provider/hospital Patient Care records, and ethnicity data is subsequently passed back to the Department of Health's Hospital Episode Statistics database. In relation to childbirth, two or more separate records are created, a birth episode for each newborn and a delivery episode for the mother. An anomaly exists in that a birth episode is the one exception where collection of ethnicity is NOT mandatory. In the Hospital Episode Statistics database extract for residents in London in 2000/01, the mother's ethnic coding was "not known" or not stated for 30% of delivery episodes, and the baby's ethnic coding was "not known" or not stated for 66% of birth episodes, the latter largely reflecting the non-mandatory nature of the requirement to record.](#)

When the mandatory collection of ethnic group data for inpatients was introduced in April 1995, the guidance stated that the mandatory requirement to collect and record the ethnic group of admitted patients did not extend to newborn babies (i.e. birth episodes) but that providers and commissioners could decide locally to collect the data (NHSE (IMG) 1994). It also stated that ethnic group of newborns should not be passed back to HES (see sect. 2.5.4). For a number of years the NHS Executive's recommendation on newborn babies was not reflected in the NHS Data Manual. Instead Ethnic Group was assigned a mandatory status on the Birth Episode of the Admitted Patient Care CMDS and Home Birth CMDS and was shown as required by HES for Birth and Other Birth Events Records. In 1998, however, the NHS Data Manual was changed to reflect the official guidance from the NHS Executive, the Ethnic Group data item being assigned



an optional status on the Birth Episode and removed from the list of data items required by HES for Birth and Other Birth Event Records (NHSE (IMC), 1998). Thus, there is no central reporting of ethnic group of newborns and voluntary recording of Ethnic Group on the Birth Episode is likely to be low. In a recent survey of NHS trusts in the (former) South Thames Region, those trusts with maternity admission facilities were asked if they voluntarily recorded the ethnic group of newborns. Only a third of 14 trusts with maternity provision reported that they voluntarily collected and recorded ethnic group of new born babies (birth episodes) (Aspinall 2000).

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2. Obtaining ethnic group through the Birth Notification Data Set

A second option is to obtain ethnic group as part of the statutory notification of birth process undertaken on maternity units in hospitals (a new Birth Notification Data Set was introduced to include the issue of NHS numbers to new-born babies by a new Central Issue System (CIS) (NHSIA 2001)). This will involve the approximately 250 maternity units within about 180 trusts in England and Wales. The total volumes involved are around 643,000 births per year (1996), including home births (12,860 per year or 2%) and births in non-NHS hospitals or elsewhere (6,430 or 1%), all of which are included in the birth notification process.

The NN4B Birth Notification Data Set (as at March 2002) specifies a number of essential or mandatory data items and some optional items (Table 3).

Table 3. Birth Notification Data Set (NHS Numbers for Babies).

Data item	Comments
<b>Information about the baby</b>	
Baby Surname	
Baby Forename	
Baby NHS number	This is only present after the CIS has allocated the baby with a number
Birth date	
Delivery Time	
Sex	
Live or Still Birth	
Birth Weight	
Gestation Length	
Number of births this confinement	
Birth Order	Only required if part of a multiple birth
Suspected congenital	

<i>anomaly</i>	
<i>Ethnic category</i>	See Appendix C for the values defined by the Office for National Statistics (ONS).
<i>Baby's usual address including post code</i>	
<i>Baby's discharge address including post code</i>	Only required if known to be different from above
<b><i>Information about the place of birth</i></b>	
<i>Organisation name</i>	Only one of these is required
<i>Organisation code</i>	
<i>Delivery place type code</i>	
<b><i>Information about the mother</i></b>	
<i>Mother surname</i>	
<i>Mother forename</i>	
<i>Mother NHS number</i>	One of these must be present if other field is blank
<i>Mother Birth Date</i>	
<b><i>Information about relevant health care professionals</i></b>	
<i>Notifying person surname</i>	
<i>Notifying person forename</i>	
<i>GP name</i>	One of these must be present
<i>National GP code</i>	
<i>Practice name</i>	One of these must be present
<i>National practice code</i>	
<i>Practice address including postcode</i>	
<i>Child Health Organisation code</i>	This is required in order for the CIS to forward Birth Notifications to the right Child Health department.

Source: NHS Information Authority. Birth Notification Dataset (NHS Numbers for Babies), Version 4.0, 10.08.2001 (11pp). <http://www.nhsia.nhs.uk/nn4b>.

Notes: Mandatory items are shown in italics.

Under 'Information about the baby', the Birth Notification Data Set specifies 'Ethnic category', and offers the ONS values in the 2001 Census question, that is, the 16-category classification (each given alphabetical codes) plus Z = Not stated, as revised by the Data Set Change Notices 21/2000 and 02/2001. The *Guide to the NN4B Birth Data Notification Data Set* (NHSIA 2002) recommends that 'when in doubt use Z for Not Stated' (NHSIA, 2002).

The full specification is as follows:

*Field description:* Ethnic category (baby)  
*Definition in Data Dictionary:* Y (yes)  
*Mapping Comment:* Defined by mother, required for monitoring of service delivery  
*Format:* an2 (alpha-numeric 2)  
*Status:* M (mandatory)

*CIS Validation:*

These are the new categories defined by ONS for the 2001 census (list given), they will become the mandatory standard with effect from 1<sup>st</sup> April 2001. The recommended classification is a single character defined from within the range A to Z and this should be stored in the first position of the field. (There is a further optional level of classification consisting of an additional character which may be used at local level if required).

Thus, it is clear from planning guidelines that the information required on ethnicity is that of the baby rather than the mother and that it is the ethnic category of the baby as defined by the mother that is being asked for. Further, the CIS will undertake validation checks on the 2001 Census codes (that the first character lies within the range A-Z).

No audit studies of the completeness of this item on the Birth Notification Dataset have been identified. Indeed, full implementation of the Dataset did not take place till May 2002. However, at an early stage in the development of the *Birth Notification Dataset (NHS Numbers for Babies)* concern was expressed about the recording of ethnic status. An NHS Information Authority Question and Answer Seminar (NHSIA 1999) reported:

'Some maternity units collect ethnic group (self-selection by the patient) and others collect ethnic origin (the true origin of the baby). The Child Health Informatics Consortium (CHIC) require ethnic group as a mandatory data item on the child health register but some midwives refuse to collect this because the current definitions are poor. We will seek to clarify exactly what information is required'.

Clearly, the Birth Notification Data Set offers one possible standard and comprehensive source of information on the ethnic group of newborns. However, although mandatory there is no guarantee that this collection will attain levels of quality and completeness to be of use in public health. Yet the value of the BNDS is the presence of the morbidity items/proxies in the dataset, including live or still birth, birth weight, gestation length, number of births in the confinement, and suspected congenital anomaly. It is unclear whether this dataset will be centrally reported for statistical purposes or whether it will be transmitted to Child Health Departments for local use only.

Information on the ethnic category produced by maternity systems can be transmitted across the NHSNet (the NHS-wide network). An important aspect of the new system is the use of a standard electronic Birth Notification. Maternity Systems will create a Birth Notification, submit it to the

CIS system which will add an NHS Number (the primary identifier for the baby) to the Birth Notification and return it to the Maternity System (NHSIA, 2001). CIS will forward the BN, including NHS number, on a daily basis via NHSNet to Child Health departments. Child Health will then forward details to Registrars of Births and Deaths to be used during the civil registration process. As Child Health departments will forward details of baby's ethnic category to the Registrars in the BN, such information would potentially be available for use in the civil registration of the birth (either as a source of information on the child's ethnic group or to confirm information given by the mother). However, the child health notification to the registrar of births and deaths and the civil registration are currently independent events, the registrar of births and deaths matching the two sets of data before sending the baby's details to the NHS Central Register.

### 3. Options for the collection of ethnic group at the time of registration

Two options are considered:

- (i) Recording of infant's ethnic group;
- (ii) Recording of father's and mother's ethnic group.

The ethnic group of the child as assessed by the mother or father at registration is one option. In such circumstances it would probably be appropriate to record the status of the person or informant undertaking the assessment. This practice has the advantage that it would greatly simplify collection, as no algorithm would be needed to determine the child's ethnic group for the purposes of statistical reporting. However, ethical objections could be raised - as they were in the US Panel's deliberations on this option - on the grounds that it is not the infant's ethnic group that is being assessed but a proxy based on a (or both) parent(s). The case for using the 2001 Census classification on ethnic group is strong given its widespread adoption across Government departments and in local government and the NHS.

The alternative would be to record the ethnic group of both the mother and father and to use these as a surrogate for the ethnic group of the child. For standard reporting purposes the data could be tabulated either by the ethnic group of the mother or by use of an algorithm that would use the ethnic group of both parents to impute the ethnic group of the child. Again, the appropriate classification to use for the parents would be that of the 2001 Census, preferably in a form that

retains the five open response (free text) write-in options. A standard algorithm could then be developed based on the father's and mother's selection from the 16-category options. Clearly, some of the combinations could be complex, as the child could be the offspring of two mixed-parentage parents (e.g., mother, White and Black-African; father, White and Black-Caribbean). However, using the *full* classification - the Department of Health's 'Optional Detailed Framework' of 62 categories ( Department of Health, 2001; NHSIA, 2001) - would be impractical because of the huge number of possible permutations of mother's and father's ethnic group. Recording of father's and mother's ethnic group and imputing the child's ethnic group using this detailed list would have significant resource implications with respect to the preparation of official reports and tabulations based on ethnic group.

Other factors that could affect the choice would be the interdependency of vital registration and census data. Birth rates are calculated on the basis of the census, completeness of birth registration is assessed by census information, and intercensal estimates and estimates of completeness of coverage in the decennial census require information on births. Clearly, the only information available on infants in the 2001 census is the form-filler's assigned ethnicity of the infant (although the Samples of Anonymised records - for around 3 per cent of the population - would provide comparable information to birth registration based on father's and mother's ethnic group). There may also be a concern about the burden on registrars and the public in collecting ethnic group of mother and father. Given that information on ethnicity would be collected for the first time and the interdependency of birth and census data, the collection of information on the ethnic group of the child (based on the 2001 Census) would be a stronger recommendation. Moreover, such collection could be cross-checked with the ethnic group item on the Birth Notification Dataset which is passed to Registrars by Child Health Departments and also uses the 2001 Census ethnic group question to assess the ethnic group of the child.

## **Chapter 7: Appraisal of options for collecting ethnic group information on deaths**

Currently, there is no mandatory collection of ethnic group data at death and no regional systems (of the kind for births) that collect this information voluntarily. Hospital episode statistics are not linked to death certification data nationally, although it has long been reported that this is feasible (Acheson 1967; Henderson, Goldacre, *et al.*, 1992). However, the Oxford Record Linkage Study has demonstrated the feasibility of such linkage in its use of anonymised statistical abstracts of hospital records linked to data from death certificates in the former Oxford health region from 1963 to 1998 [covering a population of 300,000 from 1963 to 1965; 850,000 from 1966 to 1974, 1.9 million from 1975 to 1986, and 2.5 million from 1987 to 1998] (Goldacre, Griffith, *et al.*, 2002). From April 1995 (the introduction of mandatory collection of data in the HES dataset) information on ethnic group would only be available for those persons who had been admitted as hospital inpatients prior to their death and for whom ethnic group had been recorded.

In addition, the Longitudinal Study (LS) provides access to deaths data by ethnic group for those cohort members who were in the cohort on Census night, 1991, and have subsequently died (since information for the cohort would include the 1991 Census data, including ethnic group question). It is also possible to use the proxy measure of country of birth of father and mother which was collected in the 1971 Census.

In its Public Health Information Strategy [PHIS] (Department of Health, 1993), the Department reviewed three options for linking data on mortality to data on ethnic group (in priority order):

- Adding ethnic group to Hospital Episode Statistics (HES);
- Adding ethnic group to death registration;
- Flagging a sample of Census records at the NHS Central Register (NHSCR).

### *1. Adding ethnic group to hospital episode statistics*

The Department of Health introduced, from 1 April 1995, the mandatory collection of data on ethnic group of all inpatients, for inclusion in the Admitted Patient Care contract minimum dataset and Hospital Episode Statistics (HES) central returns. Two HES fields record deaths in

hospital: 'disdest' (destination on discharge), a code which identifies where the patient was due to go on leaving hospital (death=code 79), and 'dismethod' (method of discharge), a code which defines the circumstances under which a patient left hospital (death=code 4).

There are a number of difficulties with this approach. The PHIS cites OPCS findings for 1987 that 63% of people die in hospitals. However, over the last decade, the number of deaths in hospital (as a proportion of all deaths) has fallen to 49% in 1997, and is likely to fall still further with changes in the way patients are managed at the end of life. Secondly, about 40% of HES records in England and Wales lack a valid ethnic group and improvements in data completeness during the first seven years of data collection have been slow (and in some trusts reversed), although this is being addressed in London through the stipulation of targets. Thirdly, such data would not be representative of all deaths as there are likely to be significant differences between people who die in hospital and those who die in the community. The deaths data on HES provides a measure of case fatality following hospital admission but cannot be used as a proxy for patterns of mortality in the population as a whole. Even as a measure of hospital case fatality, deficiencies in ethnic coding substantially reduce the value of this source.

## *2. Flagging a sample of Census records at NHSCR*

The Department of Health argued in its PHIS that it would be possible to take samples of people from different ethnic groups from the 1991 Census and flag the samples at the NHS Central Register (NHSCR), enabling deaths (and cancers) to be picked up routinely. Although there was a recommendation for option appraisal with OPCS and others, there was no action with respect to implementation. With the release of 2001 Census data in this year, there is, again, an opportunity to consider this option. However, measures of mortality derived from this source would not provide population-based rates since they could not take account of migrants arriving after the census enumeration (since there would be no census record to link to the NHSCR record) nor of births which result in death between census enumerations. Moreover, the attrition from such a cohort through emigration would be difficult to track.

## *3. Systematically linking mortality data to Census data whenever details of a death are passed to ONS (OPCS)*

This was a further option raised in the PHIS. However, the Department recognised that this would create a very large linked database, raising considerable resource as well as political implications, and did not recommend this option. Again, no further action was taken. The drawbacks of flagging a sample of records at NHSCR would equally apply to this option.

Since the publication of the PHIS, several other options have become available through developments in information technology.

#### *4. Populating patient records on centrally held administrative registers - the National Strategic Tracing Service database (NSTS), the NHS Central Register (NHSCR), and Open Exeter - with ethnic group*

##### The National Strategic Tracing Service Database

The National Strategic Tracing Service (NSTS) database provides all NHS Trusts and Health Authorities and such other NHS organisations - like ambulance trusts and special health authorities - that can satisfy the NSTS that their need is justified with a number of key secure and free services, notably, patient tracing and finding NHS numbers. These services are provided via registration for the NSTS Trace Line (a secure telephone based system), on-line tracing, and the batch tracing service, all of which have replaced the former Initial Tracing Service (or ITS) which was decommissioned.

Phase 1 of the NSTS became live and available to all NHS trusts and Health authorities (Health Authorities and Acute, Community, Combined, Mental Health and Learning Disabilities Trusts in England & Wales) through Data Access Agreements in 2000. The main functionality of the NSTS is to assist NHS organisations in implementing the NHS Number locally (tracing those patients without NHS Numbers) and to help to identify patients that are duplicates, have moved out of the area or have died (i.e. ensuring the accuracy of patient databases), 'User Roles' defined as Person Tracing and NHS Number Tracing. The NSTS is the single definitive resource for obtaining such administrative details.

In the first phase of the NSTS, the following NSTS fields were available: Surname, Forename, NHS Number, Date of Birth, Sex, and Health Authority 'Posting' (details of which health authority patients are currently 'posted' to, set to 'deceased' where applicable). In Phase 2 (made



available in the autumn of 2001), patient current addresses and GP details were added to the database from every Health Authority in the country. The database can be searched for individual records or a geographical subset. Although the NSTS is a separate database, it is updated with patients' details from the NHS Central Register

#### Open Exeter

Open Exeter is a service provided by the NHS Information Authority to allow remote access to the information on a health authority's 'Exeter' system. Open Exeter can also provide a patient's NHS Number and other administrative details for patients based within a given health authority. However, it also contains several items of clinical information which, for reasons of security and confidentiality, the NSTS is not permitted to hold. For example, organisations such as cervical screening laboratories that require access to the clinical information on Open Exeter use this service. Its function is different to that of the NSTS which is a major, strategic nationwide service.

#### The NHS Central Register

The NHSCR does not hold a person's address or their GP details, just the 'posting' details (Health Authority, exit or deceased).

None of these datasets is ideally suited as a repository of ethnic information. Moreover, populating patient records held on central administrative databases with ethnic group would still require initial collection of this data through Primary Care Trusts or NHS Trusts.

#### *5. Adding ethnic group to electronic registration databases (the 'life-long' administrative database) through the Electronic Patient Record (EPR)*

This could only be a viable strategy in the long-term as planning and implementation for the EPR is still at an early stage. However, it is unlikely that data of quality and completeness would be available for many years whether it came from HES (as intended in the case of the ~~EPR~~) or primary care.

Deleted: EHR

The Department of Health does not currently require ethnic group information to be collected at the primary care level. Currently discussions are taking place to develop a set of codes for recording patient personal profile information (including ethnicity, race and religious practice and language) in the Primary Care Computer Systems Requirements for Accreditation (RFA) 2001 version (RFA 1999). It is likely that PCTs will only gradually introduce the collection of ethnicity information for their patients and it may be 10-20 years before information of sufficient quality (in terms of coverage and ascertainment) is available to stratify deaths by ethnic group.

*6. Collecting ethnic group data at death registration.*

A strong case can be made for this option as it would immediately (from the time of implementation) yield comprehensive data that would be of quality on the ethnic group of all deceased persons. Again, a case can be made for using the 2001 Census classification (16 categories). Unlike birth registration, there appears to be no competing alternative to collection at the point of registration. However, if central administrative databases were populated with ethnic group data via the EPR, the ethnic group of the deceased would be the person's own assignment rather than that of a proxy such as the closest relative or an executor.

## Chapter 8: Discussion

In 1999 a consultation document *Registration: Modernising a Vital Service* was published by the Registrar General. It sought views on how to modernise a service that had essentially remained unchanged for over a hundred years. In 2002 the White Paper on Civil Registration was published setting out the changes proposed. Amongst the most important of these are the facility for informants to register births and deaths over the internet, the telephone or in person. Information provided by the informant will result in the creation of a record (eventually in electronic format) that will be corroborated by a birth notification form or a Medical Certificate of Cause of Death. It is proposed to create a 'through life record' for each individual that links vital registration data.

The various proposals have gone out to public consultation, with a parallel consultation on statistical issues, including the data items to be collected at registration. Given the size of the minority ethnic group population in London and the concerns of the London Health Observatory to improve the evidence based on health and minority ethnic groups, an opportunity is being taken to contribute to this process through the presentation of an evidence-based case in support of the addition of ethnic group at birth and death registration.

Ethnicity recording on the core demographic and health datasets in both London and nationally is very poor. Ethnicity at present is not recorded on either birth or death certificates in the United Kingdom countries. 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. While this offers a good baseline for work around the censal period (for example, for use as a 'denominator' in the calculation of rates and ratios), it quickly loses relevance as the data ages.

Civil Registration is regarded as an appropriate point of access to information on the ethnic group of parents/newborn and of the deceased because it is an administrative task that is performed by necessity at birth and death, normally by an informant who is a parent or close relative of the subject. It is performed in virtually 100% of cases, is characterised by a high standard of quality in recording and completeness, and offers the best opportunity to collect an essential data item both quickly and efficiently.

Moreover, country of birth is no longer a good proxy for the minority ethnic group population. In 2001 half the minority ethnic group population in England and Wales was born outside the United Kingdom (that is, they were migrants). 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.

The lack of availability of alternative sources of information on ethnic group at birth and death now make the collection of this information a priority. The widely used cohort component method for population projections requires information on fertility, mortality, and migration. None of the existing sources of information on fertility - decennial censuses, General Household Survey, Labour Force Survey, Hospital Episode Statistics and maternity collections - provides the means to derive robust measures of fertility across the different ethnic groups and for sub-national (local) estimates and time series analysis. Once the 2001 Census data is incorporated into the ONS Longitudinal Study, accurate estimates nationally will be available for the different ethnic groups but the LS will not satisfy the need for sub-national estimates of fertility. The Birth Notification Data Set - which contains a data item on the ethnic category of the baby as defined by the mother - may prove to be a viable alternative to the collection of ethnic group at birth registration. However, it is too soon to assess whether this new collection will result in the accrual of data that is complete and of quality. There are strong arguments for collecting ethnic group at death registration (using the 2001 Census classification) as there are no clear options. Populating of central administrative registers/records with ethnic group, whether derived through hospital episodes statistics or collection in primary care, is likely to take two or more decades to yield data that is of sufficient quality and completeness to address issues of inequity.

There is no evidence that recording of ethnicity through civil registration will detrimentally affect the current high level of registration or the quality and completeness of other data items currently collected. For example, ethnic group/race is collected on birth and death registrations in the United States, Australia, New Zealand, and Canada (6 of the 12 provinces), demonstrating the feasibility of such collection in civil registration processes. In Britain ethnic group data has been collected in two national censuses and there is no evidence that the addition of ethnic group had a detrimental effect on overall response to the census. Even the recent addition of a voluntary question on religion was judged not likely to affect overall completion rates of the census. Item

non-response for religion in the 1997 Census Test was no different from that for ethnic group or country of birth. There is also no evidence of a detrimental effect on response rates of adding an ethnic group question in social surveys.

Should a case for collection of ethnic group at birth registration be argued, the most viable solution would be a data item on the ethnic group of the baby using the 2001 census classification, as ascertained by the mother or father. This would then provide information compatible with the ethnic group item in the birth notification dataset. Collection of data on the ethnic group of the mother and father at birth registration (to impute the baby's ethnic group) raises complex issues of classification and might incur respondent and administrative burden. Tabulating birth data by the mother's ethnic group would be likely to give poorer quality data than by ascertaining the ethnic group of the child (for example, with respect to mixed parentage children). However, ethnic fertility would be easier to estimate from data on the ethnic group of mother than from ethnic group of child. Also, consideration would be needed to be given to the ethics of parental ascertainment of the baby's ethnic group if that method was chosen, although it is used in the Birth Notification Data Set and in some other collections (e.g. New Zealand birth registrations).

Recording of ethnic group at death raises less complex issues than collecting the information at birth. Again, it is recommended that the 2001 Census should be used to record the ethnic group of the deceased and that the person registering the death should be the informant. The recording of this information by funeral directors in the United States has been shown to result in poor quality data.

With respect to cost-effectiveness of collecting this additional data item, there will clearly be a cost. Research in primary care shows that, for a small percentage of the population, it takes longer than three minutes to collect the data. Moreover, evidence of discomfort in collecting data where it is time-consuming suggests a need for training with respect to the introduction of this data item. However, the registration process is already in place and registrars will already be receiving by electronic transfer the ethnic item in the birth notification dataset. The introduction of one additional data item may only represent a small marginal cost. Moreover, there may be savings with respect to current expenditure on the estimation of ethnic fertility and mortality rates from such sources as the Labour Force Survey.

There would appear to be no strong arguments for not collecting the data from the viewpoint of respondent burden. For example, there is no evidence from Censuses and government social surveys that the public object to answering ethnic questions using census classifications. The levels 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 or treated as confidential. Given its treatment in other policy statements, e.g. the Caldicott Guidelines on data confidentiality, it is recommended that 'ethnic group' at birth and death registration will be restricted to the statistical record and not made publicly available.

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**ANNEX: LONDON DATA**

*Table AN1. London Boroughs: % of persons in ethnic groups (2001 Census)*

	All people (number)	White British	White Irish	Other White	White/Black Caribbean	White/Black African	White & Asian	Other Mixed	Indian	Pakistani	Bangla- deshi	Other Asian	Black Carib- bean	B A
% of people in ethnic groups (2001 Census)														
<b>LONDON</b>	<b>7172091</b>	<b>59.79</b>	<b>3.07</b>	<b>8.29</b>	<b>0.99</b>	<b>0.48</b>	<b>0.84</b>	<b>0.85</b>	<b>6.09</b>	<b>1.99</b>	<b>2.15</b>	<b>1.86</b>	<b>4.79</b>	
City of London	7185	68.32	3.35	12.87	0.46	0.22	0.79	0.79	2.21	0.32	3.84	0.46	0.71	
Barking & Dagenham	163944	80.86	1.68	2.65	0.87	0.35	0.33	0.34	2.25	1.86	0.41	0.53	2.09	
Barnet	314564	59.86	3.35	10.82	0.53	0.51	1.02	0.96	8.62	1.26	0.46	1.99	1.31	
Bexley	218307	87.93	1.39	2.08	0.4	0.18	0.42	0.32	2.54	0.15	0.18	0.51	0.81	
Brent	263464	29.19	6.95	9.14	1.04	0.66	0.96	1.06	18.46	4.03	0.45	4.79	10.47	
Bromley	295532	86.49	1.57	3.52	0.64	0.2	0.58	0.45	1.51	0.23	0.29	0.52	1.57	
Camden	198020	52.72	4.62	15.84	0.84	0.62	1	1.3	2.31	0.63	6.35	1.09	1.84	
Croydon	330587	63.7	2.16	4.31	1.43	0.41	1.05	0.83	6.43	2.25	0.53	2.1	7.88	
Ealing	300948	44.9	4.75	9.08	1	0.45	1.21	0.96	16.53	3.75	0.36	3.91	4.49	
Enfield	273559	61.19	3.07	12.85	0.93	0.39	0.83	0.8	3.98	0.63	1.29	1.87	5.33	
Greenwich	214403	70.56	2.27	4.28	1.03	0.44	0.62	0.65	4.38	0.89	0.57	0.94	3.15	
Hackney	202824	44.12	3.02	12.26	1.52	0.79	0.78	1.11	3.76	1.07	2.94	0.82	10.29	
Hammersmith & Fulham	165242	58.04	4.83	14.95	1.22	0.63	0.97	1	1.65	1.04	0.61	1.14	5.16	
Haringey	216507	45.28	4.3	16.05	1.48	0.72	1.08	1.28	2.85	0.95	1.37	1.55	9.5	
Harrow	206814	49.9	4.38	4.49	0.66	0.31	0.98	0.88	21.91	2.09	0.46	5.19	2.96	
Havering	224248	92.03	1.51	1.63	0.37	0.1	0.31	0.24	1.23	0.2	0.1	0.29	0.69	
Hillingdon	243006	72.53	2.84	3.69	0.59	0.29	0.82	0.61	9.56	1.57	0.6	1.87	1.35	
Hounslow	212341	55.77	2.92	6.19	0.65	0.4	1.13	0.85	17.34	4.3	0.53	2.56	1.33	
Islington	175797	56.76	5.72	12.87	1.32	0.71	0.88	1.21	1.62	0.52	2.41	0.85	4.86	
Kensington & Chelsea	158919	50.08	3.26	25.26	0.81	0.67	1.17	1.44	2.03	0.76	0.72	1.36	2.58	
Kingston upon Thames	147273	75.92	2.17	6.37	0.4	0.27	0.95	0.66	3.61	1.3	0.26	2.61	0.52	
Lambeth	266169	49.57	3.26	9.55	2	0.81	0.79	1.23	2	0.99	0.81	0.77	12.07	
Lewisham	248922	56.97	2.81	6.14	1.91	0.64	0.63	0.99	1.4	0.44	0.49	1.46	12.27	
Merton	187908	64.06	2.91	8	0.87	0.39	1.02	0.84	4.28	2.4	0.91	3.49	3.71	
Newham	243891	33.78	1.32	4.31	1.22	0.68	0.68	0.8	12.14	8.46	8.8	3.12	7.35	
Redbridge	238635	57.45	2.33	3.74	0.79	0.31	0.78	0.57	13.96	6.24	1.77	3.02	3.82	
Richmond upon Thames	172335	78.72	2.79	9.47	0.39	0.26	0.89	0.67	2.46	0.39	0.36	0.67	0.37	
Southwark	244866	52.17	3.13	7.71	1.37	0.8	0.55	1.02	1.49	0.46	1.49	0.63	7.99	
Sutton	179768	83.73	2.04	3.43	0.67	0.2	0.71	0.49	2.3	0.68	0.32	1.43	1.14	
Tower Hamlets	196106	42.91	1.95	6.54	0.8	0.4	0.69	0.6	1.53	0.76	33.43	0.9	2.66	
Waltham Forest	218341	55.74	2.34	6.41	1.38	0.55	0.72	0.9	3.51	7.92	0.99	2.33	8.15	
Wandsworth	260380	64.78	3.13	10.05	1.11	0.48	0.86	0.9	2.85	2.09	0.42	1.57	4.86	
Westminster	181286	48.51	3.63	21.07	0.76	0.66	1.34	1.36	3.12	1.01	2.76	1.99	3.1	

Table AN2. Hospital Episode Statistics: proportion of records coded to each ethnic group.

Years	97/98	98/99	99/00	00/01
White	44.73	47.74	44.38	45.27
Black Caribbean	2.61	2.38	2.77	2.65
Black African	2.11	2.01	2.50	2.46
Black Other	4.33	0.99	1.24	1.33
Indian	2.85	2.75	3.07	2.89
Pakistani	0.89	0.86	0.97	0.96
Bangladeshi	0.94	0.97	1.15	1.18
Chinese	0.28	0.27	0.28	0.29
Other	4.24	4.29	5.02	5.15
not known	37.01	37.75	38.61	37.81

Table AN3. London - Proportion of population born in UK or abroad by ethnic group and age group at 1991 Census

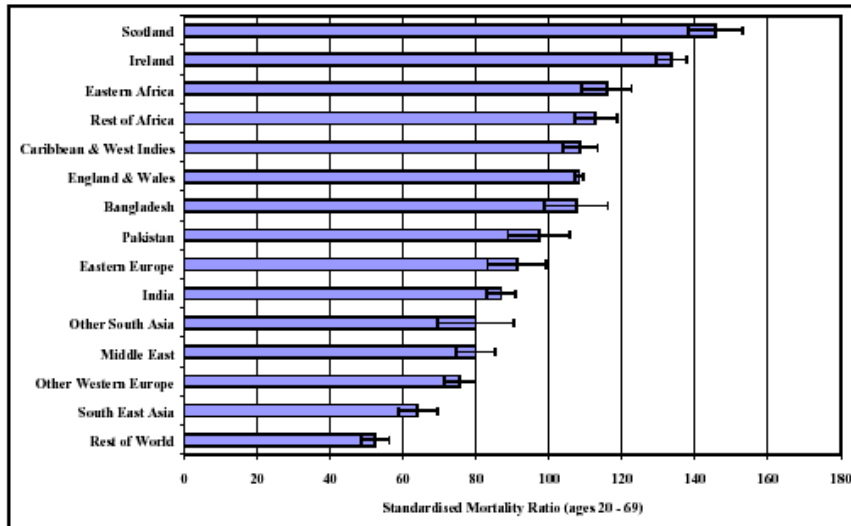
Ethnic group	White	Black Caribbean	Black African	Black Other	Indian	Pakistani	Bangladeshi	Chinese	Other Asian	Other
<b>Ages &lt;45</b>										
Born in UK*	89%	74%	39%	89%	46%	54%	41%	30%	25%	61%
Born abroad	11%	26%	61%	11%	54%	46%	59%	70%	75%	39%
<b>Ages 65+</b>										
Born in UK*	89%	7%	15%	24%	4%	8%	9%	4%	5%	17%
Born abroad	11%	93%	85%	76%	96%	92%	91%	96%	95%	83%
* 'Born in UK' includes persons born in England, Scotland, Wales, Northern Ireland, Channel Islands, Isle of Man and records that only stated UK										
Source: 1991 Census County Reports (OPCS, 1993)										

Table AN4. London - Infant mortality rates by mother's country of birth. 1993-98

Mother's country of birth	Infant mortality rate
Inside E&W	5.7
Outside E&W	6.9
Source: ONS linked mortality file	

Figure AN1. London all cause SMRs ages 20-69, by country of birth 1996-98

Deleted: (Method 4)



Source: [Developing health assessment for black and minority ethnic groups - The Health of Londoners Project](#)



**Appendix A. Data items currently collected in birth and death registrations in the different parts of the United Kingdom**

Tables 1 and 2 show data items currently collected in birth and death registrations in the different parts of the United Kingdom.

**Table 1. Data items in current birth registrations.**

<i>BIRTHS: Particulars collected</i>		
<i>England &amp; Wales</i>	<i>Northern Ireland</i>	<i>Scotland</i>
<u>For the child:</u>		
name & surname	forename & surname	forename(s) & surname
sex	sex	sex
date of birth	date of birth	when born (date & time)
place of birth	place of birth	where born (includes postcode & institution code)
	District Council of birth	
		Whether a foundling
<u>For the mother:</u>		
		<i>(if known)</i>
name & surname	name & surname	forename(s) & surname
maiden surname	maiden surname	maiden surname
surname at marriage	surname at marriage	
place of birth	place of birth	country of birth
occupation	occupation (collected since 1997)	occupation
industry/employment status*	industry/employment status	industry/employment status
date of birth†	date of birth†	date of birth†
		marital status
usual address (if different to place of birth of child)	address, with postcode	usual address (if different to birthplace of child)
<u>For the father:</u>		
		<i>(if known)</i>
name & surname	name & surname	forename(s) & surname
place of birth	place of birth	country of birth
occupation	occupation	occupation
industry/employment status*	employment status	industry/employment status
date of birth†	date of birth†	date of birth†
usual address (if different to that of mother)	usual address (if a joint registration)	usual residence (at time of birth)
<u>For the informant:</u>		
name & surname	signature	signature & transcription
address	address	address
qualification	qualification	relationship to child

Other particulars		
date of registration	date of registration	date of registration
registration district & sub-district of birth	registration reference number	registration district & entry number
Registrar's signature	Registrar's signature	Registrar's signature
Local authority	Local government district	
Birthweight*		
Postcode of usual address		Whether parents married
If parents married:	If parents married:	If married:
date of marriage	date & place of marriage	date & place of marriage†
	length of marriage†	
whether mother was married previously†	whether more than one marriage (mother)*	whether mother previously married†
number of children previously born to mother†	number of children previously born to mother*	Number of previous children (live births/stillbirths/total)†
Multiple maternities:	Multiple maternities:	
Whether a multiple maternity*	Whether a multiple maternity	
Total number of births recorded*	Total number of births recorded†	Indicator of multiple births
Number of live births and number of stillbirths*	Number of live births and number of stillbirths†	Related entry number
<b>Stillbirths</b>		
As for live births, but with additional details on:		As for live births (except that whether a foundling omitted), but with additional details on:
cause of death, & evidence for stillbirth	cause of death	cause or probable cause of death
duration of pregnancy	duration of pregnancy	duration of pregnancy
weight of foetus	weight of foetus	weight of foetus
whether a post mortem carried out		whether a post mortem carried out
		name & address of certifying doctor or midwife
		whether certifier present or not

Source: Devis, T. Recording of births and deaths in the countries of the United Kingdom. *Health Statistics Quarterly* 2000; 26: 32-39.

Notes: \* details collected for statistical purposes only, and not entered in the register.

† details collected under the Population Statistics Acts 1938 and 1960 (for England & Wales, & Scotland) or under the Registration Regulations (NI) 1973 (for Northern Ireland).

**Table 2. Data items in current death and birth registrations.**

<i>DEATHS: Particulars collected</i>		
<i>England &amp; Wales</i>	<i>Northern Ireland</i>	<i>Scotland</i>
<i>For the deceased:</i>		
name & surname, & any other names by which the deceased was known, including maiden surname	name & surname Maiden name	forename(s) & surname
sex	sex	sex
date of death	date of death	date of death (including time)
place of death	place of death	where died (including postcode, institution name & code, & length of residence)
type of institution*, & length of stay in institution*		
usual address	usual address	usual residence (if different from place of death)
		country of residence
		former residence
marital status†, & date of birth of surviving spouse†	marital status	†marital status
date & place of birth	date & place of birth	date of birth, & country of birth
age*		
cause of death	cause of death	cause(s) of death
duration of illness*		
confirmation by post mortem*	confirmation by post mortem*	post mortem
whether body seen after death*	whether body seen after death	whether body seen after death (maternal death)
date deceased last seen alive*		
whether additional information available later*	whether additional information available later*	additional information later
whether referred to coroner*	whether referred to coroner*	whether Procurator Fiscal informed
		whether found dead
whether employment contributed to death*		
		number of spouses
		names & occupations of spouses
		industry & employment status of last or only spouse
<i>On economic activity:</i>		
<i>If the deceased was male and aged 16 or over:</i>		
occupation	occupation	occupation
Industry/employment status	Industry/employment status	Industry/employment status
<i>If the deceased was a married female or a widow, aged 16 or over:</i>		
Her own occupation		Her own occupation

Name of husband or deceased husband	Name of husband or deceased husband	Name of husband or deceased husband
Occupation of husband or deceased husband	Occupation of husband or deceased husband	Occupation of husband or deceased husband
Industry/employment status of husband or deceased husband*	Industry/employment status of husband or deceased husband	Industry/employment status of husband or deceased husband
<i>If the deceased was a divorced female or a single female aged 16 or over:</i>		
Her own occupation	Her own occupation	Her own occupation
Her own industry/employment status*	Her own industry/employment status*	Her own industry/employment status*
<i>If the deceased was a child aged under 16:</i>		
Name & surname of father	Name of father	Forenames & surname of father
Occupation of father	Occupation of father	Occupation of father
Industry/employment status of father*	Industry/employment status of father	Industry/employment status of father
		Parent annotation
Name & surname of mother	Name of mother (if child illegitimate)	Forenames & surname of mother
Occupation of mother	Occupation of mother (if child illegitimate)	Occupation of mother
Industry/employment status of mother*	Industry/employment status of mother (if child illegitimate)	Industry/employment status of mother
		Parent annotation
<i>For the informant:</i>		
qualification	qualification	Relationship to deceased
address	address	name
	signature	address
Date of registration	Date of registration	Date of registration
		Registration district and entry number
<i>Regarding the certifier:</i>		
Signature		Name & address of certifying doctor
Qualifications		
Residence		
		Name of consultant
		Own doctor name and address

Source: Devis, T. Recording of births and deaths in the countries of the United Kingdom. *Health Statistics Quarterly* 2000; 06: 32-39.

Notes: \* details collected for statistical purposes only, and not entered in the register.

† details collected under the Population Statistics Acts 1938 and 1960 (for England & Wales, & Scotland) or under the Registration Regulations (NI) 1973 (for Northern Ireland).

**Appendix B. Instruction Manual, part 3a: Classification & Coding Instructions for  
Birth Records, USA, 1999-2001.**

Items: Hispanic Origin, Mother, Father.

Code Structure: Non-Hispanic - 0; Mexican - 1; Puerto Rican - 2; Cuban - 3; Central or South American (Spanish speaking countries only) - 4; Other & unknown Hispanic - 5; Not Classifiable - 9.

Coding Instructions: When there is neither a "Hispanic Item" nor an "Ancestry Item" on the certificate then code 9. Refer to Appendix H for additional Hispanic entries and codes as well as specific entries for categories 4 & 5.

For registration areas having the "Hispanic" item, follow instructions 1-8 (see Manual).

[Multiple reporting was not allowed, instruction 6 stating: 'If more than one entry is reported, code first-listed Hispanic entry, e.g. for Mexican Puerto Rican, code 1. A similar instruction was included 'For registration areas having an "ancestry" item, to follow instructions 9-12 (see Manual).]

Item: Race, Mother, Father.

Code Structure: White (includes Mexican, Puerto Rican, & other Caucasian) - 1; Black - 2; Indian (North American, Central American, South American, Eskimo, Aleut) - 3; Asian or Pacific Islander: Chinese - 4, Japanese - 5, Hawaiian (includes part-Hawaiian) - 6, Filipino - 7, Other - 8, Asian Indian - A, Korean - B, Samoan - C, Vietnamese - D, Guamanian - E; Multi-racial - F; Other Entries - 0; Not reported - 9.

Coding Instructions: The expanded Asian and Pacific Islander categories of A, B, C, D & E are required only for the following funded registration areas: California, Hawaii, Illinois, New Jersey, New York State, New York City, Texas & Washington. The remaining registration areas may choose to use the expanded codes or continue coding Asian Indian, Korean, Samoan, Vietnamese & Guamanian to 8.

[Complex instructions were given for multiple races. Code F was only to be used for entries of "multiracial", "biracial", "mixed", and other synonymous terms. Code F was not to be used when multiple races are reported. Moreover, states not mandated by law to code multi-racial as a separate category could continue to code these entries as '0'].

Instruction Manual, part 4: Classification and Coding Instructions for Death Records, 1999-2001 sets out the same coding structure and instructions for decedents (rather than Mother & Father). In Appendices to these Manuals there are detailed coding lists that map groups (n=236) to the 8 numeric race codes and A, B, C, D, E, & F and groups (n=47) to the 0-5 codes for Hispanic Origin.

## **Appendix C. 'Ethnic category' values for NN4B Birth Notification Data Set**

The following values have been defined by the Office for National Statistics (ONS).

When in doubt use Z for Not Stated

### **White**

A = British

B = Irish

C = Any other White background

### **Mixed**

D = White and Black Caribbean

E = White and Black African

F = White and Asian

G = Any other mixed background

### **Asian or Asian British**

H = Indian

J = Pakistani

K = Bangladeshi

L = Any other Asian background

### **Black or Black British**

M = Caribbean

N = African

P = Any other Black background

### **Other ethnic groups**

R = Chinese

S = Any other ethnic group

Z = Not stated