Ethnic Category Standard (v3.0.1) Change Submission			
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Ethnic Category Standard (v3.0.1) (March 2005)
Change to an Information Standard

Ethnic category collection in:
Accident & Emergency, Outpatients and Registrable Births

Amendment History:

Version	**Date**	**Amendment History**
0.1	02/10/2007	First draft
0.2	22/11/2007	Revised following review by Marion Cooper (ISB)
0.3	26/01/2008	Revised incorporating comments from the DH Equality Monitoring Group
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0.5	29/02/2008	Revised to include Disposition comments
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1.0	15/05/2008	Final version

For more information on the status of this document, please see the covering letter or contact:	The NHS Information Centre for health and social care National Datasets Programme 4th Floor, 1 Trevelyan Square Boar Lane Leeds LS1 6AE Tel: 0845 300 6016 Fax: 0113 254 7000 E-mail: datasets@ic.nhs.uk Internet: www.ic.nhs.uk
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Related Documents:

These documents will provide additional information.

Ref no	Doc Reference Number	Title	Version
	Appendix 1	Sponsor Statement	
	Appendix 2a	Statement of Support Healthcare Commission	
	Appendix 2b	Statement of Support London Health Observatory	
	Appendix 3	NHS Connecting for Health - Technology Office Statement	
	Appendix 4	Example of PHO use of Ethnicity data	
	Appendix 5	Example of Information Leaflet for Patients	
	Appendix 6	Example of poster for patient information	
	Appendix 7	Extract from Guidance Document	2005
	Attachment A	Race Relations (Amendment) Act	2000
	Attachment B	Equality Review Final Report	2007
	Attachment C	Summary of information gathering exercise	V1.0
	Attachment D	CDSV6.1 Draft Specification	V1.0
	Attachment E	A Practical Guide to Ethnic Monitoring	2005
	Attachment F	DH - Collecting Ethnic Category Data - Guidance and Training Material	2001
	Attachment G	Human Behavioural Guidance	V1.0
	Attachment H	Datasets Maintenance Process	V1.0
	Attachment I	Draft DSCN	V1.0
	Attachment J	NHS Code of Practice - Confidentiality	Nov 2003
	Attachment K	PIAG Letter	Mar 2008

Glossary of Terms:

List any new terms created in this document or any short forms (abbreviations, acronyms).

Term	Acronym	Definition
	CDS	Commissioning Datasets
	HES	Hospital Episode Statistics
	BME	Black and Minority Ethnic (groups)
	PHO	Public Health Observatories
	A&E	Accident and Emergency
	OPD	Outpatient Departments
	SUS	Secondary Uses Service
	PAS	Patient Administration System
	PCIS	Patient Care Information Systems
	ONS	Office for National Statistics
	NASP	National Application Service Provider
	LSP	Local Service Provider
	GMC	General Medical Council
	SCAG	Security and Confidentiality Advisory Group
	RRAA	Race Relations Amendment Act
	DH	Department of Health
	CRE	Commission for Racial Equality
	APHO	Association of Public Health Observatories
	FCE	Finished Consultant Episodes
	CHD	Coronary Heart Disease
	CBAG	Coronary Artery Bypass Graft
	PCT	Primary Care Trust
	PIAG	Patient Information Advisory Group

Table of Contents

NHS INFORMATION STANDARDS BOARD

1. Standard Demographics

1.1. Name of Standard

Ethnic Category

1.2. Sponsors

These specific changes to the Information Standard will be sponsored by the following:

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1.3. Developers

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The NHS Information Centre is a recognised standards development organisation and has a long history, in its previous organisational forms, working in close association with stakeholders, to successfully develop datasets and standards for use in the NHS.

1.4. Commercial Issues

These changes have been developed by the National Datasets Service, The NHS Information Centre for health and social care (The NHS Information Centre). There are consequently no known commercial licensing or Intellectual Property Rights issues relating to the use of this standard within the NHS.

1.5. Customer Need

Inequalities are experienced by different groups within society and there are many factors which can impact on health such as incidence, survival, mortality, patient experience and quality of life. In addition to these, there are cultural, religious and social factors that can also affect the way treatments are accessed and delivered.

Different ethnic communities will have different needs and the NHS is required to be able to meet these. The Race Relations (Amendment) Act 2000 (see Attachment A) states that those from different ethnic groups should expect organisations to:

- eliminate unlawful racial discrimination;
- promote equal opportunities; and
- promote good relations between people of different racial groups.

Ethnic category is one of the data elements that can be used to address these inequalities by supporting organisations to:

- monitor whether services are being delivered in a responsive way to meet the needs of their local population;
- assess whether individuals have equity of access to their services;
- determine whether certain groups are being discriminated against; and
- undertake health needs assessments.

The monitoring of ethnicity can also assist organisations to address potential complaints of racial discrimination in an appropriate way and reduce the emotional distress for those involved.

The Department of Health describes ethnic category:

An “ethnic group” [ethnic category] is identified as people who share characteristics such as language, history, culture, upbringing, religion, nationality, geographical and ancestral origins and place. This provides the group with a distinct identity as seen both by themselves and by others. A person self-assigns his or her own ethnic group [ethnic category].

It is important to distinguish the term “ethnic group” [ethnic category] from ethnic origin, or racial origin, which is not self-assigned. The term “ethnic origin” is used in medicine to describe the genetic make-up of a person, and is important in, for example, tissue typing to identify organ donors.

2. Purpose and Scope

2.1. Change Overview

The mandatory collection of ethnic category data has been part of the Admitted Patient Care Commissioning Datasets (CDSs) and Hospital Episode Statistics (HES) central returns since 1995. However, inconsistencies currently exist in the reporting of this data, and the proposed change to the Ethnic Category Standard outlined in this submission is to extend its current scope to allow it to be collected locally in Accident & Emergency and Outpatient Departments, and to flow centrally via the Commissioning Datasets.

In addition, the Admitted Patient Care Birth Episode Commissioning Data Set Types carry the data for finished or unfinished Birth Episodes. (A Birth Episode record is required when there has been a delivery resulting in a registrable birth). These currently have an ‘Optional’ status, and the proposal is to bring them in line by making them mandatory, thus providing a consistent approach.

Changes made to previous versions of the CDS XML schema do not currently permit ethnic category data to flow centrally from the Accident & Emergency and Outpatient CDSs, even if it is collected at a local level. This results in an incomplete view of the utilization of services by ethnicity at a national level, an inability to provide evidence of meeting statutory requirements, and means that the data is unavailable for secondary uses. (Birth Episode data is already able to flow via the CDSs).

2.2. Purpose

Current equality legislation means that the collection of Ethnic Category is necessary in order to demonstrate compliance, and to satisfy the requirements of Department of Health Standards. The proposed changes are essential to the monitoring of equity of access to services and to meet the requirements of the Race Relations (Amendment) Act 2000 through race Equality Schemes, thereby having implications for service commissioners, providers and regulators. The Act placed a statutory duty on NHS organisations to promote race equality and this duty covers all aspects of an organisations activities, policy and service delivery, as well as employment practices.

Organisations cannot perform their statutory functions, nor demonstrate compliance with the equality legislation, in the absence of comprehensive information on the ethnicity of patients, and a failure to meet these statutory duties, could potentially result in prosecution.

Ethnicity data can be used for a number of other purposes both at local and national level.

It is known that some ethnic groups are at particular risk of developing certain health conditions. For example, The Health Survey for England suggests that Pakistani men are significantly more likely to suffer coronary heart disease or stroke than the general population, and that people born in South Asia have the highest mortality rates from circulatory disease. Conversely, the corresponding rates for Black African men and women are significantly lower than for the general population[1].

Ethnicity data is often used in conjunction with other key information such as age and gender in identifying these groups, and using data in this way not only helps to identify disease trends, but also contributes to the forecasting of future health needs.

The CDSs support the exchange of data between providers, commissioners and other users via the Secondary Uses Service. Extending the collection of this data to include Outpatients and A&E would mean that it could be used for both local and national purposes such as health monitoring, research and surveillance. It would also help professionals gain a greater understanding of the links between ethnicity and disease, support the drive to improve outcomes for patients, and enable the provision of reliable epidemiological information on the health needs of the population in order to plan services to meet demand.

In 2005/06 there were 14.9 million[2] first attendances at Outpatient clinics and 17.7 million[3] first attendances to Accident and Emergency departments in England. The fact that ethnic category is not currently mandated for collection in these areas means that this substantial source of data does not flow centrally, and is therefore not available for secondary purposes.

The potential problems associated with lack of available data were highlighted in the recently published Cancer Reform Strategy (December 2007)[4] which noted that:

‘Links between race and cancer are complex and differ between different ethnic (BME) populations. Our understanding of these links has been hampered in the past by the poor recording of ethnicity within the NHS’.

2.3. Scope

2.3.1. What will the proposed standard be used for?

All NHS organisations are expected to use, good quality data for ethnic monitoring, which should include inpatient and outpatient activity. The proposed changes will enable them to:

- Demonstrate that they are compliant with the Race Relations (Amendment) Act 2000 which places a statutory duty on NHS organisations to promote race equality[5];
- Support the allocation of resources and develop policies relating to equality issues;

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[1] http://www.ic.nhs.uk/webfiles/publications/healthsurvey2004ethnicfull/HealthSurveyforEngland210406_PDF.pdf

[2] Latest figures available 2005-2006 from HES (published May 2007) http://www.ic.nhs.uk/statistics-and-data-collections/hospital-care/outpatients

[3] http://www.performance.doh.gov.uk/hospitalactivity/data_requests/a_and_e_attendances.htm

[4] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006

[5] http://www.opsi.gov.uk/ACTS/acts2000/20000034.htm

- Assist trusts to meet the needs of DH standards through a systematic programme of health equity audit and equality impact assessment. (e.g. National Standards, Local Action - Health and Social Care Standards and Planning Framework[6]);
- Highlight possible inequalities; investigate the underlying causes; and remove any unfairness or disadvantage;
- Improve public health by making sure that services are reaching local communities and are delivering services fairly to everyone who needs them; and
- Ensure under-represented groups receive services that are relevant to their needs, and provided fairly.

In addition:

- This change will contribute to the implementation of the recommendations made in the Final Report of the Equalities Review[7] published in February 2007 (see Attachment B).

- The data will support the implementation of the Darzi Review (Final report due out in Spring 2008), which will include the identification of current health inequalities in three areas i) health status, ii) health outcomes and iii) health access[8].

- The NHS Operating Framework for 2008-09[9] states that the revenue funding allows organisations to tackle key issues. Only 5 national requirements have been identified, one of which is "improving heath and reducing health inequalities".

All of the above are dependant on having access to comprehensive information on the ethnicity of patients.

2.3.2. Who is the subject?

All persons attending Accident and Emergency Departments, or Outpatient Departments for treatment or consultation and all babies delivered resulting in a registrable birth.

2.3.3. Who will use it?

Primary Users:

- NHS Trusts and Foundation Trusts for local use

Trusts will use the data as an integral part of their programme of health equity audit and equality impact assessments. It will be used to demonstrate that they have taken account of, and addressed the different needs and inequalities within local populations, and tackled issues of race equality. Ethnic category data can also

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[6] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4086057

[7] http://archive.cabinetoffice.gov.uk/equalitiesreview/publications.html

[8] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_079077

[9] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081094

contribute to comprehensive local patient profiles that include other demographic and needs-based information.

Ethnicity data is also part of Trusts Data Quality Indicators (DQI) in Hospital Performance Ratings which contributes to their overall data quality score (DQI score). A further emphasis on ethnic data quality introduced in 2003/2004 Performance Ratings by inclusion of an ethnic data quality indicator as a separate performance indicator, has increased its weight in overall performance rating of organisations.

Secondary Users

- The Department of Health
- The Healthcare Commission
- The NHS Information Centre for health and social care
- Public Health Observatories
- Researchers and Think Tanks e.g. Kings Fund

Public Health Observatories (PHOs) will use the data to aid understanding of the patterns of secondary care use by all ethnic groups, pointing to where care pathway inequalities exist. For example, inpatient treatment inequalities may be due to differential beliefs and knowledge, poor access to primary healthcare, low rates of referral for investigation or treatment, or delays in accessing healthcare leading to greater use of hospitals for emergency care.

PHOs work in partnership with practitioners, researchers, regional and local health policymakers and the voluntary sector. The collection of this data will support their role to deliver the following functions:

- Monitoring health, healthcare and disease trends and highlight areas for action
- Identifying gaps in health information
- Advising on methods for health and health inequality impact assessments
- Drawing together information from different sources in new ways to improve health
- Carrying out projects to highlight particular health issues
- Evaluating progress by local agencies in improving health and reducing inequality
- Looking ahead to give early warning of future public health problems.

The Healthcare Commission and the Department of Health will use the information to support the ongoing review of services for black and minority ethnic (BME) groups to ensure that services are providing equitable access to treatment in relation to need. The Healthcare Commission in particular would use this data to support their assessment of:

- commissioners in undertaking health needs assessment for BME groups
- commissioning of services for BME groups
- access to services for BME groups
- outcomes for BME groups
- commissioners in reducing health inequalities among BME groups
- provider performance in addressing the needs of BME groups

2.3.4. How will it be used in routine existing working practices?

Person based information is collected from all patients that access NHS services, and ethnic category is a key part of this essential information. The consensus is that this data item only needs to be collected at first contact with the patient and that the information recorded about ethnicity must be obtained by asking the person themselves unless there are circumstances whereby this is not possible.

For example, where due to illness, trauma or through disability, an individual is unable to respond or to be understood, it may not be possible or appropriate to collect it. Where patients and service users are in crisis, arrangements should be established for capturing ethnic category data once the crisis has passed.

Also, for babies and children a parent or guardian should be invited to respond. However, when a child is capable of understanding what they are being asked, their views should be sought, involving the parents in the process.

As with all other aspects of the care process, some individuals who have difficulty in communicating in spoken or written English, may need the support of translators or interpreters to help them understand and respond to questions about their ethnicity.

This data is predominantly collected by Medical Records Clerks, Receptionists and on rare occasions by clinical staff.

All provider units are currently mandated to collect and record data on the ethnicity of patients for inclusion in the Admitted Patient Care CDSs, and it is also extracted for HES. The proposed change would extend the current arrangements rather than introducing a new standard.

2.3.5. Where will it be used?

It will be used in NHS organisations that have Accident and Emergency Departments, Outpatient Departments and maternity services.

Outpatient activity carried out by professionals other than Consultants (for example physiotherapy, diagnostic investigations) for which an Outpatient CDS is submitted should also carry the Ethnic Category.

Similarly where Independent Sector providers submit CDSs for NHS Commissioned activity, Ethnic Category should be included.

2.4. Out of Scope

No secondary care activities identified as out of scope.

2.5. Performance Characteristics

Information flows via the Commissioning Data Sets are used solely for secondary uses and are not used for direct clinical care. The proposed extension to the current standard would mirror to the existing Admitted Patient Care data flows which include the mandatory submission of a patient’s ethnicity.

3. Business Justification

3.1. Strategic Fit

3.1.1. Criteria under which the proposed change is submitted

The Information Standard will be used by the Department of Health as part of public scrutiny of NHS services. This activity will be able to be described in terms of a structure, process and expected outcome, i.e. be a formal arrangement rather than a desirable entity or wish.

3.1.2. Business justification

The specific duties on public bodies of the Race Relations (Amendment) Act 2000, call for NHS organisations to conduct impact assessments of proposed policies and to monitor, review, and evaluate the impact of policies. Information on the ethnic groups of local communities and patients will be essential if the NHS is to carry out these duties. NHS bodies will be unlikely to be able to contribute fully and effectively to national targets and local standards, as set out in Local Delivery Plans, if the needs and circumstances of patients from different ethnic groups are ignored or misunderstood. Information for the purposes of Health Equity Audits and equality impact assessments can help NHS bodies to identify groups and communities who are experiencing health inequalities in terms of access, service receipt and health outcomes. Information can subsequently be used to monitor the impact of remedial action.

In addition the Equalities Review published in February 2007 highlights the need for good quality data and this is reinforced by the Darzi Review which will include the identification of current health inequalities in three areas i) health status, ii) health outcomes and iii) health access.

3.1.3. Review of Central Returns (ROCR)

ROCR do not "approve" CDSs at present, only the collections stemming from them. However they are aware of the proposed changes. Any specific collections arising as a result of these changes would be required to go through the normal ROCR process for approval.

3.2. Relationship to the National Programme for IT (NPfIT)

The Commissioning Dataset standards are integral to messaging of Secondary Uses Data to the Secondary Uses Service as part of the National Programme for Information Technology. It is developed by the Technology Office of NHS Connecting for Health and sponsored by Jeremy Thorp.

3.3. Operational Fit

3.3.1. Concept of Operation

The ethnic category standard is already collected and submitted for in-patients via the existing XML messaging system. It is intended that the changes required will integrate with existing operational flows to allow the submission of CDS data to continue to be sent to the centre in the way that it currently does.

SUS contains an internal model that allows ethnicity data from Admitted Patient Care to be landed in the data warehouse, and it is extracted to HES for secondary uses. The additional requirements for Accident and Emergency and Outpatient data will be included in the planned SUS Release 4 scheduled for December 2008. This will enable the data to be mandated for collection from April 2009.

3.4. Impact and Implications

3.4.1. Implications to stakeholders

Most recent HES figures for England show that there were 14.9 million[10] first attendances at Outpatient clinics and 17.7million[11] first attendances to Accident and Emergency departments. On average, this would mean that approximately 46,000 records for Outpatients and 71,000 records for Accident and Emergency would be collected by departments, though it is recognised that in A&E it would be inappropriate or not possible to collect this data in some instances.

Many organisations are already collecting ethnic category data in A&E and/or Outpatients as a matter of routine, and this data is held on their Patient Administration Systems (PAS) or Patient Care Information Systems (PCIS) for local use. Patients who are subsequently admitted from A&E have this data transferred on to the main hospital patient information system.

Organisations are required to provide mandatory training for all staff in relation to the Equality and Diversity agenda. However, there are specific needs for staff involved in collecting this and other types of sensitive information and this is being addressed through formal sessions or through targeted e-learning packages. Any additional training would need to be provided for those who do not currently collect this data in these areas.

The implications of not agreeing the change could potentially lead to NHS organisation being prosecuted due to them not fully meeting their statutory duties. This situation has already been raised with DH. It would also mean that the current inconsistencies within the CDSs would remain, and that the ability to use this data for secondary purposes would be denied.

3.4.2. Analysis of replacement of existing standards

This does not replace any existing standard.

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[10] Latest figures available 2005-2006 from HES (published May 2007) http://www.ic.nhs.uk/statistics-and-data-collections/hospital-care/outpatients

[11] http://www.performance.doh.gov.uk/hospitalactivity/data_requests/a_and_e_attendances.htm

3.5. Known Standards

3.5.1. Existing standards with a related purpose and scope

The national standard for collecting ethnic category is already in existence and is based on the 2001 ONS census ethnic categories. It is included in the NHS Data Dictionary (current version 3.0.1)[12] and is a mandated item within a range of datasets approved by the ISB. It is also used by other government bodies as part of their approved e-Gif standards. This has been used for some time throughout the NHS for inpatient activity and is recognised as the accepted standard for this purpose.

3.6. Interdependencies

The CDSs and Hospital Episode Statistics are dependent on the delivery of the Secondary Uses Service (SUS).

3.7. Consultation and Support

Support for the change comes from the Department of Health Equality Monitoring Group led by the Permanent Secretary for Health (Hugh Taylor), whose membership includes representatives from the DH Commissioning Directorate, the Knowledge and Intelligence team, Health Improvement Directorate, Standards and Quality Analytical Team, the Equality and Human Rights Group and the Healthcare Commission.

Statements of support have been provided by the Healthcare Commission (co-sponsors), who were the initial drivers for this change, and the London Public Health Observatory (see Appendices 1a and 2).

In addition, an information gathering exercise was carried out to obtain a view of what the current picture was locally with regard to A&E and OPD collection. This involved contact with a selection of NHS Trusts chosen at random. The Trusts were:

1. Barts and The London NHS Trust
2. St Mary's Hospital NHS Trust
3. Dartford and Gravesham NHS Trust
4. Wirral University Teaching Hospital NHS Foundation Trust
5. North Tees & Hartlepool NHS Trust
6. Northampton Healthcare NHS Trust
7. Scarborough and North East Yorkshire Healthcare Trust
8. United Lincolnshire Hospitals NHS Trust

Two site visits were also made:

1. Leeds Teaching Hospitals NHS Trust
2. Bradford Teaching hospitals Foundation Trust

Initial findings indicated that the data was already being collected as part of the routine patient registration process in one or both areas, and that the data collected

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[12] see www.connectingforhealth.nhs.uk/datadictionary

was used locally to inform internal trust reports and to report against Healthcare Commission Standards. The Trusts visited reported that the current level of completeness was very variable and were between 50-80% in A&E and have been up to 95% in OPD though not consistently. Almost all reported that they were actively seeking to improve this. (See Attachment C for summary.)

3.8. Governance

3.8.1. SUS programme governance

The SUS Programme Board reports to the NHS Connecting for Health National Programme Board and The NHS Information Centre Board.

The prime role of The NHS Information Centre in relation to SUS is to lead on user-facing issues, including requirements elaboration, training, benefits realisation, data quality and user support. NHS Connecting for Health is primarily focussed on supplier and technical issues, ensuring delivery within the context of the agreed business and technical architecture and standards for the National Programme for IT.

The facilities for secondary reporting from the NHS Care Records Service include both the NASP SUS requirements and requirements on each LSP for abstraction, management and reporting of information.

3.8.2. Confidentiality and Security

Confidentiality and security issues surrounding the collection and use of all patient level information are generic, and should therefore be managed in the same way. It is important to note that the proposed change is not seeking to apply any new rules to the current way this is undertaken. (See Attachment J)

Using information for a further purpose

Where a Trust wishes to use personal information provided for one medical purpose for a further medical purpose that has not been identified in the patient communications materials, the Trust must ensure that affected patients are effectively informed.

The term “medical purposes”, covers a wide range of NHS activities, including preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services.

The management of healthcare services encompasses the disclosure of patient information to:

- The Department of Health and NHS Managers
- Occupational Health Practitioners
- Bodies with statutory investigative powers, e.g. the GMC, The Audit Commission, The Health Service Ombudsman, The Healthcare Commission
- NHS Complaints Committees
- Cancer registries

Many of these disclosures will not be immediately apparent to most patients; however, there is still a duty to ensure that patients are appropriately made aware of such disclosures.

Some of these uses of personal information should be included within patient communication materials as a matter of course, e.g. disclosures to NHS Managers for the purpose of commissioning, financial audit etc. If the materials do not include information about such disclosures, they should be updated. This guidance is part of the Information Governance Toolkit[13] produced by Connecting for Health for Trusts to use in the management of information used within their organisation.

Individuals should be asked to give their consent for their personal data, including, ethnicity, to be recorded on computer and other systems. They should also be told who might have access to this information and be given the chance to say whether or not they are content for the named agencies and individuals to have access to their personal information. These matters should be communicated appropriately and individuals should not be coerced or forced into giving information about their ethnicity.

The Commissioning Datasets contain patient identifier information at the local level. However, following submission to the Secondary Uses Service (SUS), all patient identifiable data are pseudonymised to ensure that individuals cannot be identified prior to this data being made available to end users (e.g. HES).

Organisations using ethnic category data via HES must adhere to a written protocol issued by The NHS Information Centre on the dissemination of HES data and guidance is also given on handling very small numbers that sometimes occur in tables. In some cases record level data may be provided for medical/health care research purposes, but the information would only be given following a stringent application procedure, where the project can justify the need, and where aggregated data will not suffice.

Any request involving sensitive information, or where there may be potential for identification of an individual, is referred to the Security and Confidentiality Advisory Group (SCAG). All recipients of record level data must sign an agreement to use the data only for the specified purpose, to keep the data only for the specified length of time, and not to further disclose the data (in line with the Data Protection Act). The SCAG would also be involved in considering any requests for access to data that could potentially identify individual consultants.

A supporting statement from the Patient Information Advisory Group (PIAG) is included – Attachment K.

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[13] https://nww.igt.connectingforhealth.nhs.uk/RequirementFullDetails.aspx?tk=1333210988&lnv=4&cb=08%3a55%3a32&sViewOrgType=2&reqid=1371&viewid=165

4. Change Specification and Implementation

4.1. Change Specification

The CDSs permit the collection and flow of ethnic category into SUS for all Admitted Patient Care CDS types. The current version of the XML messaging schema (version 6.0) does not currently permit ethnic category data to flow centrally from the Accident & Emergency and Outpatient CDSs, even if it is collected at a local level.

The change affects the following CDSs:

010 Accident and Emergency Attendance

020 Outpatient Attendance (Care Activity)

120 Admitted Patient Care – Finished Birth Episode

150 Admitted Patient Care – Other Birth Event

180 Admitted Patient Care – Unfinished Birth Event

CDS XML Schema

The draft specification for CDSv6.1 is outlined in Attachment D.

4.2. Implementation Roll Out Plans

It is intended that this change will be incorporated into the SUS Release 4 plans currently scheduled for December 2008. A detailed project plan will be developed by BT in conjunction with SUS once the detailed requirements have been agreed.

The trusts already collecting the data in their A&E and Outpatient departments hold it on local PAS databases - although some A&E departments do have separate systems at present. However, it is anticipated that the change to systems would be minor. This is supported by the Outpatient Data Quality Report which showed that in 2004-05, levels of coding for some providers were as high as 95% demonstrating that the data can be provided from current systems.

4.3. Human Behavioural, Organisational and Technical User Implementation Guidance

The Department of Health in conjunction with the (then) Health and Social Care Information Centre (now The NHS Information Centre for health and social care) and NHS Employers, issued practical guidance in 2005 for NHS and Social Care staff who are involved in the collection and use of ethnic category and related data[14]. It built upon the guidance previously issued by the Department of Health in October 2001[15]. (See attachments E and F.)

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[14] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4116839

[15] Collecting Ethnic Category Data – Guidance and Training Materials for implementation of the new ethnic categories from April 2001

The guidance contains information on the following:

- Why ethnic monitoring is important
- The process for collecting ethnic category data – i.e. how to identify, collect and report ethnicity data
- Consent and confidentiality
- Training and public information

In addition, The NHS Confidentiality Code of Practice, published in 2003[16], is a guide to required practice for those who work within or under contract to the NHS.

The Information Governance Toolkit developed by NHS Connecting for Health also allows Trusts to assess their governance arrangements in relation to managing patient information. It covers a number of areas for assessment:

- Does the Trust ensure that patients are generally asked before their personal information is used in ways that do not directly contribute to, or support the delivery of, their care and that patients' decisions to restrict the disclosure of their personal information are appropriately respected?

- Does the Trust ensure that patients are informed about the proposed uses of their personal information and the importance of providing accurate information to NHS staff?

Further guidance is shown in The Human Behavioural Guidance document (Attachment G).

4.4. Migration Plans

There are no migration issues as this is an extension to the scope of an existing standard.

4.5. Safety

The Commissioning Data Sets are not used for direct patient care. There are consequently no known safety implications or potential adverse effects for patients in the application of these changes to this Information Standard.

4.6. Maintenance and Update Process Plans

Information that flows via the CDSs will be maintained by The NHS Information Centre in accordance with the National Datasets Service maintenance processes and procedures to ensure that it remains ‘fit for purpose’ (see Attachment H). On approval of this change request, any corresponding Data Manuals will be updated accordingly.

4.7. Conformance Tests Specification

Conformance with the changed CDS Information Standard will be enforced through the implementation of the updated CDS XML schema. All Trusts will be required to

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[16] http://www.dh.gov.uk/en/Policyandguidance/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550

make submission to the Secondary Uses Service (SUS) using the XML schema. Any records that do not conform to the updated CDS Information Standard and XML schema will be rejected, with diagnostic reports identifying issues supplied to the Trust.

Currently, ethnic category data has approximately 80% completeness in HES (Admitted Patient Care Types only), and is steadily improving. However there are limits to this as there will be some patients who do not wish to state their ethnicity. Organisations such as the Healthcare Commission and the London Health Observatory have successfully been using HES ethnicity data for a number of years. There is a particular statistical approach to analysis that gets round the incompleteness issues by looking at proportional specific diagnoses/procedures within all diagnoses/procedures for a coded ethnic category. Such HES-based analyses have been used for epidemiological research for some years.

The Healthcare Commission, with their regulatory drivers, could performance assess trusts on their coding which will drive up levels therefore circa 70% in a few years would seem possible.

APPENDIX 1: Sponsor(s) Statement

Equality and Human Rights

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SURINDER SHARMA
National Director for Equality and Human Rights
Surinder.sharma@dh.gsi.gov.uk

12 March 2008

Professor Martin Severs OBE

Sponsorship of the Ethnic Category Standard Change Submission
Statement of support

Inequalities are experienced by different groups within society and there are many factors which can impact on health such as incidence, survival, mortality, patient experience and quality of life.

The collection and use of Ethnic Category data has been mandatory with regard to hospital in-patients since 1 April 1995, and is necessary for a number of reasons:

- to comply with the requirements of the Race Relations (Amendment) Act 2000,
- meet Department of Health standards
- to support the monitoring of equity of access to services.

In addition;

- it enables the NHS to address health inequalities and discrimination experienced by some black and minority ethnic individuals and communities, and
- it assist in the allocation of resources and the development of policies relating to equality issues.

NHS organisations are expected to use good quality data for ethnic monitoring, and the changes outlined within this submission will address the inconsistencies that currently exist across the Commissioning Datasets, and will support the collection of this data for both central and local purposes. The submission and IC processes are in line with DH guidance and thus the law (i.e. Data Protection Act, Genito-Urinary Diseases, Human Fertility Acts, Embryology, Adoption, Rights of the Child).

I fully support this submission and confirm formal sponsorship of the proposed changes to the ethnic category standard

Surinder Sharma
National Director for Equality and Human Rights

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For the Attention of the Information Standards Board

The Healthcare Commission has a statutory role to inspect and regulate NHS and independent healthcare organisations in accordance with the standards set by the Department of Health and anti-discrimination legislation. *National Standards, Local Action*[1] sets out the core and developmental standards that NHS organisations are expected to comply with. The Healthcare Commission's role includes monitoring whether or not healthcare organisations are compliant with these core standards, and with the Race Relations Amendment Act (RRAA).

In order to monitor whether or not healthcare organisations are compliant with DH's standards and the equality legislation, and without imposing the burden of bespoke data collection, the Healthcare Commission needs evidence that organisations are effectively doing health needs assessment for their local minority ethnic populations and that they are monitoring services to ensure equity of access to and outcomes of healthcare and reducing inequalities. The Commission cannot do this effectively in the absence of information about the health needs of and service usage by ethnic minority groups. PCTs and providers themselves will be unable to do this in the absence of information e.g. on the local need for and uptake of outpatient services for minority ethnic groups, how it compares with other health economies etc.

Examples of how the Healthcare Commission could potentially use this data are:
- assessment of commissioners in undertaking health needs assessment for BME groups
- assessment of commissioning of services for BME groups
- assessment of access to services for BME groups
- assessment of outcomes for BME groups
- assessment of commissioners in reducing health inequalities among BME groups
- assessment of provider performance in addressing the needs of BME groups

The Healthcare Commission is but one potential user of ethnicity data on patients. There will of course be very many others, for example:
- PHOs (the London PHO has for many years been doing analyses on ethnicity data in HES)
- Commissioners
- SHAs
- researchers
- other regulators e.g. Audit Commission
- Equality and Human Rights Commission (which replaced CRE recently)

The case for having ethnicity data for outpatients is no different to that for having it for inpatients, which has been mandatory since 1995. The report by the IC on data quality of outpatient data showed that, although the level of recording is variable, many trusts are already recording ethnicity

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[1] *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/06 – 2007/08*. Department of Health, 2004.

for outpatients. For A&E patients, similar arguments apply, although clearly there needs to be some sensitivity around the data collection depending on circumstances.

The Cabinet Office's Equalities Review[2] published earlier this year was highly critical of DH for the lack of health data to support monitoring of equality issues. The Healthcare Commission contributed to this review, and highlighted lack of data for BME groups as a major national constraint in addressing the health needs of BME groups. In response to the equalities review (a) ONS has undertaken a review across government departments of the fitness for purpose of their data to support equality monitoring, highlighting the gaps in health data, and (b) Hugh Taylor set up an Equalities Monitoring Group to examine the data issues raised in the equalities review, and how they could be addressed – which includes extending recording of ethnicity to outpatients and A&E attendees. It should also be noted that the lack of routinely available data increases the need for bespoke data collections, which adds to the burden of information collection on organisations.

Dr Veena S Raleigh
Lead, Methods and Research, Informatics - Healthcare Commission

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[2] www.theequalitiesreview.org.uk

APPENDIX 2: Statement(s) of support

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w http://www.lho.org.uk

London **Health** Observatory

For the Attention of the Information Standards Board

Expanding Ethnic Monitoring Data to Outpatient and A&E Records

The LHO has a national lead role covering tackling health inequalities and ethnicity. In this role the LHO acts as the main point of contact on behalf of APHO across government and national bodies. The LHO works closely with the Department of Health and the Health & Social Care & Information Centre to support the programme of monitoring of the Cross Government programme of action to tackle health inequalities.

The drive for race equality, the Race Relations (Amendment) Act 2000 gives public authorities a new statutory duty to promote race equality. The Act also places specific duties on public – including health – authorities, including the publication of a race equality scheme. The NHS Chief Executive has added to the imperative to collect and analyse high quality ethnicity-coded data. The Ten Point Race Equality Action Plan emphasises several important activities. These include meeting the service needs of people from ethnic minorities, ensuring a greater focus on helping people with chronic diseases and tackling health inequalities. It also focuses on helping areas where ethnic minority communities are disadvantaged, targeting recruitment and development opportunities at people from different ethnic groups, whose skills are frequently underused.

To demonstrate compliance with these duties, ethnicity monitoring data needs to be collected and analysed across the workforce and service delivery areas. Such information can and has been used to identify inequalities in health, access to services, and outcomes, and to target service improvements and healthcare initiatives. Whilst it has often been argued that the data on ethnicity is not of sufficiently quality or completeness, experience has shown that improvements in data collection are possible and can be achieved relatively quickly. For example, for hospital inpatient data, in 2002/03 34 per cent of all Finished Consultant Episodes (FCEs) in London trusts did not have a stated or valid ethnic code. By 2005/06 only 16 per cent of FCEs did not have a stated or valid ethnic code. Using and publishing such data on a routine basis to monitor the implementation of national policies on ethnicity data and inequalities greatly encourages better data collection.

How would ethnicity recording of A&E episodes support the reducing inequalities programme? - The higher rates in some groups need further local explanation and having ethnicity recorded for A&E and outpatient contacts will provide a greater understanding of the patterns of secondary care use by all ethnic groups, pointing to where in the care pathway inequalities actually exist. For example, inpatient treatment inequalities may be due to differential beliefs and knowledge about CHD, poor access to primary healthcare, low rates of referral for investigation or treatment, or delays in accessing healthcare leading to greater use of hospitals for emergency care. Only better recording of ethnicity, as guided by the NHS Chief Executive, will allow NHS trust providers, commissioners, Public Health Observatories, and the Department of Health to ensure that their services are providing equitable access to treatment and outcomes across all ethnic groups in relation to need.

London Health Observatory
December 2007

Related Publications

1. Association of Public Health Observatories ***Indications of Public Health in the English Regions 4: Ethnicity and Health***
2. London Health Observatory ***Commissioning for Equity: A briefing on ethnic inequalities in access to treatments for coronary heart disease in NHS hospitals in London***

APPENDIX 3: NHS Connecting For Health – Technology Office Statement

APPENDIX 4: Example of using the data

Ethnic inequalities in treatment for Coronary Heart Disease – London Public Heath Observatory

Coronary heart disease (CHD) is the commonest cause of death and premature death in England and accounts for 3% of admissions to hospital.

The prevalence of CHD is known to be higher among South Asian ethnic groups. The LHO compared the proportion of all hospital admissions in England that are for coronary heart disease (CHD) in each of the ethnic groups to the average for all ethnic groups and found that the Asian groups have a high or average proportion of admissions due to CHD in all England regions reflecting the higher prevalence of CHD in these groups. However Black groups have a low or an average proportion of admissions due to CHD in all regions[1].

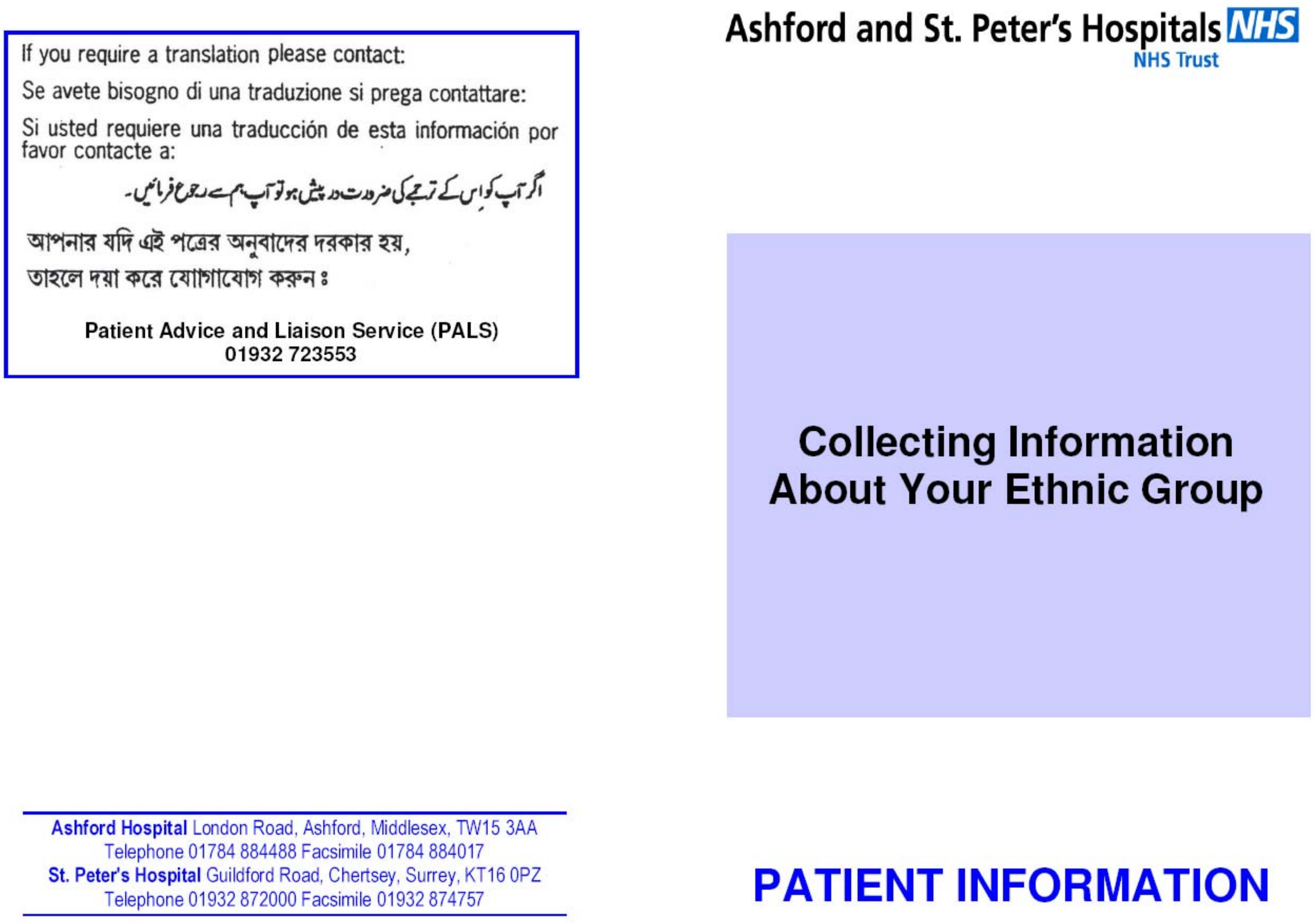
Our analysis of revascularisation rates further show ethnic inequalities in treatment. Revascularisation, by coronary artery bypass graft (CABG) or the quicker and less invasive coronary angioplasty, are effective treatments for CHD that aim to unblock the arteries supplying the heart. The National Service Framework for CHD proposed a target rate of 1,500 revascularisations per million populations (pmp) across England.

The Healthcare Commission has found considerable variation in age- and sex-standardised revascularisation rates by PCT, with a median rate in 2002/03 of 1,056 pmp nationally. Although rates were higher in more deprived areas, the association was less pronounced than would be expected. However, this does not adjust for the underlying prevalence of CHD, known to be higher than average in Asians. Therefore we attempted to make this adjustment by using all CHD episodes as the denominator in these calculations as a measure of need for revascularisation. Revascularisations account for approximately 15% of all CHD hospital episodes.

In London we found that Bangladeshi patients had only about two thirds the number of revascularisations than would be expected for the number of CHD hospital episodes[2]. People coded as Black Caribbean also had below average revascularisations in relation to their apparent need, though not always significantly so. Similar results were also found for Black Africans.

(London Health Observatory ***Commissioning for Equity: A briefing on ethnic inequalities in access to treatments for coronary heart disease in NHS hospitals in London)***

APPENDIX 5: Example of information for patients



If you require a translation please contact:

Se avete bisogno di una traduzione si prega contattare:

Si usted requiere una traducción de esta información por favor contacte a:

اگر آپ کو اِس کے ترجمے کی ضرورت در پیش ہو تو آپ ہم سے رجوع فرمائیں۔

আপনার যদি এই পত্রের অনুবাদের দরকার হয়,
তাহলে দয়া করে যোগাযোগ করুন ঃ

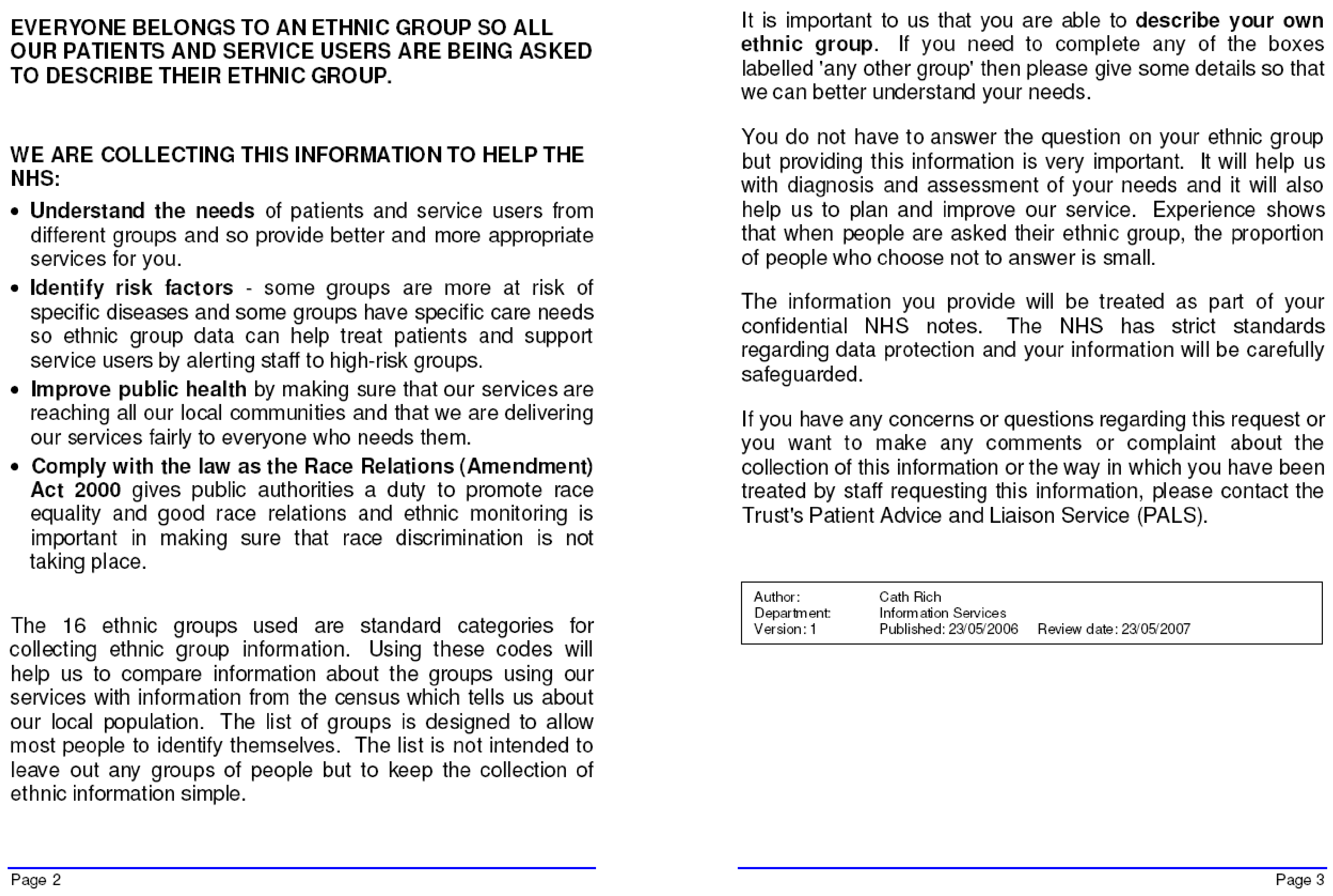
Patient Advice and Liaison Service (PALS)
01932 723553

Ashford Hospital London Road, Ashford, Middlesex, TW15 3AA
Telephone 01784 884488 Facsimile 01784 884017
St. Peter's Hospital Guildford Road, Chertsey, Surrey, KT16 0PZ
Telephone 01932 872000 Facsimile 01932 874757

Ashford and St. Peter's Hospitals NHS
NHS Trust

Collecting Information
About Your Ethnic Group

PATIENT INFORMATION



EVERYONE BELONGS TO AN ETHNIC GROUP SO ALL OUR PATIENTS AND SERVICE USERS ARE BEING ASKED TO DESCRIBE THEIR ETHNIC GROUP.

WE ARE COLLECTING THIS INFORMATION TO HELP THE NHS:

- **Understand the needs** of patients and service users from different groups and so provide better and more appropriate services for you.
- **Identify risk factors** - some groups are more at risk of specific diseases and some groups have specific care needs so ethnic group data can help treat patients and support service users by alerting staff to high-risk groups.
- **Improve public health** by making sure that our services are reaching all our local communities and that we are delivering our services fairly to everyone who needs them.
- **Comply with the law as the Race Relations (Amendment) Act 2000** gives public authorities a duty to promote race equality and good race relations and ethnic monitoring is important in making sure that race discrimination is not taking place.

The 16 ethnic groups used are standard categories for collecting ethnic group information. Using these codes will help us to compare information about the groups using our services with information from the census which tells us about our local population. The list of groups is designed to allow most people to identify themselves. The list is not intended to leave out any groups of people but to keep the collection of ethnic information simple.

Page 2

It is important to us that you are able to **describe your own ethnic group**. If you need to complete any of the boxes labelled 'any other group' then please give some details so that we can better understand your needs.

You do not have to answer the question on your ethnic group but providing this information is very important. It will help us with diagnosis and assessment of your needs and it will also help us to plan and improve our service. Experience shows that when people are asked their ethnic group, the proportion of people who choose not to answer is small.

The information you provide will be treated as part of your confidential NHS notes. The NHS has strict standards regarding data protection and your information will be carefully safeguarded.

If you have any concerns or questions regarding this request or you want to make any comments or complaint about the the collection of this information or the way in which you have been treated by staff requesting this information, please contact the Trust's Patient Advice and Liaison Service (PALS).

Author:	Cath Rich	
Department:	Information Services	
Version: 1	Published: 23/05/2006	Review date: 23/05/2007

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APPENDIX 6: Example of poster for patient information

COLLECTING INFORMATION ABOUT YOUR ETHNIC GROUP

Everyone belongs to an ethnic group, so all our patients and service users are being asked to describe their ethnic group.

We are collecting this information to help us:

- **Understand the needs** of patients and service users from different groups and so provide better and more appropriate services for you.

- **Identify risk factors** – some groups are more at risk of specific diseases, ethnic group data can help treat patients and support service users by alerting staff to high-risk groups.

- **Improve public health** by making sure that our services are reaching all of our local communities and that we are delivering our services fairly to everyone who needs them.

- **Comply with the law as the Race Relations (Amendment) Act 2000** gives public authorities a duty to promote race equality and good race relations and ethnic monitoring is important in making sure that race discrimination is not taking place.

You do not have to tell us, but providing this information is very important. It will help us with diagnosis and assessment of your needs, and it will also help us to plan and improve our service.
The information you provide will be treated as part of your confidential NHS or care notes and will not be shared with any other person or organisation.

APPENDIX 7: Example of guidance - Extract from Best Practice Guidance

A PRACTICAL GUIDE TO ETHNIC MONITORING IN THE NHS AND SOCIAL CARE

While organisations differ with respect to function, structure and procedures, there are some general principles that will stand all organisations in good stead:

- It should always be made clear to patients and service users that the provision of ethnic group data is voluntary.
- As with all personal information, procedures should be in place to ensure privacy when ethnic group data is sought.
- Patients and service users usually should be shown the full range of ethnic group codes that are in local use so that they can select the code that best describes them.
- Collecting ethnic group information at the same time as the bulk of registration, admission or referral information is collected is natural and efficient. Staff should explain why such information is required.
- Issuing ethnic monitoring forms with outpatient literature or with appointment letters saves time at registration (but only if forms are accompanied by clear guidance notes).
- Staff should be trained and supported in identifying and working with patients and users with communication needs, such as individuals with learning disabilities.

Of course in some situations, the admission will be an emergency or the individual being admitted may be in no fit state at the time to talk lucidly about themselves let alone give their ethnic group. Trusts and councils should therefore have arrangements in place for recovering ethnic group and other data following such admissions. Psychiatric hospitals or hospitals with busy Accident and Emergency departments should take particular note of this particular piece of guidance.

(see Attachment D for full guidance)