

Identification and evaluation of standardised datasets for measuring and monitoring access to health care

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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Executive Summary

Introduction

This report incorporates the findings and recommendations from our research to identify and evaluate standardised datasets for measuring and monitoring access to health care. It is the result of a project undertaken for the NHS Service Delivery and Organisation (NCCSDO) Research and Development (R&D) Programme on Access to Health Care.

As the scoping exercises commissioned by the NCCSDO pointed out, access to health care is a complex concept with many dimensions. It therefore cannot possibly be monitored by a small number of 'high level' indicators. In order to plan services, implement new policies including National Service Frameworks, monitor the implementation of these policies and other changes and compare organisations and geographical areas, much more comprehensive and focussed information is required.

The overall aim of the project was to investigate the availability and adequacy of datasets for monitoring access to health care, both overall and for socially excluded sectors of the population.

Aims and objectives

Our detailed aims and objectives were as follows:

- To review past and current research on the use of routine data to measure and monitor access to health care.
- To draw on this to establish criteria for assessing the potential for using, combining and developing routine data in order to monitor access to care for specific groups of people, including geographical populations, people with specific conditions and groups within the population.
- To review data collected routinely in hospitals, general practice and community services and assess the extent to which they can be used to measure access to health care, including differences within the population as a whole and the extent to which marginalised groups succeed in accessing care.
- To assess data collected on a population basis particularly data from routine and ad hoc surveys to ascertain to what extent, they measure associations between the incidence and prevalence of morbidity and the need for health care and the use of services. Document the level of disaggregation at which information from sample surveys can be used.
- To review current NHS initiatives to ascertain what arrangements are being made to monitor routinely their impact on equity of access, and to assess the adequacy of the arrangements and make recommendations where appropriate.

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- To review current performance indicators to assess whether they are realistic measures of access to care and whether their limitations arise from the systems from which they are derived.
- To consult data users and providers at local and national level to assess their needs, views and resources for analysis and collect information about new work being undertaken or planned to monitor equity of access to care.
- To make recommendations for changes to routine datasets, for new data collection systems and for enhancements to existing information systems to increase their capacity for measuring and monitoring access to health care.

Methods

The project was undertaken jointly by City University, the Public Health Policy Unit at University College London (UCL), and the South East Public Health Observatory. The work comprised: a review of the literature, original research, a survey of key Department of Health and NHS decision makers on requirements on different types of service providers to provide relevant data returns, and consultation at a series of workshops to consult an 'expert group' of data users and providers at local and national level.

Work was undertaken by the following methods:

- establishment of a steering group and setting a programme of meetings
- development of a framework for assessing measures of access
- application of the framework to a range of data sources relevant to access to health care
- application of the framework to selected case studies
- survey of data collection requirements by personal letter
- contact with a range of data users and providers through consultation.

Defining access to health care

We produced a framework that reflects access as a continuum, starting with the need for health care, and continuing through to outcome from care received. This approach is based upon earlier works commissioned by the SDO but is also drawn from the wider literature.

The access continuum developed has four dimensions:

- 1 need
- 2 opportunity
- 3 utilisation

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4 outcome.

A measure of population-based need is an essential component of a definition of access. This is because access to health care should be appropriate to need.

Opportunity to use health services, sometimes referred to as availability of health services, is a key component of access. Opportunity could be regarded as a proxy measure of the supply of services - are adequate services available for a given level of need within the population?

Utilisation is dependent upon not only availability or adequate supply of health care services but also the affordability of services to patients, the physical accessibility of services and acceptability to users.

Outcome in terms of either health gain or health maintenance is the final component of access in this definition as this is the end result of access to health care. The objective is that health services provided are both relevant to individual needs and effective.

From this definition of access, a framework was developed which could be applied to all the routine datasets identified in this project in order to evaluate access to health care for groups within the population.

Results

Our results were organised into two major sections. The first on health services data sources, and the second on population-based data sources. In addition six case studies were undertaken focussing on priority areas set out in the NHS Plan. Four were also the subject of National Service Frameworks. Two further case studies were on charges and transport, as these were considered to be essential to a project about access. The following main themes were identified from our work. Our recommendations are drawn from these.

Lack of socio-demographic variables within data sources by which to monitor access by various groups within the population

Many routine data sources, often due to the reasons for which they were first established, do not comprise detailed data for determining the socio-economic characteristics of those accessing health services, for example a lack of data routinely collecting ethnicity, postcode of address, socio-economic measures. This limits their usefulness in measuring difference in access by various population groups.

Breaks in continuity in series

This relates to changes in definitions, changes in boundaries for which data is collected, and gaps in time series.

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Much of this is concerned with changes in organisational structures which results in changes in definitions, breaks in series, discontinuity and loss of trend data. Frequent boundary changes make it difficult to monitor changes over time.

Lack of comprehensive and standardised primary and community data

There continues to be a lack of comprehensive and standardised primary and community data by which to construct a picture of need and provision of care, crucial in the light of the ongoing shift away from hospital settings.

Lack of private sector data

Our most important and consistent finding, applying to a number of areas of health care is the omission of data collected and available from the private sector. Even where data are submitted, this will not necessarily be in the same format, or to the same degree of quality and completeness as NHS sources.

There are particular concerns about the loss of data and of data quality as NHS provision becomes outsourced. This results particularly from changing patterns of delivery of health care despite assurances that monitoring would continue. If the reluctance to require data from independent providers is not overcome, existing data collections are likely to become less useful over time as care is increasingly provided in non traditional settings.

Downsizing of data collections

There is a trend towards downsizing data collections, with subsequent data losses, while at the same time dramatic increases in the numbers of performance targets and indicators. So there is a focus on performance indicators as opposed to the collection of data, with data collected specifically to monitor targets.

Some data losses are due to decisions to discontinue funding national statistics. Data collection has been a major target of Department of Health reductions which cut central staff posts by 38 per cent, although the establishment of the NHS Health and Social Care Information Centre will have compensated for this to some extent.

Access to routine data sources

It can be difficult to gain access to the datasets themselves. Some sources are expensive, while others restrict access, for example to only those employed by the NHS to data for their own organisation, with access to partner organisations such as local authorities disallowed. So, a contradiction exists between on the one hand a policy of promoting information sharing, but on the other hand the tightening up of data protection and confidentiality legislation. In practice, when there is uncertainty as to whether data can be made available or not, there is a tendency to restrict use so as not to risk infringing legislation.

Outsourcing of statistical analysis to commercial companies

There are issues around contracting out to commercial companies for performance and benchmarking using routine data. The potential threat to national systems is not only that data might be no longer collected, but that investment and development of such sources moves national statistical data into the sphere and control of private property. Small unlinked data sources are liable to be used and quoted rather than routine, national statistical data which are not subject to the same protocols.

Conclusions

The safeguarding of our national data collection is essential. Without comprehensive data it is not possible to monitor equity or needs and utilisation in accessing health services. This is particularly crucial at the present time of significant changes to patterns of health care delivery.

Our detailed review of the current NHS datasets for England identified an absence of data items needed for monitoring access to health care even when this was redefined in terms of utilisation. Data were missing about geographical location and individual socio-economic status. Ethnicity was more often included in datasets in response to the requirements of the Race Relations Amendment Act, but the data were often incomplete. Data to identify members of marginalised groups rarely are included in routine datasets.

There were areas for which few data were available, notably data about community health services, data about care in residential institutions and data about most of the growing range of services provided by the private sector, including those funded by the NHS. Few population-based data can be derived from general practice systems.

The continuing fragmentation and organisational changes in health care has impacted on data collection and made it difficult and sometimes impossible to monitor trends over time. The increasing tendency to outsource data to private organisations has reduced public accountability and adherence to the codes of practice notably that drawn up for National Statistics.

Data protection legislation and other restrictions on access to data means that fewer of them are in the public domain and that the NHS is increasingly less able to share data with partners such as local authorities.

Recommendations

- 1 In order to improve monitoring of utilisation of and access to health care, data about individual socio-economic status and about geographical area of residence should be added to routine datasets and reporting of ethnicity should be improved. Relevant data items should be added to monitor the uptake or the exclusion of care by people from marginalised groups.
- 2 Data collection about the use of community services should be recommenced.
- 3 General practice systems should have the capacity to derive population-based data from the individual records they hold.
- 4 Data should be collected about care in the private sector to the same extent as for the NHS, irrespective of whether or not the care was NHS funded. Records of these episodes of care should be linked to the person's records in the NHS Care Records Service.
- 5 Where NHS staff are collaborating with other partners in areas such as public health, their partners should be able to access the relevant data. Disclosure control should be operated in a way which does not unduly restrict public access to data about health and health care.
- 6 Performance targets and indicators should be constructed in a way which is explicit about the data items they comprise and how these are calculated.
- 7 In developing plans for an Independent Statistical Service, the scope should be interpreted as widely as possible to ensure that data about health and health care are subjected to public accountability and comply with codes of good practice. To support this, trends towards outsourcing of analyses should be reversed.

Introduction

Section 1 Introduction

- 1.1 Background*
- 1.2 Aims and objectives*
- 1.3 Scope*
- 1.4 What are standardised datasets?*
 - 1.4.1 Routinely collected data*
 - 1.4.2 Standardised datasets*
 - 1.4.3 Central returns*
 - 1.4.4 Official statistics*

1.1 Background

Many of the present systems for collecting routine statistics about the health of the population date back to the mid-nineteenth century, while systems for collecting data about health care have evolved in a piecemeal fashion from those set up at the inception of the NHS. These systems serve a variety of administrative and legal purposes. To fill some of the known gaps, a number of sample surveys have been commissioned. The aim of this project was to ascertain the extent to which these data can be used to monitor access to health care, so it has focused on and reviewed routine data as a whole. It therefore differs from the majority of projects commissioned in the SDO's access to health care programme which have focused on access to specific types of health care.

1.2 Aims and objectives

The aims and objectives of the project were to:

- Review past and current research on the use of routine data to measure and monitor access to health care.
- Draw on this to establish criteria for assessing the potential for using, combining and developing routine data in order to monitor access to care for specific groups of people, including geographical populations, people with specific conditions and groups within the population.
- Review data collected routinely in hospitals, general practice and community services and assess the extent to which they can be used to measure access to health care, including differences within the population as a whole and the extent to which marginalised groups succeed in accessing care.
- Assess data collected on a population basis particularly data from routine and ad hoc surveys to ascertain to what extent they measure associations between the incidence and prevalence of morbidity and the need for health care and the use of services. Document the level of disaggregation at which information from sample surveys can be used.
- Review current NHS initiatives to ascertain what arrangements are being made to monitor routinely their impact on equity of access, and to assess

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the adequacy of the arrangements and make recommendations where appropriate.

- Review current performance indicators to assess whether they are realistic measures of access to care and whether their limitations arise from the systems from which they are derived.
- Consult data users and providers at local and national level to assess their needs, views and resources for analysis and collect information about new work being undertaken or planned to monitor equity of access to care.
- Make recommendations for changes to routine datasets, for new data collection systems and for enhancements to existing information systems to increase their capacity for measuring and monitoring access to health care.

1.3 Scope

The scope of the project was to assess data relevant to health or health care in England. Although data issues relating to the interface with social care were considered, we did not aim to make a full review of social care data. The project focused specifically on the use of routine data to measure access to the services in terms of utilisation and the characteristics of the people who use them. It did not cover issues of effectiveness or users' views of care as these are better approached through other methods. Time did not allow comparisons with the other countries of the United Kingdom and with information compiled for international collaborative projects.

1.4 What are standardised datasets?

The subject of this project was to assess the extent to which standardised datasets can be applied to measure and monitor access to health care. Therefore it started by defining standardised datasets, and the ways in which these differ from other data sources.

1.4.1 Routinely collected data

Many of the datasets described in this report are 'routinely collected' in the sense that they are collected as a by-product of legal and administrative processes irrespective of the procedure or outcome. National and local databases of routinely collected data can cover whole populations over long time periods. It is possible to use these data in a number of different ways over and above their traditional uses for population health assessments and health service planning. (1)

The advantage of routine data over those collected specifically for a single purpose is that they can be used for a variety of purposes. This has to be offset against the possibility that they may lack key data items needed for a specific application. To be useful, large datasets should be accurate and accessible.(2) When using these datasets, it is vital to assess their quality and to be aware of their limitations in terms of content, changes in definitions over time, and the potential for variations in levels of accuracy and completeness.

1.4.2 Standardised datasets

In the early 1980s, NHS data for England were reviewed by the Steering Group on NHS Information. In the course of the review, the concept of the minimum dataset was formulated as:

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'a minimum set of data which should be used in all districts ... This should be quite explicitly standardised throughout the NHS as an aid to comparative performance measurement'(3). Thus the aim of standardised datasets is to enable meaningful comparisons which can be made not only between geographical areas as intended here, but also between different organisations, over time, and by a range of staff groups, target groups and other groups within the population.

1.4.3 Central returns

A central return is defined by the Department of Health as a structured collection of data from the NHS commissioned by the Centre and determined as being necessary for performance management, securing and allocating resources, and policy formulation. There is an ongoing Review of Central Returns (ROCR) whose role is *'to minimise the burden on the NHS of collecting regular and ad hoc central (including Regional Office) information requirements by ensuring that requests for information have a business justification and a realistic statement of the impact the collection would have on the Service.'* Approved collections are allocated a ROCR reference number which indicates that such returns must be completed by the NHS.

A full list of current central returns is included in Appendix A.

1.4.4 Official statistics

For the purpose of this report official statistics are taken to mean statistics collected, commissioned or published by central government departments and agencies, local government and the NHS. It is therefore broader than the concept of 'National Statistics' which has been more tightly defined, but whose definition is likely to change in response to challenges from the Statistics Commission. In addition, this report discusses some data collected or published by other bodies arising from government-funded research.

Section 2 Methods

2.1 Identification of routine datasets

2.1.1 Literature review

2.1.2 Survey of data collection requirements by personal letter

2.1.3 Contact with a range of data users and providers through consultation

2.2 Defining access to health care and developing a framework for access

2.2.1 Definitions of access

2.2.2 An operational definition of access

2.2.3 Application of the framework to a range of data sources relevant to access to health care

2.2.4 Application of the framework to selected case studies

2.3 Monitoring changes during the project

In order to provide guidance and direction for the study and to make a wide range of personal experience of routine data sources available to the project team, a steering group was set up. The steering group consisted of the co-applicants and other project staff. It met monthly to discuss progress in a formal setting. Further ad hoc meetings were held to discuss specific aspects of the project work.

The steering group played a key role in identifying the datasets relevant to health care in England. It was also invaluable in developing our definition of access to health care and in decisions about creating a framework by which datasets could be systematically appraised in terms of their ability to measure and monitor access.

While the project was underway, structural changes took place in the NHS in England and to the datasets under review. In parallel with this, a number of new policies were introduced. These changes were monitored and the steering group played an invaluable role in this.

2.1 Identification of routine datasets

It was known from previous experience that a conventional systematic literature search would be of limited value in identifying routine datasets, so alternative strategies were devised to supplement the literature search that was undertaken including the following:

- Personal knowledge of members of the steering group which included some of the authors of 'Official Health Statistics: an unofficial guide'(4)
- Searches of official web sites of government organisations including: the Department of Health, the NHS and the Office of National Statistics (ONS)
- Searches for and of UK-based web sites dealing with routine health data
- A request to the Department of Health to identify all its current returns which related to hospital activity and its workforce
- Consultation with data users.

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Relevant conferences were also attended including conferences on the Health Surveys for England, Wales and Scotland, Maternity Statistics and Human Rights and Equity in the New NHS.

2.1.1 Literature review

Attempts were made to identify routine datasets through a structured search of medical, nursing and social science bibliographic databases, including Medline, Cinhal, Embase, BIDS and HMIC. Searches were made for articles with keywords 'Access' 'Health care' and 'Data' and restricted to England between 1995 and 2004. The numbers of references identified using these searches ranged from two to about 4000. Medline yielded the most references but a structured search was difficult because neither access nor routine data are MeSH headings although there is a MeSH (Medical Subject Headings – United States National Library of Medicine – www.nlm.nih.gov/mesh/meshhome.html) heading for 'Health Care Quality, Access & Evaluation'. Combinations of free text searches with MeSH headings in Medline and other indexed subjects in other databases either identified thousands of references or a mere handful. Most of the articles identified referred to specific studies using routinely collected data rather than articles about the use of routine datasets themselves.

This process did not identify any routine datasets not previously known to the study team. This should not be surprising as these bibliographic databases were not designed to identify routine datasets. This method of identifying routine datasets was abandoned as a result.

We know that others have had a similar experience. In 2004, the Statistics Commission commissioned York Health Economics Consortium to undertake a review of official health statistics. Using the considerable experience at the University of York, it also undertook a systematic review and was unable to identify health statistics and the user perspective(5). The York team told us that it drew extensively on work already published by members of our study team.(4)

One member of the study team was a co-editor and three had contributed to this Radical Statistics publication 'Official statistics: an unofficial guide'(4) and one had been a co-editor. Two had contributed to another Radical Statistics publication, 'Statistics in society'(6; 7), one to 'Harnessing Official Statistics' (8) as well as being a co-author of 'Birth counts: statistics of pregnancy and childbirth' (9). The study team used this prior knowledge to compile a list of routine databases that might potentially be used.

They then supplemented this by searches of the web sites of the Department of Health, the NHS Health Information Authority, the NHS.uk, the Office for National Statistics, the Health care Commission and the regional public health observatories. Further web sites were identified through free text searches in Google and following links within sites. A particularly useful site identified in this way was 'DocDat', an online directory of clinical databases in the UK(10)

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These strategies were supplemented with user consultations, a letter to the Department of Health requesting a list of all central returns and attendance at selected conferences and study days relating to the use of routine data.

2.1.2 Survey of data collection requirements by personal letter

To support the work on hospital activity data and routine NHS returns, a letter was sent to a range of key Department of Health and NHS decision makers listing all data returns currently collected relating to hospital activity and workforce. The letter asked whether all providers of inpatient and outpatient care, including those in the independent sector, those treating NHS funded patients overseas, and Diagnostic and Treatment Centres are being required to submit these returns. The objective was to ascertain whether all such providers of care are being required to submit relevant returns. The letter is in Appendix A together with the results of the survey.

2.1.3 Contact with a range of data users and providers through consultation

Consultation took place with an 'expert group' to develop understanding about how people assess and measure access. These discussions included an assessment of how easily people perceived they currently approached the measurement and assessment of access and whether it was, or they believed it should be a routine part of any monitoring and evaluation that took place. The consultation took place in parallel with a consultation that was being undertaken about the development of the Health Poverty Index, a method of measuring relative deprivation. This therefore provided an opportunity to explore with people how they defined and viewed access in the context of both need and the supply of material and health care resources and also the extent to which they recognised the conflict between issues of measuring access relating to equity and those relating to performance and target issues relating to access for health care and waiting times. The consultation provided a unique opportunity for observing aspirational ideas about the measurement of access to health care.

The group consisted of people working in service-NHS posts, in local government posts where their roles had a clear link to the health and well being agenda, in academic environments. Elected members of local authorities and members of voluntary and community organisations were also consulted. All nine NHS and Government Office Regions were represented in this consultation. The make-up of the group is summarised below. For several of the roles more than one consultation took place:

- Director of Public Health, Primary Care Trust (PCT)/Strategic Health Authority (SHA)/Region
- Director of Performance Management, Data Set Charge (DSC)
- General Practitioner
- Public health information specialist
- Director, Public Health Observatory
- Senior information analyst, SHA

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- Chief Executive PCT
- Joint LA/PCT planning manager
- Academic expert on inequalities
- Health Action Zone staff
- Voluntary sector
- Community development worker
- Local authority
- Government Office

2.2 Defining access to health care and developing a framework for access

In order to assess the potential of routine data to monitor and measure access to health care for different groups within the population it was necessary to establish a definition of access that was broad, quantifiable and as objective as possible.

The definitions of access used in this report were drawn in the main from two scoping studies commissioned by the SDO(11;12) to determine the meaning of access to health care, and from earlier work cited in these scoping studies.(13;14)

Additional material has been used from other papers, including those references cited in these two SDO reports. Other work by health and social researchers and health economists on the definition of access to health care was obtained from semi-structured searches of Medline, Cinhal and HMIC. We also reviewed the definitions of access to health care used in government reports and ministerial statements.

2.2.1 Definitions of access

Because preferences for health care and the costs involved differ between individuals and groups, access in terms of provision cannot be separated from utilisation. Access to health care defined in terms of potential or opportunity is therefore a theoretical concept unless it is linked to the utilisation of health care.(15)

Other researchers confirm that there is a direct and close relationship between access as a potential to use services and access as the entry into the health care system. Access is defined as *'those dimensions which describe the potential and actual entry of a given population group to the health care delivery system'*.(16) This definition of access therefore includes two inseparable components, an opportunity component defining potential entry and a utilisation component defining actual entry.

Others have attempted to explain access as encompassing five factors:

- 1 acceptability
- 2 affordability
- 3 availability
- 4 physical accessibility
- 5 accommodation.(12;17;18)

These are defined as follows:

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- 1 Acceptability refers to attitudes and beliefs of users and providers about each other's characteristics.
- 2 Affordability applies to the cost implications to the patient in relation to need; this includes both direct and indirect costs and perceptions of value.
- 3 Availability refers to the adequacy of supply given by the relationship between volume and type of services (provision) and volume and type of needs (demand).
- 4 Physical accessibility is defined by the suitability of the location of the service in relation to the location and mobility of the patient (geographical and physical barriers).
- 5 Accommodation refers to the way services are organised in relation to the client's needs and the patient's perception of their appropriateness (opening times, booking facilities, waiting times).

These definitions of access go beyond definitions of access that are solely concerned with entry or use of services by including notions of need, appropriateness, barriers to service use and also the enabling of access to health care.

Access and utilisation might be better seen as parts of a wider continuum. In particular if we are to measure access/utilisation, what do we measure and where do we measure it? As some of the costs of providing a service are independent of the extent to which it is used, there is some argument for maintaining a distinction between the two, but it may prove difficult to do this in practice. In addition, many researchers regard outcomes as part of the definition of access, as the effectiveness of a service may influence its use or uptake. (12)

Confusing and conflicting definitions of access could be avoided if it were viewed as a continuum rather than as a discrete entity, which could arbitrarily be defined in a number of different ways. Such an approach would also allow distinctions to be made between the many facets of access.

Previous work for the SDO defines access as follows: *'Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve their health'*. (12)

The report went on to identify at least four aspects of access:

- 1 If services are available, in terms of an adequate supply of services, then a population may 'have access' to services.
- 2 The extent to which a population 'gains access' also depends on financial, organisational and social/cultural barriers that limit the utilisation of services. Thus utilisation is dependent on the affordability, accessibility and acceptability of services and not merely adequacy of supply.
- 3 Available services must be relevant and effective if the population is to 'gain access to satisfactory health outcomes'.
- 4 The availability of services, and barriers to access, must be considered in the context of the differing perspectives, health needs and cultural settings of diverse groups in society.

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Others have attempted to redefine this description of access with a further scheme of definitions and suggested a fourfold classification for future SDO research(11):

- 1 'Access-entry' and 'in-system access'. In brief, access to health care is viewed to be something about the way people enter the health care system (access-entry), and their treatment once in the health system (in-system access).
- 2 Dimensions of access. There are various geographical, temporal, financial and other factors that are known to have bearing on 'access-entry' and 'in-system access'.
- 3 The influence of 'individual', 'community' and 'health care system' factors on access.
- 4 'Absolute' and 'relative' access. There are two broad approaches to thinking about access and policy.

This is an interesting classification of access but it still seems to be overly concerned with describing arbitrary definitions of the access point. It also fails to integrate effectiveness and appropriateness into the classification system and omits outcome from the access continuum.

Identifying the main dimensions of access is important but no list will be exhaustive. Awareness that a multiplicity of factors will have a bearing on access is therefore the main point to be made here. Certainly the influence of individual, community and health service factors is an important point that has been made in earlier work.(19)

Distinguishing between relative and absolute access is important. The fundamental question is whether or not the access or changes in access are absolute and reflect the overall availability of health services across the board, or relative and concern differential changes to or differences in access for groups within the population. Relative access is relevant to addressing issues of inequalities in access to health services, while absolute access relates more closely to consumer definitions of improving access, such as waiting times and choice of provider and setting.

In its current policies, the Department of Health takes a market oriented consumerist approach of access to health care, focussing on choice, convenience and waiting times. This perspective dominates the NHS Plan(20), where factors such as patients being able to choose when and where they have treatment, and the importance of reducing waiting times, are emphasised. Paragraph 6.10 of the Plan states that patients should have fair access to high standards of care wherever they live. This is further qualified by reference to national standards including National Service frameworks, the National Institute for Clinical Effectiveness and government targets which focus upon waiting times, quality of care and the quality of facilities. Primary care trusts are given the role of simplifying access to health and social care and making such care more convenient to use.

The NHS Plan also established specific access targets of its own. It stipulated that by 2004 primary care trusts would have to guarantee that all patients would be able to see a primary care professional within 24 hours and a general practitioner within 48 hours. Waiting time reduction was targeted in all areas of health care including cancer, where pathways of care were to be streamlined. The National Cancer Plan includes waiting time targets, coronary heart diseases and the introduction of Rapid Access Chest Pain Clinics. In the care of elderly people, Care Direct would provide faster access. The Priorities and

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Planning Framework for 2003-2006 also made it clear that the health and social care priorities were improving access by achieving better emergency care and reducing waiting times.(21)

These themes tie in closely with patient definitions of access to health care. In 1998, questions about general practice in the National Patient Survey, showed that patients were most concerned by waiting times and convenience of use.(22) Twenty per cent of patients in employment put off visiting a GP because opening times were inconvenient while 25 per cent had to wait for four days or more for an appointment. Of those referred to hospital, 39 per cent felt that their condition had worsened by the time they were eventually seen. Among people who took part in 2000 in the public consultation of the NHS Plan, 20 per cent identified cutting waiting times as one of the top three priorities.(23) There was also concern about geographical variations in access to health services.

Convenience to the consumer and reduced waiting times are two important and desirable features of a modern health care system. On the other hand, as we have seen from the broad range of definitions discussed above, they do not represent the idea of access in its entirety.

Previous definitions have not taken the factor of need into account when developing definitions of access to health care. We believe a measure of population-based need is required. It is pointless or possibly harmful to have access to something that is not needed. This is particularly important in a context where others have health care needs that are denied, as can happen in any system without unlimited resource.

2.2.2 An operational definition of access

We propose an operational definition of access to health care that takes account of previous work.(11-14; 17; 19) It builds upon the idea of a continuum of factors defining 'access to health care' including a dimension of need as well as dimensions of opportunity to use services, actual utilisation of services and outcome and an assessment of the level of aggregation at which the data might theoretically and actually be available.

Table 1 is our proposed framework for a population-based dataset. A similar framework can be used for enrolled populations.

The left hand column lists the characteristics of the population. These are any factors that may be associated with inequalities in health and need for health care in the population. This list is not exhaustive.

The next three columns of the framework show the level of aggregation at which the data are available. This distinguishes between the level of aggregation which would theoretically be possible when analysing the data in the dataset and the level of aggregation at which data are routinely available.

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Table 1 Framework for access: populations

		Aggregation			Place on Access Continuum			
		Individual	Health Care system	Group/ Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access							
Characteristics of population								
	Age							
	Sex							
	Ethnicity							
	Country of birth							
	Education							
	Socio-economic							
	Geographical							
	Where care occurred							
	Residence							
	Travel time							
	Morbidity							
	Mortality							
	Health beliefs and knowledge							

The aim of this study was to determine the extent to which routine datasets can be used to measure and monitor access to health care for the population as a whole but also crucially for groups within the population who may also be deprived and marginalised.

As a result, the definition and framework that we have developed are not intended to be a prescriptive 'one-size-fits-all' tool for assessment. Instead, they are a guide to thinking critically about the potential for routine data sources to measure and monitor access to

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health care, both in a broad understanding of what is meant by access and also with particular regard to deprived and marginalised groups who may have difficulties in accessing health care.

2.2.3 Application of the framework to data sources

The framework for access created for the study was applied to a range of relevant data sources to evaluate access to health care. This entailed identifying NHS data collected routinely in hospitals, primary care and community services and reviewing them in order to assess the extent to which they can be used to measure access to health care. This review is described in Appendix B. Details of the datasets can be found in Appendix B.

Data collected on a population basis, particularly data from routine surveys, were identified and reviewed to ascertain the extent to which they can be applied to measure associations between the incidence and prevalence of morbidity and the need for health care and access to services. Details of the datasets can be found in Appendix B.

In each case, the level of aggregation at which data were available, for example at the level of the individual, ward, borough, national, practice, or hospital, was documented.

2.2.4 Application of the framework to selected case studies

As well as applying the framework for access to the data sources described above, a series of case studies was undertaken. Because it was not possible to present a high level of detail and context for all routine data sources, six areas were chosen as case studies for in-depth reviews, in consultation with the steering group. The data items and sources available to measure and monitor access to services in these specific areas were identified. Four priority areas of health care were selected. These were older people's mental health, maternity and neonatal care, cancer and coronary heart disease. They were selected because they were high on the national policy agenda and were the subject of National Service Frameworks. They also reflect a broad spectrum of clinical conditions from acute problems to chronic diseases as well as non-disease health areas such as maternity. The last two topics were NHS charges and transport to access health care. These were chosen because of their direct relevance to evaluating access to health care.

2.3 Monitoring changes during the project

Many changes took place in the NHS during the course of the project, notably the abolition of district health authorities, the establishment of primary care trusts and strategic health authorities and the establishment of the first foundation trusts. These had implications for data collection. Many other initiatives were more explicitly related to data collection, such as the National Programme for IT, the gradual emergence of plans for a 'Secondary Uses Service', the abolition of some NHS data collections, complete restructuring of the Department of Health web site, downsizing in the Department of Health and planning for the Health and Social Care Information Centre which eventually came into being on 1 April 2005. This co-incided with a review and restructuring of 'arms length' bodies, leading to the abolition of some of them. In particular, the NHS Information Authority was abolished, with some of its functions being transferred to the National Programme for IT and some to the Health and Social Care Information Centre. The Commission for Health Improvement merged with several other bodies on 1 April 2004 to form the Commission for Health care

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Audit and Inspection, but took the name, Health care Commission. On the same date, the Commission for Social Care Inspection was established to bring together the work previously undertaken by the Social Services Inspectorate, the SSI/ Audit Commission joint review team and the social care functions of the National Care Standards Commission. In March 2005, the Chancellor of the Exchequer announced a further merger with the Health care Commission.

Keeping abreast of these changes has been challenging, and has involved monitoring press releases and web sites, informal contacts with key people in the Department of Health and other bodies and attendance at meetings of the Health Statistics Users Group. Up to date information has been incorporated in successive revisions of this report. In particular, the developments in NHS Performance Measurement have been documented in Appendix D.

Section 3 Health service data

- 3.1 Introduction*
- 3.2 Hospital Episode Statistics (HES) and episode based inpatient data*
 - 3.2.1 Hospital Inpatient Enquiry (HIPE) and Hospital Activity Analysis (HAA)*
 - 3.2.2 Episode-based data: HES and the Admitted Patient Care Commissioning dataset*
 - 3.2.3 Strengths and limitations of HES and hospital activity data collections for monitoring access to health care*
- 3.3 Aggregated health service activity data*
 - 3.3.1 Aggregated Hospital Data*
 - 3.3.2 Aggregated primary care data*
 - 3.3.3 NHS and local authority community datasets*
 - 3.3.4 Waiting times data*
 - 3.3.5 Staffing and Workforce Data*
- 3.4 Communicable disease surveillance*
 - 3.4.1 Data currently collected*
 - 3.4.2 Recent developments*
 - 3.4.3 Strengths and limitations of communicable disease data to measure access to health care*
- 3.5 Access to health care and health service data*
- 3.6 Discussion*

3.1 Introduction

This section introduces the various routine datasets that relate to health care which are derived from health service activity that is publicly funded usually by the NHS. The section is structured in three parts:

- 1 hospital-based inpatient data
- 2 aggregated data including outpatients, primary care, community care and workforce data
- 3 communicable disease surveillance.

Within each section the various datasets are introduced and described with particular reference to coverage, quality future development and value in assessing access to health care.

3.2 Hospital Episode Statistics (HES) and episode-based inpatient data

In order to understand how the current system of hospital statistics has developed, we start by describing briefly the systems that preceded it.

3.2.1 Hospital Inpatient Enquiry (HIPE) and Hospital Activity Analysis (HAA)

When the NHS was established in 1948, NHS hospitals in England and Wales were originally required to maintain records of numbers of admissions and of available and occupied beds in each specialty and submit aggregated data on the SH3 hospital return.(24) From 1949 all hospitals were required to make an annual return indicating the number of staffed beds, the number in use, their daily occupancy, the number of patients treated and the waiting list for admissions on the last day of each year. In 1949 the Ministry of Health invited NHS hospitals to volunteer to supply a ten per cent sample of patient-based data for analysis for the Hospital Inpatient Inquiry (HIPE). Data items collected included age, sex, region of residence, diagnosis and operations. Patients were counted each time they were discharged from an inpatient stay in hospital, or they died, and statistics were expressed in terms of 'discharges or deaths'. The scheme became compulsory in 1957 and was administered centrally by the General Register Office.(25)

Hospital activity analysis (HAA), based on all inpatient stays, was introduced locally from 1964/5 onwards. In 1969 it was extended to collect and analyse data on all discharges and deaths at a regional level. Details of each were collected from a standard front-sheet attached to patient notes. HAA provided doctors and administrators with data based on individual patients, including diagnosis and procedure, sex, age, date of admission, discharge and length of stay. The scheme was introduced progressively and enabled consultants to relate the use of resources to the characteristics of their patients, their diagnoses and operations.(25) HAA was based on discharges and deaths rather than individual people and did not link successive admissions of the same patient. Such data are limited in that much information required for planning and for monitoring access to services is based on individuals and whole episodes of care. Each region then submitted a ten per cent sample of records to the Hospital Inpatient Enquiry.

Maternity data were also collected in a separate system of Maternity Hospital Activity Analysis but only about one third of units ever took part.(26) The remainder submitted data about a ten per cent sample of inpatient stays in maternity units directly to Maternity HIPE. Data on psychiatric inpatient care and the patient care for people with learning disabilities were also collected separately by the Mental Health Enquiry.

Record linkage

The term record linkage was originally coined in 1946 as the collation of health records into a cumulative personal file to run from birth to death. It was stressed that linked files could be used to establish the accuracy of recorded data. Pioneering medical record linkage work was undertaken in Canada in the 1950s. In 1962 the Oxford Record Linkage Study (ORLS) was established as the first such system in England under the directorship of Donald Acheson, still in operation today. It used extensive methods for calculating the probability that pairs of records related to the same person.(27) The ORLS facilitated the linking of births and deaths to information about all hospital admissions by matching based on personal identifying variables, for example name, personal and socio-demographic characteristics in lieu of a unique personal identifier. Record linkage made it possible to explore the relationships underlying bed usage more fully. The project has never been extended nationally.

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The Review by the Steering Group on Health Services Information

The 1974 re-organisation of the NHS with its emphasis on planning, highlighted the lack of NHS information, especially its availability, relevance, quality and timeliness. As described, data on patients and bed usage were derived from a variety of aggregated returns with HIPE administered by the former Office of Population and Censuses and Surveys (OPCS), the Mental Health Enquiry and regional HAA systems. These systems were fragmented and complex and a replacement information system seemed essential (28). This need was further compounded by the Government Review of Statistical Services conducted by Sir Derek Rayner in 1980 (29). The emphasis of this review was that data should only be collected to serve the needs of government and that there was no reason for the government to act as a universal provider of statistics. This led to a reduction in spending on government statistics. One consequence was that many health statistics for England were not published for a number of years.

In response to these issues, a Steering group on Health Services Information was established in 1980 to review NHS data collection. It was chaired by Edith Körner and was one of the Thatcher government's earliest management initiatives. The Committee's remit was to establish what data were needed by administrators at district level in the NHS. It did so by defining a new set of aggregated returns and a new national system of hospital statistics, the Hospital Episode Statistics (HES). The main purpose of collection was to improve management effectiveness and efficiency rather than to evaluate hospital care. (3; 30)

The Steering Group published its recommendations in a series of reports.

The first report 'A report on the collection and use of information about hospital clinical activity in the NHS' was published in September 1982. (3) It was concerned with care and diagnostic services provided on hospital premises (except radiotherapy), consultant outpatient clinics, day care facilities and those related to registerable births. It set out the format for a common spine of information, to which other items could be added for local use, but always retaining a core of essential data to allow the national assessment of comparative performance. This minimum dataset (MDS) defined the basic information requirements for local management. A subset of these data would then be submitted to the Department of Health and Social Security for central collation and analysis. Data were to be aggregated on financial rather than calendar years to aid comparability with data from financial systems.

The report recommended the collection of these minimum datasets 'by a single patient information system, on all patients who occupy a bed in a ward', on a district health authority basis. This included private patients treated on NHS premises. It recommended that there should be two basic components of a patient information system. These were:

- Finished Consultant Episode (FCE) – the care given to a patient in hospital under the care of one consultant, replacing the previous measure of inpatient stays.

The Finished Consultant Episode is essentially a single episode of care which ends when a patient has completed a period of continuous care under one consultant and is either transferred to another consultant or is discharged. A patient cannot undertake concurrent consultant episodes but one admission can lead to more than one consultant episode.

- Ward stay – the time a patient stays on one ward.

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Data could be aggregated into the district spell, the total continuous stay of a patient in one or more hospitals in a district. The system was to be capable of identifying admission, defined as the beginning of the first consultant episode, discharge, the end of the last consultant episode, and transfer at the end of any consultant episode or ward stay except the last. Two separate sets of data were to be incorporated, clinical data in the form of diagnoses and operative procedures, and non-clinical data needed at discharge or transfer.

The MDS was divided into six parts:

- 1 Data for merging and linking information about an individual patient
- 2 Personal details of patients admitted
- 3 Data about referral for admission to hospital
- 4 Data about the use of hospital resources and facilities
- 5 Data about discharge from hospital care
- 6 Data to classify patients by speciality, clinical or diagnostic groups

Table 38, Appendix B, shows the data items specified in the report.

For various reasons a number of data items were not included in the original specification of the MDS. The patient's name was considered unnecessary for management purposes and there was no national unique identification number such as the NHS number. Social class, ethnic origin, place of birth, religion, follow-up arrangements on discharge, vaccinations given, address, and resistant drugs were also omitted. Some of these absent fields would have been key in the application of the dataset to measure and monitor access to health care.

It was acknowledged that there was a need to capture data in certain specific types of care, namely care at delivery and care of long stay psychiatric patients.

Birth data are complex because a unique record must be generated for each baby and linked to that of the mother. To address this the Steering Group recommended that the MDS for each registerable birth should be divided into:

- MDS of the mother
- MDS for each baby
- Delivery/birth notification for each baby
- Data items obtained from the registration of each birth

In addition the report outlined optional datasets identifying maternity and neonatal options(31)

The report also recognised that special data were required for patients committed to long stays in health institutions. In the first instance, 'we recommend that an annual census be carried out on an agreed day on all patients who have been in mental illness/mental handicap [sic] units or hospitals for a year or more, and on all detained patients'.(3)

The six final reports were published between 1982 and 1984.(3; 32-36) The government decided to back the national implementation of the Körner recommendations in April that year. The recommendations were implemented in 1987/88 except maternity data collection which was delayed. The review proposed that regional health authorities (RHAs) should submit HES hospital activity data quarterly to OPCS. In addition data from aggregated returns were to be submitted annually from RHAs to the DHSS, including returns about

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private hospitals, NHS patients in appropriate non-NHS facilities under contract, and data from the annual psychiatric census.

Since this time most published NHS statistics have been based on the Steering Group's recommendations. A criticism from the outset was that these were primarily directed towards supporting management and in particular the functions of the district general manager, rather than meeting clinical or public health needs or facilitating epidemiological research.

3.2.2 Episode-based data: HES and the Admitted Patient Care Commissioning Dataset

The vast HES database contains records of the inpatient care of all patients admitted to NHS hospitals in England approximately 12 million records each year. HES is used for a variety of purposes including generating comparative information for use in planning, monitoring and evaluating health services.(37)

Data items in HES are an extract of those in the Admitted Patient Care Commissioning Dataset collected since the implementation of the Körner review for every NHS consultant episode. The full Admitted Patient Care commissioning dataset can be seen in Table 29, p296, Appendix B. The name was changed from 'contract' minimum dataset to 'commissioning' in April 1999 to reflect changes set out in the 1997 white paper 'The New NHS: Modern, Dependable'(38) which led to legislation which abolished the internal market. HES records are extracted from the NHS-Wide Clearing Service (NWCS) database quarterly.

The key difference between HES and the Admitted Patient Care commissioning data is that HES is made available only after the data have been cleaned, validated, with a number of fields derived or added, and 'frozen' with no further changes or additions made after it has been published. This is the inpatient dataset used to compile NHS performance ratings and indicators, in particular Clinical Indicators, data published in the annual 'Compendium of Clinical and Health Indicators', and to answer Parliamentary Questions.

Each HES record contains 82 fields of data. The items fall into five broad categories: data concerning the contract; patient details; details of diagnosis/care in the consultant episode; discharge details; and provider spell, which relates more to the whole period of care, and whether the admission was emergency or elective. Diagnoses are coded using International Classification of Diseases codes (ICD10)(39) while clinical procedures are coded using the UK Classification of Operative Procedures OPCS4(40) codes. Core HES data items are shown in Table 30, Appendix B.

HES data can be used to monitor access to acute health care services because they include some demographic data including, patients' postcodes, electoral ward and borough. Therefore rates can be related to social data derived from the census such as ward-based measures of deprivation, and more detailed geographic analyses can be undertaken.

HES was designed to count FCEs rather than numbers of admissions or individuals treated. Episodes can however be linked to count the number of spells from admission to discharge in an attempt to overcome this restriction. From 1997/98 onwards NHS numbers were included providing the means to link successive episodes of care for the same person. The NHS number is a unique ten character number assigned to every individual registered with

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the NHS in England and Wales. The current style of number was introduced in 1996, replacing a variety of inconsistent predecessors. It can be used as the common identifier for patients receiving care from different NHS organisations from birth onwards. The NHS Number Programme is now part of the NHSIA's Standards and Service Support Directorate.

HES Tails

In addition to the core HES items, data are also collected on special types of care in what are often referred to as HES 'tails'. These are three additional datasets which can be appended to the general record. Augmented care items (Appendix B, Table 31), maternity data for delivery and birth records (Appendix B, Table 32) and psychiatric data in (Appendix B, Table 33).

The Augmented Care Tail has been collected for intensive care and high dependency care(30) since October 1997.

The maternity tail contains data about labour and delivery. In 2002-03, maternity tails were still missing for 28 per cent of deliveries in England, either if maternity units do not have a computer system or if it is not fully linked to the corresponding hospital system.(41) Unlike the rest of HES, it should include births in private hospitals and at home but many are missing. Data from Maternity HES are now published annually in a series of statistical bulletins, the fifth and most recent being for 2002-3 published in April 2004.(41)

The Psychiatric Tail is collected each year for the approximately 27,000 people admitted to psychiatric departments remain in hospital at the end of the HES year.(42) These represent long-term patients, both voluntary patients and people detained under the Mental Health Act. To capture data on these patients, a special psychiatric census is carried out at the year end. Appendix B, Table 33, shows the data items included in the HES Psychiatric Census. Up to 1986, statistics on formal admissions to all psychiatric NHS hospitals and units including special hospitals, were collected through the Mental Health Enquiry and collated by calendar year.

The processing of HES data and the quality of episode-based statistics

The data about patient activity in the NHS are generated by the Patient Administration Systems (PAS) located in trusts and passed to HES through the NHS-Wide Clearing Service (NWCS).

PAS data are both administrative and clinical. Administrative details, including patient details, are usually entered by clerical staff. Clinical data, relating to diagnoses and procedures, are entered by clinical coders either directly from patients' case notes, or from discharge summaries prepared by the health professionals, usually doctors, who are responsible for the care of the patient and are required to code diagnoses and procedures.

These data are then entered into the trust's PAS system for submission to the NWCS. Some PAS systems are capable of forming limited validity checks on the data, but many systems are outdated and are not designed to process the type and volume of data currently required. As a result they can be very slow and such checks are not always performed.

The timely provision of admitted patient care records to the NWCS, complete with clinical information, is a performance measurement for NHS trusts. The Data Quality Reporting Service (DQRS) of the NWCS reports on the quality of monthly data submitted. Reports

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focus on key data fields and show the number and percentage of valid records sent. The West Midlands Data Quality Team analyses these figures and produce individual trust and strategic health authority reports which include local and national benchmarks. These reports are disseminated quarterly to trusts, primary care trust commissioners and strategic health authorities. An annual report is compiled and contributes to the trust's stakeholder meetings for Clinical Governance Reviews. It is important to note that the focus of NWCS's checking is on technical correctness and completeness. Therefore inaccurately coded records can still be passed on to HES.

Once the HES subset has been extracted from NWCS, it undergoes a detailed process of cleaning and validation. Whereas NWCS is simply an exchange and depository service, the HES team is held publicly accountable for the information placed in the public domain.

This series of processes is as follows: (43)

- 1 Verification checks to see whether data are from a known source and for the expected data year
- 2 Auto-cleaning of data where possible, overwriting inappropriate values
- 3 Validation audits of the field contents so that a comprehensive set of quality reports can be generated
- 4 Calculation of derived data from data items already held within the database

Some data items are auto-cleaned using preset and available rules, and validation checks are carried out on over 20 fields. These do not amend the data but show the ratio of valid to invalid codes. Data items such as the Health care Resource Group (HRG) and length of spell are derived from others. Some data are cleaned manually and reports specifying changes or amendments are sent back to trusts for agreement.

The process is detailed and exhaustive and described in considerable detail in the publication 'How HES Data are Processed'.(43)

Because of the importance of HES for national and local policy making, monitoring geographical inequalities in health, performance management, research and resource allocation, fairly extensive checks are made to assure the completeness and accuracy of the data.

A summary measure of the quality of HES data is one of the NHS Performance Indicators for NHS trusts. This indicator is data quality; summary measure of Hospital Episode Statistics data quality for NHS trusts with inpatient activity.(44) The Data Quality Indicator consists of 14 'components'. The arithmetic mean of these components provides a composite score for the quality of HES data from each trust.

Components of the Data Quality Indicator:

- FCE coverage
- administrative
- record linkage
- ethnic coding
- admissions
- discharge

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- diagnosis
- operation codes
- operation dates
- maternity coverage
- maternity data
- new NHS number
- augmented care coverage
- augmented care data.

Most components cover a group of related data fields in each HES record. If any field that makes up part of a component is missing or contains an invalid code then that component will fail. The score for the component is then calculated as the proportion of HES records that pass the tests applied to all relevant fields. A component will score 1 if all HES records from the trust have a valid code in all data fields examined for that component or 0 if all the HES records from the trust have an invalid code in one or more of the data fields. Minimum standards for the quality of HES data have been established by the NHS Information Authority(45) and are listed in Table 2, below.

All provider trusts are required to go through a three stage Data Accreditation Process. Trusts have to undertake an internal assessment or checklist review. Then the data processes and outputs are submitted to internal review and external audit. Standards for accreditation for data outputs are high, as can be seen in Table 2. All acute trusts are required to apply for and maintain their data accreditation every three years.

Table 2 Minimum standards for admitted patient care data items

Key data item	Percentage complete and valid
NHS Number	90
Postcode	98
Ethnic Group	95
Organisation Code (Code of Commissioner)	98
HA of Residence	99
Commissioning Serial Number	95
Code of Practice of Registered GP	98
Administrative Category Code	98
Legal Status Classification	98
Specialty Function Code	98
Primary Diagnosis Code	95
Patient Classification Code	95
Admission Method Code	98
Source of Admission Code	98
Discharge Destination Code	95
Discharge Method Code	95

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HES data have been criticised by health services researchers and others because of the quality of some of the key fields that relate to health inequalities, for example the coding of ethnicity.(46) A study of the ethnicity field found high levels of invalid coding. The authors concluded that the incompleteness of ethnic coding and questionable quality of the data made it impossible to interpret the relative access of the ethnic minority populations to hospital services. (47)

There are also particular concerns about the coverage of maternity data as there are maternity tails for only 72 per cent of all births in England. The reason for the shortfall is due to local IT arrangements in some hospitals and trusts, where the maternity system fails to communicate with the hospital PAS system while others have no maternity system and rely on paper records. As a result the hospital is unable to provide the maternity tail to the NHS-Wide Clearing Service and thus to Maternity HES. Coverage has improved in recent years, increasing from 66 per cent of deliveries in 2000-01 to 72 per cent in 2002-03.(41;48)

Significant improvement is not expected in the short term as the NWCS is currently undergoing re-tendering. This makes it unlikely that there will be IT investment in trusts to improve communication between systems until 2005-06 when the tendering process will be complete.

Maternity HES also covers home births but data were collected for only 15 per cent of home births in 2002-03 and very few of the small number of private hospital births.(41) There are other problems with HES maternity and neonatal data. If a baby is ill and admitted to a neonatal specialty this admission is not normally linked to the HES birth record. Mothers' ethnicity is required in HES for births but is under-reported. Other data, such as parents' social class are potentially available through linkage with birth registration. A feasibility study of linking maternity records from HES to birth records held by the office for National Statistics found that it was possible to link 99 per cent of records after several stages of matching. This means that HES data could be enhanced by social class data from birth records, and birth records data could be enhanced with a more complete picture of ethnicity, if maternity HES data was complete.

In HES as a whole concerns have been expressed by the former Commission for Health Improvement about the completeness and accuracy of coding of procedures and diagnoses.(49-51) This can be compounded if the original data are poorly completed by doctors. A report by the Audit Commission in 2001 found that there can also be inconsistency between and even within trusts in the way that coders operate. For instance in some trusts coders rely on case-notes while in others they may refer to junior doctors to ensure a higher degree of accuracy.(46)

The aim is to agree any coding changes resulting from the HES data cleaning process with trusts. This is not always possible, and trusts are sometimes unable to check with those responsible for the original data. Cleaning error reports sent back from HES to trusts can be treated with scepticism by managers and clinicians, especially where a trust has supplied poor quality data and the changes have not been agreed.(46)

The Audit Commission's report found that data quality assurance was satisfactory in only sixty-one per cent of NHS trusts and was completely absent in nine per cent. Only one in four trusts had a fully developed data quality policy.(46)

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Responsibility for data quality previously rested with regional health authorities but after their abolition, responsibilities for data quality were not transferred elsewhere.(46) Most of the regional offices which succeeded them were concerned about this and some took an active part in clinical coding audits, but these regional health authorities were abolished in the mid 1990s.

The timeliness of HES data have been criticised in the past. After being aggregated annually and then cleaned, the data were not available until eight months after the HES year end. Now HES refreshed quarterly with data from the NWCS, but many trusts will still find this time lag reduces the usefulness of HES data.

Whilst FCEs can be linked together as 'spells' of care there is still potential for patient throughput to be overestimated as not all FCEs may be correctly attributed to the appropriate spell.

Lastly, as HES is concerned only with patients ill enough to be admitted into hospital as an inpatient or a day-case, it cannot inform on the health needs of other patients. Even for the patients included, datasets are limited as they do not reflect theatre times, or the multidisciplinary nature of patient care.

Ownership and control of HES and episode data

HES was the responsibility of the Department of Health at the time of the project but this was passed to the Information Centre in 2005. The NWCS remains the responsibility of the NHS.

Initially HES analysis was undertaken by OPCS. It was then contracted to IBM Global Services. The contract for providing HES data moved in August 2003 from Hays Consulting and Solutions Group to Northgate Information Solutions.

Historically regional health authorities collected data from trusts and submitted them to HES. The NHS-Wide Clearing Service (NWCS) was introduced to exchange data electronically. The primary function of NWCS was to deliver contract data submitted by a provider to the correct recipients which would be purchasers, district health authorities of residence, if different, and the Department of Health. Thus the system incorporated a managed message handling function containing special routing to deliver contract data to recipients, as well as an NHS-wide database to store activity data.

The contract for the NWCS was awarded in 1995 as a Private Finance Initiative (PFI) arrangement to AT&T which developed the ClearNET system. This has been administered by McKesson since 1999. The contract due to end in 2004 was extended until May 2005 with transition to a new service programmed to take place by 31 March 2005. The re-procuring and implementing process was managed on behalf of the NHS by the NHS Information Authority (NHSIA).

HES is the principal source of NHS inpatient activity for determining access to health care in England. Data from it are published in Department of Health statistical bulletins and on the DoH web site.(52) Only limited data are made available free of charge and charges are applied to answering more complex queries. If work costs less than an hour to produce there is no charge. From one to seven hours' work costs £20 per hour and more than seven hours costs £50 an hour. Online interrogation of the database was available to HES users only in the DoH, NHS Executive and HES Safe Haven pilot sites. It is possible for other

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users to make applications for extracts from the HES database. Access to HES has been extended to Directorates of Health and Social Care, Government Offices for the Regions, strategic health authorities and Regional HES Services accessed via public health observatories.

Organisations may apply to access and use extracts of data from the NWCS database. Access is controlled by the NWCS Management Board, which takes advice from the Security and Confidentiality Advisory Group (SCAG). Applicants must justify access to each data item requested, and state the purposes to which the data will be put.

Data may generally be used for health care research, strategic planning, performance monitoring/management and benchmarking by universities and other research organisations, cancer registries and commercial companies who wish to use the data to provide services to NHS organisations.

Ownership stays with the NHS but may be used for health care research, planning, performance management and benchmarking by other organisations. Commercial companies granted access to use the data to provide services to the NHS, include:

Caspe Health care Knowledge Systems (CHKS), is a private consultancy of NHS performance analysts undertaking hospital benchmarking. The NHS set up a contract with CHKS so that trusts could provide their minimum datasets and receive summarised data comparing their performance with trusts allocated to comparable peer groups. Comparisons might be at trust, hospital, specialty and procedure or diagnosis level. CHKS was formed out of a joint venture in 1990 between the King's Fund and CASPE Research and has been building a database of acute clinical activity since 1992. It is known for its '40 top hospitals club', rating performance according to 13 indicators including death rates, waiting times for treatment, length of stay and re-admission rate after discharge. About half of acute trusts subscribe to CHKS.

Another company, Dr Foster, was a small independent publishing company established in 2000 whose chief executive is a former Sunday Times news editor. Dr Foster claims to provide the 'only authoritative and independent guides to UK health services in the public and private sectors' and its aim is to 'empower consumers and their doctors to make the best possible choices'. At the time of the project their information is compiled from data provided by trusts, to the Department of Health, or in some cases, directly to Dr Foster. In 2006 it set up a joint venture with the Information Centre.

The contracting out of these activities to commercial companies can undermine the collection of national routine data. The potential threat to national systems is not only that data might be no longer collected, but that investment and development of such sources moves national statistical data into the sphere of private property. Small unlinked data sources are liable to be used and quoted rather than routine, national statistical data which are not subject to the same protocols.

After the abolition of regional health authorities and their information functions, so-called 'safe havens' were set up to allow secure access to HES regionally. One of these, West Midlands HES Safe Haven, based at the University of Birmingham, commented that:

'The Functions and Manpower Review led to the demise of the RHA databases and analytical services. These were to be replaced by increased access to HES at Department of Health, the Clearing House service and commercially run databases. However, it is becoming apparent that

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there is an information 'gap' between what used to be available and what is currently being provided'.

It therefore aims to provide enhanced data on the health of the population and performance of the hospitals of the West Midlands Region. In addition, the project provides comparative analysis for studying health variations and for benchmarking provider performance. This is key when looking at health inequalities, social exclusion or in the development and monitoring of local services and Health Improvement Programmes.

The data available at HES 'safe havens' is not as timely as NWCS data but is thoroughly validated and cleaned as they are derived from the HES dataset. The arrangement has the advantage of providing data for the whole region and not just a particular trust. The completeness of coding enables analyses of HES data which go beyond the main diagnosis or procedure.

Future developments

The Mental Health Minimum Dataset (MHMDS) was developed to improve local and central information on mental health service use and need. It is anticipated that this will be the major source of information relating to mental health currently collected through HES, the Common Information Core, and Körner aggregated returns.

With the exception of inpatient data, currently all mental health returns sent to the DoH from trusts are limited in that they are in the form of aggregated tables rather than individual records. Therefore the DoH commissioned the NHSIA to oversee the implementation of the MHMDS. (53) From 2003/04 onwards this will be produced by all trusts providing mental health services in England. Plans for the MHMDS were cited in Information for Health(54) and the dataset is being implemented in tandem with the development of the Mental Health Information Strategy. The dataset shown in Appendix B, Table 34 forms the basis of a single record about a spell of mental health care provided to an individual using special mental health services by a provider trust. Each trust will transmit MHMDS data to the Department via the NWCS periodically. As it was developed prior to publication in 1999 of the National Service Framework for Mental Health(55) its application to assessing National Service Framework standards is still being developed.

Limitations of the dataset are that while it relates to adult and elderly patients in contact with specialist mental health care services in England, it does not cover mental health services provided only by primary care, social services or independent providers. Therefore it cannot provide information on access to services since it is not known how many people were not admitted. It can be used to examine access to mental health interventions for those who are admitted however.

A number of changes are being made to the pattern of delivery of acute hospital care. It is unclear whether arrangements are in place to capture episodes of care in non-traditional settings. As policy shifts mean that increasing levels of activity take place in a range of non-NHS settings, there could be significant losses to data collections if such episodes are not captured, weakening the capacity of routine inpatient datasets as a tool for planning, epidemiological research and monitoring care. Examples of such settings include but are not limited to the following:

- NHS funded care for patients treated abroad, for example the scheme launched in southern England in 2002 to reduce NHS waiting lists by

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sending patients abroad for elective care at a hospital in Lille, France and at eight hospitals and a day care centre in northern Germany.

- Elective care activity in Diagnostic and Treatment Centres (DTCs), many of which will be built and run by the independent sector.
- Hospital trusts that attain foundation status, whose accountability will switch from the Secretary of State for Health to an independent regulator.
- Intermediate care beds which could be NHS funded or local authority funded.
- NHS funded care in nursing homes.
- 'Super' GP Surgeries undertaking treatment traditionally carried out in hospital.

The NHS financial framework is also subject to much change as outlined in implementing the ten year plan for the strategic direction of the NHS set out in the NHS Plan. The development of funding flows or payment by results directly related to volumes of activity undertaken is regarded by HES as the biggest driver of change in information recording in a decade, with payment based on a national standard price tariff. Tariff categories are based on Health care Resource Groups (HRGs). The new system is expected to be fully operational in April 2007, with foundation trusts possibly being given the option to adopt the tariff entirely in 2004. This will mark a change to payment based on spells rather than episodes.

The tariff is being extended in 2003-04 to cover outpatients, critical care, accident and emergency and specialist services. These changes are likely to impact on the recording of activity. For example coding is likely to be complete and timeliness will improve, as the primacy of HRGs provides a direct incentive to improve the completeness and depth of clinical coding. Trusts will not be paid for spells where coding is incomplete. This will have an effect on comparisons made over time, before and after the implementation payment by results. Spells will be paid according to the tariff for the 'dominant' HRG. In time such changes could affect the sustained use of the currency of the FCE, although consultants are keen to retain episode based analyses. (56)

One implication is that it may become more difficult to use HES to identify workloads and outcomes. There could be an incentive to treat rather than not doing so, and increase referral rates. HES data trends could therefore be interpreted as worsening morbidity of patients, or conversely improved access, but this would be artefactual due to more episodes being recorded. As change is likely to be implemented very quickly there are possibilities that HES data might change dramatically in ways that are not anticipated.

Examples of how HES data have been used to measure and monitor access from the literature review

Some examples of how HES has been used to measure access to health care are shown below:

- Socio demographic analysis of access to acute hospital services, e.g. measures of deprivation, ethnicity, using HES data.
- HES and 1991 census data were used to examine the relationship between area deprivation sources and acute emergency admissions for cancers of the colon, rectum, lung and breast in south east England. Findings were that

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people living in deprived areas were more likely to be admitted as emergencies and ordinary inpatient admissions, and less likely to be admitted as day cases than counterparts from more affluent areas. Patients with lung or breast cancers from deprived areas were less likely to receive surgical treatment.(57)

- HES data were combined with socio-demographic variables to examine the access and utilisation of hospital oral surgery services. Socio-economic differences were found between those accessing elective as opposed to emergency oral and dental surgery with evidence of inequality.(58)
- The addition of ethnicity to the HES dataset extended the scope for monitoring the use of hospital care. A study in 2003 by Blackledge *et al* used episode data to look at the prognosis for South Asian and white patients newly admitted to hospital with heart failure.(59)
- There are questions about the completeness and quality of the coding of the ethnicity field as illustrated by a study of ethnic group data for hospital inpatients in the South Thames region. This found that high levels of incompleteness and poor quality data made it impossible to interpret the relative access of the ethnic minority population to hospital services.(47)
- HES data were used to compare variations in acute inpatient length of stay in the NHS in England using HES. Explanatory variables were found to include socio-economic, health status, and waiting time data, measures of access to inpatient and GP services, and measures of private health care provision.(60)
- A study of provision of carotid endarterectomy (an intervention for prevention of stroke) in the former Wessex Regional Health Authority compared regional, district and age-sex specific operation rates derived from HES with estimates of need. The study identified unmet need and conclusions included that further research was needed to evaluate strategies to improve access to diagnostic facilities.(61)

Physical access (geographic access, waiting times) to acute hospital services, using HES data

- Age and sex adjusted inpatient episode ratios were calculated from HES over a two year period for 555 census wards in Cambridgeshire, Norfolk and Suffolk to look at the effect of distances to hospital and GP surgery on hospital inpatient episodes. Results controlling for needs and provision, demonstrated possible evidence of geographical inequities limiting fair access. (62)
- A study of the use of surgery in the management of obesity found that access to surgery in two separate regions was highly variable.(63)
- In three English regions HES data were used to test the feasibility of a 600,000 population model of vascular services delivery using surgical arterial activity by trust. This included evaluating the impact on access. They found such a model feasible in urbanised regions, but not in geographically remote ones. (64)

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- The extent to which equitable access was achieved in one hospital waiting system was investigated by a retrospective study of HES data about waiting times for surgery. (65) Odds ratios were calculated associated with longer than median waiting times by age, gender, ethnicity and deprivation. For one specialty female, older and deprived patients were significantly more likely to experience longer than average waits.

Use of HES data to monitor access to acute hospital services by sector

- In 1999 (66) the completeness of HES data was tested against information obtained directly from private patient unit managers to evaluate the quality of data about private patients in the NHS. They concluded that HES underestimates the amount of such activity reported directly by NHS hospitals. HES reports are the only routine source of information on the scale of such activity.
- A separate study described the impact of private purchasing on access to hospital care in regions according to health need using details of admissions to NHS hospitals and waiting times from HES, and of patients in independent hospitals.(67) One finding was that those least deprived may make relatively more use of NHS hospitals.

There were a limited number of articles focussing on the uses of HES when considering access, despite a much larger number of studies focussing on variations in the use of services which made use of hospital episode statistics.

From those studies that were identified on the use of HES to measure access, three themes were identified as described above. The largest number of articles was concerned with socio demographic analysis of access to acute hospital services, and found evidence of inequalities. In particular, problems were identified with the quality of the ethnicity data field in HES.

HES data was able to be used in identifying geographical and waiting times variations in accessing hospital services, and one study identified a loss of data recorded in HES on private patient activity.

Despite limitations for example in data about the ethnicity and private patients, the literature review has shown that it has been possible to use hospital episode data in a number of studies that include in their findings the dimension of access to hospital services.

3.2.3 Strengths and limitations of HES and hospital activity data collections for monitoring access to health care

This is a data source that is national, nearly comprehensive and ongoing, enabling comparisons across time, place and, with manipulation, person. This enables HES to be a major monitoring tool for the prevalence of those diseases that warrant a hospital stay. Particularly if data are linked to other sources through record linkage processes which have been made more feasible through the incorporation of the NHS number, it can be used to identify inequalities by age, sex and geography. It is an important and powerful source of

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data for epidemiological research, a planning tool and determining levels of provision of health care.

Outcome, both in terms of morbidity and in-hospital mortality can be analysed by specialty or procedure. As it applies to a geographical rather than an enrolled population, diagnoses and procedures are coded in considerable detail and HES provides opportunities to derive additional useful variables to monitor access. For example, travel times can be estimated from postcode of residence and trust fields.

In addition to quality concerns identified earlier, other problems can arise when using inpatient data as a proxy measure of access to health care.

The need for health services can only be determined by using actual utilisation of health care services as a proxy measure. It is acknowledged that HES provides numerator data on episodes of inpatient care people actually receive, but not about people who need such care but do not receive it. Therefore HES is limited in its capacity to measure unmet need. Differences between areas may arise if services are provided on an inpatient basis in some areas, while in others services for people with similar health care needs may be provided on an outpatient basis, in primary care, privately, or not at all.

Comparative analyses of HES data can be affected by local differences in the level and accuracy of coding of data. There can be significant differences in the way codes are used, especially with the more detailed diagnostic codes.

A number of changes have been made to the original Körner dataset to make it more useful for measuring and monitoring access to health care. The mandatory requirement to record ethnicity, introduced in 1995/96, is one example. Studies show that this field is still under completed however. In addition, the requirement to switch to recording ethnicity data in the revised format using the 2001 census categories caused further problems.⁽⁶⁸⁾ This means that the scope for analyses of utilisation by ethnicity is limited as the data are incomplete and geographically patchy. A major limitation is that no measure of socio-economic status is included. Some analyses have used area deprivation scores such as the index of local deprivation or scores based on the postcode of residence. Such ecological analyses are unreliable as measures of differences between social groups as these exist even at the small output area level of analysis. Measures of area deprivation form a separate dimension from measures of individual socio-economic status.

The NHS number is a unique personal identifier. Adding it to NHS records facilitates linkage between hospital admissions for individuals, as well as further linkage to other health data. On the whole, this has yet to extend to agencies beyond the health service. For example it has not yet been extended to local authority social services data in order to bring together data about care from both health and social services. The current position is that social services can store and use the NHS number to support the provision of joint health and social care subject to certain controls. Work is being undertaken to address practical and legal issues which have been brought to a head by the establishment of care trusts. This includes work around data protection implications of use to the NHS numbers by social care departments, work on developing information sharing protocols, and access to NHSnet, the secure area wide network for the NHS. A pilot project established three social services authorities as demonstrator sites to look in detail at the issues associated with allowing social care organisations to access and use the NHS number and the NHS Strategic Tracing

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Service. In practice, it is hard to see how other agencies' databases will be populated with the NHS number without some difficulty.

Data can be incomplete. For example, a particular provider may not submit data for a certain time period. In particular, Maternity HES has large gaps which reduce the population-based application of data from the maternity tail. In addition the time lag in receiving HES data limits their usefulness.

All diagnoses need to be taken into account, not just the primary diagnosis. An example of the under-recording implications for certain conditions if other diagnoses are not considered is given in our case study on data about older people with mental illness.

The mental health diagnosis tends to be under-recorded with the physical diagnosis taking priority.

An important issue is the extent to which private patients receiving care on NHS premises are captured in HES data. A study which compared HES data with information obtained directly from private patient unit managers, found under-reporting of care for private patients in HES.⁽⁶⁶⁾ Reasons included the use of separate patient administration systems that failed to feed data into HES for private patients, and the omission of some provider units altogether by a small number of trusts. The study concluded that overall HES underestimates the amount of private patient activity reported directly by NHS hospitals and that there is no routine method of validating data.

As mentioned earlier, it is unclear whether routine inpatient data collections are capturing activity outside traditional NHS settings such as overseas and Diagnostic and Treatment Centres. As described in the methods Section, we sent a letter to various key personnel to ascertain how data from such episodes of NHS funded care will be captured in the future. The results are discussed in Section 4.5.

As described earlier, charges are made for analyses of HES data which are more complex than the standard tables available on the Department of Health web site.

The ongoing data collections that contribute to the admitted patient care core dataset and HES, are an important source of information relevant to access to health care services. Although the Hospital Episode Statistics have limitations arising from a system designed as a management tool, the lack of direct socio-economic markers, and the acknowledgement that the system includes information on only those who received services as opposed to those who did not, it remains a highly important dataset. It is powerful because of its national coverage, its degree of standardisation, and because of the length of time over which data have been collected.

To examine and monitor patterns in access to acute services it is important to maintain this collection of data on episodes of care, wherever treated and however funded. Therefore it is vital to ensure the requirement to submit this data are extended to the various new arrangements for the provision of care. In addition it is essential to ensure that the required data can be derived from the National Care Records Service.

HES data can contribute to a population-based approach to the measurement and monitoring of access to inpatient acute services. Crucially, in order to monitor access, data should be available to assess the arrangements and to take account of the changing delivery of care. Without comprehensive data it is not possible to monitor equity needs or utilisation of care.

3.3 Aggregated health service activity data

This section describes those data that are submitted to central government in the form of aggregated central returns, where data are pooled locally before submission to the Department of Health as opposed to being submitted individual records. The principal aggregated returns relate to inpatient hospital activity, outpatient activity, primary care activity and prescribing.

3.3.1 Aggregated hospital data

Aggregated hospital inpatient activity data

Aggregated hospital activity returns contain counts of numbers of events or activities in individual hospitals or trusts. Such data can provide an overview of trends in access to hospital over time by specialty.

The KH03 return was introduced to collect data about bed use, replacing the original SH3 hospital return. The Körner report had recommended that the SH3 be superseded by data collection based on patient information resulting from minimum datasets to allow analysis of bed usage by consultant episodes, ward stays, any aggregation of ward stays and district spells. Despite this a second return, the KP70 was introduced to collect aggregated data about hospital activity.

Data on NHS beds are collected annually from NHS trusts through the KH03 return, which records information on the numbers of available beds, both funded and staffed, and the number of those beds which are occupied. Bed occupancy is recorded as the sum of the length of stay of all episodes which ended during the year. Data on bed availability and occupancy reflect the position at midnight on each day, averaged over the year. Beds are classified by the ward in which they are located.

The KH03 return was revised in 1996-97. The main changes were:

- Changes in ward categories
- Counts of occupied bed days were added alongside the counts of available bed days
- Counts of beds in residential care wards and homes managed directly by the NHS were added
- A new classification was added for Accident and Emergency departments

Data on bed availability and occupancy, outpatients and ward attendances in England, were previously published in hard copy and are now published on the hospital activity pages of the Department of Health web site (69), while data on ordinary and day case admissions are available from the HES pages of the Department of Health web site. The annual publication 'Ordinary and day case admissions' based on the KP70 hospital activity return was no longer produced after 1997/98 as the KP70 was discontinued on the grounds that it duplicated data collected through HES.

Nationally aggregated data are vital to monitor bed utilisation over time and place. Although it is recognised that utilisation differs from access, questions about access can be raised from the data. It is possible to monitor national trends in the number of available beds by broad specialty, shown in Table 3. This makes it possible to identify the areas of care,

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mental illness and learning disability, particularly affected by reductions in the number of beds.

The ability to compare trends over time has been restricted by the definitional changes made to the KH03 in 1996. Detailed data from aggregated returns are no longer published and the abolition of the KP70 led to some loss of information despite the overlap with HES.

As with HES and episode-based datasets there are questions about how aggregated data will be captured in non-traditional settings. As with HES data, aggregated returns do not adequately capture activity and resources in the independent sector. This limits our ability to comprehensively monitor hospital activity, wherever patients are treated and however funded.

Table 3 Average daily number of available beds, by sector, England, 1995-96 to 2001-02

Sector	Thousands						
	1995-96	1996-97	1997-98	1998-99	1999-00	2000-01	2001-02
<i>All specialties</i>	206	199	194	190	186	186	185
<i>Acute</i>	108	109	108	108	107	108	109
<i>Geriatric</i>	34	32	30	29	28	28	28
<i>Mental illness</i>	39	38	37	36	34	34	33
<i>Learning disability</i>	13	10	8	7	7	6	6
<i>Maternity</i>	11	11	11	10	10	10	10

Source: Department of Health form KH03

NHS outpatient activity data

Aggregated outpatient data are collected nationally, as counts of numbers of outpatient attendances. In addition, since October 2001 it has been a requirement to exchange outpatient data via the NHS Wide Clearing Service in the same way as for inpatient episodes, using a national dataset for all consultant outpatient attendances. This development came after many NHS trust providers started routinely and voluntarily transmitting these and other data to meet their own requirements. Such a dataset is potentially valuable in monitoring access as many conditions that traditionally warranted an inpatient stay are now treated in hospital on an outpatient basis.

Prior to 1987, data about outpatient activity were collected through the aggregated hospital data SH3 return.

The first report of the Steering Group on Health Services Information published in 1982 included recommendations for a dataset for services provided in consultant outpatient clinics which was first implemented in 1987/88 and data were returned to regional health authorities for forwarding to the Department of Health and Social Security (DHSS).

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The following data items were recorded for each clinic:

- name of clinic with record of function, speciality and consultant/s in charge
- number of intended clinic sessions
- number of actual clinic sessions
- number of clinic sessions cancelled
- numbers of patients seen, categorised as referrals or consultant initiated
- attendances by private patients
- non attendees
- additional data to cover date request received (referrals); whether appointment took place, with reasons for any non-occurrence: and outcome.

The same report recommended that the components of a minimum dataset for individual attendances should include:

- district patient number
- sex
- postcode of current home address
- date of birth
- marital status
- code of GP
- category of patient
- dates of appointments
- source of initial attendance (whether by GP, emergency admission by consultant in charge, referral from A&E, following home visit by consultant in charge, referral from another consultant, self referral, or other referral)
- code of consultant in charge
- code for location of the clinic
- date discharged.

The full contents of the Outpatient patient Attendance Commissioning Dataset(70) collected since 2001 are shown in Appendix B, Table 35. The dataset includes date of birth, sex, address and postcode, but not ethnicity or social class. As described, the mandatory outpatient dataset is collected for every attendance at a consultant appointment.

The access framework is applied to the outpatient attendance commission's dataset in Appendix C, Table 64.

Consultant outpatient attendance activity and accident and emergency services activity are recorded in aggregated form on the annual Körner return KH09 collected for every NHS hospital in England. This collects information on the numbers of first and subsequent attendances by patients at consultant outpatient clinics, the numbers of written GP referrals and private patient attendances by speciality, and the numbers of first and subsequent attendances at accident and emergency departments. It also collects data on numbers of patients who did not attend. Total attendances at consultant outpatient clinics include those by both NHS and private patients.

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The KH09 return applies to all NHS hospitals in England. The smallest level of aggregation is NHS trust. It is ongoing and compiled annually by financial year. Data are usually published in the autumn through the annual statistical bulletin 'Hospital Activity Statistics'. Data which used to be published in the booklet 'Outpatients and Ward Attenders England' are available online on the hospital activity pages of the Department of Health web site.(71)

An extract from the attendance based outpatient dataset has been included in HES, since 2003-04 and made available on a similar basis to other HES data.

This is extracted from the outpatient commissioning dataset in the same way as for inpatient data, following new requirements driven by funding flows and 'payment by results' described in Part 1. As trusts will only be paid for episodes coded including outpatients, this change will ensure completion of coding and so recording of outpatients should improve. Although such completeness is to be welcomed, it will be difficult to compare trends before and after these changes.

Strengths and weaknesses of Aggregated Hospital Activity Data

Aggregated data are limited in that they do not contain data about the characteristics of patients and cannot be linked with other data. Despite this, they provide essential data for making comparisons and monitoring trends by specialty and trust to provide some indication of levels of access over time.

Now that the attendance based dataset is collected via the NWCS in the same way as for inpatient episode based data, this is likely to become a much more useful source. It is particularly important to collect outpatient data in a consistent and standardised way at a national level due to the continuing trend in treating patients outside an inpatient setting whenever possible. Although the dataset includes items for monitoring geographical access, it is even more limited than inpatient data for measuring socio-demographic differences as the dataset contains neither ethnicity nor social class.

3.3.2 Aggregated primary care data

Following a range of NHS policies that continue to shift the emphasis from acute secondary settings to primary health care, the need for good quality, population based primary care data becomes increasingly important for monitoring access to care by different groups within the population. To do so requires not only clinical information but also socio-demographic details of patients and their health care. This section describes the various primary care data sources and evaluates their capacity to monitor and measure access to health care.

The General Medical Services database

The main centralised source of information about general practice is the General Medical Services (GMS) database. The GMS Statistics division of the NHS Executive collects statistical returns twice yearly from PCTs for each registered practice in England and Wales. Information collected includes the age and sex breakdown of each practice population, details of the practice such as staffing, list size, GP characteristics, and details of service provision such as asthma and diabetes services and immunisation. The items recorded are listed in Appendix B, Table 36. Most items relate to the characteristics of the practices

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themselves rather than their patients and are described more fully in the section on staffing.

The National Health Applications and Infrastructure Service (NHAIS) (Exeter) System

The NHAIS (Exeter) System is a software system used by in England and Wales for the administration of cancer screening programmes and patient registration and contractor payments. Its main functions are: patient registration, prescription certification, breast screening call/recall, cervical screening call/recall, NHS organ donor register, and GMS quarterly payments. A large database with an excess of 60 million records which include the name, address, date of birth and registered GP for each patient. It is linked electronically to the National Health Service Central Register in Southport. The database is used to facilitate screening programmes and the capitation payment for GPs. Data are not routinely published or available from this database, although NHS users are able to do demographic analyses of the patients registered.

The General Practice Research Database

The General Practice Research Database (GPRD) has been described as 'the largest and most complete database of anonymised, longitudinal patient records from general practice in the world'.(72) It was established in the late 1980s to study outcomes of prescribing in general practice. Its unmet aims include supporting public health research, maintaining high quality data and services, and protecting patient confidentiality.

Ownership of the GPRD has undergone various changes since being established by VAMP Health Ltd. in 1987. It was subsequently owned by Reuters, then donated to the Department of Health in 1994. ONS operated the database from 1994 to 1999 then transferred it to the Medicines Control Agency in 1999. Data recorded cover four main areas, prevalence of disease, GP outpatient referrals to secondary care, prescribing of drugs, and disease management.(72)

Demographic data, including age and sex of the patient are recorded but ethnicity and social class are not routinely recorded. A range of patient information, including smoking status, height, weight, immunisations and laboratory results is recorded.

Other information collected from GPs includes medical diagnosis, all prescriptions, events leading to withdrawal of a drug treatment, referrals to hospital and treatment outcomes, including hospital discharge reports. Plans to link the GPRD to HES are under discussion.

Data are collected on approximately three million patients registered with 400 contributing UK general practices which are required to use 'In Practice Systems VISION software'. Practices were originally recruited on a voluntary basis by VAMP which aimed to achieve a representative sample of the national population.

Participating practices follow agreed guidelines for the recording of clinical data and submit anonymised, patient-based clinical records on a regular basis. Diagnostic data are recorded using OXMIS and/or READ codes and terms. Drug information is recorded using either VAMP or Multilex drug codes which can both be mapped to British National Formulary (BNF) codes. Data from each practice are routinely examined after each collection to assess whether GPRD's research recording agreement has been followed. Practices are informed if

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they fail the quality assessment criteria and must improve their recording procedures and amend records.

Access to GPRD data

Data are licensed for use only for medical and health research purposes on a non-profit basis to academic institutions, government and health services researchers and pharmaceutical industry researchers. Use of data is restricted to clinical research planning, drug utilisation studies, studies of treatment patterns, clinical epidemiology, drug safety studies, health outcomes, pharmacoeconomics and health service planning.

People wishing to use GPRD data are charged according to a four level scale. Level three, which gives restricted on-line access and query tools, costs from £55,000 per year for two named users, while level four, which gives on-line access to the full dataset and query tools, costs £300,000 per year. Provision of a data extract on CD-ROM for a single study costs from £15,000 plus charges for time spent on extraction.

Data from the GPRD have been published by ONS in 'Key Statistics from general practice: Analyses of morbidity and treatment data, including time trends, England and Wales' (73) available from the health and care section of the National Statistics web site. It contains data for 211 practices in England and Wales. These practices submitted data that passed quality checks for the five year period 1994-98.

Morbidity Statistics from General Practice (MSGP)

The National Surveys of Morbidity were carried out jointly by the Office of Population Censuses and Surveys (OPCS), the Royal College of General Practitioners and the Department of Health and their predecessors. A series of four surveys collected data about all consultations with a sample of volunteer GPs for one year periods in 1955-56, 1970-71, 1980-81 and 1991-92 respectively. Data were recorded about each episode of illness leading to one or more consultations within the survey year, even if a prescription was not issued. The date and place of consultation, diagnosis, whether it was the first consultation in the current illness, and whether the patient was referred elsewhere were recorded. Information collected included Read diagnostic codes and severity category assigned by OPCS. Practice and patient identifiers were also recorded for each record.

The survey recorded details on the doctors' or practice nurses' perceptions of why people consulted general practice. These were linked to socio-economic characteristics of each patient. This makes it a good resource for studying patterns of access and utilisation of health care. In 1991-92 the last survey found that there were ten per cent fewer consultations for people from social classes IV and V aged 16-44 than from those in social classes I and II. (74; 75)

All patients registered with the survey practices were interviewed, and socio-demographic data including marital status, housing tenure, ethnicity, household composition and occupation, were recorded.

The fourth survey in 1991-92 sampled 60 practices in England and Wales and over 500,000 patients, a one per cent sample of the population of England and Wales. Socio-economic data were available for eighty-three per cent of the contacts with a doctor. The sample is based on volunteers rather than a random sample because of the work involved in

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participating, and was restricted to practices with specific computer systems. These factors are likely to have introduced some biases in the practice sample.

In comparison with the 1991 census it was representative of the population of England and Wales in terms of age, sex, marital status, tenure of housing, economic position, occupation and whether living in urban or rural area. There were small differences in social class composition and some under-representation of ethnic groups and people living alone. Compared with the average, participating practices tended to be larger, employing more assistants and trainee doctors, and have younger principal doctors.

Manual checks of the fourth study found over 95 per cent of contacts with doctors and 93 per cent of diagnoses were recorded, although there was some under reporting of outpatient referrals. Some practices did not record practice nurse consultations. The requirement in the final study to use specific software may have improved consistency in results. Many analyses of the data are published in the Fourth (1991092) Study of Morbidity Statistics from General Practice. (76)

Prescription Analysis and Cost Tables (PACT)

PACT provides information about prescribing in general practice in England. The system includes all items dispensed in England by community pharmacists, appliance contractors and dispensing doctors, as well as prescriptions submitted by doctors for items they administer themselves. It excludes prescriptions from other groups of prescribers. At the end of each month prescriptions dispensed are sent to a special health authority, the Prescription Prescribing Authority (PPA). The PPA analyses the data and provides comparative information on both prescription items and costs to individual GPs, health authorities and the Department of Health in the form of Prescription Analysis and Cost tables. The data are available electronically via the computer system EPACT.

Only a narrow range of data are collected, mainly on drugs prescribed and their cost, with no linkage to patient-based demographic or clinical data. Data are however collected on prescriptions for which patients were not charged, either in full or in part, and these can be used to provide information on access to treatment by various groups of patients.

Some 80 per cent of all prescriptions are issued free of charge, the majority of the exemptions are by age (pensioners). Twelve per cent of prescriptions are exempt under the Low Income Scheme (LISI). (76) These represent the very poorest in the population. The low income scheme has been criticised as the forms are complex to complete and uptake is lower than it ought to be. Some very poor people fail to benefit as they miss the threshold, sometimes by pennies often because they are in receipt of other benefits. (76)

Access to prescription data

As prescription data are confidential PACT data are not made widely available. The statistical bulletin, 'Prescriptions Dispensed in the Community in England' contains trend data on the total number and costs of prescriptions over an 11 year period, including analyses by therapeutic group, category of exemption for groups such as children and young people, and elderly people and about generic prescribing. Additional information about prescriptions is made available to the Department of Health through the Prescription Cost Analysis system which also includes dentists' prescriptions. This includes more detailed data about numbers and costs of prescriptions for individual preparations.

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The potential for future developments

Although prescription data are potentially a powerful tool for monitoring access to primary care and to treatment, they cannot be linked to individual people or to other prescriptions or provide an accurate measure of the amount prescribed.

PACT prescription data could be improved by including a unique patient identifier such as the NHS number to the prescription to provide patient based PACT data. This would potentially facilitate linkage to other datasets such as hospital admissions. Adding diagnostic data to the prescription would facilitate analysis of specific clinical conditions. These two developments would not be straightforward to implement however. They are only feasible in a fully computerised environment, and implementing them would raise confidentiality issues.

Current developments in primary care data

Information for Health acknowledged the relative lack of data from primary and community care. In response to this gap the NHS Information Management Group, the predecessor of the NHS Information Authority, set up the Morbidity Information Query and Export SynTax national pilot project (MIQUEST). Its task was to develop software to extract non-identifiable data from GP computer systems to obtain information linked to the care of individual patients. MIQUEST allows this to be done remotely for large numbers of practices.

MIQUEST could potentially be used to interrogate prescribing data. Advantages over PACT data would be that this can identify what the GP prescribed, rather than what was dispensed by the pharmacist so enabling analyses to be made of items not dispensed, and the characteristics of people that did not obtain all their medicines. Most importantly prescribing could be linked to morbidity.

It is regarded that the use of MIQUEST will enable practices and primary care trusts to use their data for local priorities, commissioning, clinical governance, resource management and direct patient care. This has not so far been used specifically to look at access issues, however.

Primary Care Information Services (PRIMIS)

Primis was established in April 2000 to increase practices' use of clinical computer systems and improve data quality in primary care. It is funded by the NHS Information Authority and is based at the Division of General Practice in Nottingham. It aims to provide training to information staff working in PCTs, focussing on information management skills for primary health care teams, clinical data recording methods, improving data quality, use of MIQUEST and analysis and interpretation of primary care data.

Changes in the GP contract

Within the GP contract implemented in April 2004 for issue to GPs working in the General Medical Services is a section on 'Modernising information management and technology in general practice'. The objective is to provide clinicians and others with access to information wherever and whenever it is needed to support patient care. The contract requires the use of Read codes.

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In support of the new contract the General Practice Assessment Questionnaire has been developed at the National Primary Care Research and Development Centre in Manchester to ask patients views on their care. It specifically focuses on aspects of general practice not covered elsewhere including access and continuity of care. Some socio-demographic data are included, for example questions on ethnicity using the 1991 census categories, sex, long term limiting illness, housing tenure and employment status. Analyses of replies to these questionnaires will be undertaken only at the level of the individual practices and will not be available elsewhere.

QMAS the Quality Management and Analysis System

Further developments stemming from the new GMS contract include QMAS the Quality Management and Analysis System a new national system for England that is being developed to support the quality and outcomes framework of the new GMS contract. QMAS contains 76 clinical indicators, 56 organisational indicators, four patient experience indicators and 10 service indicators all designed to record achievement and thus remuneration based upon an holistic approach to patient care. The systems for supporting QMAS are part of the National programme for IT and will allow practices and PCTs to access the same information on patient care. Additionally it will be linked to the 'Exeter' Payment System.

Practices will be required to set up clinical disease registers and use the preferred Read Codes for the clinical indicator groups. Clinical data will be automatically uploaded to QMAS from practices on a monthly basis. Practices will be able to access their own information and PCTs will be able to see aggregated figures for all the practices within their remit, no patient identifiable data will leave GP practices. There are no plans to make the data generally or routinely available to other parties. While a host of potentially very useful data will be collected that would reflect aspects of access to health care, particularly for groups within the population it must be remembered that this is an administrative database designed to facilitate payments to GPs and is not a public health information system or indeed a monitoring system. This coupled with the level of aggregation and restriction to these data, severely limit its usefulness in assessing access to health care.

Strengths and weaknesses of aggregated primary care data

Aggregated primary care data has a role in measuring and monitoring access to health care.

The GPRD is a potentially useful data source for monitoring access to services, because it provides a wide range of information including clinical details, patient characteristics and some demographic characteristics. As well as referrals to other services it records information on outcomes such as hospital discharge reports. There are strict checks to ensure high quality of data recording. This is a comprehensive data collection which can be used to construct trend comparisons over time as it incorporates up to 12 years of longitudinal data.

The access framework as applied to the GPRD is shown in Appendix C. This highlights where the GPRD is deficient for monitoring access to health care, especially for groups within the population. In particular there are no data on socio-economic characteristics which makes it difficult to estimate how representative patients on the database are of the population as a whole. Analysis has shown that areas classified as 'lower status owner-occupier' or 'deprived industrial areas' are over-represented, while 'deprived city area', 'inner city

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estates' and 'prosperous areas' are under-represented. Additionally, analyses using the GPRD are based on the location of the practice as opposed to the patient's place of residence, which further limits the usefulness of analysis.

The voluntary nature of contributing and the fact that not all consultations are required to be recorded are likely to introduce some biases into the sample of practices and the small number of practices involved in any locality makes the GPRD inappropriate for local use and the practices may not be sufficiently representative to form a national sample.

Another drawback to using GPRD data is the extremely high financial cost of accessing the data which limits their availability to the relatively small amount of data made freely available or to a small number of specialised subscribers. However, ultimately problems with the data in terms of absent socio-demographic variables and the potential bias of recruited practices may be a more important consideration in terms of the use to which these data can be put to measure and monitor access to health care than the high cost of access.

The access framework is applied to MSGP data in Appendix C, highlights the socio-economic and socio-demographic indicators of access that are potentially available for these data.

MSGP data is linked routinely to clinical details and to socio-economic characteristics of each patient, which is a major strength in measuring access to health care. Every consultation is also recorded in the time frame. The survey is based on a large sample, the data are of good quality and it is repeated every ten years facilitating comparisons over time. Unfortunately the data from the fourth survey are now over ten years old and the series has not been continued. Had the ten year timetable continued, the fifth National Morbidity Survey would have been undertaken for 2001-2 and comparisons could have been made with the 2001 census.

Officially still no decision has been taken on continuation of the series although anecdotally this is extremely unlikely as it is no longer thought to be a good use of resources. This has left a gap which would be partially filled from estimates of the prevalence of morbidity from the Health Survey for England, although this has a smaller sample size and collects less detailed diagnostic codes. As far as its capacity to monitor access is concerned, however, there is no equivalent or replacement available. Although the MSGP produces data continuously rather than just one year in every ten, its absence of geographical and socio-economic data is a major deficiency.

The access framework as applied to PACT data is shown in Appendix C, Table 67. PACT is a potentially powerful source of comprehensive data that could be used to monitor access to health care. The analyses by category of exemption for example is particularly relevant to monitoring access to health care, since the cost of prescriptions is known to be a barrier to some people, especially those on low incomes and a more detailed discussion of this can be found in the case study on charging.

However, the lack of a link to individual patient data means that analyses are limited to the volume and cost of prescriptions. Additionally, the number of items prescribed is not necessarily an accurate measure of the amount prescribed. PACT data does not cover private prescriptions or prescriptions that a patient does not have dispensed, nor does it contain data about hospital prescribing. The absence of these data items therefore limits PACT's potential for monitoring access.

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Despite a range of initiatives to improve data from primary care, these are primarily aimed for local practice use and financial re-imburement rather than facilitating national analyses of standardised data. This means that there is still a lack of primary care data available to monitor and measure access at a population level. In particular, despite targets to get all practices fully computerised there is no requirement for practices to submit a standardised set of data about their patients and treatment for analysis at another level.

Barriers to the use of primary data sources to monitor access, are cost, with respect to the GPRD, level of aggregation of data which is often not at the individual patient level, particularly with new developments such as QMAS, and the lack of socio-demographic data about patients. In addition, the very nature of primary care data means they relate to enrolled practice populations rather than geographic populations and comparisons between the two can be problematic.

Although confidentiality is an issue with all data sources, considerations of patient confidentiality particularly limit the use of primary care data for analytical purposes. This can limit the use of data to monitor access, to health care for example using MIQUEST to interrogate GP data to explore access issues, and making prescription data available more widely.

Despite the shift in emphasis away from secondary to primary health care in the NHS, data on activity taking place in primary care settings are disparate and access to data can be prohibitively expensive. Studies based on these tend to be based on samples rather than the whole population and sample sizes are often too small for analyses at local area level. Also these systems do not include patients' postcode making it impossible to monitor use of health care according to where people live.

Despite the development of National Care Record Service and changes in requirements under the new GP contract, opportunity to collect comprehensive person based data on health care still seems to be missed. Even as patterns of access change with the introduction of NHS Direct and walk-in centres, GPs still occupy a unique position as gatekeeper to most NHS health care services apart from emergency care.

3.3.3 NHS and local authority community datasets

Many health care services are provided by NHS community services outside hospital settings. Data on such services are essential to contribute to the monitoring of access to health care.

Data on NHS health activity are collected through aggregate returns. There are no person based or episode-based data like those collected for hospital inpatients. The returns are listed in Appendix B, and the framework for access is applied in this dataset in Appendix C.

Community services were the subject of the fifth report⁽³⁵⁾ from the Steering Group on Health Services Information⁽³⁴⁾ published in the early 1980s.

The fifth report distinguished between services to the community and services in the community. Information about services to the community were concerned with immunisation, health surveillance and health promotion.

Information about patient care services in the community were classified as:

- General, district nursing services

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- Mental illness, community psychiatric nursing services
- Mental handicap, community mental handicap nursing services

Other nursing services Data were to be collected on patient 'contacts' with a health professional:

- for all contacts – programme and location which could include, the patient's home, health centre, GP premises, day care facilities, other clinic, nursing home, hospice, local authority residence, other local authority premises, and a voluntary or private facility
- for all initial contacts – age and, sex
- for all initial contacts – a source of referral which could include, hospital staff, community health staff and a GP.

The fourth report from the Steering Group 'on the collection and use of information about activity in hospital and the community in the NHS' was primarily concerned with paramedical services.(34) These services were identified as chiropody, clinical psychology, dietetics, occupational therapy, physiotherapy and remedial gymnastics, and speech therapy. An annual sample enquiry based on self-reporting was proposed to ascertain how staff time was spent. 'Face-to-face' contacts were the basic unit of workload counted.

It was acknowledged that NHS community information systems varied considerably across England and Wales. Consequently a draft Community Minimum Dataset (Community MDS) was developed between 1991 and 1993. It was designed to encompass the activities of community health staff such as district nurses and health visitors. The draft dataset was piloted in 1994 and it was proposed to introduce this as a national standard across the NHS from 1997 onwards. It was not implemented on the recommendation of the NHS Efficiency Scrutiny, *Seeing the Wood, Sparing the Trees*.(77) This triggered a review of the full minimum dataset development programme. This review concluded that minimum datasets should support a much wider range of NHS activities than contracting. They should provide information on patient activities to organisations such as health authorities, practices and trusts in collaboratively undertaking the functions of health needs assessment, service planning, effectiveness monitoring and performance management. The Minimum Dataset Programme Board identified the categories of information likely to be required within such datasets as information relating to population or patient groups, service, care or treatment inputs, and outcomes.

The board recommended that the Community MDS should be subject to a critical re-appraisal. This was undertaken (77) by the NHS Executive in 1998. The Executive's conclusions included a proposed person based minimum dataset, the components of which can be seen in Appendix B, Table 38. As can be seen, it included a 'dependency score' which could potentially have enabled a link to be made between individual and population needs and service provision. This would have contributed to monitoring access to services based on need.

In the 1998 national information strategy(54) 'Information for Health' abandoned the Community MDS programme:

'It is clear from the critical reappraisal ... that the proposed dataset will not meet the needs of local commissioning or the national performance framework... The case to abandon the development of a single episodic MDS for community health services is strong'.

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It went on to say:

'Where the cost of collection is disproportionate to the total value of the data collected, then collection of community services Körner data should in due course cease'.

As a result, data collection about community services is restricted to diminishing numbers of aggregated returns. Collections of counts of total contacts ceased in April 2000 and there were further cuts in 2004.

NHS community data currently collected

The list of aggregated returns used to collect data about the activities of community staff and services shown in Appendix B has become smaller over the years as uninformative returns have been dropped without being replaced by better data on the same subject.

For example, since the demise of the community maternity services return KCS4, no attempt has been made to collect data about maternity care in the community. Data in these returns tends to be limited to numbers of initial face-to-face contacts for each group, by age of clients, location of contact and the source of referral. Private sector activity is monitored only where services are contracted by local authorities or the NHS. The returns include no socio-economic indicators apart from age of clients in ten year age bands and their sex. The data are collected for England, with the smallest level of aggregation being at the strategic health authority level.

Summaries of the returns are available as published documents and are on the Department of Health web site. They are distributed within the Department of Health and to the NHS and are also made available to academics and the public.

Local authority data

The Department of Health requires social services departments to submit a series of annual aggregated returns about their activities relating to adults. These are listed in Appendix B, Table 39.

Most social services departments organise their services around 'client groups', including older people, adults with mental health problems, adults with severe learning disabilities and adults with physical and sensory disabilities. Revisions to returns over the years has reduced the level of detail in many of them.

In April 2000, the Referrals, assessments and packages of care (RAP) project was introduced. This aimed to provide a picture of how social services departments responded to people seeking access. A Personal Social Services statistical return relates to three broad areas: referrals to social services departments and how departments responded to them, assessments and subsequent reviews by social services staff, and clients provided with 'packages of care' or services.

Comparisons between social services departments are limited in their ability to measure the contribution of other agencies providing social care, particularly the NHS. Obstacles to sharing data include different geographical boundaries, definitions and confidentiality constraints. Although National Service Framework information strategies make frequent reference to extending the use of the NHS number to other agencies including social services, the practical means to do this remains problematic.

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Nursing home data: Körner returns, and residential home data

Nursing home data recorded on the K036 return, subsequently replaced by RH(N) return, represents a 'snapshot' in time either at 31 March or at the date of inspection between 1 October and 31 March. Local authority residential home data collected on the RA return (forms A, B and C) represents a 'snapshot' at 31 March.

Data are limited to numbers of contacts for each group. Very few data are collected about the community care activities of GPs or the nurses and other staff they employ. Private sector activity is monitored only where services are contracted to local authorities or the NHS.

Despite extensive development of a proposed community minimum dataset in the early 1990s and acknowledged weakness in this area, there remains a lack of standardised community health services data to monitor access to health care services. This affects the ability to monitor access by some of the most vulnerable people in society such as older people with mental illness. The aggregated data collected are for first and initial contacts. These are not intuitively meaningful measures of activity. Even the limited collection of numbers of face-to-face contacts has now been discontinued following the recommendations of the NHS information strategy. Even though the thrust of government policy is to shift acute care to alternative settings. However, the monitoring needed to establish whether these arrangements provide access to meet the health and social care needs of the local community can only be undertaken with data on needs, service use, and outcomes. Although the range of providers and funding arrangements for health and social care presents a strong case for universal standardised data collection, Information for Health weakened community information further by ceasing to collect numbers of total contacts.

3.3.4 Waiting times data

Perceptions of access to health care have been dominated by the issue of waiting times since the inception of the NHS. This is undoubtedly an important dimension of access, as the consequences of waiting for treatment include prolonged pain, anxiety and deterioration of health. The current government has introduced a range of high-profile targets and initiatives. It has also introduced new patterns of delivery such as NHS Direct, walk-in centres, and moves to treat NHS patients in the independent sector and overseas.⁽⁷⁹⁾ There are also moves towards improving consumer convenience, for example extending opening times and providing treatment in an expanded range of settings. To equate access to services primarily to waiting times is limited however. This is just one aspect of access. For example it does not consider whether care is appropriate to need.

Improving waiting times was a central objective of 'The NHS Plan',⁽²⁰⁾ which declared 'a war on waiting', promising that patients would experience reduced waiting times for treatment as extra staff were recruited.

It promised:

- three months maximum wait for outpatients by 2005
- six months maximum wait for an operation by 2005, falling to three months thereafter

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- treatment according to urgency and individual need within these new maximum waiting times
- guaranteed access to a primary care professional within 24 hours and to a primary care doctor within 48 hours by 2004.

Waiting lists are currently compiled and submitted for the numbers of people with given waiting times for access to both inpatient and outpatient services. Cancer registration data also includes a subset of data items on waiting times as they are required to monitor targets set out in the NHS Cancer Plan. (80)

Issues relating to the processing and quality of waiting list data include who gets to appear on the list and the factors taken into account in calculating waiting times. Such data are limited in their capacity to measure and monitor access in that they do not necessarily indicate what the wait is for or whether there is a period of waiting to access the list in the first place. Key demographic and socio-economic characteristics about those waiting are not recorded and no attempt is made to indicate needs. Only access to certain types of health care is quantified in this way. For example, waiting times to access nursing homes are not recorded. A study using life table methods has called into question the accuracy of estimates of the time to admission of those listed on NHS waiting lists. (81; 82)

The patient is removed from the waiting list when they are admitted to hospital as opposed to the point of treatment. Waiting list returns are compiled on two different bases. Commissioner based returns relate to patients in the population for which the commissioning primary care trust is responsible, while provider based returns relate to people waiting for care from an NHS trust or a primary care trust providing services.

Private patients waiting for treatment in NHS facilities are included in waiting list returns from providers but excluded from returns from commissioners.

Patients waiting for treatment at private facilities under an agreement with an NHS Trust are counted in the return from the NHS trust. Similarly, patients waiting for treatment at private facilities under an agreement with a PCT should be counted in the PCT return. A patient being given the option of care in the private sector remains on the original provider's list as the trust is commissioning treatment from the private sector on a sub-contract basis. This also applies if the patient is given the option of overseas treatment. Following the same principle, a patient opting for NHS treatment with another NHS provider remains on the original provider's list rather than that of the trust providing treatment.

Data about waiting lists and times are published on the waiting list pages of the Department of Health web site. Quarterly statistical bulletins which comply with National Statistics standards are interspersed with lower quality management information published monthly in statistical press notices. The data published are:

- provider based hospital waiting times for first outpatient appointments
- provider based hospital waiting list statistics
- provider based elective admission events: provider based patients who have deferred admission
- commissioner based hospital waiting list statistics.

Patients who are offered an appointment but do not accept it for whatever reason have their waiting time reduced to zero. This is called self-deferral.

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Waiting list data which feature predominantly in NHS performance ratings are described in Appendix D.

From the 44 indicators for acute trusts in 2002-03 there were nine key targets and 35 so-called Balanced Scorecard indicators. (83) Five of the nine key targets waiting times and 35 Balanced Scorecard targets, related directly to waiting time. In addition there were further waiting related items, such as delays in transfer of care and call to needle time for thrombolysis. These performance indicators are published on the NHS web site at www.nhs.uk and the Healthcare Commission web site at www.healthcarecommission.org.uk

Future developments

In February 2004 the Department issued a consultation document 'Standards for Better Health: Health Care Standards for Services under the NHS - A consultation'. The document refers to 'drawing several strands of the performance regime together' including 'a redesigned performance ratings system from the Commission for Health care Audit and Inspection (CHAI) incorporating the health care standards'. This consultation document sought views on proposed key standards for quality of health care. These standards were in two categories of 24 core and ten developmental standards. This approach signalled a change and softening of emphasis in the consultation with 'targets' changed to 'aspirations'. The fifth domain 'Accessible and responsive care' relates to choice in access to services and treatments, 'without unnecessary delay at any stage of service delivery or of the care pathway'.

Strengths and limitations of waiting list data in monitoring and measuring access

Although not specifically focussing on access, an analysis of NHS waiting list investigated the national distribution of prolonged waiting for elective day case and inpatient surgery and to examine associations of prolonged waiting with markers of NHS capacity, activity in the independent sector and need.(84) This pointed out that long waiting lists are a form of rationing indicating an overall disparity between demand and supply in a state health system free at the point of access.

Analysis of variations in acute inpatient length of stay in the NHS used HES data, socio-economic data from the census, health status data, measures of access to inpatient and GP services, measures of local private health care provision and waiting time data. Waiting times were identified as among the most important factors associated with variation in length of stay.(85)

Data from NHS waiting lists in Scotland were used to assess whether the priority given to patients referred for cardiac surgery was associated with socio-economic status. It found that patients from deprived areas given lower priority waited longer than those from more affluent areas. Waiting list data included age, sex, urgency, type of operation, dates of entry to and exit from the list, date of surgery and postcode.(86)

Waiting list data have also been used to identify factors influencing the growth of the independent sector in the UK. The number of independent hospital beds, as well as the numbers of people with private health insurance closely related to lengths of NHS waiting lists.(87)

Waiting times to access health care have always been an issue for the NHS. Electoral promises to reduce waiting times have the potential to win votes. As with other

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performance targets, there is the possibility of introducing perverse incentives, for example by treating less serious cases ahead of more complicated ones in order to meet targets.

The emphasis on reducing waiting times in the NHS Plan increases pressure on Trust chief executives to meet targets. Following spot checks of trusts, a report by the Audit Commission in 2001 published a list of trusts found to have inappropriately adjusted waiting lists and made a series of recommendations to stop this from recurring.(88)

Of the performance indicators for acute trusts, approximately a third are concerned with waiting times, but these do not give an indication of coverage, universality or unmet need, Further waiting lists are a function of supply and other factors, aspects over which Chief Executives may have little control. The NHS is founded on the principal of universal coverage. This has been interpreted as access, which in turn has been interpreted as waiting times. Rather than measuring met or unmet need, waiting times reflect problems within the whole health economy including access to nursing and residential homes and lack of capacity due to insufficient bed supply, staff or funds.

3.3.5 Staffing and workforce data

As a high proportion of NHS expenditure is on staff, variations in staffing levels between settings and overtime have important implications for access to services. Data on the level and quality of the workforce providing health care and related services are therefore of key importance in this context.

The framework for access is applied to staffing data in Appendix C, Table 69.

The Steering Group on Health Services Information made recommendations for collection of data about staff in its third report, 'A report on the collection and use of information about manpower in the National Health Service'.(33) The term 'manpower' was replaced by 'workforce' in the 1990s.

The recommended minimum dataset had four parts common to all posts:

- 1 skill
- 2 location where work carried out
- 3 volume of work carried out
- 4 costs.

For medical and dental staff only, data about the nature of the post were specified.

Information about employees was:

- personal data
- position of work
- employee skill including the nature of work and grade or skill levels
- absences from work
- cost – hours of work, allowances and gross payroll costs
- joining and leaving, including the reason for leaving and destination.

For doctors and dentists the following additional items were to be recorded:

- country of birth

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- country of primary medical or dental training
- month General Medical/Dental Council registration renewal due
- type of GMC registration
- name of defence union and renewal data
- post number
- postgraduate qualifications
- data of joining grade
- details of nurses skills derived from the UKCC register.

Staffing data currently collected

The main sources for data health care staffing are derived from two central returns based on annual censuses of staff in post on 30 September. These are the Hospital and Community Health Services (HCHS) medical and dental workforce census and the HCHS non-medical workforce census.

The stated purpose of these censuses is for accountability, workforce planning overview, and equal opportunities monitoring. Nevertheless the data they provide enables some evaluation of how access may be affected by staffing levels.

Staff are counted both as numbers and also as whole time equivalents. This is the number of hours each person is contracted to work expressed as a proportion of the full time contract hours. Whole time equivalents give a more accurate measure of staff resources but is affected by changes in contract hours.

The medical census records sex, grade of staff, doctors in training, ethnicity, whether full time or part time, and numbers of staff who qualified overseas. The non medical census records sex, age, ethnicity, staff group and whole time equivalent.

The medical census relates to staff holding permanent paid and/or honorary appointments in NHS hospital services, special hospitals and NHS community health services. Staff holding either directly employed or agency locum appointments are not included. Staffing figures are not available for individual trusts. Staffing data will be required from the Diagnostic and Treatment Centres, although they will not be separately identifiable.

Two statistical bulletins 'Hospital, Public Health Medicine and Community Health Services Medical and Dental staff in England', and 'The NHS Hospital and Community Health Services non-medical staff in England' with supporting data in Excel spreadsheets, are available from the workforce pages on the Department of Health web site.

The General Medical Services Database

As described in Section 3.3.2, the General Medical Services (GMS) database is a computerised register of all doctors who hold a contract with a primary care trust in England and Wales to provide general medical services. This is the main centralised source of information about general practice in England and Wales. It provides limited information about activities for which a re-imburement or 'item of service' fee is due, such as immunisation targets, cervical cytology, contraceptive advice and undertaking minor surgery.

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Information collected is about the practitioner as opposed to registered patients and contains details such as GP's age, sex, qualifications, partnership details, list size and whether certain allowances such as for deprivation are payable. It also includes the numbers of support staff such as nurses and receptionists. Such information can contribute to assessing patients' access to primary care services.

Activity information, as well as demographic and professional information about GMS is published in the statistical bulletin 'Statistics for General Medical Practitioners in England and Wales' available on the Department of Health web site. More detailed data are published in 'General Medical Service Statistics'.

Other sources of information on staffing and workforce

The annual NHS Workforce Vacancy Survey

This is used by the Department of Health, the NHS and by the Pay Review Body to inform workforce planning and to allocate 'return to practice' funding. It is completed by trusts, PCTs and SHAs and is published on the Department of Health web site.

The annual NHS Staff Earnings Survey

This is obtained from payroll services information to monitor levels and composition of pay. It informs national pay negotiations and pay modernisation policy.

Staff in the private sector

As part of the process of registering private hospitals and nursing homes, health authorities in England and Wales collect data on returns K036 and K037. These include numbers of qualified and unqualified nursing staff and resident doctors employed. However, data collected do not include the activities of doctors working in private hospitals but not employed by them.

The statistical bulletin, 'Community care statistics Private Nursing Homes, Hospitals and Clinics' contains statistics about staff employed in private hospitals and nursing homes. It also gives members of staff and beds subdivided into general nursing homes, mental nursing homes and hospitals and clinics.

No data are collected about the work of non-NHS dentists or about care given privately by self-employed practitioners in a range of professions including chiropody, and physiotherapy.

Staff employed by independent contractors providing services to the NHS

None of the data collections include information about the staff of private contractors, for example those providing catering, cleaning, laundry or other services to NHS hospitals and trusts. This makes it impossible to look at the impact on staffing levels and conditions since such services previously provided by NHS directly employed staff were tendered out. For example data are not collected on pay rates, qualifications and hours worked by such staff.

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Strengths and limitations of staffing data collections to measure access to health care

Staffing data per se are not particularly useful for building up a picture of access to health care for groups within the population except possibly an analysis of the geographical distribution of specialist staff and staff in total. However, in terms of painting a broad overall picture of the availability of health care such data is very useful.

Unfortunately there are major gaps in data collected about staff employed by independent providers, for example the staff and qualifications of those employed in nursing and residential homes, independent hospitals treating NHS funded patients, staff of contractors providing non clinical services in trusts, and under the various new patterns of delivery, including overseas providers.

It is recommended that information on staff responsible for the care of NHS funded patients and related services should be available wherever they were treated and whoever provided the care. The gaps in data about staff employed by private contractors to provide services that were previously undertaken by NHS staff before being outsourced, should be filled.

Such data should be collected on all staff providing services to the NHS in the same detail as for directly employed NHS staff. In evaluating access to services it is necessary to monitor the impact that changes in the delivery of care has had on levels, quality and conditions including pay, of staff.

3.4 Communicable disease reporting

The collection of data about infectious diseases has its roots in the nineteenth century and has made important contributions to public health reform. Local and national legislation at the end of the nineteenth century established a system of notification of infectious diseases.

The concept of a network of microbiology laboratories reporting to a national centre dates back to 1939, shortly before the start of the second world war when the Medical Research Council (MRC) established the Emergency Public Health Laboratory Service (EPHLS) in response to concerns that bacteriological warfare and the movement of large numbers of people might result in outbreaks of disease. Although fortunately such major incidents did not occur, the benefits a nationally organised service able to report findings and exchange information soon became evident. The role of the EPHLS extended to research into identifying bacteria and viruses and the development of central reference laboratories, and was established as the Public Health Laboratory Service (PHLS) in 1946 along with the passing of the NHS Act. Laboratories were often situated on the site of acute hospitals, providing bacteriological services to both the hospital and to local authorities responsible for the control of infectious disease. From 1954 its weekly summary of laboratory reports included hospital as well as community data, so becoming a comprehensive source of information on the prevalence of infection.⁽²⁵⁾ In 1977 the Communicable Disease Surveillance Centre (CDSC) of the PHLS was established to be responsible for the collection, collation and dissemination of information on communicable disease in England and Wales.

The structure of the service was subject to major re-organisation following the publication in 2002 of the report by the Chief Medical Officer *Getting Ahead of the Curve: A strategy for combating infectious diseases*.⁽⁸⁹⁾ The report recommended combining the functions of PHLS, the National Radiological Protection Board, the Centre for Applied Microbiology and

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Research and the National Focus for Chemical Incidents. Consequently these organisations were superseded by the Health Protection Agency (HPA) established in April 2003. This is a national organisation for England and Wales, designated as a Special Health Authority. Its remit is to protect health and reduce the impact of communicable disease, chemical hazards, poisons and radiation hazards.

Current major issues and challenges relating to health protection include an increasing number of people with infectious diseases such as tuberculosis and AIDS, that were previously in decline or stabilising, resistance of bacteria and viruses to drug therapy, the possibility of an influenza pandemic able to spread more quickly than in the past due to increased speed and frequency of travel, and the many animal infections which can be transmitted to humans. New diseases continue to appear in different parts of the world, and there are concerns about long-term effects of mobile phones, waste management and pollution from transport and climate change. More recently the threat of the deliberate release of chemical, biological, nuclear and radiological weapons has become a major concern.⁽⁹⁰⁾ Many of these problems fall disproportionately on vulnerable groups, and so good data that include demographic and socio-economic characteristics and risk factors are required to evaluate and monitor access to health care.

3.4.1 Data currently collected

A diversity of surveillance systems currently exist in England and Wales. The two main sources of information on communicable disease are firstly the data derived from the reporting of statutorily notifiable diseases by doctors to proper officers of local authorities, forwarded to the HPA, and secondly data derived from the reporting of microbiologically confirmed infections by NHS, private and public health laboratories to the HPA.

Statutory notification of infectious disease in England and Wales

The notification of specified infectious diseases has been a statutory requirement in England and Wales since the end of the nineteenth century and is now required under the Public Health (Control of Disease) Act 1984 and the Public Health (Infectious Diseases) Regulations 1988. Notification was introduced as a means of identifying and preventing the spread of infectious diseases and providing legal powers. The urgency of notification of some diseases for this purpose was recognised in 1968 when doctors were required to notify before confirmation of diagnosis was confirmed so that investigation and action could be taken as soon as possible.⁽⁹¹⁾ Statistics were originally collected nationally at the General Registrar Office and subsequently at the Office of Population Censuses and Surveys (OPCS). In 1997 responsibility for administering the Notifications of Infectious Disease (NOIDS) system transferred to the Communicable Disease Surveillance Centre.

Doctors in England and Wales have a statutory duty to notify a 'proper officer' of the local authority, usually the CCDC (Consultant in Communicable Disease Control), of cases of specified infectious diseases. Proper officers are required to inform CDSC and submit weekly anonymised details of each case notified. CDSC is responsible for the collation of these returns and publishing analyses of local and national trends. The list of notifiable diseases has increased over time and presently numbers about 30 as shown in Table 4, below.

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Table 4 Diseases notifiable (to Local Authority Proper Officers) under the Public Health (Infectious Diseases) Regulations 1988

Acute encephalitis	Meningitis	Smallpox
Acute poliomyelitis	Meningococcal septicaemia	Tetanus
Anthrax	Mumps	Tuberculosis
Cholera	Ophthalmia neonatorum	Typhoid fever
Diphtheria	Paratyphoid fever	Typhus fever
Dysentery	Plague	Viral haemorrhagic fever
Food poisoning	Rabies	Viral hepatitis
Leptospirosis	Relapsing fever	Whooping cough
Malaria	Rubella	Yellow fever
Measles	Scarlet fever	

Source: Reproduced from HPA web site at <http://www.hpa.org.uk>

The proper officer's weekly statistical return provides information on the name, age and sex of the patient and address of their current premises, the disease or poisoning from which the patient is suspected to be suffering and date of onset. If the premises are a hospital, the date of admission, the address from which the patient was admitted, and whether the disease was contracted in the hospital are recorded. In addition some local authorities record extra data items on forms of their own design.

Proper officers do not include details such as names and addresses in the details submitted to the HPA. A further statistical return is submitted quarterly incorporating any corrections to the original figures.(26)

Reporting of microbiologically confirmed infections by laboratories

The organisms reported by laboratories are those designated to be of public health importance, set out in reporting guidelines issued to all laboratories in England and Wales. Laboratory reporting takes place fairly rapidly so that data can be used in the early recognition of outbreaks. Items recorded include data on the laboratory, patient identification, date of birth, sex, organism, date of onset, specimen type and dates, identification methods, clinical features, and information on the source of referral, but few geographical data are recorded about the infected person.

These two systems, notification data and laboratory reporting complement each other with the former based on clinical diagnoses and the latter on proven infection. Notifications can provide information on the incidence of diseases not necessarily diagnosed in a laboratory such as measles and whooping cough, whereas some conditions can only be diagnosed reliably in a laboratory and notification on suspicion would be likely to identify large numbers of false-positives.(91)

Other sources

In addition to these two systems of surveillance there are others:

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Royal College of General Practitioners weekly returns service

A cohort of general practices serving approximately one per cent of the total population of England and Wales report diagnoses of common infectious diseases to the Royal College of General Practitioners on a weekly basis. In 2002 this encompassed 77 general practices contributing data constituting a 1.2 per cent sample, representative of the general population in terms of socio-economic status, age and sex distributions. Participating practitioners are provided with diagnostic guidelines which although not strict criteria, help to achieve some degree of standardisation. Participating GPs summarise diagnoses and consultation/episode type in other words whether they are first or new episodes or ongoing consultations for their registered population. Data are extracted to provide a weekly return which includes age specific weekly incidence of diseases. Data collection started in 1967 and was computerised in 1994 so data on all diagnoses made by GP's during a consultation are now collected. Items recorded are an identifier, administrative data, condition, intervention, short-term outcome, major known confounders and long-term outcome.

Sexually transmitted infection

Genitourinary medicine (GUM) clinics have been required to record data since they were established in 1917. This followed the creation of a network of specialist venereal disease clinics which offered free, confidential testing and treatment for sexually transmitted infections (STIs). This was in response to the high burden of morbidity and mortality caused by such diseases, particularly in the armed forces. GUM clinics have a statutory obligation to submit quarterly data.

Despite substantial declines in STI incidence throughout the 1980s and early 1990s, new diagnoses of STIs have continued to increase since the mid 1990s, particularly chlamydia, gonorrhoea and syphilis.

Analyses are published quarterly in the Communicable Disease Report (CDR) weekly electronic bulletin. The KC60 sexually transmitted disease surveillance system collects data from all NHS GUM clinics in England. The return collects aggregated data from clinics on the number of diagnoses of specific conditions each quarter, by sex, and for selected conditions, the number of male cases homosexually acquired, and age group. Data on ethnic group, area of residence and location of care are not collected, so data cannot be used, for example, to describe the characteristics of people repeatedly acquiring STIs or who present with more than one STI at any time and therefore may be at highest risk. The system contains no information on STI cases seen outside GUM clinics.(26) As diagnoses are counted rather than individuals some people may be counted more than once in the quarter. Data from KC60 will underestimate the number of STI diagnoses made by health services and the prevalence of STIs. This is because GUM clinics are only one of the services dealing with sexual health, and because the use of clinics varies between areas according to physical access and public perception of the services available.(92)

Despite limitations the system is comprehensive as all GUM clinics are statutorily obliged to report to CDSC, and the system can provide robust trend data for many STIs. Conditions and episodes recorded on return KC60 are described in Appendix B, Table 41.

A new section on waiting time indicators has been introduced to the KC60 return specifically to help monitor access to GUM clinics. This is completed by appointments clerks or receptionists. Data recorded as at the end of the quarter are:

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Open appointment clinics (appointments made over an unrestricted period):

- the number of days until the next available routine appointment.

Closed appointment clinics (appointments made over a restricted period only):

- the period for which appointments are booked
- the number of days until the next available routine appointment.

Drop-in clinics:

- the number of patients seen within one hour, between one and two hours, and after two hours respectively.

AIDS reporting system

A reporting system for AIDS was established in 1982 to provide confidential reports to PHLS. Information is collected about the patient's demography, risk group, clinical presentation and types of care. AIDS and HIV data are published in AIDS/HIV quarterly surveillance tables and in a monthly insert in CDR weekly.

As HIV is a chronic infection with a long latent period it requires multiple sources of surveillance information to provide a profile of the epidemic in the UK. The main sources of information on newly diagnosed HIV/AIDS infection are from laboratory reporting by microbiologists, and diagnoses by clinicians, made to the HPA. (93)

Reports of newly identified HIV antibody positive individuals and AIDS cases made by microbiologists and clinicians to the PHLS AIDS & STD Centre, CDSC and the Scottish Centre for Infection and Environmental Health (SCIEH).

Returns to the Oxford Haemophilia Centre for the UK Haemophilia Centre Directors' Organisation.

Paediatric data compiled at the Institute of Child Health in collaboration with CDSC and SCIEH, and from follow-up of monthly notifications to the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, and the National Study of HIV in Pregnancy at the Royal College of Obstetricians and Gynaecologists.

Surveillance centres merge records of HIV diagnosis, AIDS and death regarded as relating to the same individual to form a single record. Cumulative data from all sources are amalgamated quarterly to produce the current UK dataset of reported HIV infected individuals.

Survey of Prevalent HIV Infections Diagnosed

The Survey of Prevalent HIV Infections Diagnosed (SOPHID) provides annual data tables on diagnosed HIV-infected patients when last seen for care:

- by age group, sex and region of residence
- by ethnicity and region of residence
- by probable route of HIV infection and region of residence
- by most advanced clinical stage and region of residence

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- by level of anti-retroviral therapy and region of residence
- distribution of prevalent caseloads by region of residence and of care.

A limitation of SOPHID data is that they cover only people who are aware of their HIV infection and are currently being seen for treatment. An estimated third of people with HIV in the UK are unaware of their status so such data underestimate the prevalence of HIV.

Unlinked Anonymous Prevalence Monitoring Programme (UAPMP)

Since 1990, more than seven million samples have been tested under this programme to measure the distribution of unrecognised infection, particularly HIV, in groups of the adult population. The programme monitors HIV infection levels in people attending GUM clinics, injecting drug users attending specialist treatment and support agencies or GUM clinics, and pregnant women. It also monitors hepatitis B and C infection levels in injecting drug users attending treatment and support agencies. The programme makes it possible to estimate the prevalence of HIV infection in people who are undiagnosed and so not ascertained by other surveillance systems. Data are used in health promotion, in estimating the numbers who will need treatment in the future, and to plan services. By measuring the infection levels of people who are undiagnosed and untreated, this survey provides fuller information than those based on people receiving services. As a result it provides information on access to services, particularly by certain vulnerable groups.

Hospital Episode Statistics

Data on people with communicable disease admitted to hospital are available from Hospital Episode Statistics (HES) described in Section 3.3.2. As these will include only severe cases of disease, such statistics tend to represent a small and unrepresentative subset of overall incidence.

Mortality data

Death registration data from the Office for National Statistics, described in the section on population-based data, is likely to under-represent communicable diseases which contribute to the underlying cause of death. Such infections and diseases are often not recorded on death certificates because investigations have not been carried out. For example influenza appears as the underlying cause of only a small percentage of the excess deaths occurring during influenza epidemics.(26)

Other Surveillance

Some national infection reporting systems focus on specific diseases or problems, for example seroprevalence surveys to assess population immunity to diphtheria or tetanus, and reports of rare diseases in children as undertaken by the British Paediatric Surveillance Unit. Surveillance of Creutzfeldt-Jacob disease (CJD) began in 1990 undertaken by the National CJD Surveillance Unit in Edinburgh. Since 1996 statistics for confirmed cases of the new variant CJD have been published quarterly.

Surveys such as the National Surveys of Sexual Attitudes and Lifestyles, undertaken by the National Centre for Social Research (NatCen), can provide useful information. These were two major surveys of British sexual attitudes, firstly of 19 000 adults in 1990, then again in 2000, of 12 000 people aged between 16 and 44 years, including a boosted sample of ethnic minorities. It is anticipated that such a survey will take place every ten years.

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The processing and quality of communicable disease data

As can be seen from the above, a variety of data sources are used in surveillance. These are combined to construct a more complete and accurate profile of disease than would be available from just one source. Such linkage of data sources can be complex as datasets overlap and duplicate reports from different sources must be merged so as to avoid over estimation of disease frequency.(94) As, the main purpose of the system is speed in detecting possible outbreaks and epidemics, accuracy of diagnosis is secondary. Since 1968 clinical suspicion of a notifiable infection is the only requirement, as a diagnosis found subsequently to be incorrect can be amended.

It is acknowledged that considerable reporting delays and under notification occur and this varies between notifications of different types of diseases. For some diseases, numbers of notified cases have been far higher than numbers of laboratory reported cases. (26) In Recommendation 5 of Chapter 6 of the national strategy it was proposed to place a duty of care on all microbiology laboratories to report for public health surveillance purposes, replacing the voluntary system for NHS laboratories.(89)

Access to communicable disease data

Notification data and laboratory reports of organisms involved in outbreaks are published weekly in the CDR Report.(95) This is published by the HPA for England and Wales. Data are available on its web site down to a local and unitary authority level. Data tend to be limited to total numbers of statutory notifications by disease group. The *CDR Weekly* publication contains a range of ad hoc reports and articles with more detailed analysis of various diseases, including trend data, geographical profiles, and accounts of current developments. Specialised reports are available for some diseases, for example the Chief Executive's annual report on HIV and other sexually transmitted.(96)

3.4.2 Recent developments

The publication of the CMO's strategy *Getting Ahead Of The Curve* was a result of a pledge in the Government's White Paper *Saving Lives Our Healthier Nation*.(97) The strategy noted the problem of under reporting and under notification of infection. It pointed out that routine surveillance information at both local and national level provides an incomplete picture of the size and nature of the threat to health from infectious diseases. In addition, the gaps in surveillance can make it impossible to track major problems such as antimicrobial resistance. It noted that there was no single point of co-ordination for the many separate infectious disease surveillance systems. Importantly data are incomplete as reporting is not compulsory apart from the statutorily notifiable diseases and even these are under-reported. Therefore, as mentioned above, Chapter 5 of the strategy recommended modernisation of the system and mandatory laboratory reporting.

Subsequently the Health Protection Agency has cited strengthening information and communications systems for identifying and tracking diseases and exposures to infectious and chemical and radiological hazards as one of its strategic goals. It acknowledged the need to integrate reporting arrangements from the variety of sources, including laboratories, clinical services, local authorities, emergency responders, the public and other bodies in order to obtain more complete information and to develop a more consistent approach to surveillance. The Health Protection Agency plans to build on existing systems

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by developing surveillance in collaboration with other bodies such as hospital clinicians, PCTs and NHS Direct, Public Health Observatories, the NHSIA and to link across systems.

Pilot projects of enhanced surveillance

Pilot projects of enhanced surveillance of sexually transmitted infections have been undertaken in London and the south east of England. These extend the information collected in order to help monitor risk groups experiencing the highest rates of infection. This makes it possible to analyse the incidence and distribution of STIs by ethnic group and area of residence. This is the Programme of Enhanced STI Surveillance (ProgrESS) which aims to collect anonymised patient-based data from computerised GUM clinics throughout England. It is anticipated that this scheme will be extended to the rest of England and possibly Wales. Further data items may be included, such as the number of sexual partners, previous history of STIs and source of referral. In addition, the coding system used in the KC60 report is being revised to improve the accuracy of clinical reporting.(98)

Enhanced Tuberculosis Surveillance (ETS)

To supplement notification through NOIDS, enhanced tuberculosis surveillance was established in 1999 to provide more detailed and comparable information on the occurrence of tuberculosis in England and Wales. Data from the ETS system are not available until a year or more after being reported. Notification data are available much sooner and can provide an estimate of case numbers. The ETS system is being revised to address this delay. In 2002, for the first time, case numbers reported in ETS exceeded notifications.(99) The minimum dataset includes notification details, demographic, clinical and microbiological information on all cases of tuberculosis reported by clinicians to local co-ordinators. ETS provides an annual corrected analysis of reports by age, sex, ethnic group, country of birth, site of disease and region.

3.4.3 Strengths and limitations of communicable disease data to measure access to health care

Routine data from communicable disease surveillance have a role in measuring and monitoring access to health care, though there are serious drawbacks.

Many of the data are nationally collected and have been collected for a long period of time. As a result trends in communicable diseases can be produced for geographical areas and over time, helping to build up a picture of need and utilisation. Communicable disease surveillance and research data also confirm significant inequalities in the distribution of STIs and HIV in England and Wales with young people, gay men and ethnic minorities appearing to be at substantially higher risk of poor sexual health outcomes.(100)

There are limitations to the usefulness of such data in monitoring access to health care, however. Under-reporting and incompleteness of data is a problem as are the narrow range of data items collected. Under-ascertainment is acknowledged particularly in notifications by local authorities, who are legally responsible for the control of notifiable infections and from laboratories. Currently even the data on people accessing services are incomplete.

Although there are known to be significant social and ethnic inequalities for many of the serious infections, including HIV, meningitis and TB, common respiratory, gastrointestinal and sexually transmitted infections, data are limited in their capacity to monitor such

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characteristics. Few details are collected beyond location, and basic individual characteristics such as age and sex and these details may not be available due to confidentiality arrangements. The KC60 and laboratory reporting datasets lack demographic, socio-economic and sexual behaviour data. Though the main purpose of these systems, is detecting outbreaks and the control of infectious disease, such data would play a useful role in combating an epidemic as well as providing much useful information on the access to health services afforded to different groups within the population. Geographical analysis and analyses based upon mapping to Census derived variables are also frustrated as few sources include postcode, rather data are based upon the reporting clinic for which there is no known population denominator.

General data collections such as mortality and hospital episode data record more detailed patient and health care system characteristics, but are of limited use as most communicable diseases and infections do not result in either death or admission to hospital. Even where this does occur, the underlying infection may not be a diagnosis that is recorded. Others have found that many surveillance systems do not provide good information on risk factors for STIs and have poor coverage and are not sufficiently timely.(101)

As is the case with most routine data these sources are primarily about known cases of disease that are being treated so we can deduce something about the level of access to services. There are exceptions though, such as the Unlinked Anonymous Prevalence Monitoring Programme.

Some of the gaps in the data available from communicable disease surveillance result from necessarily from issues related to confidentiality. If the capacity of these data to measure and monitor access to health care is to be improved(102) this problem must be addressed. It has been acknowledged by the national strategy that a more integrated approach that minimises these gaps is needed.

This alone will not solve all the problems with the data. Under-ascertainment combined with the lack of socio-demographic data are major limitations for the capacity of communicable disease data to evaluate access to health care.

3.5 Access to health care and health service data

A summary of the routine Health Service datasets available to measure and monitor access to health care is presented below in terms the framework for access and in particular the four dimensions of access, need for health care, opportunity to access health care, utilisation of health care by groups within the population and the health outcomes achieved by groups within the population. The datasets are evaluated to assess the degree to which they provide robust and reliable indicators of access, in terms of the socio-demographic and socio-economic variables which allow access to health care to be measured and monitored for the population as a whole and also for specific groups within the population, though as much of the data are only available in aggregated form this must needs be fairly limited. Table 5, below, summarises the datasets in terms of the broad dimensions of access and the individual indicators of access.

Health service derived data including aggregated data returns can be a rich source of data on need, or at least derived need based upon the level of utilisation. Variations in utilisation of health services can be used as a proxy for unmet need in those areas or among those groups who appear to use less health care than others. Equally a high level of use may be

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interpreted as a high level of need in a group or area. Such analyses are useful but care needs to be taken in any conclusions drawn from the data as unknown factors, not represented in the datasets may be at work.

Morbidity statistics from general practice are probably the best source of data on needs, even though their origin is a bi-product of contact with primary care. These data are rich in socio-demographic and clinical data and are of a high quality. Unfortunately the decennial nature of the survey means the data may be out of date, though longitudinal analyses can be conducted. Unfortunately these surveys would appear to have been discontinued.

Waiting times data have also been used to derive measures of unmet need and this is a useful indicator of access to health care. A waiting list is after all just a time-based rationing of health services and rationing only exists where there is unmet need. Such data can be analysed by a small number of socio-demographic variables. The danger in over interpretation is that these data only tell us a partial picture. For instance accident and emergency (A&E) waiting times have been criticised as they do not take into account the severity of cases and suspicions have been raised that cases are inappropriately admitted to hospital in order that waiting times targets can be met.

Opportunity

A cursory glance at Table 5, will show that data reflecting the opportunity to use health services are not very abundant, this should not be surprising as health services data is all derived from utilisation of health services. NHS outpatient activity data, while not linked to individual patients, nevertheless are useful for describing the distribution of services by speciality and location as well as over time. THE GMS database also has information on the location of practices, including staffing, services available and list size. Non-aggregated health service data such as HES and some communicable disease data are also amenable to a more detailed geographical analysis. Travel times to service can be calculated and a picture of 'ease of access' to health services around the country can be built up. However any such analysis will always be constrained by the lack of data on non-geographical barriers to access such as the transport networks that are available and peoples preferences for services be they based on for example opening times or convenience of location for work, rather than home.

Utilisation

As noted above, health service data are derived from actual utilisation of health services and as such, both individual and aggregated data reflect a deep and broad picture of access for this particular dimension on the continuum. The use of these data to describe access for the population as a whole and for groups of the population in terms of utilisation is only constrained by the availability of the data, its level of disaggregation and the breadth and quality of the items within the datasets; for example socio-demographic details what is collected, how complete is the data what is the quality of the data. For example HES records ethnicity, but analysis of access by ethnicity is hampered by a high level of incompleteness and poor quality. These particular indicators of access are discussed more fully below.

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Outcome

Population-based outcome data are rarer for health services data. Some data can be derived from HES data, including the analysis of in-hospital mortality by specialty and procedure, and communicable disease data but there is no longitudinal link to enable the success or otherwise of a health care intervention to be determined. Linkage to mortality statistics, discussed in Section 3, is probably the most fruitful approach. The GPRD has outcome data for those patients registered with the system, including useful information such as hospital discharge reports, but the small number of practice in any locality make local analyses difficult and the data is difficult and expensive to access.

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Table 5 Summary of health service data sources and the Access Continuum

Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
<i>Characteristics of the Population</i>				
Age	HES, Outpatient Data, GPRD, MSGP, Community Health, Communicable Disease		HES, Outpatient Data, GPRD, MSGP, Community Health, Communicable Disease	HES, Communicable Disease
Sex	HES, Outpatient Data, GPRD, MSGP, Community Health, Communicable Disease		HES, Outpatient Data, GPRD, MSGP, Community Health, Communicable Disease	HES, Communicable Disease
Ethnicity	HES, MSGP, Communicable Disease		HES, MSGP, Communicable Disease	
Country of Birth				
Education				
Socio-economic	MSGP		MSGP	
Geography	HES, GPRD, MSGP, PACT, Community Health, Staffing, Waiting Times, Communicable Disease	HES, NHS Outpatient, GMS, Communicable Disease	HES, GPRD, MSGP, PACT, Community Health, Staffing, Waiting Times, Communicable Disease	
Travel time (as a derived variable)	HES, Outpatient Data, MSGP, Communicable Disease	HES, NHS Outpatient, GMS, Communicable Disease	HES, Outpatient Data, MSGP, Communicable Disease	
Morbidity	HES, Outpatient Data, GPRD, MSGP, Communicable Disease	HES, NHS Outpatient	HES, Outpatient Data, GPRD, MSGP, Communicable Disease	HES, Communicable Disease
Mortality	HES, GPRD, Communicable Disease			HES, GPRD, Communicable Disease
Health Beliefs and Knowledge				

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Age and Sex

The un-aggregated health service datasets reviewed in this section all include information on age and sex. HES data has good information on age and sex as does outpatient data. The primary care datasets also record age and sex as does communicable disease reporting. PACT and waiting times data have no information on age and sex.

Ethnicity

Only HES collects ethnicity for patients and this is incomplete and the quality of the data has been questioned. Staff data collects information on the ethnicity of staff working in the NHS. Some HIV data also contains information about ethnicity, but due to its confidential nature is only useful for describing broad population patterns.

Social Class

No information is available from any of the health service datasets, aggregated or otherwise, on social class or education. NHS staffing data do include information on socio-economic status and educational attainment. Census derived proxy markers of socio-economic status can be used with those disaggregated databases (principally HES) in order to do analyses access based upon socio-economic status.

Geography

Geographical data, mainly as postcodes, are available from most of the health service datasets. For the aggregated datasets outpatient, GRPD, PACT, community health service and waiting times data, the level of geographical detail is not normally lower than PCT level, although practice level data are theoretically available from some of the primary care datasets. HES and communicable disease data contain the most useful geographical data. HES in particular potentially has data on the patients residence and where the procedure/intervention took place.

Morbidity

The principal source of morbidity data for secondary care within a hospital setting is HES data, where diagnostic and treatment codes are available for analysis, although concerns have been expressed about the level of completeness of coding and its accuracy. Outpatient data also contains a limited amount of morbidity data but it is not possible to link this with individual patients. The GPRD and MSGP have more information on morbidity. The GPRD looks longitudinally at patients and collects much clinical detail. MSGP is the best source of morbidity data and is a very rich source of such data. However, the last survey covered just 60 practices and it looks unlikely that the survey will be repeated. As such the data are only useful for global analyses of access to health care.

Communicable disease reporting contains highly specific morbidity data in respect of the notifiable diseases that it monitors.

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Mortality

No population-based data on mortality are available from health services datasets although death in hospital is available from HES and sample based mortality data are available from the GPRD.

3.6 Discussion

Health service data provide a mixed opportunity to measure and monitor access to health care. On the whole, disaggregated data such as HES are better for examining access especially for groups within the population. On the other hand, aggregated data paint a detailed picture of the overall availability of health care and its organisation. In addition, important information on outpatient and prescription activity for instance is only available in aggregated form.

Hospital activity data in the form of HES data are the most useful and widely used statistics for analysing access to health care. It is a good comprehensive national database with standardised definitions and an immense amount of detail, it has the capacity to be linked to other routine datasets to allow for more detailed and comprehensive analyses of access. It has been running for some time so analysis of time trends is also possible. However, it has notable drawbacks including: a lack of socio-economic adapt, poor recording of ethnicity and questions have also been raised about the accuracy and completeness of coding not to mention poorly completed original data by clinicians. HES data also poorly records activity in the independent sector where NHS patients have been treated. This raises particular concerns given the new arrangements for treatment including Diagnosis and Treatment Centres, some of which are privately run, in the NHS.

There are also barriers to access HES data, it can be restricted, especially to the NHS, and be expensive for non-standard queries. Increasingly private companies have contracts to analyse and publish data from HES and in some instances they even collect data. This runs the danger of undermining national data collection and moving it into the private sphere. Small unlinked data sources may be used rather than national routine statistical data which is covered by protocols guarantee its validity and independence.

It is important that hospital activity data be kept in the public domain and covered by national statistics codes of practice, access to the data should be unfettered and not in the domain of private companies. It is also important that HES data be extended to cover the independent sector and the new arrangements of care in the NHS.

Aggregated data are much more limited, as they contain no details of patient characteristics and cannot be linked with other data. They are, however, invaluable for making comparisons and monitoring trends by specialty and trust. They also serve to give a global picture of access over time. Waiting time data can be used as a proxy measure of need in specific clinical areas.

Primary care data fall into two classes, those that describe practices and the resources of primary care, and those that contain detailed information on patient treatment and outcome.

The GPRD provides good quality data but access to it is expensive and restricted. Its coverage of different socio-economic areas is not even and the small number of contributing practices limits local analysis. There is no information available on socio-economic status of

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individuals nor their postcode, restricting analyses to the practice level. The MSGP is now out of date and appears to be defunct.

Data currently available from general practice are inadequate for monitoring access and both lack of relevant data and its cost make the GPRD inadequate for this purpose. We therefore propose that:

A twenty first century successor to the National Morbidity Survey should be designed and established by building it into the design of the secondary use service of the National Programme for IT and ensuring linkage with the census and other relevant data.

GPs should record ethnicity and socio-economic status of patients registered with them. This would improve the potential for monitoring socio-economic differences in access. It has been suggested that these items could be obtained from the linkage with the lifelong record proposed in the review of civil registration, but decisions about whether this will be implemented have yet to be announced.

Communicable disease data have a small role in measuring and monitoring access to health care for this highly specific area but the lack of socio-economic and demographical valuables coupled with the dearth of data on risk factors severely limits its use.

Health service data are a major resource for monitoring and measuring access to health care, but the data are dogged by an absence of important variables which would enable analyses of the data by socio-economic and socio-demographic group. This together with the fact that only those who have received treatment are to be found in the data, places a limitation on their use for analysing access unless combined with other routine data. Doing so provides a much richer analysis of the data especially for excluded and marginalised groups.

Section 4 Population-based data

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- 4.2 *Population-based censuses and continuous surveys*
 - 4.2.1 *The Census of Population*
 - 4.2.2 *The Health Survey for England*
 - 4.2.3 *The General Household Survey*
 - 4.2.4 *Other population surveys*
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- 4.3 *Cancer registration*
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- 4.4 *Registration and Notification of Vital Events*
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 - 4.4.3 *Notification of abortions*
 - 4.4.4 *Confidential enquiries*
 - 4.4.5 *Access to health care in population-based registration and notification data*
- 4.5 *Discussion*

4.1 Introduction

This section introduces the routine population-based datasets which can be used to measure and monitor access to health care. They are described in terms of the data collected, their level of ascertainment, the analyses that are routinely published and the level of aggregation for which data are available. The Section is divided into three broad sections: survey data, cancer registration, and vital registration and notification. The discussion is structured around the 'Framework for Access' set out in Section 2.2. Population-based data are examined with respect to each of the dimensions of access: need, opportunity, utilisation and outcome, and the socio-economic and socio-demographic factors related to access, to assess the extent to which these data can be used to monitor access to health care by the population as a whole and by groups within the population. Recommendations are made for data linkages and changes to datasets in order to improve monitoring and measurement of access to health care.

4.2 Population-based censuses and continuous surveys

This section describes how data from health surveys can be used to measure and monitor access to health care, focussing on the national census of the population and the major continuous surveys that include a health component, the Health Survey for England and the General Household Survey, along with other continuous general surveys. Surveys are most useful for monitoring access when they are representative, comprehensive, ongoing, extensive and based on a sample size which is sufficient to allow comparisons to be made over time, and between place and person. In addition to data about health, data on ethnic group, sex, age, and social class are required to measure and monitor inequalities in access. If the raw survey data can be accessed this increases their potential value,

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especially if linkages can be made with other datasets to build up a more comprehensive picture.

The national census is undertaken every ten years, by ONS in England and Wales and by its counterparts in Scotland and Northern Ireland. In addition, the government commissions a programme of continuous and ad-hoc surveys which are undertaken either by ONS or by other survey organisations.

The following continuous surveys contain questions that are either directly about health and health care or about wider factors influencing health:

- The General Household Survey
- The Health Survey for England
- The Expenditure and Food Survey
- The Omnibus Survey
- The Labour Force Survey
- Psychiatric Morbidity Survey
- Drug use, smoking and drinking among young people in England
- The Family Resources Survey
- The International Passenger Survey
- The National Travel Survey
- The Survey of English Housing

Historically these surveys have been undertaken continuously for some years so time trend data are available as well as a cross-sectional picture, though not all the surveys are still current. The health component in these surveys varies from one or two questions in the census to a considerable part of the General Household Survey. In the Health Survey for England and the Psychiatric Morbidity Survey (1993-94), which had a follow-up in 2000, health related issues are the main focus.

The ONS Omnibus survey periodically contains health-related questions, for example about sun exposure, contraception and sexual health. The list above does not include the ten yearly surveys of adults' and children's dental health or the five yearly infant feeding surveys. Major surveys are also commissioned on primarily a one-off basis, for example the series of surveys of adults' and children's mental health undertaken by the ONS in the 1990s with a follow-up in 2000.

Some of these surveys are described in our series of case studies. In the following sections, we focus on the population census and the two continuous surveys which collect information about health care as well as health, the General Household Survey and the Health Survey for England, with a short note about the other health related surveys particularly Psychiatric Morbidity and the Omnibus Survey.

It should be noted that the Labour Force Survey; the Annual Population Survey; the General Household Survey; the Expenditure and Food Survey and the Omnibus Survey are being combined into one Continuous Population Survey(103). The new Continuous Population Survey is expected to go 'live' in January 2008. These changes are part of wider reform of national population statistics involving the creation of an Integrated Population Statistics System(104).

4.2.1 The census of population

The census is a count of all people resident in the UK undertaken by the ONS in England and Wales, the General Register Office for Scotland and the Census Office for Northern Ireland Statistics, based on a 100 per cent sample. Using the household as the basic unit of enumeration, it asks questions about social and economic conditions to give a 'snapshot' of the population on one night. The census has been taken every ten years since 1801, except in 1941 during the Second World War. The first four censuses were simply counts and the 1841 census was the first which recorded information about individuals. The task of enumeration was carried out by local officers of the service.

The principles of census taking have remained essentially unchanged, although some questions have been added and others discontinued. Until 1911 the government had to introduce a new Census Act for every census held. This requirement was dropped following the 1920 Census Act, which made it possible for the government to hold a census at any time, but no sooner than five years after the last census. Each time, Parliament has to approve the necessary 'secondary' legislation which lays out the details of the particular census. To achieve results which are as complete as possible, completion of forms was made compulsory by the 1920 Act. The Census Confidentiality Act 1991 gives legal protection by making the unauthorised disclosure of personal census information an offence.

The census is a source of socio-demographic data as well as some health data about the whole population. A full list of questions asked in 2001 appears in Appendix B Table 43, p304. Census data are used for a wide range of purposes by many different groups of people. They are used as a basis for revenue distribution to local authorities, which use data derived from the census in planning public services including education, transport and health. Census data are also used for the essential population denominator for measuring access to health services. Between censuses, mid-year population estimates are derived from the previous census, birth and death registration data, data on internal migration collected by the NHS Central Register when people change their GP, and data about international migration.

Health data collected in the census

In 1991, for the first time since 1911, a question on health was asked. The question asked in 1991 was:

Do you have any long-term illness, health problem or handicap which limits your daily activities or the work you can do? Include problems, which are due to old age?

This question was designed to collect information directly about chronic morbidity and the need for health and social services at a local level, instead of having to use death rates as a proxy measure.

The wording of questions is crucial, for example the word 'limits' in this question might have deterred some people who might otherwise have classified themselves as ill from ticking this census box, as might have the reference to 'handicap'. Self-reported data can vary independently of the prevalence of disease because of differences in the perception and reporting of symptoms. Such differences have been found to vary by social group, for example by age and social class.

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The question was repeated in 2001 and a new question on general health was added, along with a further question about caring responsibilities. The questions are shown below:

- 1 Limiting long-term illness: 'Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? Include problems, which are due to old age?'
- 2 General health: 'Over the last twelve months would you say your health has on the whole been: Good? Fairly good? Not good?'
- 3 Provision of care: 'Do you look after, or give any help or support to family members, friends, neighbours or others because of long term physical or mental ill-health or disability, or problems related to old age?'

The recording of ethnicity in the census

The classification of ethnic identity in the census is used in other data sources, so it is important to understand its development. Until 1971 the only data available on the mix of origins in Britain was derived from the recording of place of birth. Interest in the numbers of racial groups increased during the 1960s and 70s as immigration became a major political issue. In 1966 the chief government statistician John Boreham rejected inclusion of a census question on ethnicity or race.(105)

It is extremely difficult to define 'coloured' precisely at all and is impossible to define it precisely in a way that will work in a census. We did not (and will not) attempt it, but used the unequivocal and objective concept of birthplace instead.(106)

At this time the political and statistical debate focussed on whether the immigrant population had been over or under estimated. This changed when the 1976 Race Relations Act, which focussed on the rights and conditions of people in Britain, provided a new purpose to statistically monitor the conditions of ethnic minorities. As a result, the white paper for the 1981 census proposed that there should be a direct question on ethnicity. The question was not included amid a background of fear about its consequences and a hostile media environment. Arguments against ethnic recording at that time were that in an atmosphere of fear on immigration, repatriation and racist policing, and little evidence of a commitment to prosecute racists, the question had little purpose.

The social conditions of the black population were however captured indirectly in the census data available at small area level for the first time. Results showed that ethnic groups typically had inferior social and housing conditions to the general population. Policies were established during the 1980s to direct resources to the needs of ethnic minorities, providing a positive incentive to measuring ethnicity.

A question on ethnic group was first asked in England, Wales and Scotland in 1991. The 2001 census includes an updated question on ethnic group and questions on religion were introduced in England, Wales and Scotland. These questions were different for each country in the UK although there was a common structure for the ethnic group question.

The question asked in England in 2001 is shown in Appendix B, Table 44. Categories are hierarchically structured with five bold headings equating to colour or race starting with 'White', followed by 'Mixed', 'Asian or Asian British', 'Black or Black British' and 'Chinese or other ethnic group'.

There are implicit contradictions in the question. Although 'British' is included in the Asian and Black main bold headings, the final category of British is only permitted under the main

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heading, 'white'. Further, the focus on categories other than white perpetuates the concept that only non-whites are from an ethnic group. It has been argued that the motivation to record ethnicity or race derives from two conflicting aims. One is to counter discrimination and promote multi-culturalisation, while the other is to control immigration and promote social cohesion.(105)

Access to census data

Data from the census are published in two ways, by area and by subject. Up to 1991, enumeration districts containing about 200 households, were the smallest areas for which aggregated data were available. For the first time in the 2001 census, data are available down to the level of 'output areas'. The target size of an output area is 120 households and their size ranges between 100 and 125 households. Many key statistics from the 2001 census can be freely accessed down to output area level through the National Statistics web site.

As well as information about the health of individuals, the census is also used as a source of data on the number and characteristics of people living in institutions or 'communal establishments', which include long-term homes of the elderly, psychiatric and long stay hospitals as well as hostels, barracks and prisons. The housing tables also include information about types of dwellings, distinguishing between flats and houses, and permanent and non-permanent homes.

More detailed analysis of the data tables can be undertaken through using a query language, SASPAC specifically written for the analysis and interrogation of Census Small Area statistics. It was developed at the Universities of Durham and Edinburgh for the 1981 Census, and was subsequently purchased by the Local Government Management Board. Researchers can also access individual household data to answer specific questions through the Sample of Anonymised Records (SARs) consisting of a two per cent sample of the population and a separate one per cent sample of households.

Future developments in the census - coverage and undercounting

Despite the scale of the census, increasing numbers of people are not included. They are not a random sample of the population so studies ignoring this group are likely to produce biased results. The 2001 One Number Census was designed to tackle decreasing rates of response. It combines the people counted in the census with the estimated undercount, so that all statistics from the census add up to one number, the national population estimate. A main element of the One Number Census is the Census Coverage Survey held within a month of the 2001 census which interviewed approximately 320,000 households to measure the level of the undercount. Although this reconciles population numbers at the level of the local authority, at smaller area levels numbers are likely to be less accurate for areas such as wards with a lot of non responders.

There have been concerns expressed about falling response rates in the census and other social surveys. A paper published in 2003, 'An alternative view of the 2001 census', critically examined the 2001 census results in the light of evidence on undercounting and proposed population registration systems as an alternative to a census.(107) The author, Philip Redfern, a long-standing proponent of population registers, suggests that the sex ratios in the 2001 One Number Census of England and Wales indicate a sex bias in the adjustments for the net undercount, in which there were too few males in relation to females.

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In 1971 the undercount was relatively small at approximately 50,000 persons and the 1981 census was likely to be the peak in terms of public co-operation and efficiency. Since then the undercount has increased. It is accepted that approximately 1.2 million people living in the UK avoided being included in the 1991 census and the net undercount was officially estimated at 2.2 per cent. This level of undercount was likely to be partly because of attempts to avoid poll tax registration. Other contributing factors were likely to include increased mobility of the population, more second homes, weakened family ties, less accessibility to enumerators and a culture of weakening individual civic responsibilities.

In 2001 the response worsened again. The One Number Census estimate of net non-response was 6.1 per cent nationally and as high as 22 per cent in Inner London. The term 'non-response' covers both undercount as defined in 1991 as well as imputed returns. The corresponding 1991 figure of net non-response is 3.8 per cent, making the 2001 figure 1.6 times higher. The rates of net undercount, under-coverage or non-response were higher for men in their 20s and 30s than for women of the same ages.

It is anticipated that by 2011 further changes in society and public attitudes are likely to make conventional census-taking even more difficult, and arguments are being advanced for the use of a set of administrative registers to replace the census. The first Administrative Record Census was taken in Denmark in 1981. This would require the co-ordination of major population registers, using a common personal number to improve quality. Compared to the census, advantages of a universal population register include minimal burden on the public, lower cost, greater frequency and, provided register quality is good, improved coverage. Moreover, an Administrative Record Census cannot be undermined by public dissent. Limitations are that a smaller range of topics can be included, the same biases as in a census can occur, and statistics can be heavily delayed. In particular, questions such as the health-related questions asked in 2001 could not be derived from population registers. Therefore topics not covered satisfactorily by registers would need to be supplemented by sample survey data.

4.2.2 The Health Survey for England

The annual Health Survey for England is commissioned by the Department of Health. It started in 1991 after being proposed in 1990 by the Department's Central Health Monitoring Unit in response to the lack of national data about morbidity. The aim was to improve the monitoring of national health policies and targets, such as progress towards reducing blood pressure and the levels of obesity in the population. Data from the survey are used to estimate the proportion of the population with specific health conditions and the prevalence of factors associated with these conditions. It is also used to estimate the differences between population subgroups, subdivided for example, by age, sex, region or social class. The Survey's scope has expanded over time. Initially it was undertaken by the Office of Population Censuses and Surveys. Since 1994, it has been undertaken by the National Centre for Social Research and the Department of Epidemiology and Public Health at UCL. Scotland, Northern Ireland and Wales each have their own health surveys.

The survey's stated aims are: (108)

- to provide annual data about the nation's health
- to estimate the proportion of the population with specific health conditions
- to estimate the prevalence of risk factors associated with those conditions
- to assess the frequency with which combinations of risk factors occur

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- to examine differences between population sub-groups
- to monitor targets in the health strategy.

Since 1995, it has measured the height of children at different ages, replacing the National Survey of Health and Growth.

Socio-economic indicators collected in the Health Survey for England

The survey combines questionnaire answers and physical measurements, including analysis of blood samples, ECG readings and lung function tests. An interview with each eligible person is followed by a visit from a nurse who makes a number of measurements and, in some cases, takes a blood or saliva sample. The sample is selected from people in private households in England with the exception of a special sample of older people in care homes included in 2000. This survey covered disability and cognitive function as well as the core topics. Those in care homes were asked additional questions about cardiovascular disease and respiratory symptoms, eating habits, physical activity and other activities. A questionnaire for home managers included details about the type of care home, the number of residents and the availability of services and specialised equipment.

A full set of questions covered in the 2001 Health Survey for England is shown in Appendix B, Table 45. Socio-economic indicators collected include:

- income
- economic status
- tenure
- accommodation details
- car ownership
- morbidity
- age
- sex
- employment
- education
- ethnicity
- cultural background
- country of birth.

The core questions are repeated each year together with one or more additional modules on subjects of special interest.

The 'core' questions include:

- general health and psycho-social indicators
- smoking
- alcohol consumption
- demographic and socio-economic indicators
- use of health services and prescribed medicines
- measurements of height, weight and blood pressure.

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Modules on special topics have included:

1993	Cardiovascular disease
1994	"
1998	"
1995	Asthma, accidents and disability
1996	Asthma, accidents and special measures of general health (Euroqol, SF36)
1997	Children and young people
1999	Ethnic groups
2000	Older people, social exclusion
2001	Disability, non-fatal accidents, respiratory disease and atopic conditions and fruit and vegetable consumption
2002	Children and young people, maternal and infant health
2003	Ethnic minorities, physical activity, eating habits, oral health, serious accidents, asthma in children

Coverage of health service use in the Health Survey for England

The Health Survey is designed to be nationally representative of people of different age, sex, geographic area and socio-demographic circumstances. The sample size has increased over the years and has extended from collecting data only on adults to the inclusion of a sample of children.

The 1991 and 1992 surveys sampled around 3000 and 4000 adults respectively. For 1993 to 1996 the adult sample was boosted to 16 000 to enable analysis by socio-economic characteristics and health regions. In 1995 a sample of about 4000 children aged 2-15 years was introduced. The 1997 survey was of 9000 adults and 7000 children and in 1998 the sample was 16 000 adults and 4000 children. From 2001 onwards, children under two years old were included. The estimated interview response rate was 67 per cent among adults and 74 per cent among children.

Level of data aggregation

The results of the Health Survey are normally published at a national level. In one special report, survey data for 1994 to 1996 were combined to provide information on core topics at health authority level.(109) Following the dissolution of health authorities under 'Shifting the Balance of Power(110) and the establishment of Primary Care Trusts, this had to be rethought. Some analyses of ongoing core items, combining a number of years at the level of Strategic Health Authority, were published in March 2004.(111)

Access to data from the Health Survey for England

A main report of about 500-600 pages of tables and commentary is published each year, together with a Summary of Key Findings. Main reports are available from the Stationery Office Publications Centre. Prices of reports vary but most are available online. The full datasets for the Health Survey are available through the UK Data Archive, based at the University of Essex. The full set of questions for the Health Survey for England are held on the Question Bank at the Centre for Applied Social Surveys at the University of Surrey.

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The data have been used extensively for secondary analyses. For example, a paper describing socio-economic variations in the treatment and control of hypertension in England used data on a sample of hypertensive people from the Health Survey for England for 1993 and 1994. (112)

Variations in treatment rates were explained by variations in the use of primary care and opportunistic screening for some groups. Although concerned primarily with utilisation, such findings have implications for access.

4.2.3 The General Household Survey

The General Household Survey (GHS) is a multi-purpose continuous survey carried out by ONS. It has been conducted annually since 1971 and has run continuously except for some years in the late 1990s when it was suspended. This affected 1997-98 when the survey was reviewed and 1999-2000 when it was redeveloped. The survey is designed to produce representative results over a range of social and geographical conditions covering England, Wales and Scotland. Although based on a much smaller sample size than the census it can be used to monitor regional differences and national trends.

Since the survey was redeveloped and re-launched in 2000, it has consisted of two elements, the Continuous Survey and 'trailers'. The Continuous Survey is to remain essentially unchanged for the five years from 2000 to 2005, consisting of a household questionnaire answered by the household reference person or their partner, and an individual questionnaire completed by all resident adults. (114)

The core topics about the household and the individual members are:

- household and family information
- housing tenure and household accommodation
- consumer durables including vehicle ownership
- employment
- education
- health and use of health services
- smoking and drinking
- family information including marriage
- cohabitation and fertility
- income
- demographic information about household members including migration.

Socio-demographic data are collected from each individual interviewed, including:

- age
- sex
- ethnicity
- migration
- geography
- accommodation details
- tenure
- country of birth

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- morbidity
- employment
- income and education.

Coverage of health and health service use in the General Household Survey

Questions are asked annually on general health, long-standing illness, limiting long-standing illness, acute sickness, consultations with a general practitioner or practice nurse two weeks before the interview, and outpatient attendances three months prior to the interview, and stays in hospital in the preceding year. A full list of health related items is shown in Appendix B.

The health section starts with a question on general health, as in the census. It then asks about long-standing illness, details of the illness or illnesses and whether they are limiting before going on to ask about acute sickness in terms of restricted activity. The wording of the long-standing illness question differs slightly from that of the corresponding question in the census.

Health questions asked each year in the General Household Survey are:

- Over the last 12 months would you say your health has on the whole been good, fairly good, or not good?
- Do you have any long-standing illness, disability or infirmity? By long-standing, I mean anything that has troubled you over a period of time or that is likely to affect you over a period of time?
- Does this illness or disability (do any of these illnesses or disabilities) limit your activities in any way?
- Now I'd like you to think about the two weeks ending yesterday. During those two weeks, did you have to cut down on any of the things you usually do (about the house/at work or in your free time) because of (answers to longstanding illness question) or some other illness or injury?

Questions on the use of health services are:

- During the two weeks ending yesterday, apart from any visit to a hospital, did you talk to a doctor for any reason at all, either in person or by telephone?
- Did the doctor give (send) you a prescription?
- During the last two weeks ending yesterday, did you see a practice nurse at the GP surgery on your own behalf?
- During the last three calendar months did you attend as a patient the casualty or outpatient department of a hospital (apart from straightforward ante- or post-natal visits)?
- Was this visit (were any of these visits) to the casualty department or was it (were they all) to some other part of the hospital?
- During the last year, have you been in hospital for treatment as a day patient, i.e. admitted to a hospital bed or day ward, but not required to remain overnight?
- During the last year, have you been in hospital as an inpatient, overnight or longer?

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Sample size and the processing of survey data in the General Household Survey

A sample of approximately 13 000 addresses is selected each year from the Postcode Address File and all adults aged over 16 are interviewed throughout the year in each responding household. Demographic and health information is also collected about children in the household. All interviews since 1994 have been conducted using Computer Assisted Software. The response rate was 72 per cent and the annual sample size achieved is around 8500 households.

Access to General Household Survey data

The results of the General Household Survey are used by government departments and many other organisations for planning, policy and monitoring and to profile households, families and people in Britain. It has documented major changes over three decades, including the decline in average household size and the increase in the proportion of people who live alone, in families headed by a lone parent and in numbers of couples cohabiting. It has also recorded changes in housing, such as the growth of home ownership, and the increasing proportion of homes with household facilities and goods. The survey also monitors trends in the prevalence of smoking and drinking.

The results of the Continuous Survey are published annually in a volume entitled *Living in Britain*, which is available on paper or in the 'Compendia and Reference' section of the National Statistics web site. Some of the results of trailers are included in this volume and some appear as separate publications, accessible from the same web page. Data from the survey are also used in other publications, notably *Social Trends* and *Regional Trends*. They are also widely used by people who are unaware of their original source. The individual data records are available for secondary analysis from The UK Data Archive. As with Health Survey data, they have been used extensively for this purpose.

4.2.4 Other population surveys

The Psychiatric Morbidity Survey

The Psychiatric Morbidity Survey was a series of surveys undertaken during 1993 to 1994 and contains data on just over 10 000 individuals aged 16-74 (113). The series includes surveys of adults in private households, prisons and young offender institutions, institutions catering for people with mental health problems and among the homeless. The survey was repeated in 2000. The survey instrument itself is very long running to some 76 pages. Table 6 below indicates the principle themes of the survey.

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Table 6 Items in the Psychiatric Morbidity Survey

Domain	Examples
Information on the household	
Background information	Age, sex, marital status, relationships, language
General health and long-term illness	Includes details of medication
Service use	GP consultations, hospital use and community care
Neurosis screening questionnaire	
Psychosis screening questionnaire	
Lifestyle	Smoking, drinking, drug use
Intellectual functioning	
Reading ability	
Key life events	
Activities of daily living and social support	
Socio-demographic information	Ethnicity, institutionalisation/care, schooling, qualifications, employment, benefits, income, housing tenure, debt

The surveys contain a wealth of socio-demographic information key to measuring and monitoring access to health care. Their usefulness is undermined by the irregular and infrequent nature of the surveys and the fact that data cannot be linked to other data sources. The relatively small sample size makes small area analysis problematic also.

The Omnibus Survey

The Omnibus Survey¹ was set up in 1990 and runs 12 times a year. This multipurpose survey is based on a random sample of c 2000 addresses per month. The survey is not specifically health focused, rather it is designed to provide quick answers to questions of immediate policy interest, assess the effectiveness of publicity campaigns, and test the public's awareness of new policies. The survey also provides a sample of respondents for follow-up investigation and for testing and piloting new questions.

Recent health related modules in the survey have included: contraception and smoking. Although topics may change and be revisited, the survey collects a core suite of 'classificatory' variables including:

Household variables included (among others):

- number of adults in the household
- number of children in the household
- household type
- housing tenure.

¹ ONS Omnibus Survey: <http://www.statistics.gov.uk/STATBASE/Source.asp?vlnk=657&More=Y>

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Individual socio-demographic variables included (among others):

- sex
- age
- relationship to household reference person
- marital status
- ethnicity.
- employment status
- National Statistics Socio-Economic Classification (NS-SEC)
- income
- general health.

The general health question is: 'over the last month would you say that your health on the whole has been good, fairly good or not good'?

As with other sampled surveys these data are useful but only in aggregate and cannot be linked to other data sources to provide a detailed picture, nor are small area analyses possible. The omnibus survey is therefore not particularly useful for measuring and monitoring access to health care.

4.2.5 Future developments in the population surveys

With the introduction of the Continuous Population Survey (CPS) (104), it is not entirely clear how the health components in the existing surveys will be carried forward. The new proposals envisage a fixed core of socio-demographic variables - 'Classificatory variables' together with a rotating core of variables which might be revisited every three or four years. The rest of the survey would be made up of topic modules designed to collect the sort of adapt that the existing populations surveys collect.

The provisional programme of future work for the Health Survey up until it is combined into the Continuous Population Survey envisages returning to individual topics at about five yearly intervals to monitor trends. This involves two out of each five years being an over-sample of a minority population group with consequent reduction in the main sample. The remaining three years will be a full sample so that data can be combined to give Strategic Health Authority level data on core topics. Consideration is being given to the possibility of producing synthetic estimates at PCT level under the Neighbourhood Statistics programme. The following special topics are planned for 2004 to 2006:

- 2004: Cardio-vascular disease; physical activity; and eating habits.
- 2005: Elderly people plus elderly people in institutions; disability; accidents; and social exclusion.
- 2006: Disability; asthma; and accidents.

Again it is unclear exactly how the General Household Survey will feature within the new Continuous Population Survey. Originally it was planned to retain its modular structure with a number of trailers included each year in a plan agreed by sponsoring departments. The trailers in 2002/3 were usual alcohol consumption in the last 12 months, sport and leisure, contraception and hearing.

4.2.6 Strengths and limitations of survey data

Continuous survey data can be used to monitor changes over time and between areas and groups of people. The major surveys identified in this Section have been used to identify inequalities by sex, race and income. By correlating and linking questions such as self assessed health with service provision, surveys provide rich sources of data and provide information on populations that would not be otherwise obtainable. Due to its near complete coverage, the census provides the vital denominator figure by which to measure access, therefore providing the total population from which individual cases are derived,, for example to answer questions on a health care service provided to a certain number of people, out of how many people.

A limitation of the sample surveys is that unless sample are very large, they cannot be used to produce statistics for small areas. This limits their usefulness locally to health and local authorities.

Breaks in a series can be problematical, as can changes in definitions, such as the change from using the 'head of household' as chief respondent up to 1999 in the national census to 'household reference person' from 2000 onwards and the change in social class classification in 2001. Also differences between surveys in wording of similar questions, for example differences between the chronic health questions in the General Household Survey and the census, can make direct comparisons difficult.

Response rates are decreasing in all the main continuous surveys, with declines averaging about one per cent per year since 1991. Analysis of the decline suggests that 40 per cent is due to a decline in contact rates, and the other 60 per cent is due to increases in refusals.(115) Reasons for non-contact include that fewer people are at home in the day due to increases in economic activity, household sizes are falling and lifestyles are changing. In addition there is an increasing suspicion about opening the door to strangers. The major reason for the increase in refusals seems to be due to greater public reluctance to take part in surveys. This is possibly because of rising numbers of surveys and cold calling.

Non-responders are not a random group and high non-response rates can bias results. Most surveys infer the characteristics of non responders by comparing the survey profile with the population profile derived from official statistics. Disproportionately missing are young men, people with lower educational qualifications, adults with no dependent children and people living in London. Although bias can be reduced by weighting and grossing methods, such measures cannot entirely compensate for low response rates.(115)

An article on statistical exclusion and social exclusion, describes three general characteristics of non-respondents.(116)

The largest group is people who are socially excluded through economic poverty or through special legal or cultural status. People with a negative view of government, for whatever reason, are less likely than others to be included in government enquiries. Unsettled people are difficult to include as they can be hard to find and their circumstances difficult to define.

The paper described how response to surveys is lowest among people who are either unemployed; in poor shared, temporary or rented housing; in dense urban areas; and in minority racial and cultural groups; as well as among young men.

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Questions about income receive a poor response from people for whom calculation of income is difficult, including people working in the informal sector, who are self-employed or in professions which are paid on a fee rather than a salary basis, and shareholders. The implications are that certain social groups are concentrated among non-respondents. This could result in people living in poor inner city areas receiving fewer government resources than their entitlement because data about them are missing.

To overcome these problems, it is necessary to improve coverage although making response compulsory will not necessarily solve this as is illustrated by experience with the census. Gaps in data can be reduced by asking relevant and well designed questions, by making data fully available and by ensuring that analyses are not biased by missing units. If data do become biased by non response, the impact on conclusions should be highlighted to users.

Further categories of missing data cited in the paper include the many questions never asked, and the analyses which are never made available.(116) This is because of the selectivity of official enquiries, financial constraints to the number of questions asked, and restrictions on the release of data and reports that utilise only a proportion of data. Such selectivity of analysis has the same consequences as selectivity of question and leads to a focus on a limited number of priorities at the expense of a broader view which acknowledges alternatives.

The surveys described provide vital information which can contribute to the measurement and monitoring of access to health care services.

Issues have been identified such as falling response rates, small area level analyses and access to data. Also the selectivity not only of questions, but also of the analyses undertaken restrict the full potential of data collected.

The census provides the essential denominator by which to monitor access to health care provision. It also provides comprehensive data on ethnicity and health, particularly from responses to the new questions, although flaws are identified particularly in the ethnicity question. Although the extent of the undercount is fairly well documented and there is insight into the characteristics of those missing, the deteriorating environment threatens the quality and coverage of future census results. If this continues it will be essential to find ways to overcome problems of declining coverage.(107) The government's proposals for a population register open up the possibility of a Nordic style Administrative Record Census in the longer term, but such uses of population registers can be prone to the same biases as censuses and other surveys.

4.3 Cancer registration

Cancer registration is the process of maintaining a systematic collection of data on the occurrence and characteristics of malignant neoplasms and certain non-malignant tumours. This process is widely established in many countries. Because of its existence an extensive range of data are collected, including many key items which can be applied to measure and monitor access. The cancer database held by ONS, which is populated by data from the regional registries, currently contains around six million records of cancers diagnosed from 1971 onwards.

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When radium treatment was introduced in the early 1920s a system was initiated in England and Wales to follow patient outcomes. A principle of the system was that statistical information was essential to plan and operate services. In 1945 the Radium Commission was designated as the statistical bureau to receive cancer data, but responsibility was passed to the General Register Office (GRO) in 1947. Since 1948 the GRO, and its successors OPCS and ONS, have collected and processed cancer data forwarded from registries in English regions and Wales on a voluntary basis. The scheme was revised in 1971. Since then the system has remained essentially unchanged despite a number of reviews.

The scheme was reviewed in 1980 by the Cancer Registration Advisory Committee which recommended a number of amendments to reflect the need to monitor changes in incidence and survival as improvement in treatments made mortality data a less reliable indicator of trends. In 1989, the Registrar General's Medical Advisory Committee established a working group to undertake another review of cancer registration in the light of impending NHS changes. The group made recommendations relating to the organisation of the system, the collection, processing, quality, timeliness, completeness and safeguarding of data. Its vision included the use of statistics in the planning and evaluation of services, and in preventative and curative services, far extending the traditional uses of monitoring time trends and geographical variations. The introduction in 1991 of the NHS internal market and the subsequent abolition of regional health authorities put the future of the regional registries in question for a while and held back implementation of the working party's recommendations. (26) In 1995 the Calman-Hine report on cancer in England and Wales, described in the cancer case study, acknowledged the key role of cancer registries. (117)

The National Cancer Intelligence Centre which co-ordinates work on cancer registration became part of ONS when it was formed in 1996. This was when the person-based national database at ONS went 'live'. In the same year a national core contract was issued for cancer registration in England and Wales.

In 1999, the Cancer Registration Advisory Committee commissioned Professor Charles Gillis, Director of the West of Scotland Cancer Surveillance Unit, to undertake a further review of cancer registration in England on behalf of the Department of Health. He found considerable variation between the regional registries in their organisational structure, type of host institution, data collection processes, range of tumours registered and in completeness, accuracy and timeliness of data submission to ONS. He defined an enhanced role for cancer registries, recommending a new framework accountable to a new National Cancer Registration Policy Executive and performance monitoring of data.

In response to the Gillis Report the Department of Health produced an Action Programme for Cancer Registration. One of its key recommendations was to propose a revision of the existing core contract. This was subsequently reviewed in 2001 and a new set of standards was created. Central funding was made available to support collaboration with cancer networks and the modernisation of cancer registries.

The work of cancer registries

Although notification is voluntary, cancer registries in England and Wales achieve over 90 per cent ascertainment for most cancers. Registration is conducted by 12 regional registries which collect data for their area.

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The functions of cancer registries are:

- monitoring trends in cancer incidence, prevalence and survival over time and between different areas and social groups
- evaluating the effectiveness of cancer prevention and screening programmes
- use of data to investigate differences in cancer incidence, survival and access to treatment between social groups to contribute to programmes aimed at reducing inequalities in health outcomes
- supporting investigations into the causes of cancer
- providing information for individuals and families at higher risk of developing cancer(118).

As can be seen, the third function refers to access. Data are provided by NHS and private hospitals, cancer centres, hospices, cancer screening programmes, other registers, primary care, and nursing homes. Data may be collected from several sources within the same institution, including clinical records, case notes and pathology reports, and from death certificates which are less reliable and complete. Death Certificate Only registrations (DCOs) where no data are available from other sources, are excluded from survival analysis because it is seldom possible to confirm date of diagnosis.

As well as contributing to identifying the causes of cancer, registry information can be applied to assess the effectiveness of screening programmes and treatment services. Registries also hold many other data that can be applied to evaluate access to care, including treatment, place of treatment, tumour stage, consultant and place of death.

The processing and quality of cancer registration data

The United Kingdom Association of Cancer Registries was established in 1992 and is concerned with issues including data quality and information requirements and systems. Its work has included improvements to coding and classification, developing performance indicators, issues around transmitting data to ONS, and establishing a forum to share research.

In 1997 a new contract for cancer registration was agreed by registries in consultation with the Department of Health, introducing targets for data quality and standardising the data collected.

Cancer registration data currently collected

Most registries collect a large amount of information about the patient, the tumour and the treatment. Data items can be grouped under the headings of personal data, data on the tumour; treatment data; and outcome variables. Following recommendations in 1990 by the National Cancer Registration System working party, since 1993 registries have been required to collect a common minimum dataset for cancers registered.(119) There is also a subset of data items to monitor waiting times, important for monitoring access. There are additional datasets for specific sites, breast, colorectal, lung, head and neck, urological, upper gastro-intestinal, gynaecological, sarcoma, and skin cancers. Datasets are being developed for haematological malignancies, children's cancers, palliative and primary care. The NHS Information Centre web site (www.ic.nhs.uk) provided further information on these.(120) Significantly, the private sector is not required to submit the minimum dataset, leading to a gap in information.

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Cancer registrations are 'flagged' in the NHS Central Register at Southport which has records of everyone registered for care with the NHS. It receives records of all deaths so it can be determined when a person with cancer dies, even if death is from causes other than cancer.

The data items in the current dataset, version 4 can be seen in Appendix B, Table 57. The key items which can be applied to evaluate access to cancer services by the population as a whole and between groups are, demographics (postcode, sex, age, ethnicity), referral data (dates referred, source, date seen, reasons for delay, waiting time), diagnosis and staging data, and death details and date. Socio-economic status is not recorded but this can be obtained by linking to death data. In addition registered census users may be able to obtain regional cancer registry data for linkage by postcode.

Access to cancer registration data

Most regional registries publish annual reports summarising the data. It can take a long time to obtain clinical case notes, so reports may not be published for one or two years after registration.

Researchers can apply to obtain registry data, often for a fee. The main national publications by ONS are in the MB1 series. Incidence and survival data are also published in *Health Statistics Quarterly*. In 1999, ONS published extensive analyses of 'Cancer survival trends in England and Wales, 1971-1995: deprivation and NHS region'.(121) A subsequent publication 'Cancer Trends in England and Wales 1950-1999'(122) brought together a large amount of information on incidence, deaths, prevalence and survival presented by sex, age, geographical region and deprivation. It can be purchased or downloaded from the ONS web site.

Examples of how cancer registration data has been used to measure and monitor access

A number of academic publications, although not directly focussing on access, do provide an insight into access issues. A paper in 1994 described the many possible uses of cancer registry data, for example the wealth of data vital for evaluating health care on treatment, tumour stage, place of treatment and place of death.(123)

Another paper by the same author used HES and 1991 census data to examine the relationship between deprivation and acute emergency admissions for cancers of the colon, rectum, lung and breast in south-east England. This showed that residents living in deprived areas were more likely to be admitted as emergencies and ordinary inpatient admissions and less likely to be admitted as day cases than counterparts in more affluent areas.(57) This has implications for access and stage of disease at time of admission. Another analysis of cancer registry showed that survival from most cancers was better in affluent areas than in deprived ones, for a variety of reasons.(121)

In considering inequalities in access to cancer care, a number of factors are relevant.(74) These include evidence that screening coverage programmes for lower socio-economic groups is poorer. This is important for identifying cancers at an earlier more treatable stage. Late presentation and emergency rather than elective admission may suggest difficulties in accessing care as well as differences in treatment and referrals. This article

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also cited evidence of poorer outcomes for people in lower social groups irrespective of access issues.

Over time the work of regional cancer registries has expanded from monitoring cancer occurrence. It now includes analysis of cancer prevention, treatment and care, and variations in the provision of services and outcomes between different geographical areas or by time trend.

4.3.1 Summary of the ability of cancer registration data to monitor and measure access

The counties of the UK have the world's largest and most comprehensive national cancer registration system and the minimum dataset contains many items that can be applied to monitor and measure access to health services, for instance socio-demographic variables covering ethnicity and area of residence. Unfortunately data on occupation and country of birth are only available with linkage to death certificates.

On the other hand, registration is not statutory and ONS has no organisational or financial control over the registries. Under-funding of registries over a long period has implications for data quality.

Another acknowledged limitation of cancer registry data, which affects its ability to monitor access, is that the timeliness of national data depends on the length of time that registries take to complete submissions to ONS.

Where cases are not recorded until death, there can be a time lag of many years since the disease first developed. As mentioned earlier, these Death Certificate Only registrations contain limited data and cannot be included in survival analyses. Since they are likely to include a high proportion of people with poor survival and thus less time for them to be registered in life, their exclusion from survival analyses will raise survival rates artificially. So DCO registrations need to be kept to a minimum to ensure accurate survival statistics. (26)

The charity, Cancer Research UK, has called for legislation to make cancer a statutorily reportable disease. (124) This would provide legal stability to the National Cancer Registration System, and reflect its importance as a tool for public health, cancer research and NHS cancer policy. Registration is legally required in many other western countries and is needed to enable the NHS Cancer Plan to fulfil its targets and contribute fully to population-based cancer research. Such a move would be welcome because only by achieving full population coverage can access to services by all groups be systematically evaluated.

4.4 Registration and notification of vital events

This section focuses on data from the registration of births and deaths and notification of births and congenital anomalies and data from the confidential enquiries to both measure and monitor access to health services. Registration here refers to those functions of recording data (concerned with health in its widest sense) by the state or its institutions that are mandated by statute and are a matter of public record, while notification systems, which may also have been established by statute, fulfil a monitoring function rather than one of absolute record.

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At the time of writing a major review of civil registration is underway in England and Wales. There are likely to be changes to the way in which births and deaths are registered and the sorts of information collected and analysed in aggregate returns. The government has issued a detailed document for consultation.(125) This section addresses these proposals but not 'consumer' aspects of the proposed changes such as registering deaths by telephone or internet, nor the proposed changes to marriage/partnership registration.

4.4.1 Registration of births and deaths

This section will introduce and briefly describe the important routine datasets concerned with registration and notification of vital events.

Birth registration

Registration of births is a legal requirement.(126-129) Live births must be registered with a local register office of the Registrar of Births Deaths and Marriages, within 42 days and stillbirths within three months. The Registrar issues a birth certificate and makes a 'draft entry' in the register.

The information recorded by the Registrar for live births is shown in detail in Appendix B, Table 47, and that recorded for stillbirths in Appendix B, Table 52. Fetal deaths after twenty-four or more completed weeks of gestation are registerable as stillbirths and the informant must take a Medical Certificate of stillbirth issued by a doctor or in some circumstances, a midwife.

Under the Population (Statistics) Acts of 1938 amended in 1960(130), additional information in connection with live births and stillbirths is collected in confidence for statistical purposes and does not appear in the Register.

Of particular interest when trying to analyse these data by groups within the population is the recording of data relating to the occupation of the child's parents allowing analyses to be conducted by socio-demographic factors. If the birth is within marriage or jointly registered by both parents outside marriage, the father's details should be recorded including his occupation. For births outside marriage registered by the mother on her own, only the mother's occupation is recorded. Since 1986 the mother's occupation can be recorded for any birth.

Due to the legal requirement for registration very few births are unregistered so ascertainment of births from registration data are virtually complete. This is also true for the principal data items, all of which are legally required. Although the accuracy of the information supplied is the responsibility of the informant, there are legal penalties for providing false information.(131) Some data items are optional, such as the mother's occupation, if the father's has already been recorded. By 2001, only per cent of mothers recorded a codeable occupation on the birth certificate.(132)

Analyses of birth registration data are routinely available in the ONS publication, *Birth Statistics Series FM1*.(131) These include numbers, rates and sex ratios of live births, stillbirths and maternities by seasonality, the age of the parents, multiple births, area of usual residence, place of delivery, birthplace of parents and social class of the father. Live birth and stillbirth are also analysed by number of previous live-born children within marriage and duration of marriage. Data for regions and local authorities are also available in the series VS and PP1, *Key Population and Vital Statistics*.(133) Summary figures for births, fertility rates, by age of mother, birth weight, type of institution, sex, gestational age

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for smaller local and health authority areas, are produced in a CD Rom in the DVS series but since 2002, these have not been available outside the NHS. A Public Health Birth File is available electronically to Health Authorities, however it is expensive and only available to those within the NHS. Few Health Authorities purchase this.

Aggregated data are therefore available for the whole of England and Wales, with some data available at the level of England, Wales, government office regions, metropolitan counties and strategic health authorities. More localised data are available, but in small areas the number of stillbirths may be so low that meaningful analysis is not possible. There are also confidentiality concerns that reduce the utility of these data at small area level, for instance with regard to trends among teenage mothers where it may be difficult to obtain data releases on maternal age. Many more detailed analyses are published in the ONS journal *Population Trends and Health Statistics Quarterly*. Data collected under the Population (Statistics) Acts are not normally made available to outside researchers.

Birth notification

Notification of births is also a requirement of the NHS Act 1977.(134) Within 36 hours of a birth the Director of Public Health (DPH) of the local Strategic Health Authority must be notified. The information is used to set up a new born child on a locally based Child Health System. The specific form of notification used is laid down locally but some information is in a standardised form.

Before 29 October 2002, the registrar would allocate a baby an NHS number and send it to the DPH of the district within which the birth occurred. This resulted in a delay before the baby's NHS number could be passed on to clinical staff, making it difficult to link babies' records to their mothers', hence a need for a new system. The DPH would then send the baby's birth weight to the Registrar who added it to the 'draft entry'. This was sent to ONS for processing and another copy was sent to the NHS Central Register at Southport so that a record could be opened for the baby.

Usually these systems combined the birth notification with discharge summary information, which was put on the child health system and made available to health visitors and the other relevant staff.

The format and data collected were not prescribed by law but some former Regional Health Authorities used similar systems to each other within their areas and many used the National Child Health System. The data items in the National Child Health Computing System(135) and the system used by former North East Thames RHA (RICHS) are shown in Appendix B, Table 49.

The kinds of data items collected by these two child health notification systems are broadly similar. They included demographic information about the mother, the history of previous births and various screening tests performed on the mother during pregnancy, such as sickle cell and amniocentesis, gestational age at delivery, birth weight, and details of resuscitation as well as anthropomorphic measurements and physiological scores.

Ascertainment of births was high as there is a statutory duty to notify births. As most data are not published routinely, it is difficult to comment on their accuracy and completeness.

Although the data have been used for analyses in some areas,(136;137) the notification system is intended primarily to set up the Child Health Record. Child health systems' main

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purpose is the administration of immunisations and tests of children's health and development. In child health systems, data from birth notification are relatively complete but there are major gaps in those recorded later in childhood.

The major problem with the old birth notification system was that as parents have up to six weeks to register a live birth, there could be a major delay before the NHS number was issued.

NHS Numbers for Babies

To remedy this problem a new system was set up to issue NHS numbers at birth. NHS Numbers For Babies was launched on 29 October 2002.(138;139) This provides the potential to build a comprehensive electronic record of a person's health from birth. Registrars of Births and Deaths no longer issue NHS numbers. Using a linked computer, midwives send notification details to a computer system called the Central Issue System. This allocates newborn babies with NHS numbers. The baby's NHS number is printed on the birth notification form that is produced by the maternity unit. In addition, the Central Issue System sends an electronic copy of the Birth Notification containing core information on the baby, mother and GP to the Child Health department. The information can be either printed off and entered manually into the Child Health system or automatically read in to the Child Health system.

The data items in the NHS Numbers for Babies notification are shown in Appendix B, Table 48. As can be seen, they are more limited than those available from the Birth Registration system Table 47, and even more limited than the child health systems Table 49. As a result, many maternity units continue to send the original notification to child health departments in parallel. This means that the advantages gained in issuing NHS numbers at birth have been at the expense of duplication of effort in transferring information to child health departments.

The registration and certification of deaths in England and Wales

Medical certification of the cause of death is part of the process of death registration. Registration of deaths first came into force in 1837.(126;140) (127-130;141) The processes of death registration and the way statistics are derived from it have been described in detail in an article in *Health Statistics Quarterly*.(140) Changes are under consideration as part of the review of civil registration and in response to the Shipman Inquiry.(140;142)

Upon death, if the deceased has been attended recently by a doctor, a Medical Certificate of Cause of Death is issued to the next of kin who must take the certificate to the registrar's office in order to register the death. The format of the Medical Certificate of Cause of Death is prescribed by law and can only be completed by a doctor who has been in attendance during the deceased's last illness.(128) The information recorded is shown in Appendix B, Table 50. If the death was sudden, the doctor treating the deceased is unavailable or there are suspicions, the death has to be reported to the coroner.(143) In some circumstances the attending doctor may refer the death directly to the coroner. Further details can be found on the ONS web site and in the annual volumes of Mortality Statistics in the DH1, DH2, DH3 and DH4 series.

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At present, deaths in England or Wales must be registered in the district in which they took place within five days of the date of death. Information for the registration is given to the registrar by the person registering the death. This is usually the next of kin but certain other legally prescribed persons may also register a death. The information, which is usually recorded on computer, is also recorded in the death register and the person registering the death signs the record. The data items are shown in Appendix B, Table 51.

If the deceased is under 16 years old the name, surname and occupation of the mother may be added, and those of the father must be. For a deceased woman who was married or widowed, the name and occupation of the husband may be added. Under the Population (Statistics) Acts, if the deceased was married, the date of birth of the surviving widow or widower is recorded. If the deceased was in receipt of a pension or allowance from public funds, the Registrar is informed but information is not entered on the register.

Details supplied by the informant and those from the death certificate are combined to complete a 'draft entry'. The information is sent weekly to ONS for processing.(140) Copies are sent to the local DPH who is also informed as is the NHS Central Register in Southport so that the deceased can be removed from the GP's list. A death certificate is issued and used as a legal document.

ONS has two death databases. One is text based and contains the information available publicly and required for a death certificate. The other has only coded details of each death and is used for statistical purposes. The publicly available text based database remains the same even if the cause of death details are amended as a result of a coroner's or pathologist's report. The statistical database is amended if further information is received, however.

Cause of death classifications were developed in the nineteenth century. The International Classification of Diseases was first used in 1900(140) Since 2001 the tenth revision has been used to code cause of death.(144) This was the most radical revision for fifty years and as a result there has been some discontinuity in cause of death trends.(144) Ascertainment of deaths is high as it is a legal requirement and disposal of a body without a death certificate is illegal.

Mortality statistics for England and Wales are published annually by the ONS in the DH Series. Four annual volumes can be found on the ONS web site:

- 1 Mortality statistics, general, Series DH1
- 2 Mortality statistics, cause, Series DH2
- 3 Mortality statistics, childhood, perinatal and infant, Series DH3
- 4 Mortality statistics, injury and poisons, Series DH4

Local mortality data are also provided to primary care trusts and health authorities in series VS3 and VS4. VS3 shows the number of registered deaths of residents by cause of death in five-year age/sex bands and VS4 shows the total number of registered births and deaths within each electoral ward. Public Health Mortality files are available to those within the NHS, but are expensive to purchase (£3000 per month) and are not universally used. Their expense coupled with the fact that they may not show the final cause of death limits their usefulness. Furthermore, they do not contain information that is not available elsewhere, although there may be a time delay for the other sources of mortality information.

The Office for National Statistics publishes a series of decennial supplements containing more detailed analyses in mortality. These have been published every ten years since the

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nineteenth century, when census data are analysed. Analyses of death rates by area of residence and occupation have been undertaken since 1850, showing geographical areas and occupations which have had higher and lower than average mortality. Since 1911 occupations have been grouped into social classes. Analyses have shown wide disparities in mortality between social classes. More recently the decennial supplements have included analyses of data from a wider range of sources, including the OPCS Longitudinal Survey. (26)

Updated recent supplements that are of particular interest to this section include: 'The Health of Our Children', Decennial Supplement; 'The Health of Adult Britain 1841-1994', Decennial Supplement, Volumes 1 and 2; 'Health Inequalities' Decennial Supplement and 'Geographic Variations in Health' - Decennial Supplement.

Marriage registration in England and Wales

The registration of marriages is outwith the scope of this section as data from marriage registration are not routinely linked to data relevant to health. This may change if the proposals in the review of each registration for 'through-life records' are implemented.

Proposed changes to civil registration

As part of the review of civil registration, a wide-ranging consultation took place in 2003 about proposals for changes to vital registration in England and Wales. (125) The outcome has not been announced at the time of writing. The proposals relevant to the subject of this report are summarised below.

Deaths

For death registration, it was proposed that the local authority where death occurred should be included.

Coverage would be extended to include the name and occupation of the wife of a deceased husband or widower. For a dead child, as well as recording the parents' names and occupations, those of adoptive or step parents could be recorded where appropriate.

The occupation, usual address and, if married/widowed, the occupation of the husband/wife should be recorded. If under 16 years old, the occupation of both father and mother could be recorded.

Informants' usual address and cause of death will become restricted items and not made generally available.

Live births and stillbirths

It was proposed that:

- Births could be registered away from parents' usual place of residence and the local authority area of registration and local authority area place of birth should both be recorded.
- All previous live and stillbirths, not just those within marriage, could be recorded.
- All data on marriage and partnership status for both the mother and the father, could be recorded.
- To allow record linkage, the NHS number of the mother, would be recorded.

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- The ethnicity of the baby or of the mother, should be recorded.
- The level of educational attainment of the mother and where applicable the father, could be recorded.
- The cause of death recording on the medical certificate of stillbirth should be recorded to allow the underlying cause of stillbirth to be identified.

Privacy and access to registration records

It was proposed that medical and social researchers should have access to registration information subject to the ONS code of practice and ethics approval. This would include items not on the public register. Publication of any research must be in an anonymised form.(125)

Proposals have been made in the past for changes to civil registration, but have never led to the primary legislation needed to enact them.

In order to make future changes to civil registration easier and to enable the system to be more flexible to changing demands and needs, it was therefore proposed to move away from specifying items to be collected for statistical and research purposes in primary legislation and allow them to be specified through regulatory reform.(125) This was rejected by the House of Lords.

The need for change

One of the most important proposed changes is the requirement to record ethnicity on birth certificates. This is needed to comply with legislation requiring public bodies, including the health service, to have due regard to the need to promote race equality when carrying out their functions.(145; 146) Only the parents' place of birth is currently collected. This is not an accurate reflection of ethnic origin. The 2001 census showed that only 50.2 per cent of the ethnic minority population was born outside Great Britain.(147) Place of birth is still important for monitoring health and access to health care by migrant status, however. Ethnic coding of births would enable services to be planned more accurately and appropriately for areas with higher birth rates in disadvantaged communities.

Employment status is not collected compulsorily at birth registration. In any case the data that are collected are not fully compatible with current socio-economic classification systems now that the National Statistics Socio-Economic Classification (NS-SEC) has replaced the Registrar General's social classes.

Currently only details of previous live and stillbirths are recorded only if the parents are married and are restricted to births within marriage. The proposed change would ask all mothers about numbers of all previous live and stillbirths, not just those within marriage. This should provide data about all previous live and stillbirths in a format compatible with that used in clinical practice. Data on the marriage status and partnership status for the mother and father will also be collected, particularly as the rates of stillbirths and infant death are known to be higher outside marriage.

Other proposed changes include allowing recording educational attainment of mothers and fathers on birth certificates and revising the cause of death recording on certificates of stillbirth to allow the underlying cause of stillbirth to be identified.

It is recognised that where information from the father is required that this will not always be possible as nine per cent of births have no father registered.(125; 148)

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Another major proposal is to establish a 'through-life' record. This will allow birth, death and marriage records to be linked, enabling records to be automatically updated, for example, with a change of name. The through-life record could also contain divorces, naturalisations, births, deaths and marriages overseas. While this will undoubtedly help people endeavouring to prove a certain status i.e. that they can legally marry, the changes will have little impact on the ability to assess the equity of access to health care. Not least because there are no plans to link related individuals, for example, the mother with her children.(125)

The proposals for changes to civil registration also affect the rights of access to records and data derived from them. It is proposed that medical and social researchers should have access to registration information subject to the ONS code of practice and ethics approval. Publication of any research must be in an anonymised form.(125)

4.4.2 Notification of congenital anomalies

The National Congenital Anomaly System (NCAS), was set up in 1964 following the thalidomide tragedy.(149) The system is run by ONS which receives notifications from local health authorities and regional congenital anomalies registers. It is intended to cover congenital anomalies in all births and stillbirths.

Data are collected on the specific conditions, the mother's usual place of residence, age, parity and occupation, the father's occupation and the baby's birth weight. The items are listed in Appendix B, Table 53.

Abortions are not included in the notification system, unless they take place after 24 completed weeks of pregnancy. Information relating only to live and stillbirths is collected.

The coverage of the congenital anomalies register is intended to be national but notification is voluntary and there is no legal requirement to maintain a regional register. Coverage at present includes all of Wales but only 40 per cent of births in England are covered by regional registers. Following a review, it was found that regional registers had better data than those submitted directly to the national register and that submissions from those regions with a register were of a higher quality than those regions without a register. As a result a decision was taken to share data between the national and local registries electronically to improve quality and coverage.

Congenital Anomaly Statistics are published by ONS in Series MB3. Rates are available for overall and by type of anomaly, mother's usual residence, birth weight, mother's age, parity, multiplicity, father's occupation and social class and mother's occupation and social class. The level of aggregation is for England and Wales. Data are not published for smaller geographical units.

In the past, information about anomalies apparent at birth have been passed to child health systems via birth notification. The dataset for NHS numbers for babies, records only the absence or presence of congenital anomalies, however. There is no space or requirement for any details so details have to be sought by other routes.

4.4.3 Notification of abortions

Data on abortions are collected in England and Wales under the Abortion Act 1967 and subsequent regulations. These require the practitioner terminating the pregnancy to notify all abortions to the relevant Chief Medical Officer, within seven days.(150) This legislation

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also specifies the form of the report, the HSA4. Amending legislation, the Abortion (Amendment) (England) Regulations 2002, resulted in a change in the HSA4 in April 2002. The data items are listed in Appendix B, Table 54. The changes to the HSA4 were intended to make the form more confidential so NHS numbers are used rather than names and postcodes rather than full addresses. Self-defined ethnicity is recorded but is not compulsory. Up until 2001 ONS compiled statistics on legal abortions. Since then the Department of Health has been responsible for this.

ONS published data quarterly and annually. Data are available by country and health region of termination, maternal age, marital status, previous live and stillborn children, statutory grounds, gestational age, purchaser (NHS, non-NHS and agency) and country of residence. In addition, annual data give national and regional abortion rates, numbers by method of termination, complications, duration of stay, regional and district health authority of residence and medical conditions mentioned. The Department of Health published its first year of data in October 2003.

Data from abortion notifications are combined with these from birth registration to produce estimated conception rates by age of mother. National data are published in Birth Statistics, Series FM1.

4.4.4 Confidential enquiries

Sitting alongside the registration and certification of deaths are three confidential enquiries into deaths in certain specific circumstances. These three enquiries are:

- 1 the Confidential Enquiry into Maternal and Child Health (CEMACH)
- 2 the National Confidential Enquiry into Perioperative Deaths (NCEPOD)
- 3 the Confidential Enquiry into Suicide and Homicide by People with Mental Illness (CISH).

Anonymised information from case notes and reports from professionals who gave care to the people who had died are gathered together and examined by panels of relevant professionals. The deliberations are designed to establish if the death was avoidable, whether there were elements of substandard care and whether or not lessons can be drawn for the future.

Confidential Enquiry into Maternal and Child Health (CEMACH)

Since April 2003 the two confidential enquiries relating to deaths among mothers and babies, the Confidential Enquiry into Maternal Deaths, and Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), have merged to form CEMACH(151). The remit of the new Enquiry has been extended up to 16 years of age. As well as undertaking a scoping study for this new work, it is continuing the two pre-existing enquiries.

Confidential enquiries into maternal deaths

Confidential enquiries into maternal deaths are undertaken in each of the four countries of the United Kingdom. Enquiries in England and Wales date back to 1928. In 1952 responsibility passed to clinicians and a series of three-yearly reports has been published. Since 1985, a common report has been published for all four countries of the United Kingdom. The data items collected are shown in Appendix B, Table 55.

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The most recent report focuses on specific clinical causes of death. In addition for making recommendations for practice may chart epidemiological trends.

Although not analysed explicitly, access to care has been an issue throughout the period covered by the enquiries. From 1994-96 onwards the coverage of social issues in the reports increased. Topics considered in the 1994-96 and 1997-99 reports include ethnicity, domestic violence, social exclusion, weight, parity, multiple pregnancy, geography, institution and late booking. Many problems of access to health care were documented for the small number of women who died. The most recent report, covering 2000-02 was published in November 2004.

Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI)

This enquiry was set up in 1992 in order to identify ways in which stillbirths and infant deaths might be avoided and to identify areas where further research is needed. Up until 2003 basic data were collected via a rapid report form for all late fetal deaths from 20 weeks of gestation, all stillbirths and all infant deaths. Postneonatal deaths were excluded from this from 2004. Strictly CESDI covers England, but Wales and Northern Ireland collaborate to undertake enquiries on the same basis. In Scotland, the Scottish Perinatal and Infant Mortality and Morbidity report takes a different approach based on surveys and audit.

A selection of cases is then examined by expert panels to identify any sub-standard care leading to the death or stillbirth, although these judgements can be subjective. Control groups and denominator information have been used since 1998 to improve interpretation of the findings.(26). The data items collected are shown in Table 56.

CESDI produced annual reports, the last of which was the eighth Annual Report, published in September 2001 for data relating to 1999. A general overview of the numbers and causes of stillbirths and deaths in infancy is presented along with a more detailed enquiry into specific subsets of cases, for example Project 27/28 which looked at the survival of pre-term babies born at 27 or 28 weeks of gestation.(152)

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Table 7 The work programmes of CESDI, 1993-99

<i>Enquiry topic</i>	<i>Year of study</i>	<i>Findings reported</i>
Intrapartum related deaths >2.5 kg	1993	2 nd Annual Report
Intrapartum related deaths >1.5 kg	1994-95	4 th Annual Report
'Explained' sudden unexpected deaths in infancy	1993-96	5 th Annual Report
'1 in 10' sample of all deaths >1 kg	1996-97	6 th Annual Report
All deaths 4 kg and over	1997	6 th Annual Report
<i>Case control studies</i>		
Sudden unexpected deaths in infancy	1993-96	3 rd and 5 th Annual Report
Sudden unexpected deaths in infancy	1993-96	The CESDI SUDI studies 1
Antepartum term stillbirths	1995	5 th Annual Report
Project 27/28	1998-2000	8 th Annual Report
Diabetes in pregnancy		
<i>Focus groups and central reviews</i>		
Shoulder dystocia	1994-95	5 th Annual Report
Ruptured uterus	1994-95	5 th Annual Report
Planned home delivery	1994-95	5 th Annual Report
Anaesthetic complications and delays	1994-95	7 th Annual Report
Breech presentation at the onset of labour	1994-95	7 th Annual Report
Stillbirths	1996-97	8 th Annual Report
<i>Audits and collaborative work</i>		
Postmortem reporting	1994-95	6 th Annual Report
Postmortem reporting	1993	2 nd Annual Report
CTG education	1999	7 th Annual Report
European comparisons of perinatal care	1995-98	8 th Annual Report
Use of electronic fetal monitoring	1999	8 th Annual Report

Data from the work undertaken by CESDI are published jointly for England, Wales and Northern Ireland together. Wales and Northern Ireland publish separate reports, and some English regions did so in the past.

The focus of the published data is clinical with no comment on such factors as ethnicity or social class, though the regional distribution of deaths is shown. Some social issues are

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addressed in the CESDI programme. For instance in the Enquiry into 422 stillbirths occurring 1996-97 in the eighth annual report, there was an analysis of risk factors associated with stillbirth. These included smoking and non-attendance at clinics, but there was no attempt to relate this to socio-demographic and socio-economic factors, as the relevant data are not recorded.

National Confidential Enquiry into Perioperative Deaths (NCEPOD)

CEPOD, now NCEPOD, was originally conceived in 1982 and established in 1988. Its first report was published in 1987(153;154) covering three regional health authorities in England. In 1988, its remit expanded to include all regions in England, Wales and Northern Ireland. Some independent hospitals also take part. The funding for NCEPOD, as with all the other confidential enquiries, was taken over by NICE in 1999. NCEPOD now collects data on all deaths in hospital and not just surgical deaths. The principal aim is to evaluate the quality of the delivery of care and not specifically the cause of death. In doing so, it reviews clinical practice and identifies potentially remediable factors in the practice of anaesthesia, surgery and other invasive medical procedures that may have contributed to a death. The remit extends to near-misses as well as actual deaths. At the time of writing, NCEPOD is still working out how the extended remit to cover non-surgical deaths and near-misses will be incorporated into its work.

Data on hospital deaths are submitted directly to NCEPOD by local reporters. The data year runs from 1 April to 31 March, during which the reporters send monthly or quarterly submissions of data, usually in an electronic format, containing data about all deaths on a hospital by hospital basis.

From this information, NCEPOD selects those cases that fall within the criteria for the studies being undertaken during that year. For the data year 2002-03, for instance, NCEPOD used the data to identify specific endoscopic procedures that occurred within 30 days of a patient's death. NCEPOD then sends more detailed questionnaires to the clinicians involved in these cases, the responses to which are subject to detailed peer review and analysis.(155)

The basic reporting form contains a minimum dataset for reporting perioperative deaths. The only socio-demographic or socio-economic data items collected at this stage are age and sex and possibly geographical location in the form of the hospital where the death occurred. ICD 10 diagnostic codes are available for primary and secondary diagnoses and OPCS codes are used for procedures within the 30 days before the patient's death, up to a maximum of six procedures.

A sample of all deaths is taken, varying between two and ten per cent since 1989. These are followed up with more detailed data collection. The actual data that are collected vary according to the specific study topic but is mostly clinical reflecting an interest in practice and procedures rather than the socio-economic determinants of health outcomes. Ethnicity is reported in earlier reports but only in very broad categorisations and with little analysis, being presented merely as a description of the sample.

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Confidential Inquiry into Suicide and Homicide (CISH) by people with mental illness

The Inquiry was established at the University of Manchester in April 1996. The Inquiry collects data from England, Wales, Scotland and Northern Ireland and is funded by The National Institute for Clinical Excellence in England, the National Assembly in Wales, the Scottish Executive and the Department of Health, Social Services and Public Safety, Northern Ireland. The Inquiry is conducted in association with the Royal College of Psychiatrists.(156)

The main aims of the Inquiry are:

‘To collect detailed clinical data on people who die by suicide or commit homicide and who have been in contact with mental health services and to make recommendations on clinical practice and policy that will reduce the risk of suicide and homicide by people under mental health care’.(156)

CISH is interested in specific ‘priority groups’ for whom recommendations are most needed.

These are people who are known to be at higher risk or to have greater treatment needs, or who are likely to experience difficulty in maintaining contact with services. The priority groups are patients who:

- were in-patients at the time of the incident
- were discharged from in-patient care less than three months earlier
- were subject to the Care Programme Approach at a level requiring regular multidisciplinary review
- were not compliant with treatment
- had missed their final appointment with services
- were from an ethnic minority
- were homeless.(156)

Data collection for CISH is done in three main steps. All suicides and homicides are notified to CISH. It then ascertains which of the cases notified to it have had contact with mental health services within the last 12 months. Finally, detailed clinical and socio-demographic data are collected on those who fulfil the first two criteria. Case-control studies among the suicide group are underway but have not yet been published. Analysed data from CISH are available as a report covering the five years 1996-2001.(157)

Strength and limitations of notification and registration data

A principal strength of registration data is that the coverage is universal in most cases and a legal requirement leading to a near total ascertainment of births and deaths as non-response is not a problem of the same magnitude as it is for the census and surveys. Data available from registration systems are also more up-to-date and timely than those adapted from surveys. Much useful information is available from birth registration and notification systems, particularly with regard to population markers of health such as infant mortality and low-birth weight. The decennial supplements produced by ONS have also played an important role in monitoring health inequalities in England, linking mortality and child health to socio-economic factors.

However, registration systems are primarily set up for legal and administrative purposes and in the main contain little information about morbidity with the exception of the Cancer Registries the Birth Notification Systems and the congenital anomalies register; however,

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these all cover specialist areas of health and health care. There is also a paucity of socio-demographic data available particularly ethnicity and little on socio-economic status except for death certification which has occupation and birth certification which may or may not have the occupation of the mother.

The confidential enquiries, especially the one into maternal deaths, are able to paint a more detailed picture showing the impact of social factors, in this case, on maternal mortality. The other confidential enquiries tend to be much more focused on aspects of care.

Nevertheless despite these reservations, registration data are an essential source of information for measuring and monitoring access to health care.

4.4.5 Access to health care in population-based registration and notification data

This section examines the routine datasets available from the census, the continuous surveys, cancer registration and vital registration and notification in England in terms of the framework for access and in particular the four dimensions of access, need for health care, opportunity to access health care, utilisation of health care by groups within the population. The health outcomes achieved by groups within the population. The datasets are evaluated to assess the degree to which they provide robust and reliable indicators of access, in terms of the socio-demographic and socio-economic variables which allow access to health care to be measured and monitored for the population as a whole and also for specific groups within the population.

Table 8, summarises the population-based routine data sources concerning access to health care in terms of the broad dimensions of access and the individual indicators of access. The datasets which have particular relevance to perinatal, maternal and neonatal health and are the subject of a detailed case study which forms a part of this report.

The Dimensions of Access

Need

These routine data are richest when it comes to deriving measures of need. The census and continuous surveys in particular provide a rich picture of the population in terms of its socio-demographic and socio-economic structure, with much information, especially from the continuous surveys and cancer registration having a direct bearing upon measure of need. Census data in particular are available at the small area level and are particularly useful in locally planning to meet health care needs. The health components of the continuous surveys from time to time provide detailed information on health needs for particular conditions or problems such as cardiovascular disease, disability or the elderly living in institutions. The Cancer Registration system also provides a detailed picture of the need for health care for diagnosed cancers.

Mortality data from death registration are robust and are used widely in determining levels of need for health care within the population. They form part of formulae designed to allocate resources for health care. Mortality rates, especially the infant mortality rate, have traditionally been used in public health surveillance as proxy measures of need. There are however, problems with using mortality as a substitute for morbidity in determining need for health care, especially with advances in modern medicine and the host of non-medical factors that affect survival. Nevertheless, the data are robust and the ascertainment high.

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Death registration data are available tabulated by age, sex, geographical location, socio-economic status and cause, so a reasonable picture of mortality specific to particular groups can be built up and a proxy measure of need developed. Ethnicity is not recorded at death. There is potential to link death registration data to HES data for those deaths that occur within hospital to obtain ethnicity, although this variable is poorly recorded.

Some level of need, based on morbidity, might also be deduced from the list of causes leading to death, but coding of death can vary in terms of whether all contributory causes of death are recorded.

Birth weight is to some extent a proxy measure of morbidity. Further morbidity could be compiled by record linkage to other datasets such as HES, if such a connection could be made without contravening confidentiality legislation. Age of the mother would be a useful need indicator to look at teenage pregnancies, but the utility of such analyses would be compromised by confidentiality issues and the difficulty in obtaining release of these data.

Birth notification and child health systems could potentially provide data not only on gestational age, birth weight, length and head circumference but also data on the Apgar scores, resuscitations carried out, admissions to hospital as well as details of any congenital anomalies. Socio-economic variables available include mother's age, mother's/baby's ethnicity (where available), socio-economic data in terms of whether or not the mother and baby constitute a single parent family and residence/distance from the place the birth took place. These systems can be used to collect data about previous miscarriages and neonatal deaths. Some carry data on maternal screening for sickle cell, hepatitis B, thalassaemia and screening for foetal abnormality including amniocentesis for chromosomal abnormalities and AFP for the risk of Down's syndrome and neural-tube defects. If complete data on these subjects were available from child health systems they could be used to build up a picture of need. The power of such analyses would be greatly enhanced if such data could be routinely linked to HES data and data from other sources such as general practice systems.

Opportunity

Population-based surveys and cancer registration, in common with most of the datasets reviewed in this report, are not particularly rich sources of data on the opportunity to use health services. However, the census does provide a detailed picture of the location of the population by important socio-demographic and socio-economic classifications. These data can be used to assess the extent to which health services are distributed in order to meet the needs of subgroups within the population. The addition of a question on long-term limiting illness does allow some direct measure of need to be derived; otherwise it is in terms of providing a denominator for analyses of other data by subgroups within the population at large.

Vital registration data and notification data inform very little about access to health care in terms of the availability of health care services. As birth registration and notification data include the mother's residence and place of birth it would be possible to calculate a derived variable such as estimated travel time from home to place of birth. A geographical analysis of travel times would indicate which areas of the country had better access to maternity services in terms of the distribution of services. This analysis could also be extended to include an analysis of the availability of services by the social class of the father or based on the age or country of birth of the mother. Some birth notification systems such those shown in Table 49, also collect data on the mother's and baby's ethnicity.

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Availability of services could also be examined using these birth registration data or maternity HES. These include the intended and actual place of delivery. An analysis of the variation between the two might shed light on the actual availability of services such as neonatal care to groups within the population as opposed to the 'planned' availability.

The confidential enquiries can be used to inform the relation of services to the location of patients, but only for those who have died. The data are also not published at a local level. Death registration data on their own contain no useful information on the opportunity to access health care services, but linkage to HES could yield information on this.

Geographical analysis of access to health care may be possible using some of the data available in population-based registration and notification data, but it is constrained by the lack of data about non-geographical barriers to access, such as preferences and availability of transport for different groups within the population. This is discussed more fully in the case study on transport.

Utilisation

The census contains no information on the utilisation of health services. The individual health topics covered as part of the continuous population surveys included questions on the utilisation of health services. The cancer registries contain quite detailed information on the use of health services related to oncology.

The population-based registration and notification data are limited in their ability to determine utilisation rates of health care services, as these data are not designed to reflect use but to record specific events. An example of this is given in the case study on routine maternity and neonatal care statistics. These data reflect the use of maternity services to an extent. For instance, it might be possible to identify the place of birth from records and distinguish between hospital and non-hospital births. This is likely to be difficult, if not impossible as the location of birth is not specifically coded but rather written down and only a postcode would be entered electronically. It might therefore be impossible to establish exactly where the birth occurred unless all postcodes could be classified in some systematic way.

Utilisation may also be reflected by comparing the place of abortion and place of usual residence, although such data are confidential and highly sensitive. Utilisation data are difficult to derive from the confidential enquires as they are concerned only with those who have had the most adverse outcome, death.

Outcome

The census and population-based surveys have no data on outcome. The cancer registries do have useful data on outcome both in terms of morbidity and mortality for those with cancer.

Measures of outcome derived from birth registration data include fertility rates, birth weight and stillbirth and infant mortality rates.⁽⁹⁾ Data from child health systems can be used locally to measure outcome in terms of low birth weight and preterm birth.^(136; 137) The change in numbers of teenage conceptions derived from the mothers' age are used as an outcome measure of health education/promotion strategies.

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In the long-term there is a role for mortality statistics, especially disease specific rates by locality, age, sex and social class, to be used as outcome measures relating to access to health care. Such analyses are readily confounded, by variables not collected in the routine data and so relating changes in rates to changes in access to health care is difficult. For example, changes in rates of congenital anomalies among live and stillborn babies may reflect the impact of screening programmes, but changes in the underlying incidence of the anomalies can also play a part.

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Table 8 Summary of population-based data sources and the Access Continuum

Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
Age	Census, Continuous Surveys Cancer Registration Birth Registration (confid.) NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Death Registration Confidential Enquiries	Census	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Death Registration Confidential Enquiries
Sex	Census, Continuous Surveys Cancer Registration Birth Registration (confid.) NN4B / Birth Notification (not pub) Abortions Congenital anomalies Death Registration Confidential Enquiries	Census	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Death Registration Confidential Enquiries
Ethnicity	Census, Continuous Surveys Cancer Registration NN4B (child not pub) Birth Notification (mother not pub) Confidential Enquiries	Census	Cancer Registration NN4B / Birth Notification (not pub) Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Confidential Enquiries

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Country of Birth</i>	Census Birth Registration	Census		
<i>Education</i>	Census, Continuous Surveys	Census		
<i>Socio-economic</i>	Census, Continuous Surveys Birth Registration Birth Notification (- not pub) Death Registration Confidential Enquiries	Census	NN4B / Birth Notification (not pub) Confidential Enquiries	NN4B / Birth Notification (not pub) Death registration Confidential Enquiries
<i>Geography</i>	Census, Continuous Surveys	Census		
<i>Where event occurred</i>	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Confidential Enquiries
<i>Residence at event</i>	Cancer Registration Birth Registration NN4B / Birth Notification (not pub) Congenital Anomalies Death Registration Confidential Enquiries	Cancer Registration Birth Registration NN4B (not pub) Birth Notification (not pub) Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Confidential Enquiries

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Travel time (as a derived variable)</i>	Birth Registration NN4B / Birth Notification (not pub) Confidential Enquiries	Birth Registration NN4B / Birth Notification (not pub) Confidential Enquiries	NN4B / Birth Notification (not pub) Confidential Enquiries	NN4B / Birth Notification (not pub) Confidential Enquiries
<i>Morbidity</i>	Continuous Surveys Cancer Registration Birth Registration (Child) NN4B/ Birth Notification (not pub) (Mother and Child) Congenital Anomalies Abortions Death registration Confidential Enquiries		Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Confidential Enquiries	Cancer Registration NN4B / Birth Notification (not pub) Abortions Congenital Anomalies Death registration Confidential Enquiries
<i>Mortality</i>	Cancer Registration Birth Registration (Stillbirths) NN4B/ Birth Notification (Stillbirths and neonatal deaths - not pub) Death Registration Confidential Enquiries		Cancer Registration NN4B/ Birth Notification (Stillbirths and neonatal deaths - not pub) Confidential Enquiries	Cancer Registration Birth Registration (Stillbirths) NN4B/ Birth Notification (Stillbirths and neonatal deaths - not pub) Death Registration Confidential Enquiries
<i>Health Beliefs and Knowledge</i>	Continuous Surveys			

Indicators of access

Age and sex

All the datasets reviewed here have reliable information on the age and sex of the individuals concerned, as these data items are needed for other purposes.

Ethnicity

Data on ethnicity are not widely available. The census, population-based surveys and cancer registry data all contain ethnicity. Ethnicity is recorded in Birth Notification systems and to some extent in the confidential enquiries. The categories used are those in the census and have the limitations identified. There are also issues about whose ethnicity is to be recorded for some people, for example a child with parents from different ethnic backgrounds.

Birth registration data do not include ethnic group, but do include the country of birth of the mother. An analysis seldom undertaken would be the access to health care by parents' country of origin, available from birth registration data. First and second generation migrants may have different health needs. If ethnicity data were more complete in HES, linkage would enable such comparison. A more detailed discussion of ethnicity as it relates to birth registration and notification can be found in the case study on routine maternity and neonatal care statistics and a fuller account is given in Section 4.2 about the census.

Social class

Data on social class are available from the census and the population-based surveys.

Since 2001 data about parents' occupations recorded at birth registration and occupations of deceased people and their partners recorded at death registration, are classified using the National Statistics socio-economic classification. The quality of recording is variable and women's occupations may be under-recorded when registering their deaths or their babies' births. There is also the issue of whose social class should be used with analyses of birth.

Educational attainment is used as a socio-economic indicator in some countries. In the past, when the majority of the population left full-time education at the minimum age, it was not a useful variable in the United Kingdom. This situation has changed with wider access to further and higher education and there are proposals to include a question on the subject in vital registration. Educational attainment is recorded in the census and in the population-based surveys, but not in the cancer registries.

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Geography

The census and population-based survey are a key source of geographical information. Geographical data, both on place of residence and the location where the health intervention took place, have become more widely available with the development of neighbourhood statistics. This is useful for constructing geographical patterns of access to health care, but the data available are often insufficiently precise for some geographical analyses because of confidentiality considerations. The analysis of geographical barriers to access is totally dependent upon the amount and quality of routinely available data. A more detailed discussion of the problems associated with geographical analysis of access to health care can be found in the case study Routine Transport data.

Morbidity

Morbidity data are available from the population-based surveys and to a limited extent from the census. Detail cancer morbidity data are available from the cancer registries. Some data on morbidity are available from birth notification and child health systems data. Data on congenital anomalies are also available in some areas. Cause of death recorded at death registration may indirectly provide data on morbidity. Data about morbidity leading to death are recorded in the confidential enquiries.

Mortality

Mortality data are available from death and stillbirth registration. The confidential enquiries have fuller data about the categories of death they cover.

4.5 Discussion

The biggest danger for measuring and monitoring access to health care through routine data comes from the falling response rate to the census and indeed the population surveys. The under-enumeration in the last census estimated at six per cent was not random and affected young people, males, people living in London and those from lower socio-economic groups disproportionately. Responses to this problem have included calls for a greater compulsion in completion, a re-design of questions, especially those relating to income which may deter those working in the 'black' economy, to make them more acceptable and a move to a continually updated population-based register. All have their problems. Compulsion is unlikely to be effective unless heavily policed. Redesigning questions may have only a small effect and removing questions altogether might help but at the cost of the census being broad and comprehensive. Indeed there are already criticism of the specificity of the census as being too focused on a narrow administrative view that fails to acknowledge alternatives, for example the total invisibility of lesbian, gay bisexual and transgender people in the official statistics. It has been suggested that a population register may well improve ascertainment but detailed questions such as those on health would not be possible, let alone the option of making the exercise broader and inclusive of alternatives.

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If the population-based surveys were to be enhanced in terms of their coverage this might go some way to addressing what might be lost from moving away from the census. Small area analysis would still be difficult, as it is at present, unless the sample sizes were to be greatly increased. This would not resolve the problem of falling response rates to these surveys. The move to a single continuous survey may help as it will reduce the duplication of the collection of core variables for the current multiplicity of surveys and hopefully lead to a larger sample size but probably at the cost of uncollected information.

Vital registration data are not specifically concerned with health care, but they are essential to the population-based analysis of health and to specific studies, especially those focussing on mortality. Given the central role that such data have, particularly in population-based health research it was recommended that birth and death registration should include parents' ethnicity either by recording it directly or through record linkage.⁽¹²⁵⁾ Parents socio-economic status should be recorded on birth certificates but information about mothers is often missed.

The proposal in the review of civil registration to record the educational attainment of parents at the registration of their children's births would have increased the scope for analyses based on socio-economic status, especially for parents who are not in paid employment at the time.

Although there remains the problem of small area analysis of sensitive data such as low birth weight among teenage mothers it is hard to see a way around the problem of the potential breaches of confidentiality surrounding such sensitive topics.

The through-life record is an interesting proposal but the fact that mothers will not be linked with babies is a major limitation. As such the through-life record is unlikely to be particularly helpful in measuring and monitoring access to health care, although it would fulfil important, but non-health related, administrative needs.

With a multiplicity of datasets there is a need to ensure that standard definitions are applied to data items such as ethnicity and occupation and that these definitions are widely recognised and adopted.

Many data items are collected or entered more than once. In order to avoid this it is vital that record systems are able to communicate with each other electronically. There is much potential, especially in notification systems, for registration data to be used automatically through record linkage. In addition, linkage to HES would improve the data held in notification systems as well as that held by HES. Clearly this must be carried out in ways which preserve confidentiality.

Cancer registration remains an excellent example of how routine data can be used to measure and monitor access to health care, particularly through record linkages to other datasets such as HES. Calls for Cancer Registration to become a statutory obligation are to be welcomed as this would improve its usefulness as a population-based resource for monitoring and measuring access to health care. It would also pave the way for suitable funding and oversight by an organisation

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such as ONS. The statutory requirement may also help to reduce the number of death certificate only registrations which can potentially bias analysis of survival.

In summary, population-based data are not adequate in isolation to measure and monitor access to health care across the population and for groups within the population. Though they provide the denominator and many of the building blocks for such analyses. By combination with other datasets relating to utilisation of health care, for example HES, they become a powerful and vital source of important information on socio-economic status and ethnicity. Although there remains the problem of invisible groups including travellers, lesbian, gay, bisexual and transgendered people and thought should be given to actively examining ways in which the needs of these groups can be recognised in the routine data. Geographical and time-trend analyses would be aided if the administrative boundaries used by different data collection systems could become coterminous and remain consistent over time. Similarly, harmonisation of definitions used in different datasets would also help analyses of access to health care.

Section 5 Consultation with data users

5.1 Conclusion

The consultation produced considerable discussion about what people would like to be able to monitor and measure in relation to access to health care and what the barriers are to measuring access to health care. It was commonly acknowledged that access to health care cannot be measured as a discrete entity and what is measured is access to processes, so absolute equality rather than equity tends to be measured by default. Participants working in organisations with a strategic responsibility were seeking support to aid judgement in area of performance in tackling health inequalities providing information on poverty and its effects on how people were or weren't able to access health care. Participants expressed strong doubts that the current structures of performance management information collections were capable of capturing information about access: they believed the systems observed and noted whether the process of, for example health equity audit was taking place and laid no measurable value currently on how well it was done and whether the cycle of health equity audit was completed and reviewed.

Clear definitions and dissemination of methods for assessing and measuring access to health care is particularly sought for undertaking the increasingly important area of health equity audit; it was felt that guidance thus far has been conflicting and confusing. Users acknowledged that access to health care is a complex concept with many dimensions and therefore cannot possibly be monitored by a small number of 'high level' indicators. Users require an array of data in order to plan equitable services, monitor the implementation of changes and compare institutions and geographical areas. There is clear evidence of confusion between the concepts of equity and equality in the measurement of access to health care. There was general frustration expressed that pre-occupations about data quality tend to focus on completeness rather than the quality of the data in terms of the accuracy. The use of local surveys is a popular but expensive way of looking at equity of access to services; however, concerns were expressed about robustness of methods used.

Contributors expressed enthusiasm about the possibilities of the use of record linkage both within NHS datasets and with data collected by other organisations such as social services. The main types of data available that were identified as being used or were required to assess levels of access to health care fell into the following categories:

- information about the health care workforce, its composition and distribution, for example the number of GPs per head of population

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- information about the processes which take place in health care provision, for example the number of district nurse contacts with a defined population.
- information about the performance of the health care systems, for example performance of a health economy in relation to financial constraints, such as reduction of numbers of patients waiting for health care on waiting lists
- information about clinical activity, for example rates of clinical procedures or admissions for specific diagnoses
- information about the outcomes of health care, for example re-admissions to hospital or deaths.

Users then wanted to relate these types of information to the known or attributed characteristics of an individual or an area. Users expressed particular concern in maternity and child health surveillance, where users were concerned about how stand-alone systems had been developed without linkage to other systems, making data difficult to transfer directly and introduced potential for incomplete data.

Many saw the introduction of the purchaser provider split as having had important implications for NHS data collection. They felt that the increasing emphasis on information relating to finance resulted in less information being collected on clinical data items, and a less important role being focussed on quality in coding. Many identified the rapidly changing geographies in the NHS as leading to a lack of trend data and a reduced provision of analytical support locally. It was suggested that the frequently changing configuration of NHS boundaries means that unless the data are available at individual record level there is no opportunity for comparing trends in patterns of access to health care.

Users identified the context of the information relating to workforce as being very important if using the data in the context of access to health care. This was illustrated by one interviewee who cited the example of the reduction of junior doctors working hours initiated in the late 1990s and the reduction of the nursing working week to 37.5 hours, both resulting in a reduction of resources available to the health care system, although the data appeared to show no change the same numbers of staff were providing less health care resource to the system.

There was general dissatisfaction about the adequacy of data on numbers of contacts between staff groups and patients to monitor levels and equity of access as few data are collected about who is treated, what treatment is provided and what the health problems patients may have. It was, however, suggested that this type of information can give crucial insights into questions such as whether the patterns of access are determined by the level of staffing available.

While some saw waiting lists as ways of measuring access to health care but that the aggregated, high-level form in which waiting lists are published means that there is a lack of information which relates to need and the characteristics of the patients waiting for treatment. This was felt to limit their usefulness in the

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assessment of absolute or relative equity with respect to access to health care resources.

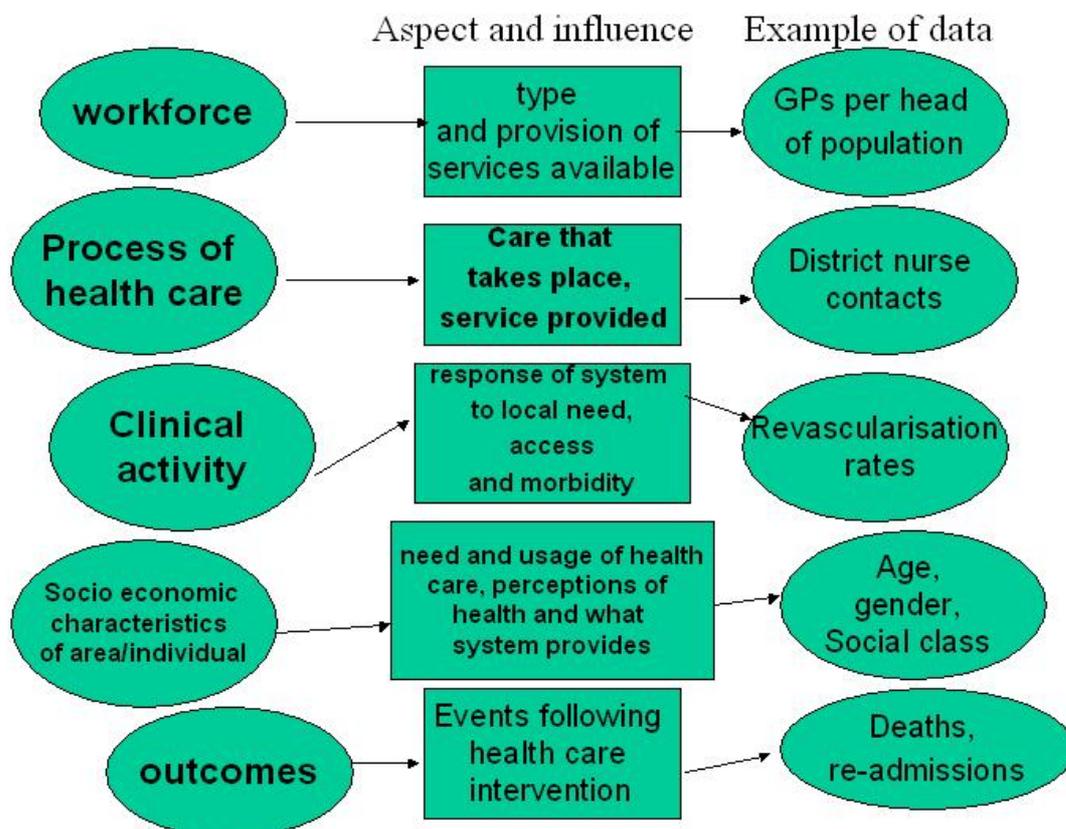
Users felt that the lack of information about the private sector means that it is not possible to explain whether high usage of the private sector in an area is due to lack of service provision by public services or whether private usage leads to greater availability of services for patients unable to pay for health care. The opportunity to undertake these types of comparisons would create greater understanding of the process of equity of access to health care, which is clearly influenced by many constraints. People felt that it was conceivable that use of the private sector by individuals personally choosing to buy care from this sector could promote greater equity of access in an area if this relieved pressure on state provided services and therefore an important aspiration area for data availability.

There was a general frustration expressed about the aggregated returns which provide limited information about services such as paramedical staff, midwives, health visitors, community nurses and services based in the community or hospitals including physiotherapy, chiropody, and speech therapy. As the information is limited to numbers of contacts with some breakdown by source of referral, age breakdown and venue of care it was seen to be poor proxy for measuring access to health care and particularly prevention. There is no possibility of linking this information to other datasets or analysing the data at locally defined aggregations. The information is therefore of limited use in the assessment of levels of access to health care in an area.

Interviewees felt that as primary care has a crucial role as gatekeeper to the NHS it should be a rich source of information about needs and utilisation of care in the NHS, both for individuals and for populations. Details are provided about service provision such as asthma, diabetes services and immunisation but this was felt to be of little use in monitoring access as it provides limited information about process type activities undertaken where re-imburement is due. The primary care data area was the one where there was an almost unanimous desire to improve access to data as GPs have such a key influence on the way secondary care is accessed and therefore in influencing access to health care resources. It was therefore bizarre and frustrating that this sector has so few obligations to provide epidemiological, socio demographic and process data about the pathways patients may take through the services of the NHS. It was suggested that the new GP contract may be an opportunity to define and specify minimum dataset return from this part of the NHS.

The different aspects and influences of access to health care and examples of data sources outlined by the interviewees are summarised schematically in figure1:

Figure 1 Aspects and influences of access to health care



5.1 Conclusions

Participants had a high level of awareness of the considerable amount of information that is recorded about resources, activities and finances of the NHS. However; the types of data collected were seen generally to not directly support the assessment of access to health care by a population or the assessment of the equity or inequity of the provision of health care available to a community. Consultees felt it was important that appropriate tools were either developed or agreed on for use to ensure that access was being examined from a perspective of health care need rather than based on the more easily measurable historic demand. There was a strong recognition that access is a multi dimensional concept and needed to be approached from this aspect and examined via an array of variables rather than being reduced to single abstract indicators. This concept was clearly important to those who were required to and wanted to work closely with non NHS partners.

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The data were seen as largely describing the extent of the process rather than the availability, need or quality of that provision. In order to assess access and provision of health care it was felt important to be able to combine information from various sources, such as HES with general practice derived data.

Section 6 Case studies

- 6.1 *The mental health of older people*
 - 6.1.1 *Introduction*
 - 6.1.2 *Types of mental illness*
 - 6.1.3 *Who provides services for older people with mental illness?*
 - 6.1.4 *Policy issues for older people's mental health services*
 - 6.1.5 *Routine datasets relating to older people's mental health*
 - 6.1.6 *To what extent can existing data be used to measure and monitor access to older people's mental health services*
 - 6.1.7 *Application of the Framework for Access to data sources for the mental health of older people*
- 6.2 *Maternity and neonatal care*
 - 6.2.1 *Introduction*
 - 6.2.2 *Who provides maternity and neonatal care?*
 - 6.2.3 *Policy issues relating to access to maternity and neonatal care*
 - 6.2.4 *Routine datasets relating to maternity and neonatal health care*
 - 6.2.5 *To what existing data sources can be used to measure and monitor access to maternity and neonatal health care?*
- 6.3 *Cancer*
 - 6.3.1 *Introduction*
 - 6.3.2 *Definition of cancer and its prevalence*
 - 6.3.3 *Who provides cancer services?*
 - 6.3.4 *Government targets and policies relating to cancer*
 - 6.3.5 *Major policies of the last ten years*
 - 6.3.6 *Routine datasets relating to cancer*
 - 6.3.7 *Summary of the extent to which existing data sources can be used to measure and monitor access to cancer services*
- 6.4 *Coronary Heart Disease*
 - 6.4.1 *Introduction*
 - 6.4.2 *Policy issues relating to access to coronary heart disease care*
 - 6.4.3 *Routine datasets relating to Coronary Heart Disease health care*
 - 6.4.4 *To what existing data sources can be used to measure and monitor access to coronary heart disease care?*
 - 6.4.5 *Conclusions*

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- 6.5 *Charging for NHS services*
 - 6.5.1 *Introduction*
 - 6.5.2 *The impact of NHS prescription charges on access to treatment*
 - 6.5.3 *Information sources on prescribing charges to monitor and measure access to health care*
 - 6.5.4 *The impact of charging for dental services on access to treatment*
 - 6.5.5 *Information sources on dental service charges to monitor and measure access to health care*
 - 6.5.6 *The impact of charging for ophthalmic services on access to treatment*
 - 6.5.7 *Information sources on ophthalmic services charges to monitor and measure access to health care*
 - 6.5.8 *The impact of charging for non clinical services on access to treatment*
 - 6.5.9 *Information sources on non clinical service charges to monitor and measure access to health care*
 - 6.5.10 *The impact of charging on those whose needs are designated as social care, for example older people, on access to services*
 - 6.5.11 *Information sources on local authority charges to monitor and measure access to health care*
 - 6.5.12 *Summary*
- 6.6 *Transport and access to health care*
 - 6.6.1 *Introduction*
 - 6.6.2 *Issues relating to transport and access health care*
 - 6.6.3 *Routine datasets relating to transport and access to health care*
 - 6.6.4 *To what existing data sources can be used to measure and monitor transport and access to health care?*
 - 6.6.5 *Conclusions*

In choosing subjects for case studies, we focussed first on the four priority areas set out in the NHS Plan.(20) These were also covered by National Service Frameworks. We decided to bring together two of these to examine datasets relevant to the mental health of older people and to undertake separate case studies related to cancer and coronary heart disease. Maternity and neonatal care is included in the National Service Framework for Children, Young People and Maternity which has been developed while this project was underway. Data on the subject have been described in detail in *Birth counts: statistics of pregnancy and childbirth*(9) so it was chosen for a fourth case study. Charging and transport were chosen for two further case studies as they are directly related to access.

Each case study explores the extent to which routine data sources in England can be used to assess the level of access to health care within the population and how this varies between groups within the population. This includes describing the shortfalls in routine data sources that hinder the measurement and monitoring of access to health care both for the population and for groups within the population. Some recommendations are made for data linkages and changes to

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datasets in order to improve monitoring and measurement of access to health care. In doing this, each case study makes use of the framework for access developed in Section 2.

6.1 The mental health of older people

6.1.1 Introduction

This case study identifies and describes the routine datasets relating to mental health services for older people and highlights issues and gaps in data which can be used to measure access to such services. The relevant data sources are listed in Table 13, according to the primary dimension of access identified, along with a brief description of coverage by time span and geographic area and a cross reference to the sections of the report where each data source is described in detail.

In addition to the reasons given earlier, this subject was chosen for a case study as it relates to the background and history of community care policy, and the recognition that older people are a vulnerable group likely to have health and social care needs. The report of the Royal Commission on long term care published in 1999 identified inequities in access and service provision in care for older people.(158) Older people's care has undergone more changes in delivery than any other target group, with respect to the well-documented shift from NHS care to the independent sector, and from institutional care into the community. In particular, as the prevalence of dementia increases with age, most government policies aimed at older people affect those who also have mental health needs. Mental health services for older people were the subject of a report '*Forget me not*'(159) published by the Audit Commission in 2000. We have drawn on the information in that report for this case study.

Definition of mental health and mental illness

The National Service Framework for Mental Health defines *mental health* as: *An individual's ability to manage and cope with the stresses and challenges of life.* (160)

It defines mental illness as: *A range of diagnosable mental disorders that excludes learning disability and personality disorder.*(160)

Mental health disorders include:

- schizophrenic and paranoid psychoses
- affective disorder
- panic, phobic, disassociative, somatoform disorder
- personality disorders.(161)

Problems associated with these disorders include:

- subjective symptoms, from phobias to hallucinations
- associated behavioural problems
- suicide and attempts at suicide
- socially embarrassing or unacceptable behaviours
- slowness, lack of motivation, poor self-care
- lack of insight into the nature of the problems

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- Overall social disablement.(161)

6.1.2 Types of mental illness

Dementia and depression are the two most common mental health conditions affecting older people and are summarised below.

Dementia

Dementia is common in older people as a result of physical changes in the brain that can lead to confusion and behavioural problems. It refers to a cluster of signs and symptoms of intellectual and cognitive functioning being disrupted, usually in a way that is progressive and irreversible.

Alzheimer's Disease is the most common form of dementia. It is characterised by memory loss and difficulties with speech in its early stages and gradually develops over several years. It accounts for approximately 50–60 per cent of cases.

Vascular dementia is the next most common form accounting for approximately 20 per cent of cases. It is the result of damage to small areas of the brain, sometimes following a stroke. The loss of functioning depends on the parts of the brain affected. Some people have both Alzheimer's and vascular dementia.

Dementia with Lewy Bodies accounts for up to 15 per cent of cases of dementia and is characterised by symptoms similar to Parkinson's disease, as well as hallucinations and a tendency to fall.

Other types of dementia can arise as a consequence of other conditions, such as AIDS, Creutzfeldt Jakob Disease, Huntington's Disease and Pick's Disease. Many people with severe dementia, especially those aged over 85, have both mental and physical problems.

Age is the main factor associated with the prevalence of dementia which is more common in women than in men, particularly in older age groups. As well as age, *functional* mental health problems, which tend not to be associated with major physical degeneration of the brain cells, may vary with social factors such as isolation and low income. It has been estimated that approximately 600000 people in the UK have dementia, representing five per cent of the total population aged 65 and over, rising to 20 per cent of the population aged 80 and over (Table 9).

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Table 9 Estimated prevalence of dementia among people aged 65 and over, 2000

Age group	Percentage of men	Percentage of women
65-74	3.4	2.5
75-84	8.5	10.1
85+	25.0	28.5

Source: Psychiatric Morbidity Survey(162)

Depression

Depression is the most common mental health problem in older people, again affecting women more often than men. It is estimated that at any one time it affects 10-15 per cent of the population aged 65 and over. More severe depressed states affect about three to five per cent of people.(163) People who are depressed are more likely than others to commit suicide, especially men over 85. Depression is often mistaken for dementia.(159)

Risk factors for depression in older people are poor health, lack of social support and prolonged difficulties such as poverty, poor housing, or disability over a period of time. Therefore prevalence varies with the characteristics of the local area, such as area deprivation and the proportion of older people living alone. People caring for a disabled relative are at higher risk than others. It has been estimated that approximately a third experience clinical depression. Major life events such as bereavement, retirement and social isolation can lead to depression and it is also common among residential and nursing home residents.(159;163)

6.1.3 Who provides services for older people with mental illness?

Services for older people are provided by health, social services and voluntary organisations.

Table 10 shows some of the settings, staff and services involved in providing services for older people.(159)

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Table 10 Staff and services involved in care of older people with mental illness

Health services	Local authority social services commissioned and/or provided
Psychiatrists of old age	Social workers
Multidisciplinary Community Mental Health Teams including community psychiatric nurses, psychologists, occupational therapists and physiotherapists	Home care workers The services provided can include: Home care Meals on wheels Day care Residential respite care Residential care Nursing home care
District nurses	
Other community professionals	
Specialist services can include: Home visits	
Outpatient clinics	
Day care in NHS day hospitals or social care day centres	
Hospital beds for acute, respite and to a lesser extent continuing care	

Local authority services usually require a financial contribution from the user or carer.

General Practitioners have a key role with regard to access to services as they are usually the first contact and can refer to specialists, make initial assessments and investigate physical causes for problems.

In 1996 it was estimated that a third of people with dementia were in hospital, residential care or nursing homes, and another third with severe dementia lived in community settings, supported mainly by spouses or children.(159)

Since the 1980s there has been a shift of long-term care of mentally ill people from hospitals into residential settings in the independent sector.(164) By 2001, 91 per cent of nursing home beds and 75 per cent of residential care beds in England were in the independent sector. Rates of admission to mental illness specialty care are highest in the oldest age groups. These trends are illustrated in Table 11 and Table 12 below.

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Table 11 Numbers of hospital beds and places in residential and nursing care homes for people with mental illness, England, 1994-95 to 2000-01

Year	Average daily available NHS beds for older people		Beds in private nursing homes, hospitals for older people	Staffed residential home places for older people
	Short stay	Long stay		
1994-95	6390	10 760	19 330	9220
1995-96	6390	9330	22 140	10 670
1996-97	7370	8230	21 450	19 260
1997-98	7380	7410	19 130	21 040
1998-99	7290	6990	20 770	21 300
1999-00	7350	6040	22 490	22 600
2000-01	7620	5540	21 490	22 910

Source: KH03, KO36, RA

Table 12 Admissions to NHS hospitals under mental illness specialties by sex and age group, rate per 1000 population, England 1994-95 to 2001-02

Year	Males			Females		
	65-74	75-84	85 and over	65-74	75-84	85 and over
1994-95	5.6	13.5	22.0	6.6	13.2	17.2
1995-96	5.3	12.4	21.4	6.2	12.9	16.8
1996-97	4.7	11.6	19.4	5.8	11.5	14.9
1997-98	4.1	10.6	17.6	5.6	10.8	13.5
1998-99	4.1	10.2	15.4	5.3	10.6	12.8
1999-00	4.3	9.7	14.9	5.4	10.2	13.2
2000-01	4.0	8.3	13.2	4.8	8.7	10.8
2001-02	4.0	8.0	12.9	4.8	8.2	10.8

Source: HES

6.1.4 Policy issues for older people's mental health services

The Audit Commission study found wide variations between health authorities in the services provided. Co-ordination between health and social services was lacking. (159) Nationally, services for older people with mental illness were patchy and inconsistent and often failed to link together into a coherent service.

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Depression is under-recognised and even when recognised is under-treated in primary and secondary care. (165)

Many carers of older people with dementia are themselves quite old. Up to 60 per cent are spouses. Such carers generally experience greater stress than people with other needs.

6.1.5 Routine datasets relating to older people's mental health

Table 13, identifies the datasources and the key variables contained within them available to measure and monitor access to health care services for older people with mental illness, and cross references to the description of the dataset. In addition some special surveys and reports relating to this group are described below.

Special studies and surveys

Audit Commission

The Audit Commission's report on mental health services for older people was based on a large study carried out in England and Wales in the late 1990s. It included visits to NHS trusts, health authorities, local authority social services and independent providers. The study incorporated the use of resource mapping, individual case information, case file analysis, a GP survey, a survey of carers, local data summary and a 60-question checklist. The study found wide variations in practice, the resources available, the views of carers, whether agencies worked together effectively, and the extent to which commissioners were able to shape the pattern of provision.

Surveys of psychiatric morbidity

The Office of Population Censuses and Surveys undertook a series of surveys of psychiatric morbidity in adults in 1992-93 but the sample included only adults aged up to 64. More recently ONS followed this up with a survey of *Psychiatric morbidity among adults living in private households*. The sample was restricted to people aged 16 to 74.

Use of general data sources

A number of limitations were encountered in the extent to which data from more general datasets can be used to identify care for older people with mental illness.

Prescribing data

As PACT prescribing data do not include information about diagnoses, it is difficult to identify the extent of drugs prescribed to older people with mental illness. In particular the usefulness of PACT data on antidepressants is limited by the fact that such drugs are also prescribed for chronic pain, irritable bowel syndrome and insomnia.

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Death registration

Mental illness is not frequently recorded as cause of death, so mortality data under-represent the extent of the problem in the population. Dementia can be legitimately assigned to one of a number of ICD categories, but the assignment of underlying cause for a particular death will depend on the clinical nature of dementia, the perceived role of dementia in the sequence of events leading to death, the certifying habits of the doctor and the application of coding rules.(162)

The recording of social class in mortality data is limited for older people because occupation is not recorded on the death certificates of men or women over 75 years. Among married women it is recorded only for those who have been in paid employment for most of their life. Therefore, alternative measures of social classification, such as housing tenure, are needed to describe socio-economic differences in mortality in older people.(166)

Staffing

Data about NHS staff do not include details of the numbers and grades of those working in the care of older people or in mental health specialties. The limited returns about activities of staff in the community have been abolished without being replaced by better data collection systems.

Independent sector data sources – nursing and residential care homes

Over half of all beds allocated for health care in the UK are in independent nursing homes for older people. Under the regulatory framework introduced by the Care Standards Act 2000, national minimum standards required that there was a care plan for each service user, but no arrangements were made to collect standardised information from care plans. So they could not be used to provide a means of determining how much care was needed, the care which was provided, and whether needs were met.(167)

Financial data

The Royal Commission on long-term care found that there was no single source of data about current total expenditure on long-term care.(158) This is because government figures on health care expenditure for people with long-term care needs are included among the figures for all health service expenditure. The Royal Commission therefore had to develop its own profile along with a method to estimate how much people spend on long-term care from their own resources.

The Audit Commission undertook a survey of expenditure on older people with functional mental health problems. Its report stated that it 'found this a difficult area'.(159)

6.1.6 To what extent can existing data be used to measure and monitor access to older people's mental health services

This case study has identified the following gaps in the routine data available to monitor and measure access for older people with mental health needs:

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- There are no detailed, standardised data on NHS community health services such as those provided by community psychiatric nurses and health visitors – particularly relevant to this group of people.
- No data are available routinely on the needs of carers of older people with mental health problems. The data available are limited and tend to apply to carers of all groups without being able to identify those looking after older people with mental illness.
- Few data are available about this particular group's access to primary care.
- No detailed data are available from the independent sector. In particular there is little information on residents of nursing and residential homes.
- No data are available about numbers and grades of staff working in the care of older people, or in mental health specialties.
- No data are available about contractors providing NHS services, for example in hospitals and nursing homes.
- No data are available about the prevalence of mental illness in older people. For example it is recognised that there is considerable under-recognition and under-treatment of depression in older people but without knowing how many older people are affected, it is difficult to assess access as it is not known how many people's needs are *not* met.
- Few data are available on charges to older people for local authority services, and there is no detailed breakdown of expenditure on older people with mental illness.

6.1.7 Application of the Framework for Access to data sources for the mental health of older people

This section applies the routine datasets available to monitor and measure the mental health of older people in England in relation to the framework for access described in Section 5. Therefore datasets are evaluated in terms of the four identified dimensions of access: need for health care; opportunity to access health care; utilisation by; and health outcomes to assess the degree to which they provide indicators of access for older people with mental health needs.

The data sources identified in this case study are listed in Table 13, and include a reference to the location in this report where they are further described.

Strengths and weaknesses of data for measuring access in terms of the dimension of need

Data sources are evaluated according to their ability to derive measures of need for this group of people.

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The national census can be applied to profile age, general health, long term limiting illness, and it also provides some information on the provision of care. However, it is not possible to specifically identify mental health needs. By applying prevalences of mental illness by age, however, to the population as measured by the census, some estimates of need can be constructed.

Mortality data from death registration are often used to determine levels of need for health care within the population. As noted elsewhere in this report, there are however problems with using mortality as a substitute for morbidity in determining need for health care. Death registration data includes age and cause, although as dementia itself is less likely to be the main cause of death, this data source is of limited value in constructing measures of need for older peoples mental health care, particularly as coding of mortality can vary depending on the extent to which all contributory causes are recorded.

The Health Survey for England contains a 'core' which is repeated each year including demographic and socio-economic indicators and questions on general health and psycho-social indicators. In 2000 there was a focus on the health of older people which included questions on cognitive functioning and included people both in private homes and a sample of residents of nursing and residential homes. Data is available only at national level however. The elderly are also the focus of the 2005 survey.

The General Household Survey (GHS) has focussed on the elderly as a main topic regularly over the years. Carers have also been a main topic. There are also large sections on health and health services including questions about longstanding illness or disability. There are no questions specifically about mental illness however. As this is a household survey it does not include people in settings such as nursing homes.

The large scale Audit Commission report 'Forget Me Not' published in 2000 described in this case study provided rich data on needs (plus the other domains in the access framework), although this was a single survey, based on a sample. Further audits based on the same methodology were continued following publication of the report.

The routine HES and the Admitted Patient Care Dataset described in Section 3 includes detailed episode-based clinical and demographic data such as age, geography, diagnoses and length of stay. There are also fields which collect data on the source of admission to hospital and discharge destination. From this data source it is possible for example to look at admissions to NHS hospitals under mental illness specialties by age group.

The mental health minimum dataset has been required to be collected by all providers of specialist mental health services for adults and older adults in England since April 2003. It aims to improve information on mental health services usage and need. All care received by individuals is to be included such as clinical problems, treatment, social care and outcome as well as geographic markers.

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NHS community data relevant to the care of older people have mostly ceased to be a central requirement since April 2004, with the reason for discontinuation cited as reduction in bureaucracy. These discontinued returns are as follows:

- KC55 Health visiting and other professional advice
- KC56 District nursing
- KC57 Community psychiatric nursing (To be replaced by data from the Mental health minimum dataset)
- KC58 Community learning disability nursing
- KC59 Specialist care nursing.

Local authority social services data include relevant items such as the numbers of supported residents in residential and nursing care, day centre provision, home help, home care and meals services available at the level of local authority. Social services returns are listed in Table 39, Appendix B.

In summary there are a variety of data available to inform on the needs of older people and those with mental illness. As noted there are no data specifically about the needs of carers of this population and data on community health services is diminishing.

Strengths and weaknesses of data for measuring access in terms of opportunity

It is possible to undertake some geographical analysis of the opportunity to access health care using data from hospital inpatient data which records place of residence and treatment site, but will not inform on other types of barriers, such as preferences and availability of transport for different groups within the population. This is discussed further in the transport case study.

Strengths and weaknesses of data for measuring access in terms of the dimension of utilisation

Many of the data sources discussed under the paragraph on the dimension of need are also relevant to evaluating utilisation of health services, i.e. survey, hospital and local authority data.

As shown in Table 11 of this case study, most beds for elderly long-term mentally ill people are provided in private nursing and residential homes. However, little detailed data beyond numbers and age groups are available.

Local authority nursing home data, as well as statistical bulletins on private homes provide some data on the provision of services. As noted, the relevant NHS community data returns have mostly ceased.

Laing and Buisson's chapter on the care of elderly people in the *Health care Market Review* provides national data on the numbers of places and homes, but this volume is expensive to purchase, and only headline figures are available on the Laing and Buisson web site.

Data from the General Practice Research Database provides data by age and by morbidity for those enrolled with contributing practices.

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The Referrals, Assessments and Packages of Care system introduced in 2000 aims to provide information on how social services departments respond to people seeking access. This is however restricted to care purchased or provided by councils with social services responsibilities and has suffered problems of non-response and data quality.(168)

Prescribing data are not detailed and does not relate to individual patients.

Strengths and weaknesses of data for measuring access in terms of the dimension of outcome

Outcome measures relating to access to health care specifically for this group of people are not readily available and mostly confined to mortality data. As noted however, the recording of mental illness in mortality data will tend to vary.

To some extent outcome can be determined from inpatient data (discharge method) which identifies death in hospital. HES has recently included a 'sensitive' (in terms of confidentiality) 'date of death' field of the patient taken from the ONS mortality dataset, added where appropriate to each HES record. This enables the death of a patient to be determined over the short and longer term whether occurring in hospital or not.

In summary, among the main data sources for older people, there are data available on needs from surveys including the census, and on utilisation, from hospital, community health services and social services data. There are fewer data available to inform on the opportunity to access services. Outcome data is available to a limited extent, primarily from mortality data.

From the data available, it tends to be possible to evaluate either in relation to access by older people, or access by those with mental illness, but there are few sources that link the two, for example older people's mental health. Therefore a special survey, such as that by the Audit Commission, is valuable in informing on access by this particular group.

Conclusions and recommendations

From this case study and Section 1.6, it can be seen that there are a number of important omissions and limitations to data available to measure and monitor access to older people's mental health services. One of the main omissions which is particularly relevant to this vulnerable group is the lack of community data. Many of the data sources are not flexible enough to permit a breakdown to evaluate the access by this particular group within the population. Also little detailed information is available from the independent sector, who provide much of the residential accommodation and care.

Our recommendations include ensuring that data is collected from the independent sector of the same quality and to the same level of detail as that required of NHS providers. In particular, this study highlights the lack of comprehensive and standardised community data. This is crucial to this particular target group whose needs are commonly met by community health services and local authority sectors. Also more data needs to be routinely available about

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access to services by carers, as well as the costs incurred by such carers and older people with these types of health needs themselves.

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Table 13 Case study 1 - Data sources relating to the mental health of older people

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
<p><i>Characteristics of the population of interest - the mental health of older people</i></p> <p>Demography <i>(also morbidity)</i></p>	National census	Every ten years, whole of the UK, data available at the level of output area (around 125 households)	Age Sex Ethnicity Country of birth Education Socio-economic Geography Travel Provision of care Housing Communal establishments General health Long term limiting illness	Section 4
<p>Morbidity</p>	Surveys Routine surveys			

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
			Longstanding illness Disability Measures of psychosocial well-being Cognitive function General Health Questionnaire (GHQ12) Contact with family and friends Perceived social support Social participation in care homes Cigarette smoking Physical activity in care homes Nutritional status GP consultations Dental health Hospital utilisation Use of prescribed medication	
Morbidity (Also mortality)	Hospital data Hospital inpatient data from the APC CDS and HES	England and Wales, available at level of Finished Consultant Episode	Age, sex, diagnoses, procedures, specialty, length of stay, method and source of admission, discharge destination, NHS number which can link to other datasets, e.g. mortality	Section 3
Morbidity	Older people's	England and Wales, data	Data on the patient	Section 3

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
	minimum dataset (in development)	available at level of Finished Consultant Episode	Administrative and assessment data Care management Care provided	
Morbidity	Consultant outpatient admissions dataset	England and Wales, data available at level of outpatient attendance	Age Sex Geography Diagnosis	Section 3
Morbidity	NHS Community health services data Körner aggregated returns: Chiropody services Clinical psychology services Occupational therapy services Physiotherapy services Speech and Language Therapy services	England and Wales, provides aggregated data at national level for initial patient contacts	Age band (ten year) Sex Region Source of referral	Section 3

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
	District Nursing Community Psychiatric Nursing			
Morbidity	Local authority data Social services departments returns: Local authority-supported residents in residential and nursing care Day centre provision for adults Home help and home care, Meals services Registered homes for adults returns Registers of disabled people and blind/partially sighted people	England and Wales, aggregated data, provides data at national level	Returns include: Number of places Number of residents Number of visits Contact hours Sector providing care	Section 3
Morbidity	Primary care data Prescribing data	England	All items dispensed by community pharmacists, appliance contractors	Section 3

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
	General Practice Research Database Morbidity Statistics from General Practice	UK contributing practices available at national level First study 1955-56 then every ten years up to 1991-92 in a sample of practices in England and Wales, provides data at national level – series seems to be discontinued	and dispensing doctors Items doctors administer themselves Demographic Patient information Clinical details Diagnosis and socio-economic characteristics of every patient enrolled with practices included in the survey	Section 3 Section 3
Mortality	Vital registration mortality data ONS VS3 and VS4 data	England and Wales, available at person level	Administrative details Date and place of death Deceased's details Date and place of birth Occupation (of husband if a married woman or widow) Cause of death	Section 4
Characteristics of health care system				

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
Workforce	Staffing data HCHS medical and dental workforce census	NHS medical staff, annual, England, data available at level of staff group	Sex Staff grade Doctors in training Ethnicity Full or part time	Section 3
	HCHS non-medical workforce census	NHS non-medical staff, annual, England, data available at level of staff group	Sex Age Ethnicity Staff group Whole time equivalent	Section 3
	General Medical Services database	Practices in England and Wales, provides data at national level	Details of all GPs holding a GMS contract with a PCT	Section 3
Workforce (Also organisation)	Nursing home data collected on returns K036 and K037	Private hospitals and nursing homes, England and Wales, provides data at national level	Numbers of qualified and unqualified nursing staff and resident doctors employed Numbers of people in nursing homes	Section 3

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
Organisation	Data from nursing and residential homes Laing and Buisson 'Health care Market Review' Chapter on the care of elderly people Residential home data collected on the RA return (forms A, B and C)	Annual, UK, provides data at national level Annual 'snapshot' at 31 st March, England and Wales, provides data at national level	Market size Expenditure Numbers of places and homes Sources of capital Numbers of people in residential homes	Section 3
Financial	Charging data No routine data source identified			Charging case study
Financial	Expenditure Royal Commission Report 'With Respect to Old Age' Audit Commission 'Forget me not'	One off report, provides data at national level One off report, England and Wales, provides data at	Current total expenditure on long term care (at that time) Survey of expenditure on older people with functional mental health problems – noted this to be a	This case study This case study

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
	Department of Health 'The Government's Expenditure Plans'	national level Annual, England and Wales, available at national level	difficult area Proportion of HCHS expenditure by programme of care – includes mental health and services intended primarily for older people	This case study

6.2 Maternity and neonatal care

6.2.1 Introduction

In addition to the reasons outlined earlier, maternity and neonatal care was selected for case study because it encompasses a very broad spectrum of routine data sources ranging from 'non-health' datasets such as registration to detailed audits such as those in the Confidential Enquiry into Maternal and Child Health and surveys, notably the Infant Feeding Survey. It also takes place in a wide range of health care settings, ranging from community, primary to secondary in-patient and outpatient and even tertiary care. Maternal and neonatal health have also historically been seen as important indicators of population health and so it is an area rich in data, analysis and international comparisons.

6.2.2. Who provides maternity and neonatal care?

Table 14 Staff and services involved in maternity and neonatal care

Settings for care	Staff involved in care
Clinics and general practitioners' surgeries	Midwives
Clinics in community settings including Sure Start	Obstetricians General practitioners
Hospital antenatal clinics	Health care assistants
At home	Anaesthetists Neonatologists
Hospital in-patient maternity units	Neonatal nurses
Neonatal intensive care units	Health care advocates or interpreters
Adult intensive care units	Physiotherapists Antenatal teachers Breastfeeding support services

6.2.3 Policy issues relating to access to maternity and neonatal care

Infant mortality rates have a high profile at a national and international level and infant mortality rates are used in one of two national targets for reducing inequalities for care. Issues of access to maternity care relate to the tension between women's access to routine maternity care for uncomplicated pregnancies without the need to travel excessive distances and the need for access to specialist services for women with complications and sick newborn babies. The

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pressure for the latter has led to the concentration of in-patient maternity services into decreasing numbers of increasingly large hospital maternity units, with variations in the extent to which routine antenatal and postnatal care is available closer to where women live.

The scope, range and quality of routine data are all vital components of our ability to monitor trends in inequalities in pregnancy and its outcome(169), which is a precursor to devising and evaluating strategies to reduce inequalities and improve access to health care.

Given the importance of maternity and neonatal care it might be expected that data about them would feature more prominently in national indicators and targets established by the government but this is not really the case. We might also have expected the government target setting exercise, inaugurated in *A First Class Service: Quality in the New NHS*(170) and *The NHS Performance Assessment Framework*(171), would lead to more and better quality data. Instead there has been a reduction in the number and range of government performance indicators of maternity and neonatal health services since June 1999.

Over the period from 1999 to 2002, health authority level indicators covered childhood immunisation rates, maternity unit costs, teenage pregnancy rates and stillbirths and infant mortality.(172-174) None were related to the category of *Fair access* although outcome measures such as stillbirths and infant mortality do relate to the definition of access used in this report.

More recent performance indicators contain even fewer data relevant to maternity care. (83;175;176) From 2003 onwards, none of the *Key Targets* for primary care trusts or trusts related to maternity or neonatal services. Primary care trust performance indicators still include teenage conception rates and a further indicator based upon access to services for early, unintended, pregnancy. A new indicator of *infant health* is welcome, though it relates only to the quality of returned data on smoking among mothers and breast-feeding. Immunisation rates are still included along with a further indicator reflecting compliance with child protection procedures.

Despite the apparent proliferation of performance indicators and targets in the NHS, maternity and neonatal services are not covered at present. Nevertheless teenage conceptions and infant mortality are important indicators of need for health care. The rate of infant death is historically at a very low level and the absolute numbers are small, making detailed analysis by population subgroups and localities difficult to achieve with any degree of precision. This may explain why this particular indicator has now been dropped.

Further, the dramatic reduction in maternal and perinatal mortality, in the last fifty years has reduced their usefulness as indicators of the health of local populations especially in subgroup analyses and in comparisons between local areas(9;177).

In order to avoid this pitfall there has been a tendency to move towards measures of morbidity but there are few quality morbidity data routinely available at the national level that would allow an analysis of access to health care, neither

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are morbidity data easy to interpret. For instance while low birth weight is easy to measure, trends are heavily influenced by the rising multiple birth rate and the increasing age of mothers at childbirth.(169)

The problem of poorly chosen targets is compounded by the proliferation of initiatives and of agencies which collect and publish data. This leads to duplication of effort and still leaves gaps in the data required to inform clinicians, managers, service users and the wider public. Some of these agencies are public bodies:

- The Clinical Governance Support Team
- The National Patient Safety Agency
- Confidential enquiries
- Collection of data for performance indicators.

Some are private concerns:

- Dr Foster
- Birthrate Plus, a commercial system for planning midwifery services.

The proliferation of agencies involved in the collection and dissemination of routine data associated with maternity and neonatal care is contrary to recommendation 28 of the report of the Bristol Royal Infirmary Inquiry(178)

“that the current dual system of collecting data in the NHS in separate administrative and multiple clinical systems is wasteful and anachronistic and should be abandoned in favour of single data collection systems, from which both clinical and administrative information can be derived.”

The Department of Health accepted this recommendation and the need to improve the quality, reliability and range of information which supports decision making and performance management. (179) In *Information for Health*, it set out a unified approach to collecting data for both clinical and administrative needs through the electronic patient record.(54) It is not clear to what extent proposals to do this through a ‘Secondary use service’ will be successful.

There are indications that many of the agencies involved in data collection and publication are unaware of what each other are doing, which explains the lack of a co-ordinated approach. There is also a lack of awareness of the need for population-based data, especially if an assessment of the level of access to health care is to be determined. Welcome initiatives such as the NHS data-spine and the electronic patient record will prove to be less valuable than they might if they fail to connect to vital registration data that would increase the scope for population-based analysis of data and analysis by important subgroups such as socio-economic class. This is not surprising as no single agency has oversight or a co-ordinating role in harmonising the data collected and establishing a more comprehensive coverage.

6.2.4 Routine datasets relating to maternity and neonatal health care

Most of the datasets referred to in the three case study tables are described in detail elsewhere in this report. Cross-references can be found in Table 15, at the end of this case study.

The principal datasets include:

Those that characterise the population:

- registration of births, deaths and marriages
- NHS numbers for babies NHS Number for Babies
- local birth notification and child health systems
- notification of congenital anomalies
- notification of abortions
- Maternity Hospital Episode Statistics
- Confidential Enquiries into Maternal and Child Health
- Infant Feeding Survey
- community maternity services – in the past
- General Practice Research Database
- Morbidity Statistics from General Practice – in the past.

Those that characterise the health care system:

- HCHS Medical and Dental Workforce Census
- HCHS Non-medical Workforce Census
- General Medical Services Database
- bed availability and occupancy data
- financial data in the government's expenditure plans.

6.2.5 Adequacy of existing data sources for measuring and monitoring access to maternity and neonatal health care

As stated in the introduction to this case study, access to health care has been defined in terms of the broad dimensions of need, opportunity, utilisation and outcome. These dimensions have been given flesh by the use of details and specific indicators of access, such as age and socio-economic status, found in the routine data sources.

Three tables, at the end of this case study, summarise the relationship of the routine data to the dimensions and indicators of access both in terms of the characteristics of the population and the characteristics of the health care system. Table 15, lists the sources of routine maternity and neonatal care data relating to the characteristics of the population. It briefly describes each dataset in terms of the principal indicators of access together with details of publication and aggregation and a reference to the section in the main report where the particular dataset is described and discussed in detail. Table 16, does the same for indicators of access that relate to the health care system rather than those that relate to the population, while Table 17, brings together all the routine data

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sources for maternity and neonatal health care in terms of the broad dimensions of access and the individual indicators of access.

Dimensions of Access

The 'need' dimension of access is a data rich area. Mortality data are robust, though due to small numbers not as useful as they were previously, and there is a range of morbidity data potentially available for both the mother and the child. Much of the potentially useful data comes from birth notification and NHS numbers for babies and is unpublished so not available. On closer examination there is much duplication of socio-demographic indicators of access such as age and sex and geographical locations, which are useful but there is a lack of good socio-economic data. In terms of characteristics of the health care system there is nothing in the routine data that could be used to build up a picture of need.

In contrast to 'need', the 'opportunity' dimension is very data poor. There are no routine data with respect to socio-demographic indicators that can be used to assess the opportunity of individuals to access health care. Such data as is available is concerned with the place of residence and place of health care intervention. This gives scope for geographical analysis of the barriers to health care such as travelling distance. More sophisticated analyses that take into account mode of travel, public transport links and congestion as well as distance would be preferred. There are no routine datasets available that would address these issues at an individual level. The main routine data relating to opportunity to access health care come principally from data dealing with the characteristics of the health care system. Health care workforce data, including GP data, hospital activity and government expenditure can be used to build up a profile of the service provision in a given area, but other than geographical analyses it is difficult to relate these data to specific subgroups within the population. For instance there may be many non-geographical barriers that reduce the opportunity to use health care services for different groups within the population.

Utilisation data are the most frequently used data in analyses of access to health care. This is not surprisingly as the data directly record contact with the health care system, a relatively easy thing to measure, especially in terms of access to health care. There are not many data sources to draw from and few data are published in the detail that would allow the measurement and monitoring to access to health care for groups within the population. HES data are not published in detail, birth notification and NHS numbers for babies are not published at all and statistics on Community Maternity Services are no longer published. The Infant Feeding Survey provides important data on contacts between patients and the health care system and also detailed socio-demographic data on the service users, for instance it shows higher levels of breast feeding are associated with higher levels of education(176). Lastly hospital activity statistics provide robust data on the average daily number of maternity beds occupied but no further data to analyse this by subgroup.

As with utilisation, outcome has some fairly robust sources of data and in terms of pregnancy some easy to measure outputs. Detailed outcome information is available from datasets such as HES. More use could be made of data from birth

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registration but they are confidential as well as of data from birth notification and NHS numbers for babies which are not published. Fairly detailed data have been available in the past on abortions although the level of detail is now being reduced. The Confidential Enquiries into Maternal Deaths analyses data in considerable detail, although the numbers are now very small. The infant feeding survey collects data on level of breast-feeding amongst new mothers and detailed analysis is possible by various key access variables. Outcome data are available for mortality and morbidity, although these data are limited by what is actually published, mainly coming from birth notification, NHS numbers for babies and HES.

It is also important that not only the range of the routine data on access to health care is explored but that some determination be made of the 'quality' of the various indicators of access.

Indicators of access

As described, basic demographic indicators of access, such as age and sex, although sex is less of an issue here as all mothers are women and the sex of a baby does not seem to be an important indicator of access to health care, are generally widely available in routine datasets. Other important indicators are harder to come by, however.

Socio-economic status is problematic because it means different things to different people in different contexts. For instance, whose socio-economic status should be recorded, the babies', the mothers', the fathers' or the households'? Data can be collected on parents' income, occupation, employment, education, marital or cohabitation status, housing conditions, access to transport, access to social support and area of residence. Few if any of these data are routinely linked to data about the health of mothers and neonates, even where such data are available.

Social class of the father, derived from birth registration, is often used in analyses. If a baby is born within marriage or jointly registered outside marriage the father's occupation is recorded. Since 1986 mothers have the option to record their occupation, but many are not in paid employment or do not do so for other reasons, so the father's occupation is most often used, unless it is a sole registration outside marriage and the father's occupation is not recorded. It is quite possible that the socio-economic status of the principal carer is the most relevant to analyses of the child's health and certainly their own. It has been argued that education may be a good determinant of socio-economic status and it is routinely used in some other countries. So far, the Infant Feeding Survey is only dataset here to routinely record mothers' educational level. This shows that higher levels of breast feeding are associated with higher levels of education(180).

Ethnicity is similarly problematic. First, by its absence from many routine datasets as in registration data or by poor completion in datasets such as Maternity HES where it should be recorded.(48) Often if a baby is ill and admitted to neonatal care or another specialty this admission is not linked to the HES birth record.

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Secondly, the definition of ethnicity is also problematic and it is unclear to classify the children of mixed couples.

Geographical data are generally good, both for the place of residence and where the health care took place. This is not surprising in view of the changes made to the NHS in terms of flows of money being linked to localities.

Mortality data are reliable in terms of coverage. Cause of death is more problematic, except in the categories of death which are the subject of confidential enquiries. Data on the health of mothers and babies is harder to come by and even harder to find published. Although the Confidential Enquiry into Maternal Deaths collects data about a wide range of social factors, there are no equivalent social data about all mothers which can be used for comparison purposes.

No routine data are collected on some very important variables including diet, access to health care or housing conditions. These data are available only from special surveys. Further there is a paucity of outcome data, which reflects the quality or appropriateness and effectiveness of health care interventions. This is vital because access to inappropriate or ineffective health care is not access to health care at all.

Generally there are poor data linkages between the various routine datasets. This means that sophisticated analysis is often difficult so there is a tendency to plump for infant mortality.

Ways forward

It should be possible to make best use of the routine data that we already have and supplement analyses of one dataset with data from another to ensure that we can always look at factors such as socio-economic status, ethnicity and parents country of birth. There have been successful attempts to link Maternity HES to vital registration data(181), but it is not done routinely. If civil registration data were linked routinely to NHS data, it would help to give us a population perspective on many routine sources of access to health care data.

It is important to improve the quality of the routine data. Harmonising questions in routine data systems to make them more consistent would facilitate the combination of datasets for analysis. Definitions should be consistent over time also to allow the proper analysis of trends. Incessant boundary changes and lack of co-terminosity with social care providers is also a major problem. Routine data cannot answer all our questions and so there is scope for local detailed surveys to enhance nationally collected routine data.

A further limitation is the unavailability of some data that are already collected. Birth notification and NHS numbers for babies have more potential for monitoring access to health care, however at present no data are published from any of the multiplicity of older birth notification systems nor from the new NHS Number for Babies. In particular there is much more detailed morbidity data and further socio-economic data such as family structure and ethnicity which could enable

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detailed monitoring and measurement of the differences in access to health care amongst different groups within the population.

The National Congenital Anomaly System should be extended so that the whole country is covered by local registers and improve the potential for comparing local areas.

Conclusions

With a huge multiplicity of datasets covering maternity and neonatal health there is a need to ensure that standard definitions are applied to data items and that these definitions are widely recognised and adopted. Previously there have been attempts to produce a Maternity Care Data Dictionary.(182) These have stalled but the project may be continued as part of the current development of NHS IT. Such harmonisation is vital if records are to be linked in analysis to produce a broad picture of access to maternity and neonatal health care.

It is important that data are not collected and entered more than once as the duplication wastes everyone's time. This promotes a culture of resentment and impedes opportunities to collect other important data. Currently there is a high degree of duplication in the collection of birth data in England, with no single system containing reliable data about the care given to women and their babies and no way of linking these with data about their social background for example. In order to avoid this and make the most efficient use of what is already collected, it is vital systems can electronically communicate with each other so that data can be shared under suitable conditions of anonymity.

The summary table (Table 16) shows that there are insufficient data to address all the dimensions of access to health care properly and that some indicators of access to health care are much more measurable through routine datasets than others. There is a further question about the 'quality' of these indicators.

There is a lack of routine data on midwifery services and it is not possible to identify the medical input from routine data sources as obstetrics cannot be separated from gynaecology

The problems with routinely available data impact on the choice and appropriateness for target for access to health care and outcome set by the government. Infant mortality is easy to measure but, as discussed above, may no longer be a helpful indicator given the small number of events in most local authority areas and consequent year to year variation.

In conclusion, the considerable body of routine data available do not give a complete and reliable picture of access to maternity and neonatal care. In particular, they inadequate for monitoring differences in access amongst subgroups of mothers and babies. This is important as in its policy document, 'Making a Difference'(183) the Department of Health said that midwives should target vulnerable groups who do not traditionally use the health services. Unfortunately routine data are inadequate for monitoring whether their attempts to do so are successful.

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Table 15 Routine maternity and neonatal care data relating to the characteristics of the population and of service users

Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Demography (also morbidity and mortality)	Registration of Births	Published annually, available down to health regional office level	Age (confidential) Sex Country of birth – parents Socio-economic Geography Travel Birthweight Stillbirth – post-mortem	Section 4

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Demography (also morbidity and mortality)	NHS Numbers for Babies	No data published	Age Sex Ethnicity Geography Travel Birthweight Gestation Presence of congenital anomaly, yes/ no Stillbirth	Section 4

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Morbidity (also demography and mortality)	Birth Notification Generic – (c 20+ different systems)	Not published	Age Sex Ethnicity Socio-economic (one parent family) Geography Travel Baby Birthweight Gestation Various physiological measurements Congenital anomaly – details Hospital transfers Stillbirth and death within 28 days Mother Some previous medical history Previous miscarriage/neonatal deaths Intended place of delivery	Section 4

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Morbidity (some demography and mortality)	Notification of Congenital Anomalies	Published annually, previously down to District HA. Not an entire population coverage: all Wales and 40% England.	Age Sex Socio-economic Geography Travel Congenital anomalies- details Gestation Birthweight Number and outcome previous pregnancies Stillbirth	Section 4
Morbidity (some demography and mortality)	Notification of Abortions	Published annually, previously down to District HA	Age Ethnicity (not published) Geography Travel Gestation Grounds for abortion Complications Maternal death	Section 4

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<p>Characteristics of the Population Indicators of access</p> <p>Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets</p>	<p>Data source</p>	<p>Coverage and smallest level of aggregation</p>	<p>Content</p> <p>The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source</p>	<p>Location in report</p>
<p>Morbidity (some demography and mortality)</p>	<p>Maternity HES. Hospital inpatient data from the APC CDS and HES –for maternity only</p>	<p>Published annually down to Strategic Health Authority and Hospital</p>	<p>Age Sex- baby Ethnicity (poorly recorded) Geography Travel Baby Gestation Birthweight Resuscitation Mother Parity Delivery/onset method Anaesthesia Stillbirth Intended place of delivery</p>	<p>Section 3</p>

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<p>Characteristics of the Population Indicators of access</p> <p>Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets</p>	<p>Data source</p>	<p>Coverage and smallest level of aggregation</p>	<p>Content</p> <p>The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source</p>	<p>Location in report</p>
<p>Mortality (some morbidity, little demography)</p>	<p>Confidential Enquiry into Maternal and Child Health (CEMACH) – incorporating the former confidential enquires into still births and deaths in infancy (CESDI) and maternal deaths (CEMD)</p>	<p>Annual reports – topic coverage is variable.</p> <p>CESDI data are not really suitable to population assessments of access to health care CEMD is more useful.</p>	<p>Age Sex – baby Ethnicity Country of birth Socio-economic (inc social exclusion and domestic violence) Geography Mother Weight Parity Multiple births Baby Birth weight Various classification 7 scoring systems Obstetric class Cause of death</p>	<p>Section 4</p>

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Morbidity (some demography)	Infant Feeding Survey(176)	Last published 2000, has been published every 5 years since 1975. Covers whole UK. Data are published for each of the home countries.	Age Ethnicity Socio-economic Education Details of : Antenatal check ups Antenatal classes Midwifery contacts – antenatal Health visitor contacts – antenatal Breast feeding instruction	
Morbidity	Community Maternity Services	No longer published (or collected) since 2000, details down to NHS Trust	Details of : Consultant outpatients attendances Midwife clinic attendances Midwife domiciliary visit Health Visitor domiciliary visit	Section 3

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Morbidity (Demography and some mortality)	General Practice Research Database (GPRD)	UK contributing practices (covers c 5% UK pop) available at regional health office level. Ad hoc publications. ONS publish an extract of information: Key Statistics from General Practice	Demographic Patient information Clinical details Pregnancy tests Recording pregnancies Outcome of pregnancy Live birth, normal infant Adverse outcomes - spontaneous abortions, terminations, etc Adverse outcomes - foetal abnormalities, intrauterine deaths, stillbirth, etc Adverse outcomes - abnormal infant Neonatal and infant deaths Birth details Birth weight	Section 3

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Characteristics of the Population Indicators of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source	Location in report
Morbidity (Demography and some mortality)	Morbidity Statistics from General Practice	First study 1955-56 then every ten years up to 1991-92 in a sample of practices in England and Wales, provides data at national level – series seems to be discontinued	Diagnosis and socio-economic characteristics of every patient enrolled with practices included in the survey Details include: Complications of pregnancy child birth puerperium Congenital anomalies	Section 3

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<p>Characteristics of the Population Indicators of access</p> <p>Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets</p>	<p>Data source</p>	<p>Coverage and smallest level of aggregation</p>	<p>Content</p> <p>The variables listed are those relevant to Maternity and Neonatal Care as opposed to all those in the data source</p>	<p>Location in report</p>
<p>Mortality and Stillbirth (Some demography, some morbidity)</p> <p>See CEMACH above also for stillbirths, neonatal deaths and maternal deaths</p> <p>For births see Birth Registration above</p>	<p>Vital registration mortality data (inc stillbirth)</p>	<p>England and Wales, available down to individual level potentially.</p> <p>Maternal Deaths: Series DH2 publishes totals of maternal death by age band for cause: ICD 10, XV, O00-O99 Pregnancy, childbirth and the puerperium</p> <p>Stillbirths and Neonatal Deaths: FM1 (Birth Statistics, review of the register General on births and patterns of family building), VS and PP1 (Key Population and Vital Statistics), DVS4, DVS5 (Births and Deaths CD –ROM) and DH3 (Infant and perinatal mortality, social and biological factors available in ONS monitors until 1988 and subsequently as reports in Health Statistics Quarterly)</p>	<p>Details of:</p> <ul style="list-style-type: none"> Date and place of death Deceased's details Date and place of birth Occupation (of husband if a married woman or widow- optional. Parents occupation- mother's, father's optional if death has occurred in a child <16 yrs of age) Cause of death <p>For Stillbirths: As per above but also including:</p>	<p>Section 4</p>

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Table 16 Routine maternity and neonatal care data about the characteristics of the health care system

Characteristics of health care system	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to older people's mental health as opposed to all those in the data source	Location in report
Workforce	HCHS medical and dental workforce census	NHS medical staff, annual, England, data available at level of staff group. No distinction between Gynaecology and Obstetrics or between Paediatrics and Neonatology	Sex Staff grade Doctors in training Ethnicity Full or part time	Section 3
	HCHS non-medical workforce census	NHS non-medical staff, annual, England, data available at level of staff group Does not distinguish between nursing, midwifery and health visiting nor staff specialty or whether community or hospital	Sex Age Ethnicity Staff group Whole time equivalent	Section 3
	General Medical Services database	General practices in England and Wales, provides data at national and regional level	Details of all GPs holding a GMS contract with a PRIMARY CARE TRUST and in particular Maternity Medical Principals on obstetric list and approved for Child Health Surveillance	Section 3
Organisational	Bed availability and occupancy	Published quarterly, available for England as a whole and in detail by NHS trust	Ave daily number of maternity beds occupancy and also neonates	This case study
Financial	Department of Health	Annual, England and Wales, available at national level	Proportion of HCHS expenditure by programme of care – includes maternity services – 5% of budget	Section 3

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Table 17 Summary of maternity data sources and the Access Continuum

Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
Age (of mother)	Birth registration (confid.) NHS numbers for babies (not pub) Birth notification (not pub) HES Notification of abortions CEMD Infant Feeding Survey		Notification of abortions Infant Feeding Survey HES	Birth registration (confid.) NHS numbers for babies (not pub) Birth Notification (not pub) HES Notification of abortions CEMD Infant Feeding Survey
Sex (of child)				
Ethnicity (of mother/father or child)	NHS numbers for babies (child not pub) Birth notification (mother not pub) HES CEMD Infant Feeding Survey		Infant Feeding Survey HES	CEMD Infant Feeding Survey HES
Country of birth (of mother/father)	Birth registration CEMD			CEMD
Education (of mother)	Infant Feeding Survey		Infant Feeding Survey	Infant Feeding Survey

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Socio-economic (of mother/father)</i>	Birth registration Birth notification (single parent family- not pub) CEMD Infant Feeding Survey		Infant Feeding Survey	Birth notification (single parent family- not pub) CEMD Infant Feeding Survey
<i>Geog</i>				
<i>Where birth/stillbirth/abortion occurred</i>	Notification of abortions Community maternity services (no longer pub)	Notification of abortions	NHS numbers for babies (not pub) Birth notification (not pub) HES Notification of abortions Community maternity services (no longer pub)	
<i>Residence at birth/stillbirth/abortion</i>	Birth registration NHS numbers for babies (not pub) Birth notification (not pub) HES Notification of abortions	Birth registration NHS numbers for babies (not pub) Birth notification (not Pub) HES Notification of abortions		

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Travel time (as a derived variable)</i>	Birth registration NHS numbers for babies (not pub) Birth notification (not pub) HES	Birth registration NHS numbers for babies (not pub) Birth notification (not pub) HES		
<i>Morbidity (of mother or child)</i>	Birth registration (birth wt and stillbirths-PM) NHS numbers for babies (birth Wt, gestation and congenital anomalies- not pub) Birth notification (not Pub) Birth notification (mother and child -not pub) HES Notification of abortions CESDI CEMD Infant Feeding Survey		Infant Feeding Survey HES	Birth registration (birth wt and stillbirths) NHS numbers for babies (birth wt, gestation and congenital anomalies- not pub) Birth notification (mother and child -not pub) HES Notification of abortions Infant Feeding Survey

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Mortality (of mother or child)</i>	Birth registration (stillbirths) NHS numbers for babies (Stillbirths- not pub) Birth notification (stillbirths and neonatal deaths- not pub) HES CESDI CEMD			Birth registration (stillbirths) NHS numbers for babies (stillbirths- not pub) Birth notification (stillbirths and neonatal deaths- not pub) HES Notification of abortions CEMD
<i>Health Beliefs and knowledge (of mother)</i>	Birth notification (Intended delivery place- not pub)?	Birth notification (Intended delivery place- not pub)?	Birth notification (Intended delivery place- not pub)	Birth notification (Intended delivery place- not pub)
<i>Characteristics of the health care system</i>				
<i>Workforce</i>		HCHS workforce censuses GMS database		
<i>Organisational</i>		Hospital activity statistics	Hospital activity statistics	
<i>Financial</i>		HCHS expenditure		

6.3 Cancer

6.3.1 Introduction

The objective of this case study is to identify and describe the routine datasets relating to cancer and to identify issues and gaps in how data sources can be used to measure access to cancer services. The accompanying tables, Table 19, and Table 20, list the relevant data sources according to their primary dimension of access (for example morbidity, mortality), plus the coverage and level of aggregation of the data source (by smallest geographic level covered), and the section in the report where each data source is described in detail. In particular it should be noted that a section on cancer registry data is provided in detail in Section 4.3.

We selected cancer as a case study because of the serious burden it places on the health of the population and because it has been designated as one of the government's key target areas.

6.3.2 Definition of cancer and its prevalence

The term cancer applies to any malignant growth or tumour caused by abnormal and uncontrolled cell division. There are over 200 types of cancer covering many conditions affecting different parts of the body. All start in the same way, by normal cells developing into abnormal cells which multiply, clustering into a lump or tumour. Those which are malignant often damage surrounding organs and may spread to other parts of the body, forming further 'secondary' cancers. Malignant cancers take different courses and have differing prognoses depending on the part of the body affected. Cancer is a major cause of ill health and death in the population with more than one in three people in England and Wales developing the disease during their life, and causing one in four deaths. Each year, over 200,000 people are diagnosed with cancer, and around 120,000 people die from the disease.

Information from the registries indicates that many cancers occur more commonly among those living in areas of deprivation, particularly cancers of the lung, stomach and cervix. Smoking is the most important risk factor for lung cancer and the well-documented socio-economic gradient in smoking almost certainly accounts for most of the observed difference. Almost all cancers are more common in older people.

Survival has improved over the years but with some notable exceptions, such as lung cancer. Despite this, only one percent of people diagnosed with cancer are still alive after ten years. Length of survival depends partly on the stage of disease when diagnosed. Survival times vary between deprived and affluent groups, although more so for some types of cancers than others. Many of the

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possible explanations are related to access to health care, including more advanced disease stage of disease by deprived groups at presentation, longer delay in diagnosis and poorer access to optimal care. Other explanations include worse general health, different histological type, more aggressive disease and lower treatment compliance(122).

6.3.3 Who provides cancer services?

On recognition of symptoms, most people visit their GP who decides whether to refer to a hospital consultant for diagnosis. Sometimes patients are referred initially from an accident and emergency department. Tests are undertaken to determine the diagnosis and a cancer specialist discusses results and treatment.

Cancer services are provided by many professional groups. GPs are central both in initial referral and subsequent care. Patients are likely to encounter a range of specialist consultants and other professionals for tests and treatment. As well as NHS, local authority staff such as social workers may be involved. Charities provide information, palliative and terminal care. Table 18, below shows some of the settings and staff involved in providing cancer services.

Table 18 Settings and staff involved in cancer care

Settings providing cancer services	Range of professionals who provide cancer services
GP surgery	GP
A&E unit	Practice Nurse
Screening service	A&E staff
Hospital	Screening service staff
Clinics	Oncologist
Home	Surgeon
Hospice	Physician
Private hospital /nursing home	Specialist nurse
Hospital outpatient clinic	Radiographer
	Allied health professional (physiotherapist, dietician)
	Palliative care nurse or doctor
	Psychologist or counsellor
	Community nurse
	Social worker

6.3.4 Government targets and policies relating to cancer

There are a range of targets and policies relating to cancer which is high on the government's agenda. England has a Cancer Action Team and National Cancer Director and a Cancer Plan and national standards have been published. The Cancer Services Collaborative was established to set up to develop good local practice in England. Cancer networks, defined as an organisational association between a Cancer Centre and Cancer Units within a distinct geographic area, cover a population of approximately one to two million people.

6.3.5 Major policies of the last ten years

Calman-Hine Report

This was a major report on cancer in England and Wales, published in 1995 which prompted many changes in the organisation of cancer services(117). It was prepared by a Committee chaired by Dr Kenneth Calman, Chief Medical Officer of England and Dr Deirdre Hine, Chief Medical Officer of Wales.

The report developed a set of principles for cancer services, making recommendations about the structure and organisation of local services. There should be two types of facility: cancer units and cancer centres. Units would provide basic cancer services to their local population while centres would provide a wider population with more specialist services, including surgery, radiotherapy and advanced forms of chemotherapy and diagnostic techniques. These centres might comprise more than one hospital. The plan intended to ensure treatment of patients close to home, while developing centres of specialisation and excellence. It also proposed a system of networks to bring together cancer services in an area and systems to ensure early recognition of the disease. Patients should have information on options for the most up-to-date treatment and care with support throughout their treatment. The report put cancer to the top of the health agenda.

Six years later, in 2001 a review by the Commission for Health Improvement and the Audit Commission(184) of the experiences of people with cancer noted that since the publication of the report improvements in NHS cancer services included:

- faster access with most urgently referred patients waiting less than two weeks from GP referral to first hospital appointment
- improved scheduling arrangements for hospital tests and clinic appointments reducing the number of patient journeys to hospital
- extended multidisciplinary working between clinicians to plan individual patients' care and to develop good practice guidelines
- development of outreach services by doctors specialising in chemotherapy and radiotherapy so that patients receive treatment closer to home
- plans to address existing inequalities in staffing and equipment
- standards established across Wales and within some English regions.

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The report found that such improvements were not made everywhere. It showed that, other than for lung and breast cancers, there were no agreed treatment policies in more than half of the trusts visited. Although the Calman-Hine report had provided a major impetus in setting an agenda to develop cancer services, it provided no central plan to implement proposals and attached no resources. Each region had to develop its own strategy resulting in variation in the delivery and organisation of cancer services.

The report found wide variations between regions, hospitals and individual cancers in cancer treatment identifying the following problems:

- Problems with waiting times for radiotherapy, even for urgent treatment in some areas. Radiotherapy machines were unevenly distributed and many were old. There was great variation in the efficiency of machine use, arising from differences in prescribing, the hours during which machines are used and availability of staff.
- Considerable variation in the availability of specialist palliative care consultants and nurses and a lack of clarity as to who had principal responsibility.
- A need to improve information systems and for managers and clinicians to agree what they are trying to achieve.
- Uneven provision of hospices across the UK despite a growth in their number.

'The New NHS' white paper (waiting times policy)

Since 1997, the policy context for cancer services has emerged as a top priority. The incoming government created and supported central systems to implement Calman-Hine and monitor progress, earmarking new resources for these tasks. The white paper, 'The New NHS' prioritised waiting times pledging(185):

We will improve prompt access to specialist services so that everyone with suspected cancer will be able to see a specialist within two weeks of their GP deciding they need to be seen urgently and requesting an appointment. We will guarantee these arrangements for everyone with suspected breast cancer by April 1999 and for all other cases of suspected cancer by 2000.

Cancer Services Collaborative

In 1999 the Cancer Services Collaborative was set up in nine areas to develop good local practice, intended to reduce delays and create a more patient centred approach. New resources were committed to help reduce waiting times.

The NHS Plan

In the NHS Plan published in July 2000(20) the government set out its commitment to reach the target in the 1999 white paper 'Our Healthier Nation'(97) of reducing the cancer death rate in people aged under 75 by 20 per cent over the years to 2010 in England. Further increases in funding for cancer were announced in the Plan, set out in more detail in the Cancer Plan. However,

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there has been some concern that these funds have not always been used specifically for the purpose intended.

The NHS Cancer Plan

The NHS Cancer Plan(80) published by the Department in 2000 set out national standards for cancer services in England. Its four aims were to save more lives, to ensure people with cancer get the right professional support and care as well as the best treatments, to tackle inequalities that mean unskilled workers are twice as likely to die from cancer as professionals, and to invest in the future through the cancer workforce, strong research and preparation for the genetics revolution.

The plan acknowledged the existence of 'a postcode lottery for cancer care', that as well as poor survival rates, the NHS suffers from unacceptable variations in access to high quality cancer services and up-to-date drugs and treatment.

The plan acknowledged that communities most at risk of ill health tended to have the poorest access to the range of preventive health services, including cancer screening programmes. Further it cited widespread geographical inequalities in the quality and type of treatment because of shortages of specialist staff, fragmentation of care, inadequate access to surgical facilities, and a postcode lottery on prescribing and insufficient radiotherapy facilities.

The plan made three commitments as follows, the second and third of which were directly concerned with access:

- 1 In addition to the existing *Smoking Kills* target of reducing smoking in adults, new targets to address the gap between socio-economic groups in smoking rates and the resulting risks of cancer and heart disease.
- 2 Targets to reduce waiting times for diagnosis and treatment so that no one should wait longer than one month from an urgent referral for suspected cancer to the beginning of treatment.
- 3 An extra £50 million NHS investment a year by 2004 in hospices and specialist palliative care, to improve access to these services across the country.

Cancer Information Strategy 2000

The Cancer Information Strategy(186) is one strand within the overall development of the information strategy set out in the 1998 white paper 'Information for Health'(54). Its more detailed source is the NHSIA document 'Towards a Cancer Information Strategy'(187).

The aims of this strategy which underpins the Cancer Plan were as follows:

- To ensure that accurate, comprehensive and comprehensible information about cancer is accessible to all those who need it.
- To enhance the quality of care given to patients with actual or suspected cancer, by ensuring that their needs for information are

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met in a timely, sensitive and appropriate way and by ensuring good communication between health care sectors.

- To underpin the Government's commitment to modernise cancer care and to monitor progress towards the achievement of specific targets to reduce the death rate from cancer.

Recommendations include implementing processes to ensure that relevant information is collected, and the monitoring of performance indicators including screening. It recommended developing nationally agreed datasets for different aspects of cancer to form an integral part of the implementation process of Information for Health. The NHS Information Authority, in collaboration with the National Cancer Director and NICE should establish a National Cancer Datasets Steering Group to oversee the development of national datasets. The cancer Commissioning Minimum Dataset should be further developed so that waiting times can be grouped by cancer type and by waiting times in days. Also there should be ensured appropriate flows of information between all providers of health and social care, including the voluntary and private sectors.

It specifically noted the key role in data collection played by cancer registries but cited unacceptable differences in standards and the need to resolve this and to introduce new management arrangements. It also considered measures to integrate registries with other cancer intelligence functions, for example establishing combining functions to form the cancer component of Public Health Observatories. It recommended taking forward the review of Cancer Registries conducted by Professor Charles Gillis and to ensure that appropriate management arrangements are in place and that the completeness, quality and timeliness of cancer registration data is addressed (Recommendation 7). More detail on the Gillis review is provided in the Section on cancer registries.

6.3.6 Routine datasets relating to cancer

The case study tables (Table 19 and Table 20) identify and summarise data sources and the key variables contained within them available to measure and monitor access to cancer services, with the location in this report where they are described in full.

The data items in the latest version of the Cancer Minimum Dataset are provided in Section 8.2.1, Appendix B, Table 57.

6.3.7 Summary of the extent to which existing data sources can be used to measure and monitor access to cancer services

Waiting times for specialist cancer care are a key government target with data items in place by which to directly monitor delays in access. Further, the UK has the world's largest and most comprehensive national cancer registration system and the data collected by registries provide a rich source of information which can be applied to monitor and measure access. Cancer is one area where data linkage is routinely employed between incidence and death data. Further, since 2000, the

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Commissioning Minimum Datasets have recorded the date of GP decision to urgently refer the patient to enable waiting times information to be sent via the NHS Wide Clearing Service.

However, this case study has identified some issues with regard to measuring and monitoring access to cancer services.

An absence of a nationally agreed mechanism for monitoring implementation of the Calman-Hine recommendations has led to regional and local variation.

The registration of cancer is not statutory. Compulsory cancer registration would ensure comprehensive data by which access to services could be monitored and measured for the whole population. Cases not recorded until death (by Death Certificate only) cannot be included in survival analyses and do not provide information with which to monitor access.

As in other areas, there are very limited cancer statistics available from the private health care sector. Although only a limited number provide acute cancer treatment (oncology or haematology specialties, chemotherapy, radiotherapy) a much larger number offer specialised imaging investigations, mammography and other screening procedures.

The majority of private registered nursing home beds are for elderly people, and the number of people with cancer in nursing and residential homes is substantial but unknown.

It is essential that private institutions should be required to provide data in the same way as NHS Trusts. Otherwise people dying in private hospitals are likely to be registered only by Death Certificate, which has implications for data quality.

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Table 19 Case study table - data sources relating to cancer

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to cancer services as opposed to all those in the data source	Location in report
<p><i>Characteristics of the population of interest (cancer)</i></p> <p><i>Morbidity and mortality</i></p>	Items collected in the cancer minimum dataset by the cancer registries	Regional level	Age Sex Ethnicity Country of birth Education Socio-economic Geography Travel time Morbidity Mortality	Section 4 For full dataset see Appendix B
<p><i>Morbidity (also mortality)</i></p>	Hospital activity data Hospital inpatient data from the APC CDS and HES	England and Wales, available at level of Finished Consultant Episode by postcode	Age, sex, ethnicity (poorly recorded) geography, travel can be derived Clinical details of cancer diagnoses, procedures, specialty Length of stay, method and source of admission, discharge destination NHS number which can link to other datasets, e.g. mortality	Section 3

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to cancer services as opposed to all those in the data source	Location in report
<i>Morbidity</i>	Consultant outpatient admissions dataset	England and Wales, data available at level of outpatient attendance	Age Sex Geography Diagnosis	Section 3
<i>Morbidity</i>	Primary care data Prescribing data	England	All items dispensed by community pharmacists, appliance contractors and dispensing doctors Items doctors administer themselves	Section 3
<i>Morbidity</i>	General practice Research database	UK contributing practices available at national level	Demographic Patient information Clinical details	Section 3
<i>Mortality</i>	Vital registration mortality data ONS VS3 and VS4 data	England and Wales, available at person level	Administrative details Date and place of death Deceased's details Date and place of birth Occupation (of husband if a married woman or widow) Cancer diagnosis as cause of death	Section 4

6.4 Coronary Heart Disease(CHD)

6.4.1 Introduction

This case study explores the extent to which routine data sources relating to coronary heart disease care in England can be used to assess the level of access to health care within the population and how this varies between groups within the population. The case study will also highlight problems with the routine data sources that might hinder the measurement and monitoring of access to health care both for the population and for groups within the population.

The case study makes use of the framework for access developed in Section 2.2.1, namely the extent to which datasets can be used to determine access (need, opportunity, utilisation and outcome) with respect to various indicators of access such as demography, morbidity, mortality and staffing, organisation and financing of health care services for maternity and neonatal care.

Coronary heart disease care was one of six topics selected for case study, primarily because it is an important area of health and one of the biggest killers in England(188). Traditionally CHD mortality rates have been seen as an important element of population health surveillance and more generally CHD is the subject of many government targets and interventions. It is also an area that is rich in datasets that cover all aspects of care and treatment from primary and secondary prevention to acute and chronic care and rehabilitation encompassing primary, community, secondary and tertiary care.

6.4.2 Policy issues relating to access to Coronary Heart Disease care

Coronary Heart Disease care benefits from being the subject of one of the first national service frameworks to be published(189) and numerous Department of Health targets and performance indicators.

The government has specified several targets for 'Fair access and effective delivery of appropriate care' for coronary heart disease in the past. Fair access is defined in the *NHS Performance Assessment Framework*(171) as being when all those eligible for treatment have received care. The aspect of fairness is further defined as the fairness of the provision of services in relation to need on various dimensions: geographical; socio-economic; demographic (age, ethnicity, sex) and care groups. Effective delivery of appropriate care is defined as the delivery of health care where the intervention is appropriate for the particular condition(171). Appropriate is further defined as clinically effective; appropriate to need; timely; in line with agreed standards; provided according to best practice models of organisation and delivered by appropriately trained and educated staff.

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The Coronary Heart Disease National Service Framework(189) sets out Department of Health's desired basket of performance indicators for coronary heart disease under six principal areas of care, primary prevention, preventing CHD among those at high risk, acute myocardial infarction and other acute coronary syndromes, stable angina and revascularisation, heart failure and cardiac rehabilitation. These indicators are not necessarily all part of the *Performance Assessment Framework* at present.

The indicators are listed in detail below:

- Primary prevention:
 - number and percentage of smokers using smoking cessation services
 - number of smokers provided with free nicotine replacement therapy
 - number of smoking cessation services (specialist smoking cessation clinics and 'intermediate interventions')
 - number of smokers using smoking cessation services who are still not smoking four weeks after quit date.

- Preventing coronary heart disease among those at high risk:
 - number and percentage of practices in a PCG/PCT with a systematic approach to following up people with CHD. New collection from 2001/02.
 - number and proportion of people aged 35 to 74 years with recognised CHD whose records document advice about use of aspirin.

- Acute myocardial infarction and other acute coronary syndromes:
 - number and percentage of patients eligible for thrombolysis receiving it within 60 minutes of call for professional help ('call-to-needle time')
 - number and percentage of patients discharged from hospital with a diagnosis of acute myocardial infarction prescribed beta blocker.

- Stable angina and revascularisation:
 - rate of coronary artery bypass graffe/million population by HA *and* PCG/PCT. Can be produced annually from existing data (HES).
 - rate of Percutaneous Transluminal Coronary Angioplasty/million population by HA *and* PCG/PCT. As above. Rate of angiography/million population by HA *and* PCG/PCT. As above.
 - number and proportion of people aged 35 to 74 with recognised coronary heart disease whose records document advice about use of aspirin
 - number and percentage of PCGs/PCTs in a region with PCG/PCT wide protocols for specialist care agreed with local cardiologists

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- number and proportion of relevant Trusts with hospital-wide protocols for the investigation and management of people with suspected angina
- number and percentage of people who receive care within prevailing waiting time targets.

- Heart failure:
 - admission rates for heart failure by *PCG/PCT* and HA. Can be produced from existing data (HES).
 - performance indicators for palliative care – being developed for Calman-Hine cancer services.

- Cardiac rehabilitation:
 - number and percentage of patients discharged from hospital after coronary revascularisation or with a primary diagnosis of AMI with documentation of arrangements for cardiac rehabilitation in discharge communication to GP. New collection from 2001/02.

This is a fairly substantial set of performance indicators however all those above in italics are described as '*sophisticated indicators which will take longer to develop*' and were not available from routine and robust data sources at the time the CHD NSF was published.

In fact on review it will be seen that the only access related performance indicators available at the time the CHD NSF was published, relate to the rates for various surgical procedures to treat CHD and to inpatient admission rates: in short traditional utilisation measures which tell us nothing of those who were unable to *access the services fairly* in the first place.

More generally CHD is covered by the NHS Performance Rating System(190) that awards stars to Acute Trusts and Primary Care Trusts and in particular the most recent full set of performance indicators(83).

Targets of particular relevance to CHD in PCTs include:

- death rates from circulatory diseases, ages under 75 (change in rates)
- CHD Register (level of GP based clinical audit).

And targets of particular relevance to CHD in acute trusts include:

- deaths following heart bypass operations
- Thrombolysis – 60 minute call to needle time (Also a PI for ambulance trusts).

Again these indicators are heavily based on a few robust data systems, for example death registration. Access is not present at all, although previously it was addressed only in terms of waiting-times. The only utilisation measure used as a performance indicator is thrombolysis treatment time; a measure that has

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attracted some criticism due to deficiencies in recording the data needed for this measure(191).

In order to meet the needs of the CHD NSF and government requirements for monitoring performance the development of a CHD Dataset recognises the:

need for common definitions along the care pathway, the production of comparative analyses for clinical audit and performance management, and to support planning and public health. Its aim... to develop nationally agreed standards, eliminate duplication, ensure compatibility between datasets. (192)

The CHD NSF Information Strategy recognises that preventive and health promotion strategies require good information so that they are soundly based and targeted. Indeed the South East Public Health Observatory is piloting a project concerned with developing a regional picture of CHD.

The need for good primary-care data is being aided by PRIMIS the Patient Care Information Service (www.primis.nhs.uk). This initiative is still reliant upon GPs own records systems and that these record systems should be computerised, some researchers have indicated that such systems may under-enumerate the number of patients with CHD and at risk of developing CHD(193; 194).

The CHD NSF Information Strategy notes that secondary and tertiary care datasets in CHD care have developed on an ad hoc basis historically(192) and that they vary greatly in their capacity to support the delivery of cardiac care and thus their capacity for use in measuring and monitoring access to health care. The CHD NSF(189) makes provision for the development of national standards for clinical information systems in CHD. It also seeks to improve clinical audit through the Myocardial Infarction Audit Project and Central Cardiac Audit Database. Rehabilitation and heart failure services are areas that the NSF points out will need further work with regard to data requirements.

A major structural change in the way CHD care is provided has been the introduction of Rapid Access Chest Pain Clinics (RACPCs). These are intended to provide a fast one-stop diagnosis for patients with chest pain that suggests possible angina. This avoids the usual long wait to see a cardiologist and then further waits for tests. The standard states that within no more than two weeks patients should be able to have the all clear or promptly moved on to further diagnostic and treatment options(189; 192). RACPCs will be able to link to PAS data. The Review of Central Returns considered reporting a system to monitor RACPCs(192), so adequate routine data is available to monitor and measure the access of the population to these clinics, although, currently the only evaluation is the waiting time.

6.4.3 Routine datasets relating to Coronary Heart Disease health care

Most of the datasets referred to in the three case study tables are described in detail elsewhere in this report (see Table 21 and Table 22, for the exact references).

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The principal datasets include:

Those that characterise the population:

- Registration of deaths
- Central Cardiac Audit Database (CCAD)
- Myocardial Infarction National Audit Project (MINAP)
- British Cardiac Intervention Society (BCIS)
- National Pacing Database (NPDB)
- Paediatrics Cardiac Surgery and Congenital Heart Disease Audit (PAEDS)
- Society of Cardio Thoracic Surgeons (SCTS)
- Implantable Cardiac Defibrillators (ICD)
- Cardiac Ablation Procedures (EPS)
- UK Heart Valve Register Service (UKHVR).
- British Association of Cardiac Rehabilitation - Register of Rehabilitation Programmes
- HES (hospital episode statistics)
- General Practice Research Database (GPRD)
- Morbidity Statistics from General Practice
- Practices-Based Registers of CHD
- Health Survey for England
- General Household Survey.

Those that characterise the health care system:

- HCHS Medical and Dental Workforce Census
- HCHS Non-medical Workforce Census
- General Medical Services Database
- Hospital Activity Statistics
- The Government's Expenditure Plans.

However several datasets specifically relate to coronary heart disease care have not been covered elsewhere in the report. These are described briefly in Appendix B.

6.4.4 Adequacy of existing data sources for measuring and monitoring access to coronary heart disease care

Access to health care has been previously defined in the terms of the broad dimensions of need, opportunity, utilisation and outcome. These dimensions are further described by specific indicators of access, such as age and socio-economic status, found in the routine data sources.

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Three tables, which have been compiled for this case study, summarise the relationship of the routine data to the dimensions and indicators of access both in terms of the characteristics of the population and the characteristics of the health care system.

Table 21 Routine Coronary Heart Disease data sources concerning the characteristics of the population lists the sources of routine data identified and briefly describes each dataset in terms of the principal indicators of access together with details of publication and aggregation and a reference to the section in the main report where the particular dataset is described and discussed in detail.

Table 22 Routine Coronary Heart Disease data sources concerning the characteristics of the health care system does the same for those indicators of access that relate to the health care system rather than those that relate to the population.

Table 23 Summary of Coronary Heart Disease data sources and the Access Continuum bring together all the routine data sources for coronary heart disease care in terms of the broad dimensions of access and the individual indicators of access.

Dimensions of access

The 'need' dimension of the access continuum for Coronary Heart Disease care is perhaps the dimension with the most and richest data available. Good mortality and morbidity data are available from robust datasets with very good population coverage. The only snag is the extent to which the data are published. Data are easily available from vital registration and HES but less so from the audits that comprise CCAD, unsurprisingly, as these initiatives are new and in some cases still defining the dataset to be collected. Survey data are excellent but cover only samples of the population and are conducted and published less frequently than routine data such as HES. Socio-economic data is not widely available (see below) and there is quite a high level of duplication in the core variables collected by the different datasets. In terms of characteristics of the health care system there is nothing in the routine data that could be used to build up a picture of need.

Data on the opportunity to use health care services for coronary heart disease are poor in comparison. No data with respect to socio-demographic variables are available, however there are data that relate to the patients' place of residence and the location that the health care intervention took place. HES and audit data can be used to determine the distribution of various CHD services and patients travel time can be estimated to reach these services. The Health Survey for England (HSE) does include some specific data on the use of hospital services in relation to CHD, especially in its CHD supplements.

The main routine data relating to opportunity to access health care come principally from data dealing with the characteristics of the health care system. Health care workforce data, including GP data, hospital activity and government expenditure can be used to build up a picture of the service provision in a given area, but other than geographical analyses it is difficult to relate these data to

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specific subgroups within the population. For instance there may be many non-geographical barriers that reduce the opportunity to use health care services for different groups within the population. These include access to a car, availability/cost of public transport, preference for/and ability to use different modes of transport and issues of personal safety. Issues relating to transport and access to health care are the subjects of the sixth case study.

Many robust utilisation data are available for coronary heart disease care. HES data and the various clinical audits that comprise Central Cardiac Audit Database (CCAD) could produce a very detailed picture of health service activity for CHD care. Again, this is limited by the degree to which the data are published or made available.

Lastly hospital activity statistics provide few data on the ward attendances and cardiothoracic high care units but no real detail on the number of CHD care beds available, as the data are not broken down to a sufficiently detailed level. No data are routinely available on CHD nursing care.

Outcome data in terms of mortality and morbidity are robust and available for CHD care. HES data and death registration provide good mortality data and HES and the CCAD audits could provide much detail on outcome by most of the important socio-demographic indicators of access such as age, sex and ethnicity, although socio-economic status is only available from death registration data.

Indicators of access

Table 23, which summarises the routine data sources available for CHD case by indicators of access shows that basic demographic details of age and sex are universally available from the datasets reviewed here. Developments such as the core dataset for all the CCAD datasets have ensured good demographic data and the addition of data on ethnicity is very welcome also. Data on ethnicity are similarly widely available in the routine data that relate to access to CHD disease care, although possibly poorly recorded in datasets such as HES.

Socio-economic data are not widely available, however. It is available from death registration and so is useful when looking at need and outcome in terms of CHD specific mortality rates for groups within the population. There are also some utilisation data available from Morbidity Statistics from General Practice (MSGP) and, from the Health Survey for England with their semi-regular publication of one-off CHD modules (1993, 1994 and 1998). The draw-back with these data sources is that they are based on samples of the population and in the case of the Health Survey are intermittent.

Geographical data are good, especially in such datasets as HES. Mortality data are robust and available from civil registration data and in the central cardiac audit database audits.

There are some other routine data on important factors associated with CHD. The Health Survey for England and the General Household Survey collect data on smoking (also available from GPRD) and alcohol consumption. The Health Survey,

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which has included three one-off modules on CHD. Data on diet and exercise are only available from special surveys.

It should be possible to make best use of the routine data that we already have and supplement analyses of one dataset with data from another to ensure that we can always look at factors such as socio-economic status. Alternatively socio-economic status could form part of the core dataset. It is important that what is already collected should be made widely available so that planners, policy makers, researchers, providers and users can make best use of the large quantities of data that are already collected. Given that the CCAD audits collect core data it is a pity that analyses by the socio-demographic variables available here are not more widely available. The confidential enquiry into maternal deaths (CMED see Maternity case study) is a good example of an audit process that makes good use of socio-economic data to provide much useful details on the importance of socio-economic factors associated with access to health care and health outcomes.

6.4.5 Conclusions

This case study illustrates that there is a plethora of routine data relating to many aspects of access to CHD care. The coverage of the data is not so impressive. The summary (Table 23) shows that there is a lack of good socio-economic data with which to monitor and measure access to CHD care in England. Further much of the data are not published, nor made available for analysis. Data on opportunity to use health care services are also poor, making routine analysis of barriers to accessing care impossible. The problems with routinely available data impact on the choice and appropriateness of target for access to health care and outcome set by the government. Use of easy to measure variables, e.g. CHD death rates and waiting times tend to predominate simply because they are available and robust. It is important that many of the 'more sophisticated' indicators outlined in the CHD NSF should be available so that access to CHD care services can be more fully described from the routine data.

While there are many data sources for CHD care in England, central initiatives such as the Coronary Care Audit database (CCAD)(195) project provide a welcome focus not necessarily seen in other areas of health care. This ensures a harmonisation between datasets and a reduction in duplication. Core datasets of important socio-demographic data will become more available in the future and set a standard for other routine datasets.

The number of indicators from the CHD NSF that are not supported by robust routine data sources is a cause for concern. While initiatives such as Information for Health(179) which recommends a single approach to collecting data for both clinical and administrative needs through the electronic patient record (EPR) are very welcome, there is a danger that they are just a technological solution to data collection and not an answer to information needs. The EPR will not collect many new data items, so the collection of data is not the primary problem. The real issue is how data are to be brought together and made available so that the

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measurement and monitoring of access to health care in the population can be improved. Further data linkage and collaboration would reduce the need for much of the data duplication seen between datasets and reduce the burden of collecting important data.

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Table 21 Routine sources for CHD concerning the characteristics of the population

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
Mortality (Some demography, some morbidity)	Vital registration mortality data	England and Wales. Available down to individual level potentially.	Details of: Date and place of death Deceased's details Date and place of birth Occupation (of husband if a married woman or widow- optional. Parents occupation - mother's, father's optional if death has occurred in a child <16 yrs of age) Cause of death	Section 4

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
	Central Cardiac Audit Database (CCAD)	This project is an over arching project covering different clinical domains detailed below. Theoretically individual data could be available from most of the databases (detailed below) that comprise CCAD. But most is published nationally and by Acute Trust/Hospital.	Data core to all these datasets includes: NHS Number Patient surname Patient forename Patient date of birth Patient sex Patient ethnic group Patient admin status Patient post code GP practice code	Appendix B
	Myocardial Infarction National Audit Project (MINAP)	All UK patients admitted with a suspected or actual MI. Published by hospital/trust	In addition to the core data, clinically specific details of admission, diagnosis, treatment and outcome	
	British Cardiac Intervention Society (BCIS)	All patients in UK undergoing coronary angioplasty	"	

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
	National Pacing Database (NPDB)	All patients in UK/Eire receiving implanted pacemakers Published by hospital/trust	"	
	Paediatrics Cardiac Surgery and Congenital Heart Disease Audit (PAEDS)	All children in UK hospitals undergoing cardiac surgery Published by hospital/trust	"	
	National Adult Cardiac Database (NACDS)	Hosted by the Society of Cardio Thoracic Surgeons (SCTS). All patients undergoing cardiac surgery in the UK Aggregated data	"	
	Implantable Cardiac Defibrillators (ICD)	All patients in UK/Eire receiving implanted defibrillators Published by hospital/trust	"	
	Cardiac Ablation Procedures (EPS)	All patients in UK receiving ablation treatment for arrhythmias	"	

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Dimensions of access	Data source	Coverage and smallest level of aggregation	Content	Location in report
Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets			The variables listed are those relevant to CHD care as opposed to all those in the data source	
	UK Heart Valve Register Service (UKHVR)	Hosted by the Society of Cardio Thoracic Surgeons (SCTS). Patients undergoing heart valve surgery. Published by hospital/trust	In addition to the core data, clinically specific details of admission, diagnosis, treatment and outcome	
	British Association of Cardiac Rehabilitation - Register of Rehabilitation Programmes	Approximately every 18 months a questionnaire is sent to all the cardiac rehabilitation centres in the UK. Last survey 84% response, but concerns over missing data items Aggregated by unit	Summary statistics about the patients Age Sex Diagnosis Compliance	
Morbidity (some demography and mortality)	HES Data Hospital inpatient data from the APC CDS and HES	Published annually down to Strategic Health Authority, hospital and PCT	Age Sex Ethnicity (poorly recorded) Geography Travel Clinical details of admission, diagnosis, treatment and discharge	Section 3

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Dimensions of access	Data source	Coverage and smallest level of aggregation	Content	Location in report
<p>Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets</p> <p>Morbidity (Demography and some mortality)</p> <p>Morbidity (Demography and some mortality)</p>	<p>General Practice Research Database (GPRD)</p> <p>Morbidity statistics from general practice (MSGP)</p>	<p>UK contributing practices (covers c 5% UK pop) available at regional health office level. Ad hoc publications. ONS publish an extract of information: Key statistics from general practice. Data are presented for the five years 1994-1998; also by country/region, ONS area classification, and deprivation category</p> <p>c1% sample of the population of England & Wales. First study 1955-56 then every ten years up to 1991-92 in a sample of practices in England and Wales, provides data at national level – series seems to be discontinued</p>	<p>The variables listed are those relevant to CHD care as opposed to all those in the data source</p> <p>Demographic data (excluding ethnicity and socio-economic status), diagnosis, management, outpatient referrals and prescribing characteristics of every patient enrolled with the practices included in the survey</p> <p>Also collected height, weight lab results and smoking status</p> <p>Socio-economic status (including occupation, ethnicity, marital status, housing tenure and household composition)</p> <p>Clinical details</p>	<p>Section 3</p> <p>Section 3</p>

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
Demography, Morbidity & Treatment	Practices-Based Registers of CHD	Intended to cover those with CHD and those at risk of CHD Position of these registers is uncertain	NHSIA has specified core of: Sex Age Ethnicity Clinical- diagnostic & treatment details and dates	

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
Demography & Morbidity	Health Survey for England (HSE)	Available at Health Authority Area	Core Data Items: Questions on general health and psycho-social indicators Smoking Alcohol Demographic and socio-economic indicators Questions about use of health services and prescribed medicines - the focus for these may vary from year to year to suit the modular content of the survey Blood pressure Measurements of height, weight and blood pressure Relevant one-off modules: 1993 cardiovascular disease 1994 cardiovascular disease 1998 cardiovascular disease	Appendix B

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Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to CHD care as opposed to all those in the data source	Location in report
	General Household Survey (GHS)		Household and family information Housing tenure and household accommodation Consumer durables including vehicle ownership Employment Education Health and use of health services Smoking and drinking Family information including marriage, cohabitation and fertility Income Demographic information about household members including migration	Section 4

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Table 22 Routine CHD sources concerning the characteristics of the health care system

Characteristics of health care system <i>Workforce</i>	HCHS medical and dental workforce census	NHS medical staff, annual, England, data available at level of staff group	Sex Staff grade Doctors in training Ethnicity Full or part time	Section 3
	HCHS non-medical workforce census	NHS non-medical staff, annual, England, data available at level of staff group	Sex Age Ethnicity Staff group Whole time equivalent	Section 3
	General Medical Services database	General practices in England and Wales, provides data at national and regional level	Details of all GPs holding a GMS contract with a PCT	Section 3
Characteristics of health care system				
Organisation	Hospital Activity statistics	Published quarterly, available for England as a whole	Av. daily number of beds Occupancy	
Financial	Department of Health 'The Government's Expenditure Plans'	Annual, England and Wales, available at national level	Proportion of HCHS expenditure by programme of care – includes maternity services – 5% of budget	

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Table 23 Summary of CHD data sources and the Access Continuum

Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
Age	Death registration HES CCAD Cardiac rehab GPRD HSE GHS		HES CCAD Cardiac rehab GPRD HSE GHS	HES CCAD Death registration GPRD
Sex	Death registration HES CCAD Cardiac rehab GPRD HSE GHS		HES CCAD Cardiac rehab GPRD HSE GHS	Death registration HES CCAD GPRD
Ethnicity	HES CCAD HSE GHS		HES CCAD HSE GHS	Death registration HES CCAD

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Socio-economic</i>	Death registration HSE GHS		MSGP HSE GHS	Death registration
<i>Geog</i>				
<i>Where health care intervention occurred</i>	HES CCAD Cardiac rehab GPRD HSE GHS	HES CCAD Cardiac rehab HSE GHS	HES CCAD Cardiac rehab GPRD HSE GHS	HES CCAD GPRD
<i>Residence</i>	HES CCAD GPRD HSE GHS	HES CCAD HSE GHS	HES CCAD GPRD HSE GHS	Death registration HES CCAD GPRD
<i>Travel time (as a derived variable)</i>	HES CCAD GPRD HSE GHS	HES CCAD HSE GHS	HES CCAD GPRD HSE GHS	HES CCAD GPRD

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Indicators of Access	Place on Access Continuum			
	Need	Opportunity	Utilisation	Outcome
Characteristics of the Population				
<i>Morbidity</i>	Death registration HES CCAD Cardiac rehab GPRD HSE GHS		HES CCAD Cardiac rehab HSE GHS	Death registration HES CCAD Cardiac rehab
<i>Mortality</i>	Death registration HES CCAD GPRD			Death registration HES CCAD GPRD
Characteristics of the Health Care System				
<i>Workforce</i>		HCHS workforce censuses GMS Database		
<i>Organisational</i>		Hospital activity statistics	Hospital activity statistics	
<i>Financial</i>		HCHS expenditure		

6.5 Charging for NHS services

6.5.1 Introduction

This case study considers how charging for NHS services impacts on access to health care. It identifies the routine data sources which are relevant to charging and can be used to measure and monitor access to health care.

Providing access to services on the basis of need, rather than ability to pay is a founding principle of the NHS. Despite the re-iteration of this principle in *The NHS Plan*, charges apply to a range of essential NHS goods and services so they are therefore not free at the point of delivery. Charging patients to access NHS care will inevitably deter some individuals in need of services, such as those on low incomes, from seeking treatment. This means that, in contravention of the founding principle, inability to pay may prevent access to health care by people in need. This section describes the charges and the stated rationale behind, as well as the data available about the charges.

A study of equity in the NHS, cited patient charges as one of a range of factors that might present barriers to access, and considered how the impact of user charges varied by socio-economic group.(74) For example, it was estimated by Citizens' Advice, formerly the National Association of Citizens Advice Bureaux, that each year around 750 000 people in England and Wales fail to get their prescription dispensed because of the cost.(79;196)

In 2002, the report of the enquiry by Derek Wanless into the long-term resource requirements for the NHS concluded that it would be inappropriate to extend charges to clinical services, but raised the possibility of extending such charges for non-clinical services.(197) The report recognised that charges were already in place for a limited number of services. It found the present structure of exemptions for prescription charges illogical and at odds with the principles of the NHS and recommended that the exemption policy should be re-examined.

'A Fairer Prescription for NHS Charges', a report by the Social Market Foundation published in 2003, argued for a radical overhaul of NHS charges arguing that the current system is illogical.(198)

The National Consumer Council (NCC) examined the impact of prescription, dental and optical charges on people who are disadvantaged or on low-incomes.(79) These groups include older people, people living in deprived areas, and people with long-term medical conditions, learning or physical disabilities and mental health problems. Its report, also published in 2003, expressed concern that the absence of a rational, transparent and coherent framework provided scope for 'creeping' charges for a limited range of clinical services.

In reality, NHS care was not completely free for long. The NHS had expenditure problems almost from the moment it was established in 1948 and the Minister of Health at the time, Aneurin Bevan, was constantly under pressure to make

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compromises. Despite being strongly opposed to charges, which he saw as 'drastic modifications of the basic principles of the NHS', he conceded to legislation to allow charges to be made for prescriptions, although he hoped to avoid ever having to levy them. In 1950, legislation was introduced to enable charges to be made for drugs, spectacles and dentures but the Labour government did not put these into effect. Bevan resigned in 1951 partly because of his opposition to the charging policy and also because he felt that the government had failed to distribute the tax burden fairly between social classes.(25) In May 1951, charges were introduced for dentures and spectacles. Later that year Labour lost the general election and the following year the Conservative government introduced a prescription charge of one shilling. Labour remained essentially opposed to the policy and in 1965 after returning to power, abolished the prescription charge which was by then two shillings. It re-introduced the charge in 1968 however, justifying it as necessary to continue with the hospital building programme. Much later, the Conservative government added charges for sight tests and dental check-ups.

The rationale behind charging is concerned with cost containment and the discouragement of inappropriate or unnecessary treatment. In practice, the reasons given for charging have been inconsistent, and have changed over time, reflecting the priorities of the day. In 1950, Prime Minister Clement Atlee justified the first initiative to introduce charges on the grounds that charges were 'a deterrence against extravagance, rather than as an economy'.(199) Other grounds for charging have included the need for funds to pay respectively for the housing building programme and for hospital development. The Audit Commission has commented that charging levels have more to do with history than with policy.(200)

There are similar inconsistencies in arrangements for exemptions for charging. For example people with transplants, Parkinson's disease, multiple sclerosis and asthma all have to pay for their prescriptions. The arrangements by which people are entitled to exemption or reduced charges are complex, with the onus on patients to find out about their entitlement. For example a survey by Citizens Advice found pre-payment certificates available for prescription costs were not routinely used. As well as not being affordable for some patients there was little awareness about their existence.(196)

Direct charges are currently made for the following:

- prescriptions
- dental treatment
- sight tests and vouchers for spectacles and contact lenses
- wigs and fabric support
- hospital travel costs.

Details can be found on the Department of Health web site. As well as direct charges for essential health services, there is an ever increasing range of indirect charges for 'non essential' services.

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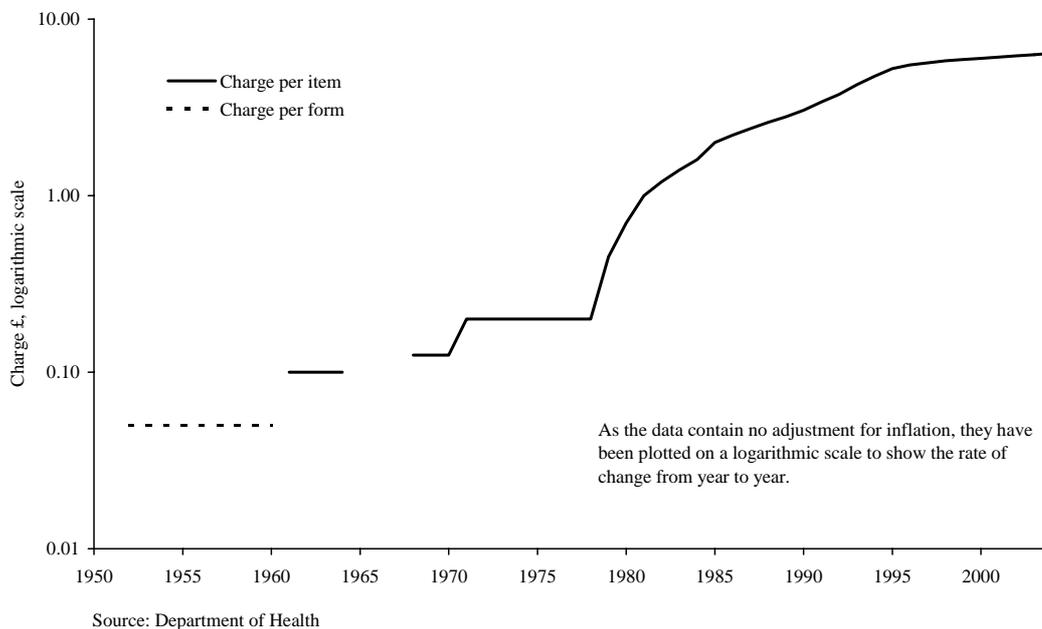
This section is concerned mainly with NHS charges but charges for home care services delivered by local authorities are also briefly described. These services are often incurred by specific groups in the population such as older people, whose needs are defined as social rather than health-related.

6.5.2 The impact of NHS prescription charges on access to treatment

In England, approximately half of the population is exempt from prescription charges, including young, older, and unemployed people and those on low incomes. In the year 2000, 85 per cent of prescription items were dispensed without charge by community pharmacists and appliance contractors. Among people aged 18-59 years, 80 per cent have to pay prescription charges and pharmacists often report seeing people who have difficulties in being able to afford to pay for their prescriptions. (79)

The price of a single prescription rises annually on the 1 April and was set at £6.40 per item in April 2004. The following graph shows how the charge has increased since its introduction in 1952. (201) As the data are not adjusted for inflation, they have been plotted on a logarithmic scale to show rates of change, which have varied as governments changed.

Figure 2 Trends in prescription charges, 1952 - 2004



A single prescription can be for anything between a week's and three month's supply of a single item. Where a prescription is for more than one item then each item still costs the full amount. Prepayment certificates to cover all prescription charges can be purchased to run for four months or a year.

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In England in 2002-03 prescription charges were expected to raise £434 million for the NHS. This represents a fraction of the total bill of over £5.5 billion for primary care prescribing in the same year. Despite that, 80 per cent of people of working age have to pay. There are likely to be particular difficulties for those whose incomes are just above exemption levels. Such charges could be regarded as a form of indirect taxation falling on a minority of only a fifth of health service users.(202)

6.5.3 Information sources on prescribing charges to monitor and measure access to health care

Prescription Analysis Cost Table (PACT) data are described in detail with other primary care data in Section 4.3 of this report. PACT data provide information about general practice prescribing in England, including all items dispensed by community pharmacists, appliance contractors and dispensing doctors as well as prescriptions submitted by doctors for items they administer themselves. Data are submitted to the Prescription Prescribing Authority, whose functions are to be taken over by the NHS Business Authority. These include providing comparative information on both prescription items and costs. The Authority administers the NHS Low Income Scheme. Information on the number of claims is collected, and whether they are for full or partial help. This is derived from the HC2 certificate for people entitled to full exemption and the HC3 certificate for people entitled to reduced charges. The statistical bulletin, 'Prescriptions Dispensed in the Community in England', available from the Department of Health web site includes summary data based on a five per cent sample of all prescriptions submitted to the Authority by community pharmacists and appliance contractors. These include annual trend data by category of exemption and data about the NHS Low Income Scheme. Dispensing doctors' and personal administration prescriptions are excluded.

An increasing proportion of cheaper medicines are being prescribed privately, particularly those which cost less than the prescription charge. In addition, with deregulation some items have been reclassified and no longer require a prescription. These items are therefore no longer recorded in PACT data, reducing their potential for monitoring access to treatment. The Framework for Access is applied to PACT data in Appendix C, Table 67.

6.5.4 The impact of charging for dental services on access to treatment

Access to dental care differs from most other types of essential health care because it is subject to charging. This has been reported as a barrier to seeking care.(200) Despite the fact that overall dental health in England and Wales has improved dramatically in the last 50 years, there is evidence to suggest that inequalities are widening with levels of disease remaining high in deprived communities.(203)

Most NHS dental care is delivered within the General Dental Services (GDS) system by dentists contracted with Primary Care Trusts (PCTs). Direct charges for

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dental care were first introduced in 1951 but NHS General Dental Services care is free for children under 18 and some adults, including pregnant women and people on income support.

It is reported that a quarter of the population have no choice but to pay the whole cost of private treatment because they are unable to access an NHS dentist. According to a survey by *Which* magazine, private sector charges can be two and a half to three times higher than equivalent NHS charges and as much as six times higher in some places. (204) A pledge was made by the Prime Minister that by October 2001 anyone would be able to find an NHS dentist by calling NHS Direct. There is some debate as to whether this refers only to urgent care or whether it includes registration for continuing care, however.

Following the implementation of a contract with dentists in 1990, many reduced the NHS component of their service and increased their private practice. The decline of NHS dentistry is largely attributed to the remuneration system which has changed little since the inception of the NHS. Payment under the GDS Scheme works on a piecework basis. The Audit Commission reported that under the scheme dentists find difficulty completing the amount of work required to pay for premises and staff costs, referred to as 'a treadmill'. (200) Perverse incentives inherent in the piecework system could be to undertake unnecessary treatment or to reduce quality in order to complete the level of activity. The Audit Commission recommended replacing the current system with one emphasising prevention and treatment, based on cost effective evidence and meeting health needs. This is being addressed through negotiations for a new contract, which are currently under way.

The Audit Commission reported that compared with more affluent areas, fewer people in deprived areas are registered with NHS dentists and that their dental health tends to be worse. (200) Three quarters of adults have to pay the full cost of NHS treatment which is 80 per cent of the total cost of a course of treatment up to a maximum of £378, (203) a sum far higher than for any other NHS charge. There are other concerns about the lack of information and a lack of clarity about charges. This includes knowing whether treatment is provided under the NHS or privately, its necessity and what is being charged for. For example, dentists are not required to display a list of either NHS or private prices. It is reported that some dentists charge a refundable deposit for a private consultation to decide whether to accept a patient, thereby introducing a charge, albeit refundable, for access to NHS services.

In addition to issues around charging, there are many other concerns about access to dental treatment. For example, there is no planning of how dentists are distributed geographically around the country. Percentage increases in the amount of private practice have risen unevenly, with wide geographical variations, with a 50 per cent increase in the south of England, compared to 15 per cent in the UK as a whole. This makes NHS dentists hard to find and access difficult for people exempt from charges, and private dentists are expensive for people on low incomes. In addition NHS registration lasts for only 15 months, so a patient who does not attend within this time is likely to be de-registered even though periods of two to three years are cited as a reasonable time to leave

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between check-ups. The numbers of people registered declined after the registration period was reduced from 24 to 15 months.(203)

In 2002 the Department set out proposals for 'a new NHS dental service for England' in its report, 'NHS Dentistry: options for change'.(205) One recommendation was to further investigate changing the patient charging system. The report recognised that 'concerns about charges centre on charging structures and lack of transparency', but went on to note that 'any change to the existing system is challenging in that there is currently a direct legislative link between remuneration and charges'. The report considered options for separating the direct link between treatment and charging, such as introducing a system of regular payments and simplifying the present system so that charges fall into a range of bands according to the complexity of treatment. The report reached no firm conclusion. Instead, it proposed that further work was need in the light of piloting of new approaches to payment, but emphasised that unlike the present system, there should be should a focus on *prevention* of disease rather than treatment.

Proposals for improving access to dental care, including an injection of funding, expansion of undergraduate training, a new dental contract and schemes to encourage ex-dentists to return to practice were announced by the Department of Health in *NHS dentistry: delivering change*, published in July 2004.(203) It also published a consultation document inviting comments on proposals for changes in professional regulation.(206)

6.5.5 Information sources on dental service charges to monitor and measure access to health care

Very few routine data are available about dental services. There is no basic information on costs, opening hours, waiting times, or quality and availability of services. There are also few data on the use of emergency dental services.(20)

Although not specifically concerned with charges, a range of statistics is available from the GDS section of the Dental Practice Board, shortly to become part of the NHS Business Services Authority. These can currently be found on the 'latest data' section of the Board's web site. Data are available for England and Wales and down to the levels of postal areas, NHS regions, strategic health authorities and primary care trusts. Prior to September 2002 these were published in a number of printed publications, which are now archived on the web site.(207)

Statistics are provided on registration, gross fees, treatment, dentists and orthodontics. With relevance to charging these include:

- Treatment statistics:
 - proportion of claims where patients are exempt or remitted of dental charges
 - treatment type and patient exemption status
 - proportion of claims costing £200 or more
 - item of service claims and treatment type.

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- Gross fees:
 - item of service fees for patients aged 18 and over
 - treatment fees for patients aged under 18
 - total gross fees
 - average treatment fees per item of service claim
 - components of gross fees
 - number of item of service claims.

Although GDS statistics do not directly provide data about those who are not on the list of an NHS dentist, it is possible to monitor the percentage of the population registered with an NHS dentist as registration data includes:

- the number of registered patients aged 18 and over
- the number of registered patients aged under 18
- the percentage of the population aged 18 years and over who are registered with a dentist (GDS)
- the percentage of the population aged under 18 years who are registered with a dentist (GDS).

There is however overall little information by which to monitor access for those not registered with a GDS dentist.

The only detailed data source of information about the capacity of private facilities for UK dental care is the publication produced by Laing and Buisson. Only headline figures from this are available on Laing and Buisson's web site and the volume itself is expensive (£420), as its function is 'market intelligence'.(208)

The press release accompanying this publication stated:

A new survey by health and care analysts Laing & Buisson has found that 51% of UK dentists' income is now generated from treating private patients. More than a quarter of UK dental patients now pay privately for their care, including a growing number of patients enrolled in private dental benefit plans. Because private prices have grown at a faster rate than NHS prices (private fees are now approaching double the fees dentists receive from the NHS), and treatment options available to private patients continue to increase, particularly cosmetic and specialist dental treatment, half of dentists' income comes from private patients.(209)

Two ten-yearly surveys are undertaken in order to collect data about the dental health of the population, one on adults and one on children. The Adult Dental Health Survey began in 1968. The latest 1998 survey entitled 'Oral Health in the United Kingdom 1998' was based on 6204 interviews and 3817 home dental examinations of people in private households in the United Kingdom. The survey's purpose is to provide information on the condition of adults' teeth and oral health in the UK, as well as to measure changes since the previous survey. Topics include the condition of teeth, dental experiences, attitudes and knowledge, dental care and oral hygiene, the use of dentures, and progress towards government oral health targets.(210) Although it does not report specifically on

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charges, it provides useful information about the population's dental health and changes over time.

The Dental Health Survey of Children and Young People undertaken in 2003 was the fourth since 1973. Like the survey of adults, it is based on questionnaires and dental examinations to provide information on the dental health of children, their experiences of treatment, oral hygiene and changes over time.

6.5.6 The impact of charging for ophthalmic services on access to treatment

Direct charges are made for access to NHS ophthalmic services, both for sight tests and for dispensing spectacles and contact lenses. Many people purchase such items privately. Under the General Ophthalmic Services (GOS) scheme some groups of people are eligible for NHS vouchers and free sight tests, including people over 60, children, glaucoma patients, people registered blind and young people in full-time education. Vouchers may only partly meet the cost of glasses. The Department of Health reimburses optometrists for only 90 per cent of the costs of the service so the rest is subsidised by dispensing which tends to increase the price of glasses and lenses. As with prescription charges, people eligible under the NHS Low Income Scheme can be issued with HC2 or HC3 certificates.

The main policy changes in the General Ophthalmic Services over the past 15 years are as follows:

- restriction of NHS sight tests to certain eligible sectors of the population from 1989 onwards
- legislation permitting the sale of ready-made reading glasses by unregistered suppliers from April 1989 onwards
- extension of eligibility for NHS sight tests to people aged 60 or over from 1999.

6.5.7 Information sources on ophthalmic services charges to monitor and measure access to health care

The Department of Health's annual statistical bulletin 'Ophthalmic Statistics for England' presents summary information about general ophthalmic services in England.(211) The sources of the information are data provided by primary care trusts and prior to 2002 by health authorities, which contract with ophthalmic practitioners to provide NHS sight tests and optical vouchers, and from practitioners themselves. Prior to April 1996, Family Health Service Authorities were responsible for general ophthalmic services. Statistics include the number of sight tests and vouchers paid for by PCTs, by eligible group, rates of sight tests and vouchers reimbursed at the level of the Strategic Health Authority, type of glasses for which the voucher was provided such as single vision, bifocals or complex, cash expenditure, numbers of optometrists with NHS contracts and rates of practitioners by health authority. A special analysis of sight test data for 1997-98 by age-band and whether tests were provided by the NHS or privately

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was published by National Statistics in Social trends 30, dataset name ST30809.(212)

As with the deregulation of some prescription items, the legislation permitting the sale of ready made glasses means that there are no dispensing data available on such sales. As a result, there is a gap in information about the population's access to treatment.

6.5.8 The impact of charging for non clinical services on access to treatment

As mentioned earlier, the Wanless report raised the possibility of extending charging for non-clinical services. An increasing range of such charges is already made, including charges for single rooms in maternity units, televisions, telephones, computer access and car parking. Although deemed as non-essential, and thus more easily justified and sitting less uncomfortably with NHS founding principles, the introduction of car park charges at most hospitals directly impinges on access to health services.

6.5.9 Information sources on non clinical service charges to monitor and measure access to health care

No data are collected centrally about non-clinical services.

A question was raised in the House of Commons in 2002 about the amount of money received by trusts from car parking charges and whether such funds were taken into account in the allocation of funds. The reply stated that amounts collected from individual income generation schemes are not reported separately in trusts' accounts and that income raised is not taken into account in allocating funds. In January 1996 the Department of Health issued guidance to trusts in the booklet *NHS income, generation, car parking charges, a guide to implementation*, available in its library. Hospitals can decide whether or not to charge and those patients eligible under the hospital travel costs scheme may have charges reimbursed.(213)

6.5.10 The impact of charging on access to social care

Although this project focuses on health care provided by the NHS, it is recognised that many services for some groups such as older people are designated as social care as opposed to health care and are provided by local authority social services.

Charges apply only to social care as opposed to health care, according to the founding NHS principle cited at the beginning of this section. Despite this, there is sometimes little difference between users of either social or health care in their needs or dependency. This leads to questions about equity of access, with some people paying for care that is free elsewhere. This can result from varying charges applied by different social services departments, or where a facility, such as day care, is used by a mix of people funded by either health or social services.

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Such services include:

- district nursing
- nursing care
- meals on wheels
- day care
- residential respite care
- residential care.

These services usually require a financial contribution from the user or carer.

The report of the Royal Commission identified wide variations between local authorities in home care charging policies.(158) Councils have been empowered to charge for social services since the 1948 National Assistance Act which recognised the principle that, while health services should be delivered free, charges for social services were acceptable. However, Section 17 of the 1983 Health and Social Services and Social Security Adjudications Act gave wide discretion over how they set charges (214). Councils came under increasing pressure to increase charging as successive governments expected them to use these discretionary powers, with a funding formula based on the assumption that a proportion of costs was recovered. Community care policies aimed at keeping people out of care homes further increased pressure on councils for home care services.

Since 1993, the proportion of total spending on personal social services recouped in fees and charges has increased. For example 10.2 per cent of total spending on Local Authority Personal Social Services was met from charges and receipts in 1992-93(215) compared with 16.5 per cent in 1999-2000.(216) Since 1990, government policy has actively encouraged charging whenever possible. In 2000, the Audit Commission report 'Charging with Care'(214) found that councils increasingly rely on charges to fund services. Guidance issued in 2003 in 'Fairer charging policies for home care and other non-residential social services'(217) aims to encourage authorities to achieve more consistent policies. Charging continues to remain locally determined, which means that users in similar circumstances will still face different charges for the same care package depending where they live. In addition as there is no requirement to charge, more affluent authorities may be better placed to waive such charges than more poorly funded authorities.

6.5.11 Information sources on local authority charges to monitor and measure access to health care

The Audit Commission carried out their own survey of home care charging policy and practice across 140 councils in England and Wales.

The annual statistical bulletin 'Personal Social Services current expenditure in England' derives data from return (RO3) which is made annually to the Department of Environment, Transport and the Regions (DETR) by Local

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Authority Treasurers departments in England. This includes summary data on sales, fees and charges by client group category.

6.5.12 Summary

User charges, or co-payments as they are known in North America, are the everyday experience of old and frail, chronically sick and disabled people and most people in need of dental or optical care. (218) Charging for essential NHS services will inevitably have a direct effect on access to NHS treatment by some groups of people, particularly those on low incomes. Even for people who are exempt, access will still be difficult in areas where services are no longer generally offered by the NHS. The rationale and justification for the particular treatments and items charged for is inconsistent and has been criticised for being illogical, unfair and outdated.

There is little routine information which can be used to directly monitor and measure the impact of charging on access to services. A major obstacle is the lack of routine data about services provided by the private sector data. This gap is particularly important in the fields of dentistry and ophthalmology, where many people use services that are completely private rather than chargeable NHS services. This also applies to those who pay for private prescriptions or who purchase over the counter treatments rather than visiting a general practitioner for a prescription. Except where special studies have been undertaken, little is known about people's access to care, their characteristics and needs or their utilisation of services for which charges are made.

A key question raised by this case study is whether, given the objectives of the NHS, appropriate data exist to enable the evaluation and monitoring of whether or not people are being deterred from accessing health services by user charges.

There are few available data which can be used to assess this question. There has in the past been useful related information provided by the General Household Survey (GHS), although no direct questions were asked about charges for health care and their impact on households.

The GHS includes sections on sight and hearing, and dental health. Despite that there are no questions specifically about charging, there are other questions that are relevant, although sometimes these have not been asked recently, such as 'whether had a sight test in the last 12 months' asked from 1990 until 1994. Also asked in the same years was 'whether sight test was paid for by informant or employer, provided free by optician, or covered by insurance.'

A question on 'whether goes to the dentist for check-ups, or only when having trouble with teeth' was asked recently in 2003, as well as 'how long since last visit to the dentist?'

A survey such as the GHS would potentially be a useful data source to assess the impact of charging on access if core questions on this subject were introduced and included regularly.

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This case study indicates that there is likely to become a point at which some charges could become a deterrent and hindrance to accessing health services. An obvious example is hospital car parking charges. The impact of charges will depend on the frequency, length and purpose of visits. As described above in charges for non-clinical services, a reply to a question raised on the topic in the House of Commons in 2002 was that income raised through fees collected from individual income generation schemes are not reported separately in trusts' accounts and not taken into account in allocating funds. Therefore there seems to be no cap placed on such charging schemes, which are not monitored and for which no plans exist to do so.

Crucially the impact of charges depends on income. There is a need for data on the extent to which those not eligible for free or subsidised services are deterred by charging. This is necessary in order to address the key question concerned with the extent to which charges deter those with a relatively low income, and whether data are available to enable the subsequent impact on access to health services can be measured and monitored.

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Table 24 Case study - data sources relating to health service charges

Dimensions of access Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to NHS charges as opposed to all those in the data source	Location in report
<i>Financial</i>	Primary care data Prescribing data Statistical bulletin 'Prescriptions Dispensed in the Community in England'	England	Number of claims collected, category of exemption and NHS Low Income Scheme	Section 3
<i>Characteristics of the health care system</i> <i>Financial</i>	Dental Practice Board GDS quarterly statistics	England and Wales, smallest available level is the PCT	Item of service claims by cost bands. Proportion incurring a charge or exempt	This case study
<i>Financial</i>	Ophthalmic services Statistical bulletin Ophthalmic Statistics for England	England, smallest level PCT	Sight tests and vouchers paid for, vouchers reimbursed and voucher type	This case study
<i>Financial</i>	Personal services (local authorities) Statistical bulletin 'Personal social services current expenditure in England'	England	Sales, fees and charges by client group category	This case study

6.6 Transport and access to health care

6.6.1 Introduction

This case study explores the extent to which routine data sources relating to transport and access to health care in England can be used to assess the level of access to health care within the population and how this varies between groups within the population. The case study will describe the shortfalls in routine data sources that hinder the measurement and monitoring of access to health care both for the population and for groups within the population and make recommendations for data linkages and changes to datasets in order to facilitate an improved monitoring and measurement of access to health care. In doing so, the case study makes use of the framework for access developed in Section 2.

Transport and access to health care was one of six topics selected for case study for a number of reasons. Firstly many people understand accessibility as *the* determinant of access to health care. Secondly, the health impact of transport goes beyond the obvious concerns of accidents, environmental damage and pollution. Thirdly, transport policy, as well as patterns of transportation, have changed rapidly in the UK over the last decade or so and the statistics required to serve these new transport policies and understand the new patterns of peoples transportation have been found to be inadequate(219) let alone the need for good statistics on transport and access to health care. Transport rather than geography was chosen as it's theme because the major issue with regard to access to health care has more to do with transport links: their availability, suitability, convenience and cost rather than geographical barriers per se.

This case study does not examine the direct health impacts of transport such as accidents, environmental damage and pollution or the social and general well being benefits of travel; which while very important factors associated with health, they are not directly concerned with access to health care. There has been a considerable amount of research on transport and access to health care. This case study cannot cover it all in detail, so the focus is specifically on routine data sources that relate to access to health care. A broader and more thorough review of the issues of transport, geography and access to health care is available elsewhere(220) as is a descriptive critique of the official statistics relating to transport and all aspects of health(219).

6.6.2 Issues relating to transport and access health care

Given that it is not possible to provide equal access to health care for everyone, regardless of where they live in relation to the distribution of hospital services(220), then it is not surprising that distance and availability of transport have been shown to be important barriers to access primary and secondary cares services(74). There is a particular tension with regard to the accessibility of services with two principle factors at play: first the distribution of the provision of

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services to the population and secondly the personal mobility of the population(220). The accessibility of health care services is key to meeting people's health care needs as it influences the choice of services are used but also the costs to the individual of using the services, such as direct travel costs and time. Indeed the issue of choice has the potential to increase health inequalities as groups who are disadvantaged with regard to transport may be less able to exercise choice in the new NHS and as a result receive delayed and poorer quality health care than they might otherwise have done if transport to health care had not been a problem for them. This would be compounded by the fact that such socially excluded groups are known to have a higher need for health care in the first place.

Historically the distribution of health services in England is not equitable and still partly reflects the pre-NHS days when services were located in areas that could afford to pay for them. There is still an inequitable distribution in the number of GPs between poorer areas in the north and more affluent areas in the south(20). This inequitable distribution relates to the quality of services as well as the quantity with single handed GPs being concentrated in deprived inner city areas(220). This is particularly crucial given the gate keeping function that GPs have in respect of secondary care services and the suggestion that poorer access to health services leads to worse health outcomes(74). Government initiatives have sought to address these inequities with hospital building plans since the 60s and changes to resource allocation formulas(221;222)and special payments to GPs in deprived areas as well as the formation of initiatives such as Health Action Zones and Sure Start.

The desire to distribute health care facilities more equitably to enable fairer access is counter balanced by the need to improve on effectiveness and efficiency which favours the creation of larger centralised specialist services, with higher through-puts, which can offer the most up-to-date treatments and have lower complication rates(20).

The fact that there are these limitations of effectiveness and efficiency imposed upon the distribution of health care services, as well as historical inequities in the distribution and quality of health care services; means that personal mobility is key to health care accessibility.

Access to transport is important in limiting the access to health care of socially disadvantaged groups such as older people, poor and those with young children. The non-ownership or lack of access to a car may affect access to health care services and lead to poorer health outcomes(74;220). A recent report(223) noted that there was a clear connection between transport and social exclusion which was particularly marked among the unemployed, families with young children, young people, older people and people on low incomes. This was as true of urban areas as of rural areas. Although socially excluded people were not found in the same densities in rural areas as in the inner city, their travel problems were often exacerbated. The particular problems, related to access to health care, were lack of bus links to the local hospital, problems getting to a lack of GPs within reach, and unavailability of home visits. Elsewhere patients have reported delays in reporting symptoms of angina due to poor transport(224) and up to 20 per cent

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of antenatal appointments in east London were missed due to transport problems(225).

An analysis by the Office for National Statistics showed that households without a car are almost twice as likely as others to face difficulties in accessing local services. Thirty-eight per cent of people without access to a car had difficulty in visiting their local chemist, GP or hospital compared to 21 per cent of those with car. Overall 20 per cent of adults said that they had problems getting to their local hospital. Women also had more difficulties than men, experiencing longer journey times and having lower car use. Younger people (16-24) and older people (aged 75 and over) also had more difficulty accessing local services than the general population. These differences persisted even after controlling for car availability(226).

Transportation preferences are known to vary by age, sex and ethnicity(227) and it is important to be aware of the way that problems with transport and access to health care may differentially affect groups within the population, especially some which have been identified as vulnerable. For instance, both older people, and those from ethnic minority groups have a higher car dependence than the population at large(228), these groups may find it particularly difficult to use public transport because of mobility and linguistic barriers.

There have been efforts to draw together transport and access to health care but these have relied upon data collected locally specifically for the study in question. A study in Southport, Merseyside found that access to health care in terms of transport and geography was variable for groups within the population but it relied heavily on specially collected data.(229)

While there are many government mandated targets related to transport there are none related to transport and access to health care. Others have also found an absence of routine data to answer questions about access to health care and transport.(230) In fact the problem with routine transport data is that it falls within different spheres of interest with respect to the collection analysis and publication of data. Transport statistics falling under the aegis of the Department of Transport only address access to health care incidentally, although there is an increasing awareness in the public arena of the importance of access to health care in terms of limiting the harm of social exclusion(223). On the other hand health statistics have rarely collected anything about transport, as it has not been traditionally seen as having anything to do with health care provision. There are currently no government performance indicators reflecting the role of transport and access to health care.

6.6.3 Routine datasets relating to transport and access to health care

Unlike the other case studies the principal datasets relating to transport and access to health care are not generally discussed in detail elsewhere in the report. This is primarily because there are not good population-based transport data that relate to access to health care, especially for groups within the population. Rather there is important background information on the central role that transport plays

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in access to health care and why it is important that transport issues are considered fully in relation to access to health care. These data also provide some glimpses into specific transport and access related factors that may point the way to changes and improvements in the way such data might be collected in order to take better account of the issue.

Transport statistics is the core dataset as far as transport relates to health(219). Data are gathered together from a range of administrative and survey sources. However, from an access to health care point of view there is not a great deal. Most of the very detailed information relates to issues around travel demand.

Appendix B briefly describes the routine datasets that fall within the scope of this case study and other data sources mentioned elsewhere in the report.

The principal datasets that characterise the population in terms of its access to health care include:

- Census 2001
- The National Travel Survey
- Hospital Episodes Statistics (HES)

The census and HES have been discussed elsewhere in this report. Hospital Episode Statistics is included as an example of a health dataset which records information on the residence of a patient and the location at which they received their health care. As such it would be possible to model the distance and or time to travel. This analysis is possible from many health datasets. HES will be briefly discussed here as a typical example.

The National Travel Survey (NTS)(226) has been a source of information on personal travel since the mid 1960s, monitoring changes in travel behaviour over time. It provides a range of detailed information on different types of travel including where people travel from and to, distance, time, purpose, by whom and how often. In addition this is the only source of national information on cycling and walking. One of the stated uses of the survey is to examine travel by particular population groups such as children, older people or the disabled.

The NTS is based on a random sample of private households. The 2001 sample size was 5796 addresses drawn from the Postcode Address File designed to be nationally representative. Two methods were used to collect data: face-to-face interviews and seven-day travel diaries. This continuous dataset is usually analysed in three-year periods.

The 2001 questionnaire introduced a question on ethnicity. Harmonised questions were introduced to facilitate comparison with other government social surveys. The National Statistics Socio-economic Classification is now used for all official surveys, replacing Social Class based on occupation.

The detailed list of household variables collected in the survey includes 'H28/29 Walk/bus distance to nearest General Hospital'.

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The comprehensive range of items collected includes data on purpose of trip, mode of travel, travel time, mode of transport, where car parked and cost, time and day of week.

6.6.4 Adequacy of existing data sources for measuring and monitoring transport and access to health care?

This case study will consider the routine datasets relating to transport and access to health care under the framework for access developed earlier in this report. Access to health care has been defined in the terms of the broad dimensions of need, opportunity, utilisation and outcome. These dimensions can be given flesh by the use of detailed and specific indicators of access, such as age and socio-economic status, found in the routine data sources.

Two tables, compiled for this case study, summarise the relationship of the routine data to the dimensions and indicators of access in terms of the characteristics of the population:

- **Table 25 Routine transport & access to health care data sources concerning the characteristics of the population** lists the sources of routine data identified and briefly describes each dataset in terms of the principal indicators of access together with details of publication and aggregation and a reference to the Section in the main report where the particular dataset is described and discussed in detail.
- **Table 26 Summary of transport & access to health care data sources and the Access Continuum** pulls together all the routine data sources for transport and access to health care in terms of the broad dimensions of access and the individual indicators of access.

Dimensions of Access

Need for health care per se cannot be determined from the few routine datasets that have been reviewed in this case study. They simply do not tell us anything about people's health needs. However, what they can tell us is who has an unmet need for access to health care or to put it another way, they tell us about people's opportunity to use health in terms of some of the barriers, relating to transportation, that impede appropriate utilisation of services.

It is possible to make determinations of need from all sorts of freely available population-based data, indeed this has been the basis for resource allocation formulas used in the NHS. Given a particular level of need in the population it is possible to say, generally, who has need of better access to health in terms of their transportation availability and the location and structure of health care services that they need to use. It is not possible to say anything from the routine data about how this may function in a particular locality but broader conclusions with respect to sex, ethnicity, socio-economic status, life cycle and disability can be drawn. Patterns of impaired access to health care in terms of accessibility can be measured and monitored nationally for these groups within the population.

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The routine datasets that cover transport and access to health do not, as would be expected, cover the actual utilisation of health nor the outcome, as we have seen from the discussion above, the data that are available relate primarily to the opportunity to use health care services.

It is important that not only the range of the routine data on transport and access to health care is explored but also that some determination be made of the availability of the 'quality' of the particular indicators of access, such as age, sex and socio-economic status for example.

Indicators of access

Basic demographic indicators of access, such as age and sex are available in the three routine datasets examined in this case study.

Socio-economic data are more problematic both in terms of their availability and in terms of their definition and a more detailed discussion of socio-economic status is included in the Maternity case study). The census uses its own classifications of socio-economic status, which are thorough and widely used by other researchers and organisations. The National Travel Survey also uses the Census definitions. Indeed it would be possible to look at wider measures of socio-economic status from these two datasets as data are available on housing for example as well as employment. HES data has no socio-economic data and the National Travel Survey uses.

Ethnicity data are also problematic. First, by their absence from the NTS and secondly, by their poor completeness in HES data. Census data again has its own widely used categories of self reported ethnic group.

Geographical data is good for both the place of residence and where the health care took place in these three datasets.

There are no links between these datasets and other routine data, which might enable more sophisticated analyses of transport and access to health care.

There are no census analyses of estimated travel time to hospital or GP services. As the census does not collect data on the location of health services, although it does have invaluable socio-demographic and socio-economic data. Their census derived analyses of travel to work show what might be possible. They show that men are more mobile than women in terms of car access and that women take more bus journeys to work(231).

While the National Travel Survey does collect data on travel on foot and by bus (walking/bus distance) to a doctor, nearest chemist and nearest general hospital this data are not published in detail and have no break down by age, sex or social class. There is also an important assumption made here that the nearest GP, chemist or hospital is actually the one that a person *needs* access to. As the NTS is a sample survey it is difficult to extrapolate the findings to specific localities, rather it paints a general national picture, highlighting important issues but not in sufficient detail for local policy action.

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Way forward

More sophisticated use of data and linkage to other datasets would make better use of such data as is already collected so that supplementing one dataset with another would ensure that we can always look at factors such as socio-economic status and ethnicity for example.

Census data, particularly with respect to car ownership at the level of enumeration districts, has been successfully used in conjunction with HES data, vital statistics and data on the supply of health services to develop models of consultation rates from GPs and the use of NHS inpatient facilities(224; 232; 233), though these studies relied on ad hoc survey data as well as routine datasets. In Wales new resource allocation formulas have been looked at which have used census data and other data on the location of hospitals and GPs to determine the numbers of people living more than 15 minutes travel from a GP and 30 minutes travel from a hospital(234).

Research using a deprivation index partly derived from census data and including a 'geographical access to services' element has shown that poor access to services in urban areas is correlated with morbidity but that 'access to services' is insufficiently specified for the purposes of health research(235).

Routinely available data, again supplemented with survey data, have been used to look at the role that new information technology might have in improving transport and access to health care(236) and the impact on the accessibility of health due to congestion charging and the work place parking levy(228).

Unfortunately these examples show what might be possible with better routine data, but not that which is currently possible as these studies had to be supplemented with detailed surveys of individuals. The Welsh resource allocation study had to make assumptions about which services needed to be accessed or were found to be inadequate for health research in the use of a deprivation index with a 'geographical access to services' element.

Even in the absence of adequate routine data sources, it is clear that access to transport and accessibility of health care services should be a major consideration in the reconfiguration of health services. This is particularly relevant given the creation of new PFI hospitals many of which are located on the out-skirts of centres of population, in precisely those places where socially-excluded groups such as older people, young, poor, families with children and ethnic minority groups will have more difficulties in accessing services.

6.6.5 Conclusions

This case study and other research(236; 237) shows that while there may be much data, much of it routine, on the impacts that transport has on the health of people, especially accidents and air-pollution, there is little that directly addresses issues of transport and access to health care, particularly in terms of routine data sources.

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This is especially true if we expect to be able to monitor and measure transport and access to health care for particular groups within the population. Groups which we already know have problems with transport and access to health services(228).

The summary in Table 26, shows that there are insufficient data to address all the dimensions of access to health care properly, including how accessibility relates to actual utilisation rates for health services and the outcome of interventions.

At the present, vulnerable groups with low accessibility to health care are fairly invisible. These people will also have an impaired choice of health care provider as a result of their low accessibility, compounding their high level of health inequality by potential delayed access to care and access to care that may not be of the same quality as that available elsewhere. If these people's health needs are to be met, it is important that they are properly identified so that strategies to improve their accessibility can be put in place. This includes improvement to health care capacity in terms of the location and opening times of new and existing health services, the planning of public transport and transport generally.

It is unlikely that adequate routine data on accessibility to health care will be available soon. Instead, planners and service providers will have to rely on ad hoc surveys and one-off research projects. This is a pity because transport is a heavily regulated and taxed area and as such has many opportunities for high quality data collection(219).

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Table 25 Routine transport & health care data sources concerning the characteristics of the population

Characteristics of the population Indicators of access Data sources are listed according to dimensions of access.	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity & Neonatal Care as opposed to all those in the data source	Ref
Socio-economic and socio-demographic	Census	Potentially available down to census enumeration district Used widely in the form of census enumeration 'centroids' used to calculate distance and travel time to local services including primary and secondary care	Q How do you usually travel to work? Work mainly at or from home Underground, metro, light rail, tram Train Bus, minibus or coach Motor cycle, scooter or moped Driving a car or van Taxi Bicycle On foot Other Q Number of cars or vans owned or available for use by a household	Section 4

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Characteristics of the population Indicators of access Data sources are listed according to dimensions of access.	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity & Neonatal Care as opposed to all those in the data source	Ref
Demographic Socio-economic morbidity	National Travel Survey		Age Sex No ethnicity Socio-economic status Transportation use Car availability Specific questions on walking distance to nearest hospital and bus distance to nearest hospital Collects data on disabled people's difficulties in using different forms of transport	Appendix B

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Characteristics of the population Indicators of access Data sources are listed according to dimensions of access.	Data source	Coverage and smallest level of aggregation	Content The variables listed are those relevant to Maternity & Neonatal Care as opposed to all those in the data source	Ref
Demography	HES hospital inpatient data from the APC CDS and HES	Published annually down to Strategic Health Authority and hospital level	Age Sex Ethnicity (poorly recorded) Residence Location of health intervention NB data on residence and location of health intervention are available from 100s of different data bases, HES is shown here as an example	Section 3

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Table 26 Summary of transport data sources and the Access Continuum

Indicators of Access	Place on Access Continuum				
	Need	Opportunity	Utilisation	Outcome	
Characteristics of the Population					
<i>Age</i>	HES	Census HES National Travel Survey	Routine data sources for transport and access to health care do not address issues of actual utilisation and health outcome		
<i>Sex</i>	HES	Census HES National Travel Survey			
<i>Ethnicity</i>	HES	Census HES			
<i>Socio-economic</i>		Census National Travel Survey			HES does address these issues but is dealt with in detail elsewhere in the Section on NHS data sources
<i>Health care location</i>	HES	Census HES			
<i>Residence</i>	HES	Census HES			
<i>Travel time (as a derived variable)</i>	HES	Census HES			

Section 7 Summary, discussion and recommendations

- 7.1 *Summary of findings and issues identified in each section*
 - 7.1.1 *Hospital Episode Statistics (HES)*
 - 7.1.2 *Data from Primary Care*
 - 7.1.3 *Community data collections*
 - 7.1.4 *Staffing data collections to measure access*
 - 7.1.5 *Communicable disease data*
 - 7.1.6 *Surveys and the Census*
 - 7.1.7 *Vital statistics*
 - 7.1.8 *Consultation with data Users*
 - 7.1.9 *Case Studies*
- 7.2 *Discussion*
- 7.3 *Conclusions*
- 7.4 *Recommendations*

7.1 Summary of findings and issues identified in each Section

7.1.1 Hospital Episode Statistics (HES)

Changes in the delivery of acute hospital care

The coverage and completeness of data is being adversely affected by the changes which are being made to the pattern of delivery of acute hospital care. As policy shifts mean that increasing levels of activity take place in a range of non-NHS settings, there could be significant losses to data collection if such episodes are not captured, weakening the capacity of routine inpatient datasets as a tool for planning, epidemiological research and monitoring. Examples of such settings include the following:

- NHS funded care in independent hospitals
- NHS funded care for patients treated abroad
- elective care activity in Diagnostic & Treatment Centres (DTCs); given that these centres are being built and run by the independent sector and many do not involve formal admission
- hospital trusts that have attained foundation status given that their accountability is being switched from the Secretary of State for Health to an independent regulator
- intermediate care beds which could be NHS funded or local authority funded
- NHS funded care in nursing homes

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- 'Super' GP surgeries undertaking treatment traditionally carried out in hospital.

The survey carried out for this project identified gaps, particularly in the submission of returns from overseas. Where data will be collected, the provider will not be separately identifiable, particularly the case in DTCs. It has to be recognised that although the intention is to collect from all sectors, this might not always be possible, or that data might not be as comprehensive as elsewhere.

Other concerns relating to HES data are as follows:

- Accuracy of coding Likely to improve and change in the light of Payment by Results, although the possibility of coding 'drifting' to more expensive procedures cannot be discounted.
- Ethnicity Despite the mandatory requirement introduced in 1995/96 this field is still under-completed. No measure of socio-economic classification is included, so ethnicity cannot be set in context.
- Capacity to link data The NHS number project has mostly yet to extend to agencies beyond health, for example to local authority social services data sources, in order to analyse inputs from both health and social services.
- Activity in the independent sector. There is the important issue of how private patients are captured in HES data.
- Financial costs of accessing HES data. There is a charge for more complex analyses of HES data than are available as standard tables up to £50 per hour. Many analyses of HES previously routinely available are no longer so (e.g. acute length of stay).

Statistical analysis by commercial companies

Commercial companies may be granted access to use the data to provide services to the NHS, for benchmarking and comparative analysis. Such companies include Caspe Health care Knowledge Systems (CHKS), which is a private consultancy of NHS performance analysts undertaking hospital benchmarking and Dr Foster, which claimed to provide the 'only authoritative and independent guides to UK health services in the public and private sectors'. Its information is compiled from data provided by NHS trusts, as well as from the Department of Health.

Maternity data

There are particular concerns about the quality of maternity data that cover only 70 per cent of all births in England. Only a quarter of the two per cent of births at home are included and there are virtually no data about births in private hospitals. There are other problems with HES maternity and neonatal data. If a baby is ill and admitted to a neonatal centre this admission is not linked to the HES birth record. Ethnicity is required in HES for births but is under-reported.

7.1.2 Data from primary care

Even with the development of the electronic health record, and changes in requirements under the new GP contract, attempts to compile comprehensive person based data on health care in an aggregated and anonymised form are limited.

Despite a range of initiatives to improve data from primary care, these are primarily designed for remuneration systems for general practice and local planning use rather than facilitating national standardised data. There is very little available from current primary care data sources on the socio-demographic characteristics of those enrolled with practices.

The National Surveys of Morbidity should be continued and a successor should be developed to collect the data compiled in the series as there is currently no other source of these data about care in general practice.

7.1.3 Community data collections

Data were limited to numbers of contacts for each group, a collection has stopped without replacing it with some more up to date method of data collection. Very few data are collected about the community care activities of GPs or the nurses and other staff they employ. Private sector activity is monitored only where services are contracted to local authorities or the NHS.

Despite extensive development of a proposed community minimum dataset in the early 1990s and acknowledged weakness in this area, there remains a lack of standardised community health services data to monitor access to health care services. This affects the ability to monitor access by some of the most vulnerable people in society. The thrust of government policy is to shift acute care to alternative settings but the monitoring needed to establish whether these arrangements provide access to meet the health and social care needs of the local community can only be undertaken with data on needs, service use, and outcomes.

7.1.4 Staffing data collections to measure access

There are gaps in data required to monitor access to care from independent providers, for example the staff and qualifications of those employed in nursing and residential homes, independent hospitals treating NHS funded patients, staff of contractors providing non clinical services in trusts, and under the various new patterns of delivery, including overseas providers.

Some losses of data have occurred with respect to staff now employed by private contractors to provide services previously undertaken by NHS staff before being outsourced. Such data should be collected on all staff providing services to the NHS to the same detail as directly employed NHS staff. In evaluating access to services it is necessary to monitor the impact that changes in the delivery of care have had on levels, quality and conditions including pay, of staff.

7.1.5 Communicable disease data

Data on care for communicable diseases show limitations in terms of under reporting and completeness of data. Generally few details are collected beyond location, and basic individual characteristics such as age and sex. Even these details may not be accessible due to confidentiality arrangements. There can be significant social and ethnic inequalities for many of the serious infections. Data are limited in their capacity to monitor such characteristics, however. For example, few sources collect residential address postcode which could map to census data, instead submitting data based on the clinic for which there is no known population denominator. Some of these gaps are strongly related to patient confidentiality issues which must be addressed if the capacity of data to measure and monitor access to health care is to be improved.

7.1.6 Surveys and the Census

Census

Despite the scale of the census, increasing numbers of people are not included. They are not a random sample of the population so studies ignoring this group are likely to produce biased results. The rates of net undercount, under-coverage or non-response are higher for men in their 20s and 30s than for women of the same ages.

It is anticipated that by 2011 further changes in society and public attitudes are likely to make conventional census-taking even more difficult and arguments have been advanced for the use of a set of administrative registers to replace the census. A particular concern are the questions on health and carers and whether they will be retained in the census.

Surveys

A limitation of the main health surveys is that unless samples are very large, they cannot be used to produce statistics for small areas. Even though methods have been developed for synthetic estimates this limits their usefulness locally to health and local authorities.

Breaks in series can be problematical, as can changes in and differences between surveys in wording of similar questions, making direct comparisons difficult. It may be that some of these problems will be resolved by the move to the continuous population survey.

Response rates are decreasing in all the main continuous surveys, with declines averaging about one per cent per year since 1991. Analysis of the decline suggests that 40 per cent is due to a decline in contact rates, and the other 60 per cent is due to increases in refusals. Non-responders are not a random group and high response rates can bias results. Disproportionately missing are young men, those with lower educational qualifications, adults with no dependent children and those living in London.

7.1.7 Vital statistics

Data on ethnicity are not widely available. Socio-economic data are available from birth registration and notification, death registration and some but not all of the confidential enquiries, but the latter may not be consistent with data from birth and death registration. In relation to maternal and neonatal health there is much duplication but also many gaps in the collection of statistics in England. No single system contains reliable data about the care given to women and their babies and also links these with data about their social background.

7.1.8 Consultation with data users

Consultation took place with data users too as part of the consultation into the Health Poverty Index. Consultees were aware of the considerable amount of information in the NHS that is recorded about the resources, activities and finances of the NHS. They felt that access to health care could not be measured as a discrete entity, but was rather a multi dimensional concept best examined by an array of variables rather than being reduced to a single abstract indicator.

The data currently collected were not seen to support the assessment of access to health care by the population or groups within the population.

Consultees felt it was important that appropriate tools were either developed or agreed on for use to ensure that access was being examined from a perspective of health care need rather than based on the more easily measurable historic demand.

In order to assess access and provision of health care it was felt important to be able to combine information from various sources, such as HES with general practice derived data

7.1.9 Case studies

Older people's mental health

The case study identified many gaps in routine data sources available to monitor and measure access for older people with mental health needs:

- a lack of detailed, standardised data on NHS community health services such as community psychiatric nurses and health visitors
- a lack of data on the needs of carers of older people with mental health problems
- few data available about this group's access to primary care
- a lack of detailed data from the independent sector, particularly information on residents of nursing and residential homes
- no breakdown of numbers and grades of staff working in the care of older people, or in mental health services
- a lack of data on contractors providing NHS services, for example in hospitals and nursing homes

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- a lack of data about underlying morbidity. For example it is recognised that there is considerable under-recognition and under-treatment of depression in older people, without good data about how many older people are affected, it is difficult to evaluate access. This is because it is not known how many people's needs are not met
- A lack of data on charges for local authority services, and no detailed breakdown of expenditure on elderly people with mental illness.

Maternity

There are a large number of datasets covering maternity and neonatal health with a high level of duplication of data between them. No single system contains reliable data about the care given to women and their babies and there is no way of linking these with data about their social background for example. There is much duplication of socio-demographic indicators of access such as age and sex and geographical locations, which are useful but there is a lack of good socio-economic data. Ethnicity is poorly recorded in HES and is not recorded in birth registration. Socio-economic status is not available from HES and is not systematically recorded for the mother in birth registration data.

There is a need to ensure that standard definitions are applied to data items and that these definitions are widely recognised and adopted. The stalled maternity care data dictionary project should be given more impetus

There is a lack of routine data on midwifery services and it is not possible to identify the medical input from routine data sources as obstetrics cannot be separated from gynaecology.

Despite the apparent proliferation of performance indicators and targets in the NHS, maternity and neonatal services are not covered at present. Such targets that do exist, notably infant mortality, are no longer appropriate due to the dramatic reduction in maternal and perinatal mortality. Morbidity based indicators may be more useful but they are not easily available. Indicators such as low-birth weight are difficult to interpret because trends are heavily influenced by the rising multiple birth rate and the increasing age of mothers at childbirth.

No routine data are collected on some very important variables including mother's level of education, diet, access to health care or housing conditions.

Access to datasets is problematic. HES data are not published in detail, data from birth notification and NHS numbers for babies are not published at all and statistics on community maternity services are no longer published. Generally there are poor data linkages between the various routine datasets. Welcome initiatives such as the NHS data-spine and the electronic patient record will prove to be less valuable than they might if they fail to connect to vital registration data which would greatly increase the scope for population-based analysis of data and particularly analysis by important factors such as socio-economic class.

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Cancer

An absence of a nationally agreed mechanism for monitoring implementation of the Calman-Hine recommendations has led to regional and local variation. The registration of cancer is not statutory. Compulsory cancer registration would ensure comprehensive data by which access to services could be monitored and measured for the whole population.

There are very limited cancer statistics available from the private health care sector. Although only a limited number provide acute cancer treatment in terms of oncology or haematology specialties, chemotherapy, radiotherapy, a much larger number offer specialised imaging investigations, mammography and other screening procedures.

The majority of private registered nursing homes beds are for older people. The number of people with cancer in these nursing and residential homes is substantial but unknown, however.

Coronary Heart Disease (CHD)

There is a lack of good-socio economic data by which to monitor and measure access to CHD care in England. Many of the data are not published, nor made available for analysis. Data on opportunity to use health care services are also poor, making routine analysis of barriers to accessing care impossible. The problems with routinely available data impact on the choice and appropriateness of targets for access to health care and outcome set by the government. Use of easy to measure variables, such as CHD death rates and waiting times tend to predominate because they are available and robust.

NHS charges

User charges, or co-payments, are the everyday experiences of older people, the frail, chronically sick and disabled people and most people in need of dental or optical care. Charging for essential NHS services will inevitably have a direct effect on access to NHS treatment by some groups of people, particularly those on low incomes. In addition, even for those exempt, access will still be difficult in areas where services are no longer generally offered by the NHS. The rationale and justification for the particular treatments and items charged for is inconsistent and has been criticised as being illogical, unfair and outdated.

There is little routine information by which to monitor and measure the impact of charging on access to services. A major obstacle is the lack of available private sector data. Particularly in the fields of dentistry and ophthalmology, many people use services that are completely private rather than NHS services, particularly in areas where there are few dentists offering NHS care. This also applies to people who pay for private prescriptions or who purchase over the counter treatments rather than visiting a GP for a prescription. There is therefore no routine information and little known about the access, characteristics, needs and utilisation of these people.

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Transport

Despite data on the impacts of transport, especially accidents and air-pollution on the health of people, there is little information that directly addresses issues of transport and access to health care, particularly in terms of routine data sources.

Vulnerable groups with low accessibility to health care are fairly invisible. If these people's health needs are to be met, it is important that they are properly identified so that strategies to improve their accessibility can be put in place. These include the location and opening times of health services, the planning of public transport and transport generally.

NHS Performance Ratings

There has been an explosion in such indicators since the 1990s. There have been constant changes to and increases in the type and number of performance indicators applied to the NHS. There is a pressure to change behaviour to improve the indicators, regardless of whether or not this improvement actually improves the performance of an organisation or furthers its objectives. Performance indicators have had a mixed reception around the world and for example the withdrawal of indicators such as school league tables in some countries. This is partly due to dissatisfaction at the lack of contextualisation and also the adverse effects on institutions of publication: far from engendering positive change, the publication of PIs has undermined performance and attempts to turn around failing organisations.

Coupled with these doubts over the design and execution of PIs is the opacity of the PIs used in the NHS in England. It is difficult for those outside the NHS to know whether the PIs are valid or not, or if they reflect accurately those features of the system that the particular indicator purports to be about. Given the criticisms of the concept, practice and publication of PIs in the NHS it is difficult to see how these items can be used to measure and monitor access to health care.

Use of waiting list data to monitor and measure access

Waiting times to access health care have always been an issue for the NHS. Electoral promises to reduce waiting times have the potential to win votes. As with other performance targets there is the possibility of introducing perverse incentives, however, for example by treating less serious cases ahead of more complicated ones in order to meet targets.

Of the performance indicators for acute trusts, approximately a third are concerned with waiting times. These do not give an indication of coverage, universality or unmet need. Further waiting lists are a function of supply and other factors, aspects over which Chief Executives may have little control. The NHS is founded on the principal of universal coverage, but this has been interpreted as access, which in turn has been interpreted as waiting times. Rather than measure met or unmet need, waiting times reflect problems within the whole health economy, such as access to nursing and residential homes or lack of capacity due to insufficient bed supply, staff shortages or funds.

7.2 Discussion

In pursuing in detail our overall aim of investigating the availability and adequacy of existing and other datasets for monitoring access to health care, a number of major themes emerged.

The first was the impossibility of keeping pace with the continuing changes in NHS data collection. These ranged from downsizing as a result of the government's desire to reduce the size of the civil service and disperse it out of London, to the potential for positive new opportunities as a result of major investments in NHS IT as a result of the establishment of the NHS Health and Social Care Information Centre. In finalising in November 2005 a report completed in mid 2004 and responding to referees' comments received in January 2005, we have done our best to reflect the changes over this period, but a few may have escaped our attention.

Data collection can also be affected indirectly by the continuing changes in structures and responsibilities of health care organisations. This leads to problems in reconciling data based on registration with general practices in an area with geographic population data from routine sources based on area of residence. For example primary care trusts are registered rather than resident population-based. In monitoring and measuring access to service it is vital to be able to identify the denominator population to assess how many people would be expected to need services and are not receiving services.

Changes in organisational structures can also result in changes in definitions, breaks in series, discontinuity and loss of trend data. Added to this, frequent boundary changes make it difficult to monitor changes over time.

As we have shown in detail, using the access framework we have defined, based on earlier work commissioned by the SDO, most of the data about health care are based on activity and thus reflect utilisation rather than access. Even the datasets which are collected about utilisation lack key variables which might be used to assess access indirectly. In particular, many NHS datasets lack the items needed to assess the socio-economic characteristics of people using health services. The lack of routinely collected data about ethnicity, postcode of address, and socio-economic status makes it difficult to monitor response to the inequalities agenda. Data about marginalised groups of people, including refugees, asylum seekers, homeless people and travellers are even harder to find.

In contrast to this, surveys which sample the population are better able to assess unmet need, but have other problems arising from being derived from samples. In addition, response rates have fallen over the past 20 years and this trend is likely to continue.

Other gaps relate to whole areas of health care for which data are sparse or non-existent. With the move away from hospital settings, comprehensive and consistent data about primary and community care are crucial. Despite considerable developments in general practice computing, these are largely centred on remuneration and supporting individual patient care. There are few population-based data about utilisation, let alone access to primary care. The

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situation is far worse with respect to community care, where the few limited data collections have been discontinued during the course of our project without being replaced by anything, let alone the more up to date systems which are required. This reflects both the decision to abandon the community dataset and lack of access to appropriate IT systems with the hospital and general practice focus of the National Programme for IT.

Major gaps were identified throughout the report in data from the private sector. In addition, where data are submitted, they may not be in the same format, or be more limited than data about NHS care. This has been compounded by the increasing trend towards outsourcing NHS care. Losses of data and data quality may make it difficult or impossible to monitor the impact of these trends. The downsizing of data collections, and subsequent data losses, has co-incided with dramatic increases in the numbers of performance targets and indicators. This has led to a focus on performance indicators rather than on information sources but in isolation from a wider range of background information to set them in context, performance indicators can be hard to interpret.

In both survey and administrative data, there is an overall lack of health data for people in institutions such as nursing and residential homes and a lack of data for small areas.

In considering the gaps in health care statistics it is important to focus not only on the recording and collection of data, but also on the processing, analysis, interpretation and dissemination of data and the extent to which they are accessible to both professionals and the wider public.

Problems can arise with access to the datasets themselves. Some are expensive to access. Others can only be accessed by people employed by the NHS and cannot be shared with partners such as local authorities thus restricting their use. As a result, there is a tension between on the one hand a policy of promoting information sharing, but on the other hand the tightening up of data protection and confidentiality legislation. Sometimes when it is not fully understood whether data can be made available or not, there is a tendency to restrict use so as not to take the risk of infringing legislation.

In this context, it can be frustrating to find that the statistical analyses of routinely collected data which are difficult to access are nonetheless contracted out to private companies such as DrFoster. There are issues around contracting out to such commercial companies for performance and benchmarking using routine data. The potential threat to national systems is not only that data might be no longer collected, but that investment and development of such sources moves national statistical data into the sphere and control of private property. Small unlinked data sources are liable to be used and quoted rather than routine, national statistical data which are not subject to the same protocols.

7.3 Conclusions

The safeguarding of our national data collection is essential as without comprehensive data it is not possible to monitor equity or needs and utilisation in

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accessing health services. This is particularly crucial at the present time of significant changes to patterns of health care delivery.

Our detailed review of the current NHS datasets for England identified an absence of data items needed for monitoring access to health care even when this was redefined in terms of utilisation. Data were missing about geographical location and individual socio-economic status. Ethnicity was more often included in datasets in response to the requirements of the Race Relations Amendment Act, but the data were often incomplete. Data to identify members of marginalised groups rarely are included in routine datasets.

There were areas for which few data were available, notably data about community health services, data about care in residential institutions and data about most of the growing range of services provided by the private sector, including those funded by the NHS. Few population-based data can be derived from general practice systems.

The continuing fragmentation and organisational changes in health care has impacted on data collection and made it difficult and sometimes impossible to monitor trends over time. The increasing tendency to outsource data to private organisations has reduced public accountability and adherence to the codes of practice such as that drawn up for National Statistics.

Data protection legislation and other restrictions on access to data means that fewer of them are in the public domain and that the NHS is increasingly less able to share data with partners such as local authorities.

7.4 Recommendations

- 1 In order to improve monitoring of utilisation of and access to health care, data about individual socio-economic status and about geographical area of residence should be added to routine datasets and reporting of ethnicity should be improved. Relevant data items should be added to monitor uptake of care by people from marginalised groups.
- 2 Data collection about use of community services should be recommenced.
- 3 General practice systems should have the capacity to derive population-based data from the individual records they hold.
- 4 Data should be collected about care in the private sector to the same extent as for the NHS, irrespective of whether or not the care was NHS funded. Records of these episodes of care should be linked to the person's records in the NHS Care Records Service.
- 5 Where NHS staff are collaborating with other partners in areas such as public health, their partners should be able to access the relevant data. Disclosure control should be operated in a way which does not unduly restrict public access to data about health and health care.

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- 6 Performance targets and indicators should be constructed in a way which is explicit about the data items they comprise and how these are calculated.
- 7 In developing plans for an Independent Statistical Service, the scope should be interpreted as widely as possible to ensure that data about health and health care are subjected to public accountability and comply with codes of good practice. To support this, trends towards outsourcing of analyses should be reversed.

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Appendices

Appendix A Letter on data collections from all providers

Dr Nicholas Drey
Department of Midwifery
St Bartholomew School of Nursing and Midwifery
20 Bartholomew Close
City University
London EC1A 7QN

3rd July 2003

Dear Xxxx

Re: Availability of routinely collected data about health and community care

We are currently undertaking a project funded by the NHS Service Delivery and Organisation R & D Programme (SDO) which aims to identify the extent that data from routine sources can be used to determine equity and access to health care for specific groups of people within the population. We attach a copy of the aims and objectives.

As part of the project we are undertaking a review of the availability, quality and comprehensiveness of routinely collected data currently submitted centrally.

A list of aggregated and person based returns including those related to activity, beds, bed availability and workforce, is appended.

We are seeking to ascertain whether all providers of health and social care, including those in the independent sector, those treating NHS funded patients overseas and Diagnostic & Treatment Centre are being required to submit the relevant returns. If such providers are not being required to submit returns in these formats, we should like to know what data items are collected.

Thank you in anticipation for your response to this enquiry. Please do not hesitate to contact us if you need any more details of our project.

Yours sincerely

For and on behalf of:

Project SDO/27/2002: Identification and evaluation of standardised datasets for measuring and monitoring access to health care*

*Alison Macfarlane, Professor of Perinatal Health and Dr Nicholas Drey, Senior Research Fellow, Dept. of Midwifery, City University.

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Allyson Pollock, Professor of and Chair Health Policy & Health Services Research and Sylvia Godden, Senior Research Fellow, Health Policy & Health Services Research Unit, UCL.

Dr Anita Sims, Public Health Specialist, South East Public Health Observatory, Oxford.

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8.1.1 Attachments to letter: data returns currently collected

Activity (hospital and community) returns

Name of return	Code of return	Collection period
Consultant Outpatient Clinic Activity and Accident and Emergency Services Activity (KH09)	KH09	Annually & Quarterly
Consultant Outpatient First Attendances (Health Authority Based)	QM08R	Quarterly
Consultant Outpatient First Attendances (Provider Based)	QM08	Quarterly
Critical Care Census 15 July/15 January (formerly Bed availability & occupancy :intensive care and high dependency provision)	KHO3a	Bi-annual
Demand for Elective Admission (Health Authority Based)	QF01	Quarterly
Demand for Elective Admission: Events occurring during the Quarter (Provider Based)	KH06	Quarterly
Demand for Elective Admission: Events occurring during the Quarter (Relevant Population Based)	KH06R	Quarterly
Demand for Elective Admission: Number of People who have Deferred Admission Waiting at the End of the Quarter (Health Authority Based)	KH07AR	Quarterly
Demand for Elective Admission: Number of People who have Deferred Admission Waiting at the End of the Quarter (Provider Based)	KH07A	Quarterly
Demand for Elective Admission: Position at the end of the Quarter (Provider Based)	KH07	Quarterly
Diagnostic Departments: Radiology, Nuclear Medicine and Medical Physics	KH12	Annual
Health visiting and other Professional Advice and Support in the community	KC55	Annual
Hospital Episode Statistics	HES	Quarterly and Annual Refresh
Informal Patients and Patients detained under the Mental Health Act: The Number of Uses of the Act	KP90	Annual
Mapping Child and Adolescent Mental Health Services (CAMHS)		Yearly
Mental Health Minimum Dataset (MHMDS)		Yearly
National Cancer Dataset Waiting times subset		Quarterly and monthly
National Joint Registry		
NHS Day Care: Availability and Use of Facilities	KH14	Annual
NHS Performance Fund		

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Name of return	Code of return	Collection period
Patient Care in the Community: Community Learning Disability Nursing	KC58	Annual
Patient Care in the Community: Community Psychiatric Nursing	KC57	Annual
Patient Care in the Community: District Nursing	KC56	Annual
Patient Care in the Community: Specialist Care Nursing	KC59	Annual
Service and Financial Framework (SaFFR) 2001 – 2 (formerly CIC)	SaFFR	Quarterly
Smoking Cessation Services return		Quarterly
Summary of Bed Availability and Bed Occupancy	KH03	Annual
Summary of Chiropody Services	KT23	Annual
Summary of Clinical Psychology Services	KT24	Annual
Summary of Contraceptive Services	KT31	Annual
Summary of Occupational Therapy Services	KT26	Annual
Summary of Physiotherapy Services	KT27	Annual
Summary of Speech and Language Therapy Services	KT29	Annual
Summary of Ward Attenders (KH05)	KH05	Annual
Surveillance of Hospital Acquired Infection		Annual

Source: ROCR ongoing approved non-finance data collections 2003-04 as at 20 June 2003.

Available at: <http://www.doh.gov.uk/stats/rocr/nfdc.htm>

Workforce

Name of return	Code of return	Collection Period
Annual HCHS medical and dental workforce census	SBH 50-56	Quarterly until 2004
Annual HCHS non-medical workforce census		Annual
Attribution Dataset (GP Postcodes)	ADS	Annual
Earnings Survey		Annual
Financial and Workforce Information Return	FWIR	Annual
Monitoring sickness and absence targets		Annual
GP Recruitment, Retention and Vacancy Survey - GMS Partnership and single handed and PMS Vacancies Return	Stage 1	Annual
Junior Doctors' Hours		Bi-annual
Landlord's expenses survey: notional rents and Not undertaken every year, next		

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interest on loans	one in 4 years	
Monitoring violence, accidents and harassment targets		Annual
Monitoring equalities and education targets		Every 18 months
NHS Plan Monitoring of Planned Workforce Increases		
Nursing Campaign Return		Bi-annual
Personal Medical Services		Ad-hoc
Quarterly Manpower Return	QMX6	Quarterly
Survey of Registration and Inspection of Local Authority and Health Authority Units	R&I	Annual
NHS Workforce Vacancy Survey		Annual

Source: ROCR ongoing approved non-finance data collections 2003-04 as at 20 June 2003.

Available at: <http://www.doh.gov.uk/stats/rocr/nfdc.htm>

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Table 27 Response from the Department of Health Statistics Division

ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/O R/0002/001	Consultant Outpatient Clinic Activity and Accident and Emergency Services Activity (KH09)	KH09	annual & qrtly	Performance Management - e.g. did not attend and ratio of first to subsequent attendances. Accountability - e.g. Public Expenditure Inquiry: evidence for Health Select Committee.	Outpatients and ward attenders - on Hospital Activity section of the web site at http://www.doh.gov.uk/hospitalactivity . The statistical bulletin on 'Hospital Activity' has been discontinued.	No	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	No. Includes only patients treated in NHS hospitals	
ROCR/O R/0005/001	Critical Care Census 15 July/15 January (formerly Bed availability & occupancy :intensive care and high dependency provision)	KHO3 a	Bi-annual	Monitor availability of IC and HD provision and to inform and support policy development for Critical Care Services. Includes specialist high dependency provision and specialist intensive care provision as at 15 January and 15 July.	Bed availability and occupancy for England & Critical care census 15 July/15 January - on Hospital Activity section of the web site at http://www.doh.gov.uk/hospitalactivity	No	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	N/A as this is a count of beds not patients	

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ROCR REF NUM	Information Request	Ref. Period	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/O R/0012	Diagnostic Departments: Radiology, Nuclear Medicine and Medical Physics	KH12	annual	Provides information to the National Radiological Protection Board to monitor population exposure to medical ionising radiation. Also used in policy development and monitoring of changes in imaging services.	Imaging and radiodiagnostics -on Hospital Activity section of the web site at http://www.doh.gov.uk/hospitalactivity	Yes	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	No. Includes only patients treated in NHS hospitals	
ROCR/O R/0020	NHS Day Care: Availability and Use of Facilities	KH14	annual	Used to monitor NHS Day Care facilities; total attendance figures are required as a measure of activity.	NHS day care -on Hospital Activity section of the web site at http://www.doh.gov.uk/hospitalactivity	Yes	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	No. Includes only patients treated in NHS hospitals	
ROCR/O R/0036	Summary of Ward Attenders (KH05)	KH05	annual	Measures essential hospital activity for patients seen in hospital by nursing staff.	Outpatients and ward attenders - on Hospital Activity section of the web site at http://www.doh.gov.uk/hospitalactivity .	No	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	No. Includes only patients treated in NHS hospitals	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
					The statistical bulletin on 'Hospital activity' has been discontinued.						
ROCR/O R/0029	Summary of Bed Availability and Bed Occupancy (KH03)	KH03	annual	Used to calculate throughput, measures of efficiency and service provision. It is an important indicator of scale of shift from secondary to primary care. Accountability – e.g. Public Expenditure Inquiry: evidence for Health	Bed availability and occupancy for England - on Hospital Activity section of the Statistics web site at http://www.doh.gov.uk/hospitalactivity . Statistical bulletin on 'Hospital activity' discontinued.	No	NHS Trusts & PCTs	No. Only NHS providers	Yes if DTC provided by an NHS Trust	N/A as this is a count of beds not patients	
ROCR/O R/0003/001	Consultant Outpatient First Attendances (Health Authority Based)	QM08 R	Quarterly	Used as performance management measures of waiting times by HQ. Also used in PES negotiations; for the production of inpatient and	Waiting Times for first outpatient appointment in England. Detailed statistics (Relevant Population Based). On waiting times section of the web site at	Yes	PCTs and Commissioners)	No	No	Yes	

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ROCR REF NUM	Information Request	Ref. Period	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				outpatient modeling tools; risk analysis and for Departmental accountability.	http://www.doh.gov.uk/waitingtimes						
ROCR/O R/0004/001	Consultant Outpatient First Attendances (Provider Based)	QM08	Quarterly	as QF01	Waiting Times for first outpatient appointment in England. Waiting Times for first outpatient appointment in England: Detailed statistics. On the waiting times section of the web site at http://www.doh.gov.uk/waitingtimes	Yes		No	No	Yes	
ROCR/O R/0006/001	Demand for Elective Admission (Health Authority Based)	QF01	Quarterly	Used as performance management measures of waiting times by HQ . Also used in PES negotiations; for the production of inpatient and	Waiting times. On the waiting times section of the web site at http://www.doh.gov.uk/waitingtimes	Yes	PCTs (as Commissioners)	No	No	Yes	Some Trusts may include activity commissioned from IS where funding arrangements exist.

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				outpatient modeling tools; risk analysis and for Departmental accountability.							
ROCR/O R/0007	Demand for Elective Admission: Events occurring during the Quarter (Provider Based)	KH06	Quarterly	as KH05	Hospital Waiting List Statistics, England.. On the waiting times section of the web site at http://www.doh.gov.uk/waitingtimes	Yes	NHS Trusts and PCTs	No	No	Yes	
ROCR/O R/0008	Demand for Elective Admission: Events occurring during the Quarter (Relevant Population Based)	KH06 R	Quarterly	as KH05	Hospital Waiting List Statistics: (Responsible Population Based). On the waiting times section of the web site at http://www.doh.gov.uk/waitingtimes	Yes	NHS Trusts and PCTs	No	No	Yes	
ROCR/O R/0009	Demand for Elective Admission: Number of People who	KH07 AR	Quarterly	as KH05	Not published.		NHS Trusts and PCTs	No	No	Yes	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
	have Deferred Admission Waiting at the End of the Quarter (Health Authority Based)										
ROCR/OR/0010	Demand for Elective Admission: Number of People who have Deferred Admission Waiting at the End of the Quarter (Provider Based)	KH07 A	Quarterly	as KH05	Not published.		NHS Trusts and PCTs	No	No	Yes	
ROCR/OR/0011/001	Demand for Elective Admission: Position at the end of the Quarter (Provider Based)	KH07	Quarterly	as KH05	Hospital Waiting List Statistics: England. Health and Personal Social Services Statistics. Annual Reports.	Yes	NHS Trusts and PCTs	No	No	Yes	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/OR/0013	Health visiting and other Professional Advice and Support in the community	KC55	annual	Monitors changes in health visitor workload. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/OR/0022	Patient Care in the Community: Community Learning Disability Nursing	KC58	annual	Used in the implementation and monitoring of the LD White Paper "Valuing People" Also used in the implementation and monitoring of Community Care Reforms. Also used in SR negotiations, resource allocation to the NHS and	Published in hard copy and on DH web site. Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health	Yes	Trusts (incl PCTs)	no	no	no	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				Departmental accountability.	h_care.htm#commcare						
ROCR/OR/0023	Patient Care in the Community: Community Psychiatric Nursing	KC57	annual	Monitors the provision of care in the community and the implementation of the National Service Framework. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/OR/0024	Patient Care in the Community: District Nursing	KC56	annual	Used in the implementation and monitoring of Caring for People and Community Care Reforms. Also used in SR negotiations, resource allocation to the NHS and	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on	Yes	Trusts (incl PCTs)	no	no	no	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				Departmental accountability.	the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare						
ROCR/OR/0025	Patient Care in the Community: Specialist Care Nursing	KC59	annual	Used in the implementation and monitoring of Community Care Reforms. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/OR/0030	Summary of Chiropody Services	KT23	annual	Assists in developing and monitoring the delivery of chiropody services in the NHS. Also used in SR	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and	Yes	Trusts (incl PCTs)	no	no	no	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				negotiations, resource allocation to the NHS and Departmental accountability.	NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare						
ROCR/O R/0031	Summary of Clinical Psychology Services	KT24	annual	Data needed for the Health of the Nation Mental Illness key area and the continued development and improvements in comprehensive local services for mentally ill people.	Annual statistical summary. Now discontinued.	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/O R/0032/001	Summary of Contraceptive Services	KT31	Annual	Monitors Our Healthier Nation objective to ensure provision of effective contraceptive services. Used to evaluate progress in the Government's	Published in hard copy and on DH web site. Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the	Yes	Trusts (incl PCTs)	no	no	no	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				targets to reduce teenage pregnancies and implementation of the Sexual Health and HIV Strategy.	public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare						
ROCR/OR/0033	Summary of Occupational Therapy Services	KT26	annual	Assists in developing and monitoring the delivery of occupational therapy services policy in the NHS. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	Published in hard copy and on DH web site. Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/OR/0034	Summary of Physiotherapy Services	KT27	annual	Assists in developing and monitoring the delivery of physiotherapy services in the	Published in hard copy and on DH web site. Distributed within DH to policy sections and professional	Yes	Trusts (incl PCTs)	no	no	no	

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ROCR REF NUM	Information Request	Ref. Period	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				NHS. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare						
ROCR/OR/0035	Summary of Speech and Language Therapy Services	KT29	annual	Assists in developing and monitoring the delivery of speech therapy services policy in the NHS. Also used in SR negotiations, resource allocation to the NHS and Departmental accountability.	Published in hard copy and on DH web site . Distributed within DH to policy sections and professional colleagues in DH and NHS. Available to academics and the public. Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#commcare	Yes	Trusts (incl PCTs)	no	no	no	
ROCR/OR/0085/002	Annual HCMS medical and dental	SBH 50-56	Bi-annual	Accountability, workforce planning overview, equal	Published and used to monitor NHS Plan workforce targets.	No	StHas, NHS Trusts, PCTs, PHLS,	no	yes	N/A	DTCs covered but not separately

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
	workforce census			opportunities monitoring.	Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm		SHAs national blood authority				identifiable; no patient data in this collection
ROCR/OR/0086/003	Annual HCHS non-medical workforce census		annual	Accountability, workforce planning overview, equal opportunities monitoring.	Published and used to monitor NHS Plan workforce targets. Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	Trusts, PCTs, StHas, Special Has	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection
ROCR/OR/0088	Earnings Survey		annual	Monitor levels and composition of pay. Informs national pay negotiations and pay modernisation policy.	Pay Review Bodies, HRD-NHS-Pay, Modernisation agency. Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	Obtained from payroll services information	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection
ROCR/OR/0090	Monitoring sickness and absence targets		annual	Monitors progress towards healthy workplace targets.	Treasury, ministers, NHS organisations, the public	No	Trusts, StHAs, SHAs, PCTs	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/O R/0091/001	GP Recruitment, Retention and Vacancy Survey - GMS Partnership and single handed and PMS Vacancies Return	Stage 1	annual	Provides information on GP recruitment, retention and vacancies for workforce planning and DDRB purposes.	Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	PCTs	no	no	N/A	Only GPs covered.
ROCR/O R/0095	Monitoring violence, accidents and harassment targets		annual	Monitors progress towards healthy workplace targets.	Treasury, ministers, NHS organisations, the public. Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	Trusts, StHAs, SHAs, PCTs	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection
ROCR/O R/0096	Monitoring equalities and education targets		Every 18 months	Monitors progress towards targets for the gender and ethnicity of executive board members and staff PDPs	Will be available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	Trusts, StHAs, SHAs, PCTs	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection
ROCR/O R/0101	Quarterly Manpower Return	QMX6	Quarterly	Used by ONS in estimates of quarterly change in GDP and other	Not published.		Sample at Trusts	Abolished			

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				economic statistics.							
ROCR/O R/0103	NHS Workforce Vacancy Survey		annual	Used widely within the Department, by NHS users and external bodies; used by the Pay Review Body, as an aid to workforce planning and to allocate return to practice funding.	Published and used to monitor NHS Plan workforce targets and supply evidence to NPRB. Available on the web site at http://www.doh.gov.uk/public/work_workforce.htm	No	Trusts, PCTs, Care Trusts, StHAs and SHAs	no	yes	N/A	DTCs covered but not separately identifiable; no patient data in this collection
ROCR/O R/0099	Personal Medical Services		Ad-hoc	Monitors applications for and take up of, PMS status and collects subsequent on-going financial and workforce information.	Supports policy in monitoring the development of PMS	No	StHas/PCGs	no	yes	N/A	
ROCR/O R/0087/001	Attribution Dataset (GP Postcodes)	ADS	annual	Data collection from HAs classified by age, sex, postcode and the GP with whom they are registered.	Resource allocation performance indicator, published on the compendium of clinical indicators	No	Extracted from the Exeter system	No	No	N/A	For both the ADS and Landlords' Expenses the information relates to NHS GPs. The ADS relates to the

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
											patients of NHS GPs.
ROCR/O R/0094	Landlord's expenses survey: notional rents and interest on loans		Not undertaken every year next one in 4 years	Survey of Health Authorities, Health Boards and GP accountants to establish what proportion of the notional rent payments are used to cover interest on loans.				No	No	N/A	
ROCR/O R/0014/008	Hospital Episode Statistics	HES	Quarterly and Annual Refresh	Many diverse uses in DH and the NHS ranging from high level analyses of different diagnoses and operations, eg: - Treasury negotiations and allocation of NHS funds.	Published on web site at http://www.doh.gov.uk/hes and by making data available to users.	No	NHS Trusts PCTs and all providers of NHS hospital inpatient care.	No - only if patient treated in an NHS trust	DTCs are currently unclear - HES would like to collect data from these organisations, but may not be able to.	The 'commissioning' NHS Trust is encouraged to submit details	

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/OR/0015	Informal Patients and Patients detained under the Mental Health Act: The Number of Uses of the Act	KP90	annual	Monitors the uses made of the Mental Health Act 1983; Provides input to needs assessment for type of hospital accommodation.	Information is fully within the public domain. Information is published externally as a statistical bulletin (In-patients formally detained in hospitals under the Mental Health Act 1983 and other legislation, England: 1990-1991 to 2000-2001) Available on the web site at http://www.doh.gov.uk/public/work_health_care.htm#menthealth	Yes	Trusts, Care Trusts, Primary Care Trusts, and Private Hospitals and Nursing Homes registered to detain patients under the MHA 1983.	Yes	Yes	No	
ROCR/OR/0027/005	Local Delivery Plan Return	LDPR	quarterly	Collects information needed to monitor and deliver NHS Plan Targets and National Service Framework milestones.			StHas, Trusts, PCGs	Only if activity is commissioned by the NHS	DTCs; yes if activity is within a Trust. If IS, assumed activity will be	If service commissioned by a PCT and carried out by an overseas provider then that	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
									returned via either sub-contracting Trust or a commissioning PCT.	activity should be returned.	
ROCR/O R/0028/004	Smoking Cessation Services return		Quarterly	Monitors number of people setting smoking quit dates and number successfully quitting at 4 weeks. Also information about people using the services – e.g. age, gender, ethnicity. Used to monitor targets in National Priorities and Planning Framework	Ministers, policy customers, NHS managers and service providers, professionals in the field, academics, general public. Available on the web site at http://www.doh.gov.uk/public/work_public_health.htm#SDD	No	Smoking Cessation HA/HAZ Co-ordinators	No	No	No	
ROCR/O R/0102/002	Survey of Registration and Inspection of	R&I	Annual	Information collected as at 31March.	Within 12 months of the reference point. Now discontinued.	Yes	StHAs, Las	Abolished			Collection stopped in 2001 when R&I

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
	Local Authority and Health Authority Units*			Information is collected on resources and workload of the units – comparisons by authority area							units ceased to exist. If information on care homes (previously known as residential and nursing homes) is needed please contact the National Care Standards Commission (NCSC).
ROCR/OR/0016	Mapping Child and Adolescent Mental Health Services (CAMHS)		Yearly	Introduction of a mapping exercise for CAMHS starting in autumn 2002 to provide baseline and, subject to further approval, ongoing information about CAMH services in England.	Atlas available on the Internet at http://www.dur.ac.uk/camhs.mapping/	Yes		No 2002, yes 2003	N/A	N/A	Seeking to include all providers this year, but depends on willingness to volunteer and statutory sector knowledge of independents activity.

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
ROCR/O R/0097	NHS Plan Monitoring of Planned Workforce Increases			Collects data on a quarterly basis from Workforce Development Confederations (WDCs) covering their constituent Trusts' plans for expanding the workforce in accordance with NHS Plan and manifesto targets.				No	No	N/A	
ROCR/O R/0093	Junior Doctor's Hours		Bi-annual	Accountability, Policy development and monitoring.			Regional Action Teams	Only hospices that train junior doctors	no	no	
ROCR/O R/0089	Financial and Workforce Information Return	FWIR	annual	Monitors the supply and demand for non-medical health care professionals to support workforce planning, keep Ministers informed of likely workforce	Not published.			Yes	No	No	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
				pressures, and support the PES and budget setting processes.							
ROCR/O R/0098	Nursing Campaign Return		Quarterly	Assessment of numbers of nurses returning to the NHS.	Not published.	No	Communications unit	No	no	N/A	
ROCR/O R/0017	Mental Health Minimum Dataset (MHMDS)		Annually	Collection of data from Trusts on their locally held Mental Health minimum Dataset (MHMDS) from April 2003. Provides comprehensive patient centred data on secondary data and monitor the implementation of the NHS plan	The data will be used in the 'detained patients' and the 'guardianship' bulletins and other departmental submissions	Yes		No	No	N/A	
ROCR/O R/0018/001	National Cancer Dataset Waiting times subset	Cancer Waiting Times Database	This is a "live" database; trusts enter data at any time, but	Collects data on waiting times during a cancer patient's journey from primary to secondary and	Subject to ministers views, data from Q3 2002/03 onwards will be published quarterly on the web.	No	Trusts	No. System based round encrypted NHS-net	Not at present, though possible to extend	No. The system is based around NHS providers	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
		ase (CWT -Db)	must be complete 25 days after the end of a month or quarter so system can report to commissioners and DH.	possibly tertiary care and replace existing data collections on cancer waiting times.				site within the Exeter system. Organisations entering data required to have NHS-net connection and be registered with the organisational code service	system to NHS DTCs if registered with the OCS and have hardware.	entering patient level data	
ROCR/O R/0019/001	National Joint Registry			Collection of a minimum datasets from all Trusts performing hip and knee joint replacement.	None in local phase. Wide dissemination of data is proposed for national phase	No		Yes	Yes	Intended - see comments	- NJR collects data on total hip and knee replacements in NHS and private sector in England and Wales. Covers all bodies that carry out total

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
											hip and knee replacements, including DTCs. NJR Centre working with trusts that send NHS patients overseas to develop model of how data is returned for input. Also doing similar work with trusts bringing in overseas surgical teams.
ROCR/O R/0021	NHS Performance Fund		annual	Collection to assist the evaluation of implementation of Performance Fund. Used to ensure the Fund is being used for its intended purpose.	Data collected will be available on a Lotus Notes database to all NHS organisations, using a universal user ID and password	No	NHS Trusts and PCT/Gs complete forms submit to web site	Abolished			
ROCR/O	Surveillance of		Annual	Provides Trusts,	CDR Weekly, health		Hospital	No NHS	Will need	No only	

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ROCR REF NUM	Information Request	Ref.	Collection Period	Description /Purpose	Publication details/audience	National statistics	Who completes	Independent sector?	Other bodies eg DTCs?	NHS funded patients overseas?	Comments
R/0037/001	Hospital Acquired Infection			ROs, DH, Parliament and the public with a clearer picture of levels of infection and informs decisions on how best to tackle them locally.	service mainly		Trusts	Acute Trusts only	to cover DTCs in future	bacterias identified in the Trust laboratory	

Appendix B Items in datasheets described in the Report

Table 28 The original HES dataset

Data input at time of admission

Sex

Normal home address plus postcode

Date of birth

Marital status

Code of normal GP

Category of patient – whether NHS, private or maternity and whether informally or formally detained under the Mental Health Act

Date of admission

Method of admission – elective admission, emergency, maternity, and other

Source of admission – normal or temporary place of residence, penal establishment, special hospital, NHS hospital outside district, local district residence, other NHS institution and those with no previous address

Need to admit – the date it was decided that there was a need for admission, or if for a delivery, the date of the first antenatal assessment from an antenatal co-operation card

Management intention – whether the intention is to admit the patient for a least one night, for less than this, or for a planned sequence of admissions

Data input at the start of each episode

Code of every consultant or GP responsible for care

Data input at start of ward stay

Code of ward

Data input on discharge

Date of discharge

Method of discharge – on medical advice, by self or relative, by statutory body, death or stillbirth

Destination on discharge – usual residence, temporary residence, penal establishment, special hospital, other NHS ward or hospital - general, maternity or mental, local authority care, non-NHS care

Data input at end of each episode

Up to six diagnoses in ICD9 format and OPCS operation codes

Patients to be classified as: ordinary admission, day case admission, regular day or night admission and interval admission

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

Table 29 The Admitted Patient Care Commissioning Minimum Dataset General Episode

Commissioning Details	Consultant Episode Details
M Organisation Code (Code of Provider)	M Episode Number
M Organisation Code (Code of Commissioner)	M Last Episode In Spell Indicator
M Commissioning Serial Number	M Site Code (Of Treatment)
O Health Care Contract Line Number	O Ward Type At Start Of Episode
M Commissioner' s Reference Number	M Start Date (Consultant / Midwife Episode)
	M End Date (Consultant / Midwife Episode)
Patient Details	M End Date Status
M NHS Number	M Specialty Function Code
M NHS Number Status Indicator	M Consultant Specialty Function Code
O Patient Name	O Local Sub-Specialty
O Name Format Code	M Consultant Code
O Patient's Usual Address	M First Regular Day Or Night Admission
M Postcode Of Usual Address	M Neonatal Level Of Care
M HA Of Residence	M Psychiatric Patient Status
M Sex	Mandatory ICD-10 diagnostic coding
M Marital Status (psychiatric patients only)	M Primary Diagnosis (ICD)
O Carer Support Indicator	M Subsidiary (if necessary) (ICD)
M Birth Date	M 1 st Secondary (ICD)
M Birth Date Status	M 2 nd Secondary (ICD), etc., to 12 th Secondary
M General Medical Practitioner (Code of Registered GMP)	Optional READ diagnostic coding
O Code Of GP Practice (Registered GMP)	O Primary Diagnosis (READ)
M Local Patient Identifier	O Subsidiary (if necessary) (READ)
M Ethnic Group	O 1 st Secondary (READ)
	O 2 nd Secondary (READ), etc., to 12 th Secondary
Referral Details	Patient Procedure Codes
M Referrer Code	M Operation Status (per episode)
M Referring Organisation Code	Mandatory OPCS procedure coding (up to 12 operative procedures per episode)
	M Primary Procedure (OPCS)
Provider Spell Details	M Procedure Date
M Hospital Provider Spell Number	M Procedure Date Status
M Decided To Admit Date (for this provider)	M 2 nd Procedure (OPCS) to 12 th Procedure

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M Decided To Admit Date Status	(OPCS) - items as for Primary Procedure (OPCS)
M Start Date (Hospital Provider Spell)	Optional READ procedure coding (up to 12 operative procedures per episode)
M Admission Method (Hospital Provider Spell)	O Primary Procedure (READ)
M Duration Of Elective Wait	M Procedure Date
M Intended Management	M Procedure Date Status
M Source Of Admission (Hospital Provider Spell)	O 2 nd Procedure (READ) to 12 th Procedure (READ) – items as for Primary Procedure
M Discharge Date (Hospital Provider Spell)	M Record Type
M Discharge Date Status	
M Discharge Method (Hospital Provider Spell)	
M Discharge Destination (Hospital Provider Spell)	
M Patient Classification	
M Administrative Category	
M Legal Status Classification	

M = Mandatory, O = Optional

Table 30 Core HES data items by category (excluding tails)

Patient	Organisations
Administrative and legal status of patient	Commissioner code
Administrative category	Commissioner code status
Age at end of episode	Commissioner's Directorate of Health and Social Care
Age on admission	Commissioner's Regional Office
Baby's age in days	Commissioner's Strategic Health Authority
Date of birth - patient	Commissioning serial number
Date of birth check flag - patient	Directorate of Health and Social Care area where patient's GP registered
Ethnic origin	Health Authority area where patient's GP was registered
Legal category of patient	Primary care group
Legal group of patient	Primary care group origination indicator
Legal status classification	Primary Care Trust area where patient's GP was registered
Local patient identifier	Provider code
Neonatal level of care	Regional Office area where patient's GP was registered

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NHS number	Site code of treatment
NHS number indicator	Strategic Health Authority area where patient's GP registered
Patient identifier - HES generated	
Postcode district of patient's residence	Geographical (derived)
Postcode of patient	County of residence
Sex of patient	Current electoral ward
Admission and Discharge	Directorate of Health and Social Care area of treatment
Admission date check flag	Government office region
Date of admission	Health Authority of residence
Date of decision to admit	Health Authority of treatment
Date of decision to admit check flag	Local authority district
Date of discharge	Patient's Directorate of Health and Social Care of residence
Destination on discharge	Patient's electoral ward in 1981
Discharge date check flag	Patient's electoral ward in 1991
Method of admission	Patient's Health Authority of residence provided by NHS
Method of discharge	Patient's Primary Care Trust of residence
Source of admission	Patient's Strategic Health Authority of residence
Waiting time	Primary Care Trust area of treatment
	Region of treatment
	Regional Office of residence
Episodes and Spells	Strategic Health Authority area of treatment
Bed days within a year	
Beginning of spell	Practitioner
Date episode ended	
Date episode started	Consultant code
Duration of spell	GP practice code
End of spell	Patient's general medical practitioner
Episode duration	Person referring patient
Episode order	Referring organisation code
Episode start date check flag	
First regular day or night admission	HRG and costs
Hospital provider spell number	Cost of treatment
Intended management	

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Main specialty	Cost per day
Patient classification	Dominant procedure code assigned by NHS during HRG derivation Health care resource group - latest version Health care resource group - original version NHS generated HRG code NHS generated HRG code version number Total cost
Status of episode	
Treatment specialty	
Type of episode	
Ward type at start of episode	
Diagnoses	System
Diagnosis	Combined grossing factor Coverage grossing factor Date data received by NHS wide clearing service Record identifier
Diagnosis (primary)	
External cause code	
External cause of injury or poisoning	
Operative procedures	
Date of operation	
Operation (main)	
Operation status code	
Operation codes	
Post operation duration	
Pre operation duration	

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Table 31 HES augmented care dataset

Data Item	Description
Location	Location of a patient during a period of augmented care
Disposal	Destination of a discharged patient after a period of augmented care
End date	
Indicator	Whether or not augmented care was planned
Local ID	No national definitions for this
Number	The number of this episode in a sequence of periods of augmented care
Outcome indicator	Identifies whether patient survived. For deaths it indicates whether organs were donated
Source	Location of the patient immediately before the period of augmented care
Speciality function code	The main specialty of the consultant clinically managing the period of augmented care
Start date	
High dependency care level	Number of days of high dependency care in a period of augmented care
Intensive care level days	Number of days of intensive care in a period of augmented care
Number of augmented care periods within episode	
Number of organ systems supported	

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Table 32 HES maternity tail

Pregnancy and delivery

Date of birth of mother
First antenatal assessment date
Total previous pregnancies
Length of gestation
Delivery place type (intended)
Delivery place type (actual)
Delivery place type (reason for change)
Labour/delivery onset method
Delivery method
Status of person conducting delivery
Anaesthetic given in labour/delivery
Anaesthetic given in post-labour/delivery
Number of babies

For each baby

Date of birth of baby
Sex
Birth order
Live or stillbirth
Birth weight
Method of resuscitation

Table 33 HES psychiatric census

Psychiatric census – detained or long term

Date detained

Status of patient

Age at census

Duration of care to census date

Legal status

Mental category

Ward type

Diagnosis on census date

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Table 34 The mental health minimum dataset

Patient data	Administrative data
Patient identifiers	GP Practice
Sex	Health Authority
Date of birth	Electoral ward
Marital status	
Ethnic group	Assessment data
Year of first mental health treatment	
	Outcome score (HoNOS)
Care Management data	- first in spell
	- most recent in spell
Spell start and end dates	- worst in spell
Specialty function	- best in spell
Care Co-ordinator occupation	Diagnoses
Source of referral	
Days in reporting period	
- On each level of Care Programme Approach (CPA)	
- Under Mental Health Act	
Indicators at end of reporting period	
- CPA level	
- Legal status	
Care given without consent	
Most restrictive legal status in Period	
Date last seen by Care Co-ordinator	
Care provided in Reporting Period data	
Health	Health cont.
Bed days	Patterns of care
- ordinary inpatient	- number of admissions
- medium secure	- number of discharges
- other secure where help is provided	- days between admissions

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- NHS funded community

Number of attendances

- NHS day care

- Outpatients

Number of contacts

- community psychiatric nurse (CPN)

- clinical psychologist

- occupational therapist

- social worker (optional)

- other therapists

Treatment, including ECT

- lengths of inpatient stays

Daily care and legal status

Other Care

Residential care

- residential/nursing care

- other accommodation

Day care

- day centre attendance

- sheltered work

- social work

- domiciliary care

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Table 35 The Outpatient Attendance Commissioning Dataset

CDS DATA ITEM	CDS DATA ITEM cont
M local patient identifier	M medical staff type seeing patient
M organisation code (local patient identifier)	M operation status
M organisation code type	M outcome of attendance
M NHS number	M appointment date
M birth date	M commissioning serial number
O carer support indicator	O NHS service agreement line number
* ethnic category	O provider reference number
* marital status (psychiatric patients only)	M commissioner reference number
M NHS number status indicator	M organisation code (code of provider)
M sex	M organisation code type
O name format code	M organisation code (code of commissioner)
O patient name	M organisation code type
O address format code	O procedure scheme in use
O patient usual address	O primary procedure (OPCS)
M postcode of usual address	O procedure (OPCS)
M organisation code (pct of residence)	O procedure scheme in use
M organisation code type	O primary procedure (Read)
M consultant code	O procedure (Read)
M specialty function code	M location class
M consultant specialty function code	M site code (of treatment)
O diagnosis scheme in use	M organisation code type
O primary diagnosis (ICD)	M priority type
O secondary diagnosis (ICD)	M service type requested
O diagnosis scheme in use	M source of referral for outpatients
O primary diagnosis (read)	M referral request received date
O secondary diagnosis (read)	M referrer code
M attendance identifier	M referring organisation code
M administrative category	M organisation code type
M attended or did not attend	M last dna or patient cancelled date
M first attendance	O health care resource group code
	O health care resource group code-version number

M- mandatory, O- optional and *- must not be used.

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Notes: The outpatient attendance commissioning dataset contains data for out patient attendances and missed appointments. The dataset applies only to consultant attendances and appointments.

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Table 36 Items held on the GMS database

GP Characteristics	Practice Activity	Practice Characteristics	Patient Characteristics
GPs by country of qualification	Number of Practices	Total Patients	Patients by Age and Sex
GPs by Age Group	Total number of GPs	Female Patients	Fringe Patients
Female GPs	GPs offering Asthma Services	Male Patients	Deprivation Claims
Part-time GPs	GPs offering Diabetes Services	Rural Patients	Patients for whom Drugs are Dispensed
Female Part-time GPs	GPs offering Minor Surgery	PMS Pilots	Patients in Rural Areas
Salaried GPs	GPs offering Child Health Surveillance Services		
Female Salaried GPs	GPs using Deputising Services		
Restricted GPs	Health Promotion Services		
Female Restricted GPs	Out of Hours cover		
Course Organisers	Contraceptive Services provision		
Approved Trainers	Maternity Services provision		
Seniority Allowance Entitlements (1997)	Smallshare Partners		
	Dispensing GPs		
	Postgraduate Education Allowances		
	Basic Pay Allowances		
	Deprived Patient Claims		
	MMR2 provision		
	Telephone Treatment for Temporary Residents		
	Practice Quality Service Payments		
	Claims for Minor Surgery (1997)		
	Claims for Night Visits (1997)		

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Table 37 Community returns

Community Return	Number	Discontinued or Identified for discontinuation *
Summary of Chiropractic services	KT23	
Summary of Clinical psychology services	KT24	
Summary of Occupational therapy services	KT26	
Summary of Physiotherapy services	KT27	
Summary of Speech and Language Therapy services	KT29	
Community Maternity Services	KC54	Yes
Health visiting and professional advice and support programmes in the community	KC55	Yes
Patient care in the community, District Nursing	KC56	Yes
Patient care in the community, Community Psychiatric Nursing	KC57	Yes
Patient care in the community, Community Learning Disability Nursing	KC58	Yes
Patient care in the community, Specialist Care Nursing	KC59	Yes

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Table 38 Contents of the 1995 proposed person based contract minimum dataset

Field	Notes
Purchaser ID	
Provider ID	
Contract Serial Number	
Sequence number	Used to distinguish between or link records relating to the patient but which may refer to different concurrent problems
Record status	Marks the record subject as new, completed, closed, continuation, update or correction
Care Aim	
Health Needs Group	Rewritten as Health Needs Groups from Care Programmes
Discharge Reason	
Postcode	
NHS Number	
Birth date	
Sex	
Code of GP Practice	
Code of GP referring	
Code of GP Practice referring	
Source of referral	Can refer to a uni or multi disciplinary care episode, or care profile, depending upon the value of the record subject flag
Start date	
End date	
Patient/Client status	To indicate whether the patient is on a waiting list, under active care etc.
Record subject flag	A field to indicate if the subject of the dataset is e.g. a uni or multi disciplinary care episode or a care profile
Ethnic origin	
Care profile(s)	To denote the current care profile(s) relevant to the episode
Outcome	To communicate the outcome of the care in relation to the episode or care profile
Lead profession	Denotes the lead profession in multidisciplinary care who are responsible for the episode or care profile
Dependency score	To embrace factors that might influence workload and outcome of the episode or care profile

Table 39 Social services returns

Social services returns made to the department of health

Social services departments returns to the Department of Health - Adults

Local authority-supported residents in residential and nursing care (SR1)

Day centre provision for adults (DC3)

Home help and home care (HH1)

Meals services (MS1)

Registered homes for adults returns (A/B/C)

Registers of disabled people blind/partially sighted (SSDA 902)

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Table 40 Waiting times data returns

Information Request	Ref	Collection Period	Description /Purpose	Publication Details/Audience	ROCR No.
Consultant Outpatient First Attendances (Commissioner Based)	QM08R	Quarterly	Used as performance management measures of waiting times by HQ. Also used in PES negotiations; for the production of inpatient and outpatient modeling tools; risk analysis and for Departmental accountability.	Waiting Times for first outpatient appointment in England. Detailed statistics (Relevant Population Based). http://www.performance.doh.gov.uk/waitingtimes/index.htm	0003/001
Consultant Outpatient First Attendances (Provider Based)	QM08	Quarterly	"	Waiting Times for first outpatient appointment in England. http://www.performance.doh.gov.uk/waitingtimes/index.htm	0004/001
Demand for Elective Admission (Commissioner Based)	QF01	Quarterly	"	Waiting times. http://www.performance.doh.gov.uk/waitingtimes/index.htm	0006/001
Demand for Elective Admission: Events occurring during the Quarter (Provider Based)	KH06	Quarterly	Measures essential hospital activity for patients seen in hospital by nursing staff.	Hospital Waiting List Statistics, England. http://www.performance.doh.gov.uk/waitingtimes/index.htm	0007
Demand for Elective Admission: Events occurring during the Quarter (Relevant Population Based)	KH06R	Quarterly	"	Hospital Waiting List Statistics: (Responsible Population Based). http://www.performance.doh.gov.uk/waitingtimes/index.htm	0008
Demand for Elective Admission: Number of People who have Deferred	KH07AR	Quarterly	"	Not published.	0009

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Information Request	Ref	Collection Period	Description /Purpose	Publication Details/Audience	ROCR No.
Admission Waiting at the End of the Quarter (Commissioner Based)					
Demand for Elective Admission: Number of People who have Deferred Admission Waiting at the End of the Quarter (Provider Based)	KH07A	Quarterly	"	Not published.	0010
Demand for Elective Admission: Position at the end of the Quarter (Provider Based)	KH07	Quarterly	"	Hospital Waiting List Statistics: England. Health and Personal Social Services Statistics. Annual Reports.	0011/001
National Cancer Dataset Waiting times subset	Cancer Waiting Times Database	Monthly and quarterly	Collects data on waiting times during a cancer patient's journey from primary to secondary and possibly tertiary care and replace existing data collections on cancer waiting times.	Subject to ministers views, data from Q3 2002/03 onwards will be published quarterly on the web.	0018/001

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Table 41 Conditions and episodes recorded on return KC60

Condition

Primary and secondary infectious syphilis
Early latent syphilis (first 2 years)
Other acquired syphilis
Congenital syphilis, aged under 2
Congenital syphilis, aged 2 or over
Epidemiological treatment of suspected syphilis
Uncomplicated gonorrhoea
Gonococcal ophthalmia neonatorum
Epidemiological treatment of suspected gonorrhoea
Complicated gonococcal infection – including PID and epididymitis
Chancroid/LGV/Donovanosis
Uncomplicated Chlamydia infection
Complicated Chlamydial infection – including PID and epididymitis
Chlamydia ophthalmia neonatorum
Epidemiological treatment of suspected Chlamydia
Uncomplicated non-gonococcal/non-specific urethritis in males or treatment of mucopurulent cervicitis in females
Epidemiological treatment of NSGI
Complicated infection (non-chlamydial/non-gonococcal) – including PID and epididymitis
Trichomoniasis
Anaerobic/bacterial vaginosis & anaerobic balanitis
Other vaginosis/vaginitis/balanitis
Anogenital candidosis
Epidemiological treatment of C6 & C7
Scabies/pediculosis pubis
Anogenital herpes simplex: first attack
Anogenital herpes simplex: recurrence
Anogenital warts: first attack
Anogenital warts: recurrence
Anogenital warts: re-registered cases
Molluscum contagiosum
Viral hepatitis B (HbsAg positive): first diagnosis**
**of which were acute viral hepatitis B
Viral hepatitis C: first diagnosis

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Urinary tract infection

Other conditions requiring treatment at GUM clinic

Other episodes not requiring treatment

New HIV diagnosis: asymptomatic

New HIV diagnosis: symptomatic (not AIDS)

Subsequent HIV presentation (not AIDS)

AIDS: first presentation - new HIV diagnosis

AIDS: first presentation - HIV diagnosed previously

AIDS: subsequent presentation

Sexual health screen (no HIV antibody test)

HIV antibody test (no sexual health screen)

HIV antibody test and sexual health screen

HIV antibody test offered and refused

Hepatitis B vaccination (1st dose only)

Contraception (excluding condom provision)

Cervical cytology: minor abnormality

Cervical cytology: major abnormality

Source: Form KC60

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Table 42 Sources of surveillance data to CDSC

Topic	Source of data	Information received
Laboratory diagnosis	HPA, NHS and private laboratories	Laboratory report
Diagnosis	Clinicians	Notifications of infectious disease
STI Diagnosis	GUM clinic	KC60 return
Vaccine coverage	Immunisation co-ordinators	COVER data
Death	Clinician/Coroner via Office for National Statistics	Death registration
Survey of prevalent diagnosed HIV infections	HIV treatment centre	Case record
Outbreaks and incidents	Consultants in Communicable Disease Control, Environmental Health Officers, Clinicians, Others	Incident report
International outbreaks and incidents	WHO, CDC, other national agencies	Incident report
Food, water and environment specimens	Laboratories	Laboratory report
Rare diseases	Clinicians	Case report
Serological surveys and special studies	Laboratories	Laboratory report
Adverse event monitoring	Clinicians, laboratories	Various details
Hospital episode	Hospital records via Department of Health	Hospital episode statistics
International surveillance	Clinicians, laboratories	Various details
Primary care diagnosis	Spotter practices via Royal College of General Practice	Diagnosis
Surveys and studies	Various	Various details

Source: Reproduced from HPA web site at <http://www.hpa.org.uk>

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Table 43 List of questions asked of a household in the England and Wales 2001 Census

Household accommodation

Type of accommodation
Whether accommodation is self-contained
Number of rooms
Whether have sole use of bath/shower and toilet
Lowest Level of accommodation
Central heating
Car/van ownership
Ownership of accommodation and type of landlord

Household members and their relationships: individual questions

Sex
Date of birth
Marital status
Address one year ago
Country of birth
Ethnic group
Religion (voluntary)
Knowledge of Welsh language (Wales only)
Limiting-long term illness
General Health
Provision of care
Academic and vocational qualifications
Professional qualifications
Economic Activity
Time since last employment
Employment status (employed or self-employed)
Size of workforce and place of work
Occupation
Supervisor status
Industry
Hours usually worked
Name and address of employer
Method of travel to work

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Table 44 Wording of health and race questions in the England and Wales 2001 Census

Census Question 8: What is your ethnic group?

A White

British Irish

Any other white background

B Mixed

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed background

C Asian or Asian British

Indian Pakistani

Bangladeshi

Any other Asian background

D Black or Black British

Caribbean African

Any other Black background

E Chinese or other ethnic group

Chinese

Any other

Census Question 11: Over the last twelve months would you say your health has on the whole been:

Good?

Fairly good?

Not good?

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Census Question 12: Do you look after, or give any help or support to family members, friends, neighbours or others because of:

long-term physical or mental ill-health or disability, or problems related to old age?

Time spend in a typical week

No

Yes 1-19 hours a week

Yes 20-49 hours a week

Yes, 50+ hours a week

Census Question 13: Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?

Yes No

Source: 29 April 'Count me in' England Household Form

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Table 45 Health Survey for England information collected

Household level information

Household size, composition and relationships
Smoking in household
Heating/cooking appliances
Household pets
Car and telephone ownership
Type of dwelling and area
Accommodation tenure and number of bedrooms
Accident prevention equipment
Mould and dampness
Household income/sources of income
Economic status/occupation of household reference person

Individual level information

Age <2 2-3 4 5-6 7 8-9 10 11-12 13-15 16-64 65+

General health, longstanding illness, limiting longstanding illness, acute sickness
Use of health services
Use of dental services
Use of child health services
Fruit and vegetable consumption
Disability
Accidents, including fractures
Respiratory problems (asthma), hayfever and eczema
Smoking and drinking
Reported birth weight
Economic status/occupation
Educational attainment
Ethnic origin
Height measurement
Weight measurement
GHQ12
Social support
Social capital
Incontinence

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CAGE

Use of contraceptive pill and hormone replacement therapy

Nurse visit information

Prescribed medicines and vitamin supplements

Nicotine replacements

Immunisations

Length measurement

Blood pressure

Waist and hip circumferences

Lung function

Demi-span

Saliva sample - cotinine

Blood sample - haemoglobin, ferritin

Blood sample - IgE, HDM IgE

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Table 46 Health related questions in the General Household Survey

Annual Questions

Family Information/Fertility

- Expected family size
- Intentions for further children
- Age at which most recent baby was born
- Age expected to have last baby
- Date of birth and sex of each birth in present marriage

Chronic Sickness

- Prevalence and type of longstanding illness or disability
- Prevalence of limiting longstanding illness or disability

Acute Sickness

- Prevalence and duration of restricted activity

Health in general in the 12 months before interview

- Prevalence of chronic health problems

GP Consultations

- Consultations in the two weeks before interview
- Was a prescription given

Outpatients attendances

- Attendances at hospital OP departments in a three month reference period

Day patients visits

- Number of separate days in hospital in the last year

Inpatients spells

- Stays in hospital as an inpatient in a 12 month reference period

Health and personal social services

- Persons aged 65 and over
-

Occasional Questions

Family Information/Fertility

- Contraception and sterilisation

Mobility aids

- Difficulty in getting about without assistance, what help is needed

Elderly persons

- Do any relatives live near by

Sight and hearing

- Difficulty with sight, wearing glasses

Dental health

- Presence of natural teeth

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Table 47 Birth registrations: data items from the draft entry form used for registering live births in Form 309 (rev)

Birth	Birth
GRO reference number	Register number
District and sub-district numbers	Entry number
Register number	Registration district and number
Date of registration	Sub-district and number
Entry number	Administrative Area
Birthweight	
Sex	Child
Father	
Mother	Date and place of birth
Postcode	Name and surname
Multiple birth, yes or no	Sex
Number of births this maternity	
Confidential particulars	Father
Father's date of birth (if named)	Name and surname
Mother's date of birth	Place of birth
Where child born in within marriage	Occupation
Date of marriage	
Has the mother been married more than once	Mother
Number of mother's previous children	
Number born alive	Name and surname
Number stillborn	Place of birth
	Occupation
	Maiden surname
	Surname at marriage if different from maiden name
	Usual address
Informant	NHS number

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Table 48 NHS Number for Babies: NN4B Data Items

Baby	Mother
Name	Name
NHS number	NHS Number
Date of Birth	Date of Birth
Delivery Time	
Sex	Health care Professionals
Live or Still Birth	
Birth Weight	Name (of person notifying birth)
Gestation Length	GP Name
Number of births in this confinement	Practice Name
Birth Order	Practice address
Suspected congenital anomaly Y or N	Postcode of Practice
Ethnic Category (Defined by mother)	National GP code
Patient's (baby's) Usual Address	National Practice Code
Postcode of Patient's (baby) Usual address	Child Health Organisation Code
Baby Discharge address	
Postcode of Baby Discharge address	
Hospital or maternity unit	
Delivery Place Type Code	

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Table 49 Child Health Systems: Data Items collected as part of the National Child Health Computing System (NCHCS) and the Regional Interactive Child Health System (RICHS)

NCHCS	RICHS
Baby	Baby
DoB	DoB
Surname	Surname
Sex	Sex
Ethnicity (optional)	(See mother's ethnicity below)
Length of gestation	Gestation period
Live/Still birth	Live/Still birth
Birth weight	Birth weight
	Length at birth
	Head circumference at birth
	Onset of regular respirations
	Apgar Score
Infant resuscitation after delivery (optional)	Resuscitation (Y or N and details)
Date of death	Died within 24 hrs
"	Died between 1 to 7 days
"	Died between 8 to 28 days
Hospital admissions after birth	Transferred to hospital within 28 days
	Special care baby unit
Congenital malformation observable at birth	Congenital abnormalities (Y or N and details)
Mother	Mother
DoB	DoB
	PAS #
	NHS #
(See baby's ethnicity above)	Ethnicity
Previous live births	Previous live births
Previous stillbirths	

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NCHCS	RICHs
Previous miscarriages / terminations	Previous miscarriages
Previous pregnancies	Previous pregnancies
Previous neonatal deaths	
Single parent family	One parent family
	Sickle Cell Test
	HEP B Screen
	Thalassaemia Test
	Alphafetoprotein (AFP)
	Amniocentesis
Birth	Birth
Gestation @ booking	When Booked
Number of babies born	No births this confinement
Ranking for multiple births	Rank within birth
Time of birth	Time of birth
Place of birth	Place of birth
Labour on-set method (optional)	Type of Labour
Method of delivery	Mode of delivery
Place of birth	Place of delivery
DHA of hospital at birth	(Can derive)
DHA of hospital subsequent to birth	
Intended place of birth (optional)	Intended place of delivery
Reason for change (optional)	Reason for change
Other	Other
GP at birth	GP at birth
	Health clinic at birth
	Health visitor at birth
Address at birth	Postcode at birth
Address subsequent to birth	
	Born in RICHs
	Resident in RICHs
	Transfer code?

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Table 50 Medical Certificate of Cause of Death: data items

Person Details	Cause of Death
Name of deceased	I (a) Disease or condition leading to death
Date of death (as stated to Dr)	I (b) Other disease or condition if any leading to 1 (a)
Age	I © Other disease or condition if any leading to 1 (b)
Place of death	
Last see alive (by Dr completing the cert)	II Other significant conditions contributing to death but not related to the disease or condition causing it.
	Basis on which death is certified
	1 PM
	2 PM data available later
	3 PM not being held
	4 Death reported to Coroner
	a Seen after death by me
	b Seen after death by another Doctor
	c Not seen after death by a Doctor

Table 51 Death Registration: Data Items from the draft entry form used for registering deaths

Data item
Name of sub-district
Administrative area
Date and place of death
Name and surname of the deceased
Sex
Maiden surname, if the deceased was a woman who had married
Date and place of birth
Occupation
Name and occupation of husband, where the deceased was a married woman or widow
Usual address
Informant: name, surname, qualifications, usual address
Cause of death/doctor or coroner's name and qualifications
Signature of informant
Date of registration
Signature of registrar

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Table 52 Stillbirths: Data items from the draft entry form used for registering stillbirths in Form 308 (rev)

Stillbirth	Stillbirth
Dist and Sub-Dist Nos	Register No
Register No	Entry No
Date Registration	Registration District and No
Entry No	Sub-district and No
Birthweight	Administrative Area
Weeks of gestation	
Post-mortem	Child
Before labour, after labour n/k	
Father	Date and Place of birth
Mother	Name and Surname
Postcode	Cause of death
Multiple birth	Sex
Number of births this maternity	
Confidential particulars	Father
Fathers DoB (if named)	Name and Surname
Mothers DoB	Place of birth
Where child born in within marriage	Occupation
Date of Marriage	Mother
Has the mother been married more than once	
Number of mother's previous children	Name and Surname
Number born alive	Place of birth
Number still-born	Occupation
	Maiden surname
Informant	Surname @ marriage if different from maiden name
	Usual Address

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Table 53 Congenital anomalies: data items collected in Form SD56

Child	Mother/Father
NHS Number	Mother's Address (inc Post code)
HA in which baby was born	HA of usual residence
Place of birth	DoB/age
DoB	Date LMP
Sex	Mother's occupation
Live or Stillbirth	Fathers occupation
Single or Multiple birth	Number and outcome of previous pregnancies
Estimated Gestation	
Birth weight	
Congenital anomalies reported	

Table 54 Data items collected on Forms HSA4 Abortion Notification (rev April 2002)

Data items:	
Details of practitioner terminating the pregnancy	Patients hospital number
Details of certifying practitioners	DoB
Details of place of termination	Post-code
Date of termination	Non-UK state residence
Details of method of termination	Ethnicity
Grounds for termination	Parity (details of stillbirth, miscarriage and terminations)
Emergency or selective termination	Gestation
Chlamydia screening	Complications
	Death of woman (date and cause)

Notes: Data on abortions are collected in England and Wales under the Abortion Act 1967 as amended. Regulations under the act (The Abortion Regulations 1968, Statutory Instrument 1968 No 390 as amended) require the practitioner terminating the pregnancy to notify all abortions to the Chief Medical Officer, within seven days.

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Table 55: Confidential Enquiry into Maternal Deaths (CEMD)

Background details	This pregnancy
Timing of death in relation to pregnancy	LMP
Marital/ partnership status	Gestational age at booking
Country of birth	Initial arrangements for antenatal care
Immigration status	Initial arrangements for delivery
Social circumstances	Antenatal visits, place and results
Known to social services?	
Ethnic group	Details of miscarriage or termination
Drug/ alcohol/ smoking status	Details of ectopic pregnancy
Occupation	Details of other death before labour
Partner's occupation	Labour and delivery
Summary of social and medical history	Place
	Staff in attendance, including garde
	Date of admission
	Duration of labour
	Onset of labour
	Method of delivery
	Whether delays in obtaining help
	Blood loss and drugs in third stage
	Anaesthesia and analgesia
	Baby
	Live/ stillbirth
	Survival of live births
	Sex
	Birth weight

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Table 56 Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) Rapid Report Form Data Items

Mother	Infant
Name	Name
Hospital number	Hospital number
Usual residence at birth	Baby's residential address if different from mother
Post code	Post code
DoB (or age)	Sex
Ethnic group	Birth weight
Parity	Place of death
Estimated Date of Delivery (EDD)	Is place of death in baby's region of residence
Basis of EDD calculation	Date and time of diagnosis of death
Clinical estimate of gestation	How long before first diagnosis of death was baby thought to have died
Date and time of delivery	Timing of death (stillbirth/late fetal losses)
Place first booked for delivery	Signs/observations at birth
Type of care first booked	Cause of death
Place of actual delivery	Details of cause of death
Type of care at delivery	Fetal and Infant classification
Number of fetuses/babies this pregnancy	Obstetric classification
Birth order	Postmortem carried out
Hx of maternal infection during pregnancy	
	Reporting
	Reported by
	Position/post
	Contact address
	Contact phone
	Date of form completion

8.2.1 Data sources specific to the case studies not previously described

Case Study 3: Cancer

Table 57 Data items, cancer dataset version 4.0

Data Item	Description
1 Demographics	It is anticipated that some of the demographic data items listed below will be collected by every provider with which the patient has contact.
1.1 NHS Number	The patient's unique 10 digit new format NHS Number
1.2 Local patient identifier	The local number by which the patient is known at this hospital. This may be hospital site specific i.e. there may be different hospital numbers collected for the patient at different points in the pathway.
1.3 Organisation code	The organisation code of the Unit providing the diagnosis or care to the patient.
1.4 Care spell identifier	To link all activities for a patient to the same care spell. It is envisaged that this will be allocated on diagnosis, at the organisation where the diagnosis takes place, and will be communicated to all organisations providing care to the patient.
1.5 Patient family or surname	The patient's Surname
1.6 Patient forename or personal name	The patient's Forenames
1.7 Patient usual address	ONS rules for completion of this field will need to be followed.
1.8 Postcode of usual address	ONS rules for completion of this field will need to be followed.
1.9 Sex	The patient's sex
1.10 Birth date	The patient's date of birth
1.11 GMP (code of registered GMP)	The GP with whom the patient is registered
1.12 Code of GP practice	Practice with whom the patient is registered
1.13 Organisation code	PCT corresponding to the GP Practice Code
1.14 Patient family or surname (at birth)	The patient's surname at birth
1.15 Ethnic category	The ethnic category of the patient, as specified by the patient.

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Data Item	Description
<p>2 Referrals</p> <p>2.1 Source of referral for cancer</p> <p>2.2 Referring organisation code</p> <p>2.3 Referrer code</p> <p>2.4 Cancer referral priority type</p> <p>2.5 Cancer referral decision date</p> <p>2.6 Referral request received date</p> <p>2.7 Consultant code</p>	<p>For 'two-week wait' referrals, only one referral needs to be recorded. This will be the referral to the consultant (or team) who makes the actual diagnosis of cancer.</p> <p>If the original GP referral was to a non-cancer specialist, with subsequent referral to a cancer specialist, then record all referrals. Where this information is exchanged, the appropriate data item name should be used to identify the particular instance of the data (See Description column).</p> <p>The Cancer Data Manual will detail particular requirements for screening, where the diagnosis takes place within screening services and referral is for treatment. Relevance of the data items in this section to the screening services will be investigated further.</p> <p>From where the referral originates</p> <p>The organisation at which the person referring the patient is based e.g. the hospital or site's organisation code, the GP's Practice Code</p> <p>The code of the person referring the patient e.g. GP Code, Consultant Code, General Dental Practitioner, Nurses</p> <p>This field is to be submitted in conjunction with data item 2.16 "SOURCE OF REFERRAL FOR OUTPATIENTS" in order to differentiate those records that fall within the boundaries of the two-week wait standards. This data item is to refer to the initial referral into the first secondary care unit on the patient pathway.</p> <p>The date on which the referral was made:</p> <p>The date that the referral request is received by the provider:</p> <p>The person to whom the referral is made. If the referral is to a team, then this refers to the first consultant seen.</p>
<p>2.8 Speciality function code</p>	<p>The code for the specialty to which the patient is being referred.</p>
<p>2.9 Date first seen</p>	<p>The date that the patient is seen by the person 'referred to' in 2.7 above</p>
<p>2.10 Delay reason referral to first seen (cancer)</p>	<p>This data item is only applicable to those patients who are urgent GP referrals for suspected cancer</p>
<p>2.11 Delay reason comment (first seen)</p>	<p>This is a free text item that must be completed to inform the return on reasons why the existing standard was breached (after any adjustments have been made):</p> <p>The reason why the maximum two week wait from urgent GP referral for suspected cancer and date first seen could not be met.</p>
<p>2.12 Urgent cancer referral type</p>	<p>This is the site where cancer is suspected by the GP or GDP.</p>
<p>2.13 Cancer status</p>	<p>The status of this referral</p>

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Data Item	Description
2.14 Waiting time adjustment	Record here the number of days that should be removed from the recorded waiting time between referral decision date and date first seen. Adjustments are allowed in the same circumstances as for outpatients in general waiting times
2.15 Waiting time adjustment reason (first seen)	Record the prime reason for adjustment to waiting time. When there are multiple adjustments, the reason for the longest adjustment should be recorded. If the patient chose not to have an appointment within two weeks, this code should always take precedence over any other code.
2.16 Source of referral for outpatients	A classification which is used to identify the source of referral of each CONSULTANT OUTPATIENT EPISODE.
3 Imaging	This must be collected for all imaging performed to establish diagnosis and/or staging. '-oscopies' should be entered as a procedure. Imaging performed as an intervention should be entered as a procedure e.g. imaging plus biopsy. Imaging relevant to a patient's cancer follow-up should be recorded. It is not intended to record imaging that is not considered to be relevant to cancer follow-up.
3.1 Site code (of imaging)	The organisation at which the imaging took place
3.2 Clinical intervention date	The date the test took place
3.3 Cancer imaging modality	The type of imaging technique/equipment used to produce the image e.g. Ultrasound, Mammography
3.4 Anatomical examination site	The site (part of the body) for the examination. It refers to the site that is the subject of the image, rather than the site of the suspected or confirmed cancer.
3.5 Invasive leisure size	The widest dimension of the tumour as measured by imaging. An estimate of the size of the tumour from the image produced is useful to record where possible.
4 Diagnosis	These fields should record the definitive diagnosis as known to the hospital in question, based on the information available at the time the items were completed. There will be only one definitive diagnosis entry held.
4.1 Diagnosis date (cancer)	This field records the date of diagnosis of the tumour. It is required with the date of birth to derive the age at diagnosis and is used in the analysis of incidence trends and in the calculation of survival rates. The definition provided conforms to the international requirements specified by the European Network of Cancer Registries (ENCR).
4.2 Primary diagnosis (ICD)	The main cancer site for which the patient is receiving care.
4.3 Tumour laterality	The laterality of the primary tumour. To differentiate tumours in paired organs.

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Data Item	Description
4.4 Basis of diagnosis (cancer)	This field records the eligibility of the tumour for registration based on the best source of information known to the Trust and allows derivation of the degree of certainty of diagnosis. It is therefore an indicator of data quality, with microscopic histological verification being viewed as the 'gold standard' diagnosis. The definition provided conforms with the international requirements specified by the European Network of Cancer Registries (ENCR).
4.5 Histology (snomed)	The cell type of the malignant disease
4.6 Grade of differentiation	Qualitative assessment of the differentiation of the tumour expressed as the extent to which a tumour resembles the normal tissue at that site. Note: This data item also appears in the Pathology section. It is repeated here in order to record the definitive grade of the tumour at the point of diagnosis (there may be a number of Pathology reports contributing to the diagnosis).
5 Cancer Care Plan	There may be a number of cancer care plans, on different dates.
5.1 MDT discussion indicator	To record the fact that the care of this patient was formally reviewed by a specialist team. The MDT is as defined by National Guidance.
5.2 Multidisciplinary team discussion date	The date that cancer care plan was discussed by the specialist team. The MDT is as defined by National Guidance
5.3 Care plan agreed date	The date that the cancer care plan was agreed and the decision to treat was made.
5.4 Recurrent indicator	To indicate whether this care plan is for a recurrence of the primary cancer.
5.5 Cancer care plan intent	The intention of the treatment being planned. Curative – treatment given with the potential for cure (radical treatment) even if the proportion of patients achieving long term disease control (> 2 years) is small Palliative – anti-cancer treatment given with the aim of symptom control Palliative - supportive treatment
5.6 Planned cancer treatment type	What treatment(s) are planned for the patient
5.7 Treatment type sequence	The sequence of the treatment(s) above
5.8 No cancer treatment reason	The reason for no specific anti-cancer treatment at the date of the MDT meeting. Note that this will be a multiple response item i.e. any number of reasons may be recorded.
5.9 Co-morbidity index for adults	The nature of any relevant co-morbidity, to be recorded at the MDT meeting prior to the beginning of treatment. Note that a different index would be required for children.

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Data Item	Description
5.10 Performance status (adult)	The patient's performance status, to be recorded at the MDT meeting prior to the beginning of treatment. Note that a different index would be required for children.
6 Staging	These fields should be recorded at the time that the first cancer care plan is agreed. Cancer registries require the first pre-treatment stage, i.e. the stage at diagnosis.
6.1 T category (final pre-treatment)	The 'T' part of the TNM classification used to describe the clinical stage of the tumour prior to treatment
6.2 Staging certainty factor (T category)	The validity of the T part of the TNM classification according to the diagnostic methods employed.
6.3 N category (final pre-treatment)	The 'N' part of the TNM classification used to describe the clinical stage of the tumour prior to treatment. Note that micro-metastases should be considered as positive.
6.4 Staging certainty factor (N category)	The validity of the N part of the TNM classification according to the diagnostic methods employed.
6.5 M category (final pre-treatment)	The 'M' part of the TNM classification used to describe the clinical stage of the tumour prior to treatment
6.6 Staging certainty factor (M category)	The validity of the M part of the TNM classification according to the diagnostic methods employed.
6.7 TNM category (final pre-treatment)	Overall clinical TNM stage of the tumour, derived from each T, N, M component prior to treatment
6.8 Staging certainty factor	The validity of the TNM classification according to the diagnostic methods employed.
6.9 Site specific staging classification	Non-TNM staging system, which may or may not map on to an equivalent TNM stage. Coding system will be specified as appropriate for each site.
6.10 TNM category (integrated)	The combination of pT with pN and pM into stage groups that are more or less homogeneous in respect of survival and for which the survival rates are distinctive.
6.11 T category (integrated stage)	The 'T' part of the TNM classification used to describe the integrated stage of the tumour
6.12 N category (integrated stage)	The 'N' part of the TNM classification used to describe the integrated stage of the tumour. Note that micro-metastases should be considered as positive.
6.13 M category (integrated stage)	The 'M' part of the TNM classification used to describe the integrated stage of the tumour
7 Surgery and Other Procedures	This can be adapted for other procedures including interventional radiology, laser treatment, endoscopies etc. and photo-dynamic procedures. This also includes procedures offered as supportive care.
7.1 Site code (of surgery)	The hospital at which the surgery takes place.
7.2 Consultant code	The consultant in overall charge of the patient's treatment.
7.3 Speciality function code	The managing consultant's speciality code

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Data Item	Description
7.4 Cancer treatment intent	The purpose of the surgical procedure(s) being carried out
7.5 Decision to treat (surgery)	The date that it was decided that this patient should receive surgery. This is the date that the consultation between the patient and the clinician took place and a treatment plan for surgery was agreed.
7.8 Start date (surgery hospital provider spell)	Where the procedure took place with the patient as an admitted patient – either as an in-patient or as a day case - record the date of admission for the hospital stay during which this procedure took place.
7.9 Procedure date	The date that the surgical procedure(s) below started.
7.10 Primary procedure (OPCS)	The main surgical procedure carried out
7.11 Procedure (OPCS)	Any sub-procedure carried out
7.12 Discharge date (hospital provider spell)	The date that the patient was discharged.
7.13 Discharge destination (hospital provider spell)	The destination of the patient on completion of the in-patient stay.
8 Pathology Details	Note: it is expected that all the data items on the minimum RCPATH dataset will be collected. The pathology data items below are a subset of that dataset. A patient may have any number of pathology reports, and there may be more than one pathology report per specimen. If the original report is reviewed or revised, then a new pathology module will need to be completed and dated, with the data item 'Second Opinion' on the RCPATH Dataset marked as 'Y'.
8.1 Pathology investigation type	Cytology, Biopsy or Excision
8.2 Sample receipt date	The date that the specimen was received by the pathology laboratory.
8.3 Investigation result date	The date of the pathology report
8.4 Consultant code (pathologist)	The code of the pathologist authorising the report
8.5 Organisation code (of reporting pathology)	The organisation at which the authorising pathologist is based.
8.6 Primary diagnosis (ICD)	The topographical site of the tumour
8.7 Tumour laterality	Side
8.8 Invasive lesion size	To record the size of the tumour
8.9 Synchronous tumour indicator	To record the presence of multiple tumours for a tumour site.
8.10 Histology (snomed)	The cell type of the malignant disease
8.11 Grade of differentiation	Qualitative assessment of the differentiation of the tumour expressed as the extent to which a tumour resembles the normal tissue at that site.
8.12 Cancer vascular or lymphatic invasion	To record the presence of unequivocal tumour in vascular spaces.

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Data Item	Description
8.13 Excision margin	Whether all the excision margins were clear of tumour.
8.14 Nodes examined number	The number of local/regional nodes examined. Local/regional nodes are defined by the UICC TNM Atlas and vary with the primary cancer site
8.15 Nodes positive number	The number of local/regional nodes reported as being positive for the presence of tumour metastases. Local/regional nodes are defined by the UICC TNM Atlas and vary with the primary cancer site
8.16 T category (pathological)	The extent of the primary tumour after excision or biopsy of the primary cancer. This is derived from Local Invasion - Tumour Extent and Structure (s) Invaded data items on the Pathology dataset
8.17 N category (pathological)	The histological evidence of the absence or presence and extent of regional lymph node metastases. This is derived from Local/Regional nodes positive, Other Nodes positive and Marker lymph node 1 positive data items on the Pathology dataset.
8.18 M category (pathological)	The histological evidence of the absence or presence of distant metastases. This is derived from the Distant Metastases data item on the Pathology dataset.
8.19 TNM category (pathological)	The combination of pT with pN and pM into stage groups that are more or less homogeneous in respect of survival and for which the survival rates are distinctive.
8.20 Service report identifier	This field is a unique identifier allocated to the cytology, biopsy or excision report authorised by the pathologist.
8.21 Service report status	This field is a flag to indicate that the report is a second opinion or supplementary report on the tumour.
8.22 Speciman nature	This field records the nature of the specimen reported.
9 Chemotherapy and other drugs	Chemotherapy and/or other anti-Cancer and/or Supportive drugs given to the patient during their treatment.
9.1 Site code (of cancer drug treatment)	The hospital at which the drug treatment takes place
9.2 Consultant code	The consultant in overall charge of the patient's drug treatment
9.3 Speciality function code	The managing consultant's speciality code
9.4 Decision to treat date (anti-cancer drug regimen)	The date that the decision was made to treat the patient with drug therapy. This is the date that the consultation between the patient and the clinician took place and a treatment plan for drug therapy was agreed. The decision is made by the managing consultant or the managing consultant's representative.
9.7 Drug therapy type	The type of drug therapy administered
9.8 Drug treatment intent	The intended outcome of treatment
9.9 Drug regimen acronym	The acronym for this drug regimen
9.10 Start date (anti-cancer regimen)	Record the date on which the first dose of the drug is administered to the patient.

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Data Item	Description
9.11 Recorded height (cancer drug treatment)	The patient's height
9.12 Recorded weight (cancer drug treatment)	The patient's weight
9.13 Person body surface area	The surface area of skin, used to calculate the dose for the patient.
9.14 Creatinine clearance	The creatinine clearance (CrCl) in ml/minute. This needs to be recorded only when the drug carboplatin is prescribed, but can also be recorded for cisplatin, mitomycin and capecitabine if required.
9.15 Start date (anti-cancer drug fraction)	The date for each administration of drug treatment.
9.16 Anti-cancer drug cycle identifier	It is possible that this data field could be derived from other data items within this section.
9.17 Day number (anti-cancer drug cycle)	It is possible that this data field could be derived from other data items within this section.
9.18 Drug identification (anti-cancer drug fraction)	Drug protocols used in each episode of treatment
9.19 Drug dosage and admin specification	The actual dose given to the patient
9.20 Drug identification	The number of doses given per day
9.21 Duration of anti-cancer drug cycle	The number of days over which the treatment was given
9.22 Drug response programme	For chemotherapy: this should be assessed at the completion of the planned chemotherapy. For continuous treatment: record the maximum response.
9.23 Planned treatment change reason (cancer)	To record whether the treatment was delivered as planned.
9.24 Health care resource group code	This can be derived from the tumour site and the chemotherapy regimen
10 Radiotherapy	
10 Radiotherapy (teletherapy)	A course of teletherapy is defined as a string of prescriptions which are consecutive.
10.1 Site code (of teletherapy)	The hospital at which the teletherapy takes place
10.2 Consultant code	The consultant in overall charge of the patient's teletherapy treatment
10.3 Decision to treat date (teletherapy treatment course)	This is the date that the consultation between the patient and the clinician took place and the treatment plan for teletherapy was agreed.

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Data Item	Description
10.6 Cancer treatment intent	<p>Curative - any treatment where long-term survival is the aim of a significant proportion of patients</p> <p>Palliative - any treatment where the clear intention is to improve symptoms and possibly prolong life but where long-term survival is unlikely</p> <p>Adjuvant - an adjunct to a potentially ablative local treatment</p> <p>Neoadjuvant - an adjuvant treatment given prior to a potentially ablative local treatment</p> <p>Not known</p>
10.7 Radiotherapy anatomical treatment site	The part of the body to which the prescription is administered.
10.8 Start date (teletherapy treatment course)	The date on which the first fraction of teletherapy for this prescription is administered to the patient.
10.9 End date	The end date of the teletherapy course
10.1 Radiotherapy prescribed course 0	Total dose prescribed
10.1 Teletherapy prescribed fractions 1	Number of fractions prescribed
10.1 Radiotherapy prescribed duration 2	Total number of days over which treatment is planned to be given
10.1 Radiotherapy actual dose 3	Total dose given
10.1 Teletherapy actual fractions 4	The number of fractions given
10.1 Duration of teletherapy treatment 5	Total number of days over which treatment was given (can be derived from end date - start date)
10.1 Teletherapy beam type 6	The type of radiation given
10.1 Teletherapy beam energy 7	The energy of the beam
10.1 Teletherapy fields 8	The number of fields
10.1 Teletherapy complexity group 9	The grouping that classifies the complexity of the prescription
10.2 Radiotherapy anaesthetic 0	Is anaesthetic required during treatment?
10.2 Teletherapy multiple planning 1	An indication whether a treatment course requires a full repeat of planning and preparation to be undertaken
10.2 Health care resource group code 2	The HRG for this prescription reflects what was actually prescribed for the patient. The field is derived from data items above.
10.2 Treatment course status 3	The reason why the prescribed treatment was not given.

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Data Item	Description
11 Radiotherapy (Brachytherapy)	A course of brachytherapy is defined as a string of prescriptions which are consecutive.
11.1 Site code (of brachytherapy)	The hospital at which the brachytherapy takes place
11.2 Consultant code	The consultant in overall charge of the patient's brachytherapy treatment
11.3 Decision to treat date (brachytherapy treatment course)	This is the date that the consultation between the patient and the clinician took place and a treatment plan for brachytherapy was agreed.
11.6 Cancer treatment intent	<p>Curative - any treatment where long-term survival is the aim of a significant proportion of patients</p> <p>Palliative - any treatment where the clear intention is to improve symptoms and possibly prolong life but where long-term survival is unlikely</p> <p>Adjuvant - an adjunct to a potentially ablative local treatment</p> <p>Neoadjuvant - an adjuvant treatment given prior to a potentially ablative local treatment</p> <p>Not known</p>
11.7 Bachytherapy type	The type of brachytherapy being used
11.8 Radiotherapy anatomical treatment site	The part of the body to which the prescription is administered.
11.9 Start date (brachytherapy treatment course)	The date on which the first fraction of brachytherapy for this prescription is administered to the patient.
11.1 End date	The end date of the brachytherapy course
0	
11.1 Radiotherapy prescribed dose	Total dose of brachytherapy in grays
11.1 Radiotherapy prescribed duration	Time over which treatment is planned to be given
11.1 Bachytherapy prescribed fractions	The prescribed number of fractions of a Brachytherapy Treatment Course
11.1 Radiotherapy actual dose	Total dose of brachytherapy in grays
4	
11.1 Bachytherapy dose rate	The prescribed dose rate of the course
5	
11.1 Duration of brachytherapy treatment course	Time over which treatment was given (can be derived from end date - start date)
6	
11.1 Bachytherapy isotope type	The type of the radiation
7	
11.1 Radiotherapy anaesthetic	Is anaesthetic required during treatment?
8	
11.1 Unsealed source patient type	The classification of a patient (required for an Unsealed Source type of treatment only)
9	

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Data Item	Description
11.2 Brachytherapy delivery type 0	The type of delivery of brachytherapy treatment
11.2 Health care group resource code 1	The HRG for this prescription reflects what was actually prescribed for the patient. The field is derived from data items above.
11.2 Treatment course status 2	The reason why the prescribed treatment was not given.
12 Palliative Care	<p>Note: the Palliative Care data items are in the process of being developed.</p> <p>It is expected that this section will be completed whenever an intervention occurs that involves one face-to-face contact with the patient.</p> <p>It is expected that a Cancer Care Plan will also be completed for the Palliative Care Management Plan.</p>
13 Clinical Trials	Additional information corresponding to patients ineligible for a trial, or whether there is no trial available, can be recorded if required.
13.1 Patient trial status	The status of the clinical trial entry for the patient
13.2 Cancer clinical trial type	The type of the clinical trial being undertaken
14 Clinical Status Assessment	This section will be completed if the patient's status changes (e.g. the patient reports toxicity as a result of treatment) or at a review point.
14.1 Clinical status assessment date (cancer)	The date that the patient was seen.
14.2 Primary tumour status	The status of the primary tumour at this contact. This may need qualification according to certainty/confidence.
14.3 Nodal status	The status of the nodal metastases at this contact. This may need qualification according to certainty/confidence.
14.4 Metastatic status	The status of the distant metastases at this contact. This may need qualification according to certainty/confidence.
14.5 Marker response status	To record the marker level, for those cancers which produce a chemical which circulates in the blood.
14.6 Performance status (adults)	The patient's overall performance status at this contact Note that a different index would be required for children.
14.7 Treatment type (cancer morbidity)	Any morbidity, relevant to previous treatments that the patient has received, recorded at any subsequent patient contact
14.8 Morbidity code (cancer surgery)	Any morbidity, relevant to previous surgical treatments that the patient has received, recorded at any subsequent patient contact.
14.9 Patient follow-up status	To record the patient's follow-up status
14.1 Morbidity code 0 (chemotherapy)	Any morbidity, relevant to previous chemotherapy treatments that the patient has received, recorded at any subsequent patient contact

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Data Item	Description
14.1 Morbidity code 1 (chemotherapy)	Any morbidity, relevant to previous radiotherapy treatments that the patient has received, recorded at any subsequent patient contact Please note that for Radiotherapy morbidities, the European group will be producing definitions.
14.1 Morbidity code 2 (combination)	Any morbidity, relevant to previous combination treatments that the patient has received, recorded at any subsequent patient contact
15 Death Details	
15.1 Death date	The date the patient died. Left blank if the patient is still alive.
15.2 Death location type	Where the patient died
15.3 Death cause identification method	The source of the information about the death of the patient
15.4 Death cause cancer	The cause of death of the patient in relation to their diagnosis of cancer. Left blank if the patient is still alive.
15.5 Death cause code (immediate)	As recorded on the death certificate. Will be provided by Cancer Registry if death did not take place in the Trust.
15.6 Death cause code (condition)	As recorded on the death certificate. Will be provided by Cancer Registry if death did not take place in the Trust.
15.7 Death cause code (underlying)	As recorded on the death certificate. Will be provided by Cancer Registry if death did not take place in the Trust.
15.8 Death cause code (significant)	As recorded on the death certificate. Will be provided by Cancer Registry if death did not take place in the Trust.
15.9 Death code discrepancy indicator	The originator of the information that a death code discrepancy is present. This is a discrepancy between the cause of death presented on the death certificate and other evidence available.

Notes: The data items shaded are not mandated until electronic systems are in place; however Trusts can collect this information if they wish.

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Table 58 Cancer Dataset Version 4.0, additional data items required to monitor waiting times

Data Item	Description
16 Waiting Times Details	The following details need to be collected by the organisation providing the 'first definitive treatment'.
16.1 Waiting time adjustment (decision to treat)	<p>This is mandatory, whenever an adjustment is appropriate, for all tumours that came through the urgent GP suspected cancer route, irrespective of whether a target is in place.</p> <p>Record here the number of days that should be removed from the recorded waiting time between date first seen and decision to treat date. Adjustments are allowed in the same circumstances as for general waiting times:</p> <ul style="list-style-type: none"> when a patient defers an in-patient admission when a patient cancels an outpatient appointment. when a patient suspension from the elective admission list is made because they are medically unfit for treatment or when they are unavailable for treatment for a specified period because of family commitments, holidays or other reasons when a patient Fails To Attend an in-patient admission when a patient Does Not Attend an outpatient appointment
16.2 Waiting time adjustment (treatment)	<p>This is mandatory, whenever an adjustment is appropriate, for all tumours, irrespective of whether a target is in place.</p> <p>Record here the number of days that should be removed from the recorded waiting time between decision to treat date and date of first definitive treatment. Adjustments are allowed in the same circumstances as for general waiting times:</p> <ul style="list-style-type: none"> when a patient defers an in-patient admission when a patient cancels an outpatient appointment. when a patient suspension from the elective admission list is made because they are medically unfit for treatment or when they are unavailable for treatment for a specified period because of family commitments, holidays or other reasons when a patient Fails To Attend an in-patient admission when a patient Does Not Attend an outpatient appointment
16.3 Waiting time adjustment reason (decision to treat)	<p>Record the prime reason for adjustment to waiting time. Where there are multiple adjustments the reason for the longest adjustment should be recorded.</p> <p>The adjustment will be added to the adjustments between date of urgent GP referral for suspected cancer and date first seen, and between date of decision to treat and date of first definitive treatment, in order to adjust the total waiting time from urgent GP referral for suspected cancer to first treatment.</p>

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Data Item	Description
16.4 Waiting time adjustment reason (treatment)	<p>Record the prime reason for adjustment to waiting time. Where there are multiple adjustments the reason for the longest adjustment should be recorded.</p> <p>The adjustment will be added to the adjustments between date of urgent GP referral for suspected cancer and date first seen, and between date of decision to treat and date of first definitive treatment, in order to adjust the total waiting time from urgent GP referral for suspected cancer to first treatment.</p>
16.5 Delay reason referral to treatment (cancer)	<p>This is a coded data item that can be used to record why patients wait longer than target times, to help identify how to reduce waiting times.</p>
16.6 Delay reason decision to treatment (cancer)	<p>This is a coded data item that can be used to record why patients wait longer than target times, to help identify how to reduce waiting times.</p>
16.7 Delay reason comment (referral to treatment)	<p>This is a free text item that must be completed to inform the return on reasons why the existing standards were breached (after any adjustments have been made). The standards which will be in place at the end of 2002 are:</p> <ul style="list-style-type: none"> • maximum one month wait from urgent GP referral for suspected cancer to first definitive treatment for testicular cancer (ICD code C62), acute leukaemia (ICD codes C91.0, C92.0, C92.4, C92.5, C93.0, C94.2, C95.0) and children's cancer (under 16 years of age at date of first definitive treatment) • maximum two month wait from urgent GP referral for suspected cancer to first definitive treatment for breast cancer (ICD codes C50 and D05)
16.8 Delay reason comment (decision to treatment)	<p>This is a free text item that must be completed to inform the return on reasons why the existing standards were breached (after any adjustments have been made). The only standard which will be in place at the end of 2002 is:</p> <ul style="list-style-type: none"> • maximum one month wait from decision to treat to first definitive treatment for breast cancer (ICD codes C50 and D05)
16.9 Decision to treat date (active monitoring)	<p>The date on which it was decided that the patient should be actively monitored.</p> <p>This applies to prostate cancer only.</p>
16.1 Start date (active monitoring)	<p>The date of the consultation on which this plan of care was agreed with the patient.</p> <p>This applies to prostate cancer only.</p>

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Case study 4 Coronary Heart Disease

Table 59 Central Cardiac Audit Database (CCAD) core demographic data items

Item Number	Description
1.01	Hospital identifier
1.02	Patient Case Record Number
1.03	NHS Number
1.04	Patient Surname
1.05	Patient Forename
1.06	Patient Date of Birth
1.07	Patient Sex
1.08	Patient Ethnic Group
1.09	Patient Admin status
1.1	Patient Post Code
1.11	GP Practice Code

Table 60 Health Survey for England

Cardiovascular Disease Module 1998 data items

Total cholesterol
HDL cholesterol
Fibrinogen (a clotting agent - raised levels can contribute to CVD and stroke)
Haemoglobin
Ferritin
c-reactive protein
Cotinine (a metabolite of nicotine)

Case Study 6: Transport

Table 61 The National Travel Survey

Social and economic variables

H50	Type of tenancy
H65	Head of Household (HoH) /Household Reference Person (HRP) economic status
H66	HoH/HRP employment status
H67	SEG of HoH/HRP
H68	HoH/HRP age/sex
H69	HoH/HRP industry
H70	Household income
H72	Origin of household income
H84i	Real household income equivalent semi-decile (1998/2000)
H85i	Real household income equivalent quintile (1998/2000)
H83	Employed in household
H108	ACORN classification (from 1996)
H121	Index of deprivation (from 1998)

Appendix C The framework for access applied to the datasets reviewed in the Report

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8.3.1 NHS data sources: applying the framework for measuring and monitoring access to health care

Table 62 Hospital Episode Statistics (HES) and the Access Continuum – General episode

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Out-come
Dimensions of Access	Indicators of Access						
Characteristics of population at risk			PCT, SHA, NHS Region, National				
Characteristics of enrolled pop at risk	Age	Yes	Yes	Yes		Yes	Yes
	Sex	Yes	Yes	Yes		Yes	Yes
	Ethnicity	Yes	Yes	Yes		Yes	
	Country of Birth	No	No				
	Education	No	No				
	Socio-economic	No	No				
	Geography	Yes	Yes	Yes	Yes	Yes	
	Travel time	Yes as a derived variable	Yes as a derived variable	Yes	Yes		
	Morbidity	Yes ICD10, OPCS4	Yes ICD10 OPCS4	Yes		Yes	Yes
	Mortality	Yes if in hospital	Yes if in hospital	Yes			Yes
	Health beliefs and knowledge	No	No				
Characteristics of enrolled pop at risk	HES relates to the whole population						

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Table 63: Maternity Hospital Episode Statistics (HES)*

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access							
Characteristics of pop. at risk		Baby	Mother	England, NHS Region, SHA, Hospital				
	Age	NA	Yes	Yes	Yes			Yes
	Sex	Yes	NA	Yes-baby				
	Ethnicity	Yes	Yes	Yes	Yes		Yes	
	Country of Birth	Yes	No	-				
	Education	No	No	No				
	Socio-economic	No	No	No				
	Geography							
	Where birth occurred	Yes	Yes	Yes	Yes	Yes	Yes	
	Residence at birth	Yes	Yes	Not routinely	Yes	Yes		
	Travel time	Yes as a derived variable	Yes as a derived variable	Yes as a derived variable	Yes	Yes		
	Morbidity	Yes, gestation, birthweight, resuscitation	Yes, parity, delivery/onset method, anaesthetics	Yes	Yes			Yes

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	Mortality	Live or Stillbirth	Yes, in hospital	See mortality stats	Yes			Yes
	Health beliefs and knowledge	No	Yes intended delivery place		Yes	Yes	Yes	Yes

**NB relates only to the Maternity tail*

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Table 64 Outpatient data

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age	Yes		Yes		Yes	
	Sex	Yes		Yes		Yes	
	Ethnicity	No					
	Country of Birth	No					
	Education	No					
	Socio-economic	No					
	Geography	Yes	Yes, HC System by NHS Trust	Yes		Yes	
	Travel time	No		Yes			
	Morbidity	Yes		Yes		Yes	
	Mortality	No		Yes			
	Health beliefs and knowledge	No					

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Table 65 General Practice Research Database

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- - come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age	Yes	Practice	Yes		Yes	
	Sex	Yes	Practice	Yes		Yes	
	Ethnicity	No					
	Country of Birth	No					
	Education	No					
	Socio-economic	No					
	Geography		Yes, by practice	Yes		Yes	
	Travel time	No					
	Morbidity	Yes	Practice	Yes		Yes	
	Mortality	Yes		Yes		Yes	Yes
	Health beliefs and knowledge	No					
<p><i>These characteristics are of an enrolled population, i.e. those enrolled with contributing practices.</i></p>							

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Table 66 Morbidity statistics from General Practice

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- - come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age	Yes		Yes		Yes	
	Sex	Yes		Yes		Yes	
	Ethnicity	Yes		Yes		Yes	
	Country of Birth	No					
	Education	No					
	Socio-economic	Yes		Yes		Yes	
	Geography	Yes		Yes		Yes	
	Travel time	Yes		Yes		Yes	
	Morbidity	Yes		Yes		Yes	
	Mortality	No					
	Health beliefs and knowledge	No					
<p><i>These characteristics are of an enrolled population, i.e. those enrolled with contributing practices.</i></p>							

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Table 67 Prescription Analysis and Cost Tables (PACT)

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age	No					
	Sex	No					
	Ethnicity	No					
	Country of Birth	No					
	Education	No					
	Socio-economic	No					
	Geography		Yes, HC system, by GP practice	Yes		Yes	
	Travel time	No					
	Morbidity	No					
	Mortality	No					
	Health beliefs and knowledge	No					

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Table 68 Community health services data

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- - come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age		Yes, contacts	Yes		Yes	
	Sex		Yes, contacts	Yes		Yes	
	Ethnicity		No				
	Country of Birth		No				
	Education		No				
	Socio-economic		No				
	Geography		Yes, contacts	Yes		Yes	
	Travel time		No				
	Morbidity		No				
	Mortality		No				
	Health beliefs and knowledge		No				

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Table 69 Staffing data workforce censuses (medical and non-medical)

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			PCT, SHA, NHS Region, National				
	Age		Yes, staff group			Yes	
	Sex		Yes, staff group			Yes	
	Ethnicity		Yes, staff group			Yes	
	Country of Birth		No but does have staff who qualified overseas				
	Education		Yes, staff group			Yes	
	Socio-economic		Yes, staff group			Yes	
	Geography	No		Yes			
	Travel time	No					
	Morbidity	No					
	Mortality	No					
	Health beliefs and knowledge	No					

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Table 70 Waiting times data

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Oppor- - tunity	Use	Out- - come
Dimensions of Access	Indicators of Access						
Characteristics of pop. at risk			NHS Trust, by specialty				
	Age		No				
	Sex		No				
	Ethnicity		No				
	Country of Birth		No				
	Education		No				
	Socio-economic		No				
	Geography		Yes	Yes		Yes	
	Travel time		No				
	Morbidity		No				
	Mortality		No				
	Health beliefs and knowledge		No				

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Dimensions of access	Data source	Coverage and smallest level of aggregation	Content	Location in report
Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets			The variables listed are those relevant to communicable disease as opposed to all those in the data source	
Characteristics of the population of interest				
Morbidity	RCGPs weekly returns	Approximately 77 GPs contributing data constituting just over 1% of the total population	Personal identifier, admin info, condition, intervention, short term outcome, major known confounders and long term outcome	Communicable disease Section 3 HS Data
Morbidity	KC60 data	National coverage, by clinic	Data by clinic, by diagnosis, by sex and number of male cases homosexually acquired and by age group for selected conditions.	Communicable disease Section 3 HS Data
Morbidity (also mortality)	HIV data - SOPHID	National coverage. Those currently being seen for treatment by region	Total numbers, age, sex, region of residence, ethnicity, probable route of HIV infection, most advanced clinical stage, by level of anti-retroviral therapy	Communicable disease Section 3 HS Data
Morbidity	HIV data – UAPMP	Based on a sample. Approximately 650,000	HIV prevalence among homo and bisexual men, heterosexual men	Communicable disease

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Dimensions of access	Data source	Coverage and smallest level of aggregation	Content	Location in report
Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets			The variables listed are those relevant to communicable disease as opposed to all those in the data source	
Characteristics of the population of interest		anonymous samples. Smallest area, London for some analyses, otherwise national, by England and Wales, Scotland	and women, injecting drug users, and pregnant women	Section 3 HS Data
Morbidity (also mortality)	Hospital activity data From the APC CDS and HES	National coverage England and Wales, available at level of Finished Consultant Episode by postcode	Age, sex, ethnicity (poorly recorded) geography, travel can be derived Clinical details of communicable disease diagnosis, procedures, specialty, length of stay, method and source of admission, discharge destination NHS number which can link to other datasets, e.g. mortality	Health service data sources section

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Dimensions of access	Data source	Coverage and smallest level of aggregation	Content	Location in report
Data sources are listed according to dimensions of access. If more than one, subsequent dimensions are listed in brackets			The variables listed are those relevant to communicable disease as opposed to all those in the data source	
Characteristics of the population of interest				
Mortality	Vital registration mortality data ONS VS3 and VS4 data	England and Wales, available at person level	Administrative details Date and place of death Deceased's details Date and place of birth Occupation (of husband if a married woman or widow) Communicable disease as cause of death	Population data sources section

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8.3.2 Surveys and population-based data sources: applying the framework for assessing access to health care

Table 72: The Census of population

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access						
Characteristics of population at risk							
	Age	Yes		Yes			
	Sex	Yes		Yes			
	Ethnicity	Yes		Yes			
	Country of Birth	Yes		Yes			
	Education	Yes		Yes			
	Socio-economic	Yes		Yes			
	Geography	Yes		Yes			
	Travel time	Yes		Yes			
	Morbidity	Yes		Yes			
	Mortality	No		No			
	Health beliefs and knowledge	Yes		Yes			
These characteristics apply to a geographical population							

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Table 73 The Health Survey for England

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access						
Characteristics of population at risk			Household				
	Age	Yes		Yes			
	Sex	Yes		Yes			
	Ethnicity	Yes		Yes			
	Country of Birth	No					
	Education	Yes		Yes			
	Socio-economic	Yes		Yes			
	Geography	Yes		Yes			
	Travel time	No					
	Morbidity	Yes		Yes			
	Mortality	No					
	Health beliefs and knowledge	No					
<i>These characteristics apply to a survey sample of a geographical population</i>							

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Table 74 The General Household Survey

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access						
Characteristics of population at risk							
	Age	Yes		Yes			
	Sex	Yes		Yes			
	Ethnicity	Yes		Yes			
	Country of Birth	Yes		Yes			
	Education	Yes		Yes			
	Socio-economic	Yes		Yes			
	Geography	Yes		Yes			
	Travel time	No					
	Morbidity	Yes		Yes			
	Mortality	No					
	Health beliefs and knowledge	Yes		Yes			
These characteristics apply to a survey sample of a geographical population							

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Table 75 Cancer registration

		Aggregation	Place on Access Continuum			
		Individual and population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access					
Characteristics of population at risk						
	Age	Yes	Yes	Yes	Yes	Yes
	Sex	Yes	Yes	Yes	Yes	Yes
	Ethnicity	Yes	Yes	Yes	Yes	Yes
	Country of Birth	No (unless linked to death data)				
	Education	No				
	Socio-economic	No (unless linked to death data)				
	Geography	Yes	Yes	Yes	Yes	Yes
	Travel time	No				
	Morbidity	Yes	Yes	Yes	Yes	Yes
	Mortality	Yes	Yes	Yes	Yes	Yes
	Health beliefs and knowledge	No				
These characteristics apply to a geographical population						

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Table 76 Birth registration

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access	Baby	Mother/Father	Series FM1				
Characteristics of population at risk				E&W; government office regions; Greater London; metropolitan counties and health regional office areas				
	Age	N/a	Confidential	Yes	Yes			Yes
	Sex	Yes	N/a	Yes				
	Ethnicity	No	No	No				
	Country of Birth	Yes	Yes	Yes	Yes			
	Education	N/a	No	No				
	Socio-economic	N/a	Yes	Yes	Yes			
	Geography							
	Where birth occurred	Yes	N/a	Yes			Yes	

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	Residence at birth	Yes	M Yes, F No	Yes	Yes	Yes		
	Travel time	Derived variable, mothers' place of residence & birthplace.			Yes	Yes		
	Morbidity	Birth weight, PM if stillbirth	No		Yes			Yes
	Mortality	Yes, stillbirth and by record linkage	Yes, by record linkage		Yes			Yes
	Health beliefs	No	No	No				

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Table 77 NHS Numbers for Babies

		Aggregation			Place on Access Continuum				
		Individual		Population		Need	Oppor- tunity	Use	Out- come
Dimensions of Access	Indicators of Access	Baby	Mother	Not routinely published					
Characteristics of population at risk									
	Age	N/a	Yes	Potential		Yes			Yes
	Sex	Yes	Yes	Potential (Baby)					
	Ethnicity	Yes	No	Potential (Baby)		Yes			
	Country of Birth	N/a	No	No					
	Education	N/a	No	No					
	Socio-economic	N/a	Yes*	Potential		Yes			
	Geography								
	Where birth occurred	Yes		Potential				Yes	
	Residence at birth		Yes	Potential		Yes	Yes		
	Travel time	As derived variable		As derived variable		Yes	Yes		
	Morbidity	Cong anomaly Y/N (No details), Gestation, Birth weight		No	Potential	Yes			Yes
	Mortality	Alive/Still		No	Potential	Yes			Yes
	Health beliefs	N/a		No	No				
Characteristics of enrolled pop at risk	NN4B is not concerned with an enrolled population, as it is a legal requirement for all births. However there are details about whether or not the mother is registered with a GP.								

*Socio-economic status only by linkage to Birth Registration (see above).

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Table 78: Birth notification: RICHS (Regional Interactive Child Health system)

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Oppor- tunity	Use	Out- come
Dimensions of Access	Indicators of Access	Baby	Mother	Not routinely published				
Characteristics of population at risk	Age	Yes	Yes	Potential	Yes			Yes
	Sex	Yes	Yes	Potential (Baby)				
	Ethnicity	No	Yes	Potential (Mother)	Yes			
	Country of Birth	Yes	No	No				
	Education	N/a	No	No				
	Socio-economic	N/a	Yes* 1 parent family status	Potential (Mother)	Yes			Yes
	Geography							
	Where birth occurred	Yes	Yes	Potential			Yes	
	Residence at birth	Yes	Yes	Potential	Yes	Yes		
	Travel time	As a derived variable		As a derived variable	Yes	Yes		

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	Morbidity	Gestation Birthweight Length circumference Mode of delivery Onset regular respirations Apgar score Resuscitation SCBU Congenital abnormalities (details) Transfer to hospital	Sickle cell HEP B Thalassaemia AFP Amniocentesis Previous miscarriages	Potential	Yes		Yes	Yes
	Mortality	Live/still Deaths within 28 days	No	Potential	Yes			Yes
	Health beliefs and knowledge	No	Yes intended place of delivery	Potential	Yes?	Yes?	Yes	Yes

*Socio-economic status only by linkage to Birth Registration (see above).

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Table 79 Birth notifications: NCHS (National Child Health Computing System)

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access	Baby	Mother	Not routinely published				
Charact. of pop at risk	Age	Yes	Yes	Potential	Yes			Yes
	Sex	Yes	Yes	Potential (baby)				
	Ethnicity	Optional	No	Potential (baby if available)	Yes			
	Country of Birth	Yes	No	No				
	Education	N/a	No	No				
	Socio-economic	N/a	1 parent family	Potential (mother)	Yes			Yes
	Geography							
	Where birth occurred	Yes	Yes	Potential			Yes	
	Residence at birth	Yes	Yes	Potential	Yes	Yes		
	Travel time	As derived variable		As derived variable	Yes	Yes		
	Morbidity	Gestation Birthweight Mode of delivery Congenital abnormalities (details) Subsequent hospitalisations	Previous miscarriages Previous neonatal deaths	Potential	Yes		Yes	Yes
	Mortality	Live/still deaths within 28 days	No	Potential	Yes			Yes
	Health beliefs	No	Yes	Potential	Yes?	Yes?	Yes	Yes

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Table 80 Mortality statistics and the Access Continuum

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access						
Characteristics of population at risk							
	Age	Yes	Yes	Yes			Yes
	Sex	Yes	Yes	Yes			Yes
	Ethnicity	No	No				
	Country of Birth	No	No				
	Education	No	No				
	Socio-economic	Yes	Yes	Yes			
	Geography	Yes	Yes	Yes			
	Morbidity	Yes	Yes	Yes			
	Mortality	Yes	Yes	Yes			Yes
	Health beliefs and knowledge	No	No				

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Table 81 Notification of Congenital Anomalies (SD56)

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access			Series MB3				
Characteristics of enrolled pop at risk		Baby	Mother/Father	E&W; health regional office areas, District Has. But no population coverage				
NCAS is voluntary And not population-based	Age	N/a	Mother	Yes				
	Sex	Yes	N/a					
	Ethnicity	No	No	No				
	Country of Birth	Yes	No	No				
	Education	N/a	No	No				
	Socio-economic	NA/a	Occupation just before pregnancy	Father's occupation, social class Mother's occupation, social class				
	Geography							

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Where birth occurred	Yes DHA	Yes DHA (mother)	No	See text in Maternity Case Study
Residence at birth	Yes	Yes (mother)	Yes	
Travel time	As a derived variable		As a derived variable	
Morbidity	Congenital Anomalies Single or multiple birth Gestation Birth weight	Number and outcome of previous pregnancies	Yes By conditions By parity By birth weight	
Mortality	Live/Still	No	No	
Health beliefs and knowledge	N/a	No	No	

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Table 82 Notification of abortions HSA4

		Aggregation			Place on Access Continuum			
		Individual		Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access	Foetus	Pregnant Woman	Series AB				
Characteristics of population at risk				Country, Health region, regional office, local authority, district health authority				
	Age	N/a	Yes	Yes	Yes			Yes
	Sex	No	N/a	No				
	Ethnicity	N/a	Yes	No				
	Country of Birth	N/a	Country of residence	Yes				
	Education	N/a	No	No				
	Socio-economic	N/a	No	No				
	Geography							
	Where abortion occurred	N/a	Yes (premises)	Yes	Yes	Yes	Yes	
	Residence	N/a	Yes	Yes	Yes	Yes		
	Travel time	Unavailable as data are confidential						
	Morbidity	Gestation Grounds for abortion Method	Complications (esp haemorrhage, uterine perforation and sepsis)	Yes	Yes			Yes
	Mortality	N/a	Yes (and cause)	No	Yes?			Yes
	Health beliefs	N/a	No	No				

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Table 83 Confidential enquiry into maternal deaths

		Aggregation		Place on Access Continuum			
		Individual	Population	Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access						
Characteristics of population at risk		Mother	UK, specific areas of concern, case study				
	Age	Yes		Yes			Yes
	Sex	N/a					
	Ethnicity	Yes		Yes			Yes
	Country of Birth	Yes		Yes			Yes
	Education	No					
	Socio-economic	Yes, social class, marital status, social exclusion		Yes			Yes
	Geography						
	Where birth & death occurred	Yes		Yes	Yes	Yes	Yes
	Residence at birth & death	Yes			Yes		
	Travel time	No					
	Morbidity	Yes, weight, parity,		Yes			Yes
	Mortality	Yes		Yes			Yes
	Health beliefs	No					

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Table 84 Confidential enquiry into stillbirths & deaths in infancy

		Aggregation			Place on Access Continuum				
		Individual		Population		Need	Opportunity	Use	Outcome
Dimensions of Access	Indicators of Access								
Characteristics of population at risk		Baby	Mother	England, Wales & Northern Ireland; Some CESDI Regions; Some international comparison					
	Age	-	Yes	Potentially			CESDI data are not really sufficient to determine these aspects on a population-basis		
	Sex	Yes	-	Potentially					
	Ethnicity	As per mother	Yes	Potentially					
	Country of Birth	N/a	No	No					
	Education	N/a	No	No					
	Socio-economic	No	No	No					
	Geog								
	Where birth occurred	Yes	Yes	Yes		Yes			
	Residence at birth	Yes	Yes	Potentially					
	Travel time	N/a							
	Morbidity	Yes Birthweight, Signs/obs. at birth, Fetal/Infant class., Obstet. class.		Yes Parity, Multiple births	Yes Baby Potentially Mother	Yes			
	Mortality	Yes Cause of death		No	Yes	Yes			
	Health beliefs and knowledge			No	No				

Appendix D The development of NHS performance ratings

Since the mid 1980s, indicators have been used in the NHS to monitor progress towards pre-set targets, make comparisons between providers of care or populations, detect outliers and rank service providers, in order to identify institutions requiring intervention and enable improvements to take place. Although useful, there are also risks that performance indicators (PIs) can lead to perverse incentives and loss of institutional morale.

The use of statistics to compare hospitals has a much longer history, however: (238)

- 1687 William Petty compared the mortality of hospitals in London and Paris (239)
- 1840 The Statistical Society of London set up a Committee on Hospital Statistics
- 1860 Florence Nightingale's 'uniform plan' for hospital statistics was presented to the International Statistical Congress (240)
- 1860s Statistical Society published hospital statistics (241)
- 1880s Henry Burdett started to publish hospital statistics in his weekly journal *The Hospital*.

Florence Nightingale noted that hospital mortality statistics are difficult to interpret as they can reflect differences in discharge policies and that morbidity statistics are a better test of the sanitary state of a hospital than mortality returns. (242)

This Appendix starts with an overview of the development of NHS performance indicators since the 1980s. It then looks in detail at the indicators for 2003-04, which were current at the time this work was done.

In the early 1980s, performance indicators were developed mainly for use by NHS managers. These indicators contained large amounts of data but were not available to the public nor did they identify individual hospitals or health authorities. These indicators were used to identify failing institutions that were found to be out of line on a number of indicators. It was accepted that performance indicators were not an absolute measure of performance and were affected by local conditions.(243) Their role was to alert managers to potential problems. Measures of efficiency were also developed such as the number of cleaners per square metre of floor area. (238)

By the late 1980s and early 1990s 'Health Service Indicators' (HSIs) were being made available to the press and the public and starting to generate debate. Interest seemed to wane in the mid 1990s but was stimulated after 1997 by the Bristol Infirmary Enquiry. (243)

The 1990s

The Citizens Charter issued in 1991,(244) led to the introduction of a small number of indicators that were presented in league tables developed for all public services. Health Service indicators included more patients being treated, shorter waiting times and immunisation rates and were put into practice through the Patient's Charter.(245)

After the change of government in 1997, a *First Class Service: Quality in the New NHS* (170), published in July 1998, set out a three-part approach to improving quality through

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new national standards; dependable local delivery systems; and significantly improved monitoring and performance assessment. The Labour Government's, *The NHS Performance Assessment Framework (PAF)*, (171) was published in April 1999. It set out a broad based approach to performance assessment. This encompassed setting standards, delivering these standards and monitoring these standards using high-level indicators for health authorities and clinical indicators for hospital and community trusts.

The NHS PAF required action across six areas of health care:

- 1 health improvement
- 2 fair access
- 3 effective delivery of appropriate care
- 4 efficiency
- 5 patient/carer experience
- 6 health outcome of NHS care.

The NHS Performance Assessment Framework was supported by the publication in June 1999 of the first sets of high level performance indicators(173) based on the areas above and clinical indicators(246) of which there were initially six. For details see Table 89 and Table 90 at the end of this appendix.

2000 onwards

In July 2000, the indicators within the NHS PAF were updated(174). The high level indicators were still structured around the six action areas for health and the clinical indicators were expanded and organised into two areas, effective delivery of appropriate health care and health outcomes of NHS health care. These are listed in detail in Table 89 and Table 90.

The second indicator set was designed to reflect government priorities for health more closely than before. In particular the set included more indicators relating to cancer services, primary care, the new NSFs for CORONARY HEART DISEASE and Mental Health, a range of indicators from the National Survey of NHS Patients(247) and the *Saving lives*(97) public health white paper, as well as some indicators which reflected the interface between the NHS and Personal Social Services.

A further addition to the NHS Performance Assessment Framework was the introduction of a data quality indicator for each Health Authority, comprising admissions and procedures carried out in hospital and derived from the coverage and record quality in HES data.

Also in 2000, *The NHS Plan*(20) was published introducing NHS targets, a further two jointly with social care and four for social services. These were as follows:

For the NHS :

- 1 To reduce the maximum wait for an outpatient appointment to three months and the maximum wait for inpatient treatment to six months by the end of 2005.
- 2 Patients will receive treatment at a time that suits them in accordance with their clinical need. Two thirds of all outpatient appointments and inpatient elective admissions will be pre-booked by 2003/04 on the way to one hundred per cent pre-booking by 2005.

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- 3 Guaranteed access to a primary care professional within 24 hours and to a primary care doctor within 48 hours by 2004.
- 4 To secure year-on-year improvements in patient satisfaction including standards of cleanliness and food as measured by independently audited surveys.
- 5 To reduce substantially the mortality rates from major killers by 2010, from heart disease by at least 40 per cent in people under 75, from cancer by at least 20 per cent in people under 75, and from suicide and undetermined injury by at least 20 per cent. Key to the delivery of this target will be implementing the National Service Frameworks for Coronary Heart Disease, and Mental Health and the National Cancer Plan
- 6 To narrow the health gap in childhood and throughout life between socio-economic groups and between the most deprived areas and the rest of the country. Specific national targets will be developed with stakeholders and experts early in 2001.
- 7 The costs commissioned from trusts which perform well against indicators of fair access, quality and responsiveness, will become the benchmark for the NHS. Everyone will be expected to reach the level of the best over the next five years, with agreed milestones for 2003/04.

For the NHS in partnership with social services, the targets were:

- To provide high quality pre-admission and rehabilitation care to older people to help them live as independently as possible by reducing preventable hospitalisation and ensuring year-on-year reductions in delays in moving people over 75 on from hospital. We expect at least 130 000 people to benefit and we will monitor progress in the Performance Assessment Framework.
- To increase the participation of problem drug users in drug treatment programmes by 55 per cent by 2004, and one hundred per cent by 2008.

These targets fed directly into the continuing development of performance indicators for the NHS.

The *Star Rating* system was also introduced in 2001-02.(248) Under this, trusts are awarded 0 for the worst performance, and 1, 2 or 3 stars for the best performance, based upon the performance indicators in the Performance Assessment Framework.

Minor changes were made to the performance indicators in February 2002(172) although they were still structured around the six areas of health care originally specified in Performance Assessment Framework.(171) These are shown in Table 89 and Table 90.

Health authorities were replaced by primary care trusts (PCTs) in 2002. The Commission for Health Improvement (CHI) (249) took over responsibility for compiling the performance indicator reports for primary care trusts and acute trusts in 2003, publishing the *Star Ratings* for 2002/03 onwards.(176) These indicators are shown in Table 91 and Table 92.

Changes were made to the categories grouping the performance indicators, although essentially the same items were collected. There were also changes to some of the definitions with some indicators being dropped and new ones added. In 2002/03 Key Targets were introduced for both trusts and PCTs. These were not new indicators but rather a selection that the government prioritised to highlight. In 2003 Mental Health Trusts and

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Ambulance Trusts were included in the performance ratings exercise for the first time although, they had previously been included on an 'indicative basis' in a dry run. These indicators are shown in Table 93 and Table 94.

The Commission for Health Improvement commented on the changes made to the indicators.(250) In particular it said that some were too difficult to collect or proved not to be particularly useful. As a result, some indicators were changed and some dropped completely. set between 2002-03 to 2003-04.

Table 85, summarises the overall changes in the indicators set between 2002-03 to 2003-04.

Table 85 NHS performance indicator changes

Trust type	Number of Indicators 2002/03	Number of Indicators 2003/04	Indicators the same	Indicators similar	New indicators
<i>Acute</i>	45	44	13	23	8
<i>Ambulances</i>	13	24	7	4	13
<i>Mental Health</i>	30	38	12	14	12
<i>PCT</i>	46	42	19	13	10
<i>Total</i>	134	148			

Source CHI(246)

New indicators focused on patient experience, as Tables 92 to 95 show. For the first time, they included the results of the patient surveys carried out in ambulance and mental health trusts. The Commission for Health Improvement reviewed the work it carried out to compile the star ratings published in July 2003. This helped shape the indicator sets for 2004 and 2005, shown in Tables 92 to 95. Those for 2005 have been published in advance of the financial year to help Trusts with planning.(251)

In April 2004, the Commission for Health Improvement was abolished. Publication of the 2004 star ratings was undertaken by the newly created Commission for Health care Audit and Inspection (CHAI), better known as the Health care Commission. (252)

As the independent regulator for NHS performance, the Health care Commission is responsible for the ratings process. Government ministers retain responsibility for setting overall priorities for the NHS. These, in turn, determine key targets and certain performance indicators included in the performance ratings. Key targets are the most significant factors in determining overall performance ratings. The broader range of indicators are included in the 'balanced scorecard' and are used to refine the judgement on ratings.

8.4.1 Performance Indicators relating to access to health care services and the availability of routine data

It is beyond the scope of this report to examine the data requirements of all the indicators used to measure performance in the NHS. Rather this section will concentrate on the 2003-

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04 *Key Targets* indicators that relate to PCTs and acute trusts. (253) Table 86 and Table 87 show these Key targets, the data sources from which they are compiled and the extent to which the data are routinely available in published form and whether they are within National Statistics protocols.

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Table 86 PCT key targets and their data sources

2004-05 CHI (254)/Health Commission (248)	Data source	Routinely available?
Key Targets		
Access to a GP	Primary Care Access Survey ROCR/OR/0120.	Not routinely available. Not published, not covered by National Statistics Code of Practice
Access to a primary care professional	Primary Care Access Survey ROCR/OR/0120	"
Elective patients waiting longer than standard	Monthly Monitoring Returns (commissioner)	"
Outpatients waiting longer than the standard	Monthly Exception Reports (provider and Commissioner)	"
Total time in Accident and Emergency: 4 hours or less	Quarterly monitoring: accident and emergency services QMAE quarterly return (A&E)	Routinely available. Published on DoH web site (http://performance.doh.gov.uk/hospitalactivity/data_requests/index.htm) Undecided whether or not covered by National Statistics yet.
Four-week smoking quitters	Statistics Division Smoking Cessation Return	Routinely available. Published as a Statistical Bulletin (http://www.publications.doh.gov.uk/public/sb0325.pdf) covered by National Statistics Code of Practice.
Financial management	Month 12 Forecast Financial Returns held by Finance & Investment Directorate - Financial Management (FID-FM) at DoH Financial Plans held by FID-FM at DoH Other relevant data source eg audit reports Planned Support Data collected by FID-FM at DoH	Not routinely available, not published, not covered by National Statistics Code of Practice.
Drug misusers accessing treatment	Local Delivery Plans National Drug Treatment Monitoring System	Not routinely available. Not covered by National Statistics Code of Practice. Routinely available. Published on the NDTMS web site http://www.nta.nhs.uk/programme/national/monitoring.htm . Not covered by National Statistics Code of Practice.

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For most of these key target indicators there are no data routinely available to calculate the indicator and few data that are published. The data source covered by the National Statistics Code of Practice is the *Smoking Cessation Return*. The same may be true of the *Quarterly monitoring: accident and emergency services (QMAE)* although the position of this return had yet to be finalised at the time of writing in the first half of 2004.

The picture is similar for acute trusts, as Table 87 shows.

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Table 87 Acute Trust key targets and their data sources

2004/05 CHI (255)/Health Commission (248)	Data source	Routinely available?
Key Targets		
12 hour waits for emergency admission via A&E post decision to admit	Hospital Situation Reports (SitReps)	
Financial management	Financial Plans held by FID-FM at DoH Planned Support Data collected by FID-FM at DoH Other relevant data source eg audit reports Month 12 Forecast Financial Returns held by FID-FM at DoH	Not routinely available, not published, not covered by National Statistics.
Hospital cleanliness	Patient Environment Action Team (PEAT)	
Elective patients waiting longer than standard	Monthly Monitoring Returns	Not routinely available, not published, not covered by National Statistics.
Outpatients waiting longer than the standard	Monthly Monitoring Returns	Not routinely available, not published, not covered by National Statistics
Outpatient and elective (inpatient and daycase) booking	Monthly booking return	
Total time in A&E: 4 hours or less	QMAE quarterly return (A&E)	Routinely available, published on DoH web site (http://www.performance.doh.gov.uk/hospitalactivity/data_requests/index.htm), undecided whether or not covered by national statistics yet.
All cancers: 2 week wait	Quarterly Monitoring of Cancer Waits return (QMCW) quarterly waiting times returns	

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Many of the Key Targets that form part of the PAF are not based upon routinely available data. In the main, they are also not covered by the *National Statistics Code of Practice*. This means that public scrutiny of the PIs themselves, let alone the organisations relative rankings, is made difficult if not impossible as so much of the data are based upon internal, and private, information flows to which the public has no access.

4.2 Discussion of NHS performance ratings

This brief description of the history of performance indicators in the NHS illustrates the expansion in numbers of such indicators since the 1990s.

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Table 88, below, from a written answer to a parliamentary question, shows this multiplication clearly. It is interesting that the Government announced a reduction in numbers in July 2004. (256)

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Table 88 Summary of NHS performance indicators in England since 1994-5

Period covered	Title	Number of indicators	When published
2002-03	Primary care trusts	46	July 2003
	Mental health trusts	30	July 2003
	Learning disability trusts	17	July 2003
	Acute trusts, Specialist trusts	45	July 2003
	Ambulance trusts	13	July 2003
	Total	151	
2001-02	Primary Care organisations	21	July 2002
	Acute trusts, Specialist trusts	29	July 2002
	Ambulance trusts	10	July 2002
	Mental health trusts	16	July 2002
	Total	76	
2000-01	Acute NHS hospital trusts	21	September 2001
1997-2002	Health Authorities	51	February 2002
1999-2001	Acute NHS hospital trusts	28	February 2002
1996-99	NHS performance indicators	49	July 2000
1995-99	High level performance indicators	41	June 1999
1996-97	The NHS Performance National Guide	19	July 1997
1995-96	The NHS Performance National Guide	19	June 1996
1994-95	The NHS Performance National Guide	19	June 1995

Source: House of Commons Hansard Written Answers for 20 Nov 2003 (pt 62)

The present government has demonstrated commitment to performance indicators, but account must be taken of their purpose, and of their limitations if we are to make sensible use of them. Performance indicators are used across many sectors, private, state and voluntary, to monitor progress, to make comparisons and to detect outliers. All these purposes have one underlying aim, to improve performance. (257)

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Indeed because PIs are intended to improve performance, by initiating change, there is an incentive to change behaviour to improve the indicators, regardless of whether or not this change actually improves the performance of an organisation or furthers its objectives.

(257) This leads managers to pursue the indicator rather than attain the strategic goals of an organisation. A famous Soviet cartoon showed a factory producing a giant nail weighing several tons in order to *efficiently* fulfil its annual tonnage quotas. (257)

This would be less of a problem if PIs encompassed exactly the goals of an organisation. Such a situation is highly unlikely in a health care context, where complexity and heterogeneity characterise not only patients and their conditions but also the processes and organisation of care itself. A small number of indicators that relate mainly to processes and not outcome are unlikely to reflect a situation accurately. (258) As can be seen from the tables in this section there have been constant changes to and increases in the type and number of performance indicators applied to the NHS. Ever greater attempts at sophistication have characterised the process in order to capture organisational behaviour to a degree that ensures the validity of the measures, thus ensuring delivery of Government objectives. The fact that so many changes have taken place would seem to indicate that attempts so far have been less than perfect. Indeed a recent study of *Star Ratings* and the performance of Adult Critical Care Units showed that, after adjustment for case mix, there was no difference in the outcomes of Adult Critical Care units in zero rated Trusts and those in three star rated Trusts. (258) This led the authors to conclude that the Government is failing in its stated aim of 'providing patients and the general public with comprehensive and easily understandable information on the performance of their local health services' .(248)

Another report published by the Royal Statistical Society in 2003 discussed performance monitoring in a wider context of public service. It criticised the way that targets have been set, how they have been designed, how they have been analysed and how the results have been reported. (259) The authors are particularly critical because of the dual role that Government has in relation to performance indicators. The government monitors public services through PIs and is itself monitored by PIs. The Royal Statistical Society in March 2004 called for the process to be shielded from undue political interference in the same way that *National Statistics* (260) are shielded.

In particular the Royal Statistical Society called for:

Performance monitoring protocols, to ensure that statistical standard are met. Protocol record of decisions made from design to analysis and reporting but also reasoning and calculations behind the decisions.

Independent scrutiny, to safeguard the wider than government public interest, the individuals and institutions being monitored and the methodological rigour.

The reporting of measure of uncertainty, to avoid over-interpretation and the false labelling of performance.

Research on different strategies other than name and shame for the public release of data and better design (including randomisation) for evaluating policy initiatives.

Much wider consideration of the ethics and cost-efficiency of performance monitoring. (259)

Source: Royal Statistical Society, 2003.

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If adopted, these recommendations would improve the quality of performance management and obviate some of the pitfalls encountered with poorly conceived and designed indicators, such as creating perverse incentives and damaging institutional morale, as well as introducing a higher degree of contextualisation in the interpretation of performance indicators.

It has been argued, however, that professionals and indeed the public pay relatively little heed to published performance indicators and league tables. (243) Managers and health care professionals in the health service are often slow to act against poorly performing colleagues. For example, at the Bristol Royal Infirmary, concerns about poorly performing doctors were widespread for some time but no action was taken. (243;261) If there is action it is usually among those who have been named and shamed. The public and the media have shown little interest in the statistics as a method of applying pressure to change their local services. (243)

Experience has shown us that performance indicators have also had a mixed reception around the world. Failure of PIs has been seen in Ireland and New South Wales, Australia, where legislation has been passed against school league tables based school tests. In Wales and Northern Ireland the publication of such league tables has also been banned. This is partly due to dissatisfaction at the lack of contextualisation and also the adverse effects on institutions of publication. Far from engendering positive change, the publication of PIs has undermined performance and attempts to turn around *failing* organisations.

Coupled with these doubts over the design and execution of PIs is the opacity of the PIs used in the NHS in England. It is difficult for a member of the public to know whether or not the NHS PIs are valid or indeed whether or not they reflect accurately the aspects of the system that they purport to measure.

Given the criticisms of the concept, practice and publication of PIs in the NHS it is difficult to see how they can be used to measure and monitor access to health care.

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Table 89 NHS performance indicators 1999-2002, health authority level indicators

June 1999 (173) DoH	July 2000 (174) DoH	Feb 2002 (172) DoH
Health Improvement	Health Improvement	Health Improvement
Deaths from all causes (ages 15-64)	Deaths from all causes (ages 15-64)	
Deaths from all causes (ages 65-74)	Deaths from all causes (ages 65-74)	
		Life expectancy (male)
		Life expectancy (male)
		Infant mortality rates
Deaths from Malignant neoplasms	Deaths from cancer	Deaths from cancer
Deaths from all circulatory diseases	Deaths from all circulatory diseases	Deaths from all circulatory diseases
Suicide rates	Suicide rates	Suicide rates
Deaths from accidents	Deaths from accidents	Deaths from accidents
	Serious injury from accidents	Serious injury from accidents
Cancer registrations		
		Conceptions below age 18
		Decayed, missing or filled teeth in five year old children
Fair Access	Fair Access	Fair Access
Inpatient waiting list	Inpatient waiting list	
Adult dental registrations	Adult dental registrations	
Child dental registrations		
Early detection of cancer	Early detection of cancer	

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June 1999 (173) DoH	July 2000 (174) DoH	Feb 2002 (172) DoH
		Breast cancer screening
		Cervical cancer screening
	Cancer waiting times	
	Number of GPs	Number of GPs
	Practice availability	
Surgical rates (selected operations)	Elective Surgery rates	
		Surgery rates – joint replacement
		Surgery rates – cataract removal
	Surgery rates - Coronary heart disease	Surgery rates - Coronary heart disease
		Increase in drug misusers accessing drug treatment services
Effective Delivery of Appropriate Health care	Effective Delivery of Appropriate Health care	Effective Delivery of Appropriate Health care
Childhood immunisations	Childhood immunisations	Childhood immunisations
		Flu vaccinations
Inappropriately used surgery	Inappropriately used surgery	
Acute care management	Acute care management	Primary care management - acute conditions
Chronic care management	Chronic care management	Primary care management - chronic conditions
Mental health in primary care	Mental health in primary care	Mental health in primary care
Discharge from hospital – Stroke	Returning home following treatment for a stroke	Returning home following treatment for a stroke
Discharge from hospital - FNF	Returning home following treatment for a fractured hip	Returning home following treatment for a fractured hip

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June 1999 (173) DoH	July 2000 (174) DoH	Feb 2002 (172) DoH
Early detection of cancer (see also Fair Access above)		
Surgical rates (selected operations) (see also Fair Access above)		
Cost effective prescribing	Cost effective prescribing	
		Prescribing of antibacterial drugs
		Prescribing of ulcer healing drugs
		Organ donors
Efficiency	Efficiency	Efficiency
Day case rate	Day case rate	Day case rate
Length of stay	Length of stay	Length of stay
Maternity unit costs	Maternity unit costs	
Mental health unit costs	Mental health unit costs	
Generic prescribing	Generic prescribing	Generic prescribing
		Missed out patient appointments
		Data quality
Patient/Carer experience of the NHS	Patient/Carer experience of the NHS	Patient/Carer experience of the NHS
Patients who wait less than 2 hours for emergency admission (through A & E)	Patients who wait less than 2 hours for emergency admission (through A & E)	
Outpatients seen within 13 weeks of GP referral	Outpatients seen within 13 weeks of GP referral	Outpatients seen within 13 weeks of GP referral
Percentage of those on waiting list waiting 12 months or more	Percentage of those on waiting list waiting 18 months or more	

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June 1999 (173) DoH	July 2000 (174) DoH	Feb 2002 (172) DoH
		Six month inpatient waits
		Two week cancer waits
Cancelled operations	Cancelled operations	
Delayed discharge	Delayed discharge	Delayed discharge
First outpatient appointments for which patient did not attend	First outpatient appointments for which patient did not attend	
		Access to a GP
	Patients satisfaction	
	Health Outcomes of NHS health care	Health Outcomes of NHS health care
Conceptions below age 16	Conceptions below age 18	
Decayed, missing or filled teeth in five year old children	Decayed, missing or filled teeth in five year old children	
		Emergency admissions
Emergency admissions rate for over 75s	Emergency admissions of older people	
		Emergency readmission to hospital following treatment for a fractured hip
		Emergency readmission to hospital following treatment for a stroke
Emergency psychiatric re-admissions	Emergency psychiatric re-admissions	Emergency psychiatric re-admissions
		Emergency admissions to hospital for children with lower respiratory infections
Adverse events/ complications of treatment		
	Readmission to hospital following discharge	Emergency readmission to hospital following

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June 1999 (173) DoH	July 2000 (174) DoH	Feb 2002 (172) DoH
		discharge
Cancer survival		
	Breast cancer survival	Breast cancer survival
	Cervical cancer survival	
	Lung cancer survival	Lung cancer survival
	Colon cancer survival	Colon cancer survival
Stillbirths and infant mortality	Stillbirths and infant mortality	
Potentially avoidable mortality		
In-hospital premature deaths		
	Deaths in hospital following surgery (emergency admissions)	Death within 30 days of surgery (non-elective admissions)
	Deaths in hospital following surgery (non-emergency admissions)	Death within 30 days of surgery (elective admissions)
	Deaths in hospital following a heart attack (ages 35-74)	
		Death within 30 days of a heart bypass operation
	Deaths in hospital following a fractured hip	Deaths in hospital following a fractured hip
		Death within 30 days of admission to hospital with a stroke
		Four-week smoking quitters

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Table 90 NHS performance indicators 1999-2002, acute trust level indicators

June 1999 (246) Department of Health	July 2000 (174) Department of Health	Feb 2002 (172) Department of Health
Clinical Indicators		
	Health Improvement	Health Improvement
	Fair Access	Fair Access
	Effective Delivery of Appropriate Health care	Clinical Effectiveness and Outcomes
Discharge to usual place of residence within 56 days of emergency admission from there with a stroke for patients aged 50 and over	Discharge from hospital (stroke)	Returning home following hospital treatment for stroke
Discharge to usual place of residence within 28 days of emergency admission from there with a hip fracture (neck of femur) for patients aged 65 and over	Discharge from hospital (fractured neck of femur)	Returning home following hospital treatment for fractured hip
	Efficiency	Efficiency
		Day case rate
		Length of stay
		Reference costs

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June 1999 (246) Department of Health	July 2000 (174) Department of Health	Feb 2002 (172) Department of Health
	Patient/Carer experience of the NHS	<p>Missed outpatient appointments</p> <p>Patient/Carer experience of the NHS</p> <p>Six month inpatient waits</p> <p>Thirteen week outpatient waits</p> <p>Two week breast cancer waits</p> <p>Trolley waits</p> <p>Complaints</p> <p>Cancelled operations</p> <p>Cancelled operations not admitted within a month</p> <p>Hospital Cleanliness</p>
	Health Outcomes of NHS health care	Clinical Effectiveness and Outcomes
Emergency readmission to hospital within 28 days of discharge from hospital	28 day emergency readmission	<p>Emergency readmission to hospital following discharge</p> <p>Emergency readmission to hospital following treatment for a fractured hip</p> <p>Emergency readmission to hospital following treatment for a stroke</p>
Deaths in hospital within 30 days of surgery by method of admission	In-hospital premature deaths (30 day	

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June 1999 (246) Department of Health	July 2000 (174) Department of Health	Feb 2002 (172) Department of Health
	<p>Perioperative mortality -emergency admission)</p> <p>In-hospital premature deaths (30 day Perioperative mortality - non-emergency admission)</p>	<p>Death within 30 days of a heart bypass operation</p> <p>Death within 30 days of surgery (non-elective admissions)</p>
<p>Deaths in hospital within 30 days of emergency admission with a heart attack (myocardial infarction) for patients aged 50 and over</p> <p>Deaths in hospital within 30 days of emergency admission with a hip fracture (neck of femur) for patients aged 65 and over</p>	<p>In-hospital premature deaths (30 day mortality following AMI)</p> <p>Deaths following fractured neck of femur</p>	<p>Death within 30 days of admission to hospital with a fractured hip</p> <p>Death within 30 days of admission to hospital with a stroke</p> <p>Capacity and Capability</p> <p>Junior doctors' hours</p> <p>Vacancy rate - Qualified Allied Health Professionals</p> <p>Vacancy rate - Qualified nursing, midwifery & health visiting staff</p> <p>Vacancy rate – Consultants</p> <p>Sickness absence rate</p> <p>Clinical negligence</p> <p>Data quality</p>

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Table 91 NHS performance indicators 2002-2003 onwards, PCT level

2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (262)/Health care Commission (252)
Key Targets	Key Targets	Key Targets
Access to a GP	Access to a GP	Access to a GP
Access to a primary care professional	Access to a primary care professional	Access to a primary care professional
Number of inpatients waiting longer than the standard	Patients waiting longer than the standard for elective admission	Elective patients waiting longer than standard
Number of outpatients waiting longer than the standard	Outpatients waiting longer than the standard	Outpatients waiting longer than the standard
Total time in A&E	Total time in A&E: 4 hours or less	Total time in A&E: 4 hours or less
Single telephone access - Implementation Plans	Single telephone access (part of Balanced Scorecard below)	
Four-week smoking quitters	Four-week smoking quitters	Four-week smoking quitters
Improving Working Lives	Improving Working Lives	
Financial Management	Financial management Drug misuse: treatment	Financial management Drug misusers accessing treatment
Access to quality services	Balanced Scorecard	Balanced Scorecard
Emergency readmission to hospital following treatment for a fractured hip		
Substance Misuse - Percentage of GP practices in a shared care scheme	Drug misuse: shared care	To be advised during 2004
Sexual health - Access to services for early unintended pregnancy	Sexual health	
Level of 24 hour access to specialist mental health services		
A&E Emergency admission		

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2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (262)/Health care Commission (252)
waits (12 hours)		
Twelve month heart operation waits	Six-month inpatient waits	
Delayed transfers of care	Delayed transfers of care	
Access to NHS Dentistry	NHS dentistry	
PCT Survey - Access and waiting	PCT patient survey: access and waiting	
PCT Survey - Better information, more choice	PCT patient survey: better information, more choice	
PCT Survey - Building closer relationships	PCT patient survey: building closer relationships	
PCT Survey - Clean, comfortable, friendly place to be	PCT patient survey: clean, comfortable, friendly place to be	
PCT Survey - Safe, high quality, coordinated care	PCT patient survey: safe, high-quality, coordinated care	
Prescribing of atypical antipsychotics		
Improving health Results	Balanced Scorecard cont	
Death rates from circulatory diseases, ages under 75 (change in rate)	Death rates from circulatory diseases, ages under 75 (change in rate)	
Death rates from accidents, all ages (change in rate)		
Death rates from cancer, ages under 75 (change in rate)	Death rates from cancer, ages under 75 (change in rate)	
Breast Cancer Screening		
Cervical Screening	Cervical screening	
Flu Vaccinations	Flu vaccinations	
Teenage pregnancy - Conceptions below age 18 (change in rate)	Teenage pregnancy	
Diabetes services baseline assessment	Diabetic retinopathy screening	
CORONARY HEART DISEASE Audit	CHD register	
Suicide audit	Suicide audit	

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2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (262)/Health care Commission (252)
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Service provision Results Balanced Scorecard cont

Emergency admissions (change in rate)

Emergency admission to hospital for Commission for Health care Improvement
Children with lower respiratory tract (LRT) infections (change in rate)

Primary Care Management - Acute conditions (change in rate)

Primary Care Management - Chronic conditions (change in rate)

Community equipment

Patient complaints procedure

Prescribing rates of antibacterial drugs

Prescribing rates for drugs acting on benzodiazepine receptors

Staff opinion survey

GP Appraisal

Sickness absence rate

Fire, Health and Safety

Generic prescribing

See above key targets

Prescribing: mental health

Staff opinion survey: health, safety and incidents

Staff opinion survey: human resource management

Staff opinion survey: staff attitudes

GP appraisal

Prescribing rates: selected drugs

Workforce datasets: data quality on ethnic group

Single telephone access

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2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (262)/Health care Commission (252)
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Balanced Scorecard cont

CAMHS (Child & Adolescent
Mental Health)

Child protection

Community equipment

Health equity audit

Immunisation: MMR

Infant health

PCT commissioning of NHS
Plan deliverables

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Table 92 NHS performance indicators 2002-2003 onwards, acute trust Level

2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (263)/Health care Commission (252)
Key Targets	Key Target	Key Target
A&E emergency admission waits (12 hours)	12 hour waits for emergency admission via A&E post decision to admit	12 hour waits for emergency admission via A&E post decision to admit
Cancelled operations not admitted within 28 days		
Financial management	Financial management	Financial management
Hospital cleanliness	Hospital Cleanliness	Hospital cleanliness
Improving Working Lives	Improving Working Lives	
Number of inpatients waiting longer than the standard	Patients waiting longer than the standard for elective admission	Elective patients waiting longer than standard
Number of outpatients waiting longer than the standard	Outpatients waiting longer than the standard	Outpatients waiting longer than the standard
	Outpatient and elective (inpatient and day case) booking	Outpatient and elective (inpatient and day case) booking
Total time in A&E	Total time in A&E: 4 hours or less	Total time in A&E: 4 hours or less
Two week cancer waits	All Cancers: 2 week wait	All cancers: 2 week wait
Capacity & Capability	Balanced Scorecard	Balanced Scorecard
Consultant appraisal	Consultant appraisal	
Data quality	HES & Workforce datasets: data quality on ethnic group	To be advised during 2004
Fire, Health & Safety		
Information Governance	Information governance	
Junior doctors' hours	Junior doctors' hours	
Sickness absence rate		
Staff opinion survey	Staff opinion survey: health, safety and incidents Staff opinion survey: human resource management	

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2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (263)/Health care Commission (252)
	Staff opinion survey: staff attitudes	
Clinical focus	Balanced Scorecard cont.	
Clinical Negligence	Clinical negligence	
Deaths within 30 days of a heart bypass operation	Deaths following a heart bypass operation	
Deaths within 30 days of selected surgical procedures	Deaths following selected non-elective surgical procedures	
Emergency readmission to hospital following discharge	Emergency readmission following discharge (adults)	
Emergency readmission to hospital following discharge for children		
Emergency readmission to hospital following treatment for a fractured hip	Emergency readmission following discharge for a fractured hip	
Emergency readmission to hospital following treatment for a stroke	Indicator on stroke care	
Infection control procedures Results	Infection control	
Methicillin Resistant Staphylococcus Aureus (MRSA) bacteraemia improvement score		
Thrombolysis treatment time	Thrombolysis - 60 minute call to needle time	
Patient focus	Balanced Scorecard cont.	
A&E emergency admission waits (4 hours)	A&E emergency admission waits (4 hours)	
Better hospital food	Better Hospital Food	
Breast cancer treatment	Breast cancer: 1 month diagnosis to treatment	
	Breast cancer: 2 month GP urgent referral to treatment	
Cancelled operations	Cancelled operations	
Day case booking	Day case patient booking	
Delayed transfers of care	Delayed transfers of care	

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2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (263)/Health care Commission (252)
Nine month heart operation waits		
Outpatient A&E survey	Adult inpatient and young patient survey	
Outpatient A&E survey - access & waiting	Adult inpatient and young patient surveys: access and waiting	
Outpatient A&E survey - better information, more choice	Adult inpatient and young patient surveys: better information, more choice	
Outpatient A&E survey - building relationships	Adult inpatient and young patient surveys: building closer relationships	
Outpatient A&E survey - clean, comfortable, friendly place to be	Adult inpatient and young patient surveys: clean, comfortable, friendly place to be	
Outpatient A&E survey - safe, high quality, co-ordinated care	Adult inpatient and young patient surveys: safe, high- quality, coordinated care	
Paediatric outpatient did not attend rates		
Patient complaints procedure	Patient complaints	
Privacy & dignity		
Six month inpatient waits	Six month inpatient waits	
Thirteen week outpatient waits	Thirteen week outpatients	
Total inpatient waits		
Waiting times for Rapid Access Chest Pain Clinic	Patients waiting longer than standard for revascularisation	
	Balanced Scorecard cont.	
	Child protection	
	Clinical governance composite indicator	
	Composite of participation in audits	
	'Winning ways' – processes and procedures	

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Table 93 Mental health trust performance indicators

2002-03 Commission for Health care Improvement (176)	2003-04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (264)/Health care Commission (252)
<p>Key Targets</p> <p>Assertive Outreach Team Implementation</p> <p>CMHT integration</p> <p>Mental Health Minimum Dataset implementation</p> <p>Number of outpatients waiting longer than the standard</p> <p>Improving Working Lives</p> <p>Hospital cleanliness</p> <p>Financial management</p>	<p>Key Target</p> <p>Assertive Outreach Team implementation</p> <p>CMHT integration</p> <p>MHMDS implementation</p> <p>Improving Working Lives</p> <p>Hospital cleanliness</p> <p>Financial management</p> <p>CPA systems implementation</p>	<p>Key Targets</p> <p>MHMDS implementation</p> <p>Hospital cleanliness</p> <p>Financial management</p> <p>CPA systems implementation</p> <p>Crisis resolution team implementation</p>
<p>Clinical Focus</p> <p>Clinical Negligence</p> <p>CPA systems implementation</p> <p>Psychiatric readmissions (adult)</p> <p>Psychiatric readmissions (older people)</p> <p>Suicide rate</p>	<p>Balanced Scorecard</p> <p>Clinical negligence</p> <p>Now a key target- above</p> <p>Psychiatric readmissions (adults)</p> <p>Psychiatric readmissions (older people)</p> <p>Suicide rate</p> <p>Clinical governance composite indicator</p> <p>CPA/complex care indicator</p>	<p>Balanced Scorecard</p> <p>To be advised during 2004</p>
<p>Patient Focus</p> <p>Transition of care between adult services and OPMH</p> <p>Transition of care between CAMHS and adult services</p> <p>Patients with copies of their own care plan</p>	<p>Transition of care between adult services and OPMH</p> <p>Transition of care between CAMHS and adult services</p> <p>CAMHS: increased services</p> <p>Patients with copies of their own care plan</p>	

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Patient complaints procedure	Patient complaints
Better hospital food	Better Hospital Food
Privacy and dignity	Privacy and dignity
	Service user survey: access and waiting
	Service user survey: better information, more choice
	Service user survey: building closer relationships
	Service user survey: safe, high-quality, coordinated care
	Outpatient booking

Capacity and Capability

Missed outpatient appointments	Missed outpatient appointments
Crisis Resolution Team Implementation	Crisis Resolution Team implementation
Out of catchment area treatments (adults)	Out of catchment area treatments (adults)
Out of catchment area treatments (older people)	Out of catchment area treatments (older people)
CAMHS service mapping	CAMHS service mapping
Data quality	HES & Workforce datasets: data quality on ethnic group
Junior doctors' hours	Junior doctors' hours
Consultant Appraisal	Consultant appraisal
Sickness absence rate	
Information Governance	
Staff opinion survey	Staff opinion survey: human resource management
	Staff opinion survey: staff attitudes
Fire, Health & Safety	Staff opinion survey: health, safety and incidents
	Child protection
	Physical environment

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Table 94 Ambulance trust performance indicators

2002-03 Commission for Health care Improvement (176)	200- /04 Commission for Health care Improvement (83)	2004-05 Commission for Health care Improvement (265)/Health care Commission (252)
<p>Key Targets</p> <p>Category A calls meeting 14/19 minute target</p> <p>Category A calls meeting 8 minute target</p> <p>Financial management</p> <p>Improving Working Lives</p>	<p>Key Target</p> <p>Category A calls meeting 14/19 minute target</p> <p>Category A calls meeting 8 minute target</p> <p>Financial management</p> <p>Improving Working Lives</p>	<p>Key Targets</p> <p>Category a calls meeting 14/19 minute target</p> <p>Category a calls meeting 8 minute target</p> <p>Financial management</p>
<p>Clinical Focus</p> <p>Clinical Negligence</p> <p>Thrombolysis protocols and procedures: Training of paramedic staff</p>	<p>Balanced Scorecard</p> <p>Clinical negligence</p> <p>Thrombolysis - 60 minute call to needle time</p>	<p>Category b/c calls meeting national 14/19 minute target</p> <p>Balanced Scorecard</p> <p>To be advised during 2004</p>
<p>Patient Focus</p> <p>Category B/C calls meeting national 14/19 minute target</p> <p>GP urgent calls meeting national 15 minute target</p> <p>Patient complaints procedure</p>	<p>Category B/C calls meeting national 14/19 minute target</p> <p>GP urgent calls meeting national 15 minute target</p> <p>Call answering time</p> <p>Patient complaints</p> <p>Ambulance patient survey: access and waiting</p> <p>Ambulance patient survey: better information, more choice</p> <p>Ambulance patient survey: building closer relationships</p> <p>Ambulance patient survey: clean, comfortable, friendly place to be</p> <p>Ambulance patient survey: safe, high-quality, co-ordinated care</p>	

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Capacity and Capability

Information Governance	Clinical governance composite indicator Data quality of computer aided dispatch (CAD) data Participation in selected audits Percentage of frontline ambulances with 12 lead ECG equipment Transport management
Sickness absence rate	
Staff opinion survey	Staff opinion survey: human resource management
Fire, Health & Safety	Staff opinion survey: health, safety and incidents Staff opinion survey: staff attitudes
	Child protection Transport management

Appendix E Glossary

AFP	Alpha-fetoprotein
AMI	Acute Myocardial Infarction
APC CDS	Admitted Patient Care Commissioning Dataset
BNF	British National Formulary
CABG	Coronary Artery Bypass Grafting
CCAD	Central Cardiac Audit Database
CCDC	Consultant in Communicable Disease Control
CDSC	Communicable Disease Surveillance Centre
CEMACH	Confidential Enquiry into Maternal and Child Health
CEMD	Confidential Enquiry into Maternal Deaths
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy
CHAI	Commission for Health care Audit and Inspection
CHD	Coronary Heart Disease
CHI	Commission for Health Improvement
CHKS	Caspe Health care Knowledge Systems
CISH	Confidential Enquiry into Suicide and Homicide by people with a Mental illness
CJD	Creutzfeldt-Jakob Disease
CMO	Chief Medical Officer
DCO	Death Certificate Only
DETR	Department of Environment, Transport and the Regions
DPH	Director of Public Health
DQRS	Data Quality Reporting Service
DTCs	Diagnostic and Treatment Centres
ETS	Enhanced Tuberculosis Surveillance
FCE	Finished Consultant Episode
GDS	General Dental Services
GHS	General Household Survey
GMS	General Medical Services
GPAQ	General Practice Assessment Questionnaire

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GPRD	General Practice Research Database
GRO	General Register Office
GUM	Genitourinary Medicine
HAA	Hospital Activity Analysis
HCHS	Hospital and Community Health Services
HES	Hospital Episode Statistics
HIPE	Hospital Inpatient Enquiry
HPA	Health Protection Agency
HRG	Health care Resource Group
HSE	Health Survey for England
ICD	International Classification of Diseases
MDS	Minimum Dataset
MHMDS	Mental Health Minimum Dataset
MIQUEST	Morbidity Information Query and Export SynTax
MRC	Medical Research Council
MSGP	Morbidity Statistics from General Practice
NCAS	National Congenital Anomaly System
NCC	National Consumer Council
NCCSDO	National Co-ordinating Centre for NHS Service Delivery and Organisation
NCEPOD	National Confidential Enquiry into Perioperative Deaths
NHSIA	NHS Information Authority
NOIDS	Notifications of Infectious Disease
NSF	National Service Framework
NTS	National Travel Survey
NWCS	NHS Wide Clearing Service
ONS	Office of National Statistics
OPCS	Office of Population Censuses and Surveys
ORLS	Oxford Record Linkage System
PACT	Prescribing Analysis and Cost Data
PAF	Performance Assessment Framework
PAS	Patient Administration System
PCT	Primary Care Trust
PHLS	Public Health Laboratory Service

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PIs	Performance Indicators
PPA	Prescriptions Pricing Authority
PRIMIS	Primary Care Information Services
PTCA	Percutaneous Transluminal Coronary Angioplasty
QMAS	Quality Management and Analysis System
RACPCs	Rapid Access Chest Pain Clinics
RAP	Referrals, assessments and packages of care
ROCR	Review of Central Returns
SARs	Sample of Anonymised Records
SCAG	Security and Confidentiality Advisory Group
SHA	Strategic Health Authority
SOPHID	Survey of Prevalent HIV Infections Diagnosed
STI s	Sexually Transmitted Infections
UAPMP	Unlinked Anonymous Prevalence Monitoring Programme
VS	Vital Statistics
WHO	World Health Organisation

Identification and Evaluation of Standardised Datasets for Measuring and Monitoring Access to Health Care

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