# Statistics Commission

REPORT OF JULY 2003 SEMINAR
ON HEALTH STATISTICS

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## Research and Review Sub-Committee

**REPORT OF THE JULY 2003 SEMINAR ON HEALTH STATISTICS**

**Introduction**

1.      On 29 July 2003, the Commission held a seminar on health statistics.  A list of those who attended is appended to this report.  The purpose of the seminar was to develop an awareness of key issues in health statistics.  This summary report highlights the issues that were raised.  It has been prepared on behalf of the Research and Review Sub-Committee, primarily as background to the development of the Commission's plans for research in the field of health statistics.  The views expressed are those of individuals who attended the seminar.  They are not intended to represent a consensus.

2.      The seminar highlighted a wide range of issues.  They are addressed below under the following headings:

## Policy on health data and information

3. Among the views expressed at the seminar:

- 'The NHS is data rich and information poor'.

- Regulation and the improvement process will increasingly be an information-driven process.

- There needs to be a UK-wide policy on health information.

- Clinical governance is an example of the unco-ordinated collection of health data.

- An appropriate IT strategy will help, but not solve, problems of this kind because they are about culture and not about technology.

- One of the important things about the national IT programme is that there is somebody in charge of that – a single point of focus. There is a need for a similar point of focus for the collection of health data.

### The current situation

4. Currently in the Department of Health (DH) there is a division of c. 200 people, of whom about 60-70 are professional statisticians. More generally in government, there is a National Statistics theme group on health and care, which takes a UK-wide view. The theme group addresses issues such as ease of access to UK health statistics and social care statistics.

5. DH is building new agencies outside the department, such as the new Commission for Healthcare Audit and Inspection (CHAI) and the Commission for Social Care Inspection.

6. There are proposals for a Centre for Information Management that will serve the health and social care system, giving wider ownership by including other organisations. The functions of the Centre might include:

- facilitating the sharing and use of information

- controlling burdens: recognising the burden on certain groups and understanding the uses of the information to justify its collection

- setting standards
- promoting common tools
- working with data intermediaries

- developing capacity and skills.

7.  It was suggested that there needs to be an improvement in the quality, reliability, and range of information to support decision-making and strengthen the monitoring of performance.  This might require a comprehensive and integrated information system and culture that enables patients to make choices and to have the information they need.  Any such system would need to:
    - give managers easy access to relevant information
    - support accountability to the public and Parliament
    - allow assessment of services against agreed standards.

**National Patient Record Analytic Service (NPRAS)**

8.  A major DH initiative, which is part of the NHS 21st Century IT programme, is the National Patient Record Analytic Service (NPRAS).  It will advise on what data to collect, setting information standards, collecting and publishing, extending the range of useful and accessible material, modernising information collection across the system, and modernising access to information.

**Office for National Statistics**

9.  A large amount of public health information is collected by ONS.  The DH is working with ONS to provide a single point of access to healthcare information and part of the role of a new Centre would be to pull together information for a range of organisations.

## Priorities

10.  A wide range of people wish to use health statistics, and they all need to be considered when looking at what kind of statistics to provide.  There is a tension between meeting all their information needs and giving absolute priority to treating patients.

> **Health statistics users are of many different types**
>
> - public
> - press
> - special interest groups
> - NHS Health Information Specialists
> - health and health care professionals (not data experts)
> - professionals in other areas where health statistics are relevant eg education, social care, crime, housing
> - researchers and students
> - Department of Health / NHS Executive
> - Office for National Statistics
> - other government departments
> - Parliament
> - International Agencies
> - others?

11.     It was noted that people in the NHS are required to gather and record data which are not directly relevant to their day-to-day work and which do not directly inform the care of their patients, or the planning of services.

12.     There is a tension between the increasing need for local information, with local targets and local users of information on the one hand, and the need to be able to draw national and international comparisons on the other.  At the moment the emphasis is on producing information geared towards comparative performance and accountability, as opposed to how the things actually work on a day-to-day basis.

13.     Confidentiality is an important issue because it can constrain the research which can be done into aspects of health policy.  There may be more opportunities to present information in a way that could not be traced back to the individual: it could be anonymous but still be detailed enough to be more helpful than at present.

14.     It was noted that health outcomes are very long-term, particularly when looking at avoidable premature death.  Measuring the intermediate outcomes is therefore important but can be more difficult.

15. The work of the Audit Commission and Commission for Healthcare Audit and Inspection (CHAI) sometimes point up problems such as local hospitals falsifying data.

16. Clinical databases, when compared with Hospital Episode Statistics (HES), have more data but there are question marks regarding the quality of data collected by clinicians.

17. A danger with new information initiatives is that insufficient thought is given at the beginning to what the users want to do with the data and how to present the data for that purpose. The people who fill in the medical records and do the coding are fundamental to any improvement.

18. There is some fragmentation of existing data gathering: there are hospital medical records, hospital accident and emergency records, hospital out-patient records, GP patient records, and various primary care patient records.

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**EXAMPLE**: if trying to map a year of care for Chronic Obstructive Pulmonary Disease (COPD) patients, district nurses have their own way of recording what happens to those patients which stands on its own and does not relate to other entries. While these data provide some basis for comparing hospital workloads, their case-mix, and their technical efficiency, they provide little basis for making judgements about their clinical performance, for example, in comparing how hospital A, as compared with hospitals B, C, and D, does in hip replacements.

**EXAMPLE**: length of stay can be calculated on the basis of spells or episodes. An acute trust wanting room for manoeuvre will want activities counted on the basis of completed consultant episodes, whereas the primary care trust (PCT), interested in improving efficiency, will want it funded on the basis of spells. *(A spell is from admission to discharge and within a spell there can be cross-referral between consultants.)*

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19. Improving medical records is important; it is the base on which everything else is built. Electronic patient records have been proposed on numerous occasions but they are always 'around the corner'.

20. It was suggested that sample surveys should be adequate to measure whether the productivity of the Health Service is improving. Moving to a sample collection for some types of data could reduce the overall burden. Is there an unnecessary burden on the providers of health data because of a belief that a

complete enumeration is needed?  Sometimes it is wiser to do less but focus on the right things.

## Medical records

21.　　Use of administrative data, coupled with patient identifiers, could open up the possibility of considerably enriched information.  Hospital Episode Statistics (HES) is one of the largest databases available and is a unique resource compared to the rest of Europe and other countries.  One problem is that databases are not as well used as they might be and the focus needs to be on making better use of them as much as on improvement.

22.　　Medical records are often not sufficiently complete.  Key pieces of information are often missing.  The records are sometimes poorly organised and do not follow a chronological ordering of episodes of patient care.  Medical, nursing, and allied health notes are filed separately without clear reference to individual episodes.

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**Medical records**

The main purpose of the medical record is to:

- ensure continuity of patient care
- ensure communication between all staff caring for the patient in relation to patient's past medical history, diagnosis and ongoing management plan
- be available for use as a record in the event of a legal enquiry
- be available for research and quality assurance and audit
- provide data for performance evaluation and funding purposes; and
- meet all of the criteria about timeliness and accuracy.

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23.　　The resulting absence of an integrated record inhibits cross-professional communication, and hence care integration; raises questions about coding accuracy; and hinders the use of the medical record in research, quality assurance and audit activities.

## Information technology

24.　　It was suggested that IT in the NHS has been limited by under-investment over a long period.  On top of that there have been successive reorganisations of management structures within the NHS, which have led to the loss, from time-to-time, of information departments and fragmentation of information

skills.  It is important that clinical and other databases are not developed in isolation.  Integration of standard NHS systems seems to be the way forward.

25.    Better IT is needed not just for information provision; it is needed to support the efficient use of resources.  The NHS has not been very successful in providing the right information at the right time, whether on a local basis or nationally.

26.    The development of an IT programme is a good opportunity to instigate a change in culture, both medical and managerial.  An IT strategy without that will have little direction.

## Information skills

27.    There is a national framework for the sorts of skills that people should have in the information and IT field, which the NHS Information Agency has taken on board.  In practice, however, there is a lack of understanding about the skills that are needed.  Data need to be collected appropriately but people also need to analyse them in an appropriate way to support decision-making.

## Standardisation and aggregation

28.    Users feel they have to struggle with information that is not integrated, not flexible, and not easy to bring together.  This constrains the improvement of the service.

29.    It was suggested that each UK health department should have a single source of validated health and social care information, based as far as possible on common definitions across the UK.  A consistent measure of performance and a greater harmonisation of definitions is important, as is the compatibility of indicators of socio-economic inequality.

30.    One issue is whether it is sensible to try to answer questions at a UK aggregate level.  In terms of the four home countries, how can valid comparisons be made given different definitions?  Whilst National Statistics aims to work at a UK level, the NHS does not.  In fact there are four National Health Services.  The international context is even more complex in terms of making valid comparisons.

## Fitness for purpose

31. Fitness for purpose will differ for different users.  It is difficult to separate out the quality of statistics from the use to be made of them and that applies not just to the processing, but to the data definitions.  *The quality that is needed for strategy is going to be different from that needed for operational use.*

32. As data become more widely available, the data producers do not know who is using the information.  They must make sure users know how it was collected and what has been done with it, so they can be confident that the user is properly informed.  This is a difficult task because of the variety of different users.  Many of the things that go wrong are due to misuse of the data, rather than something wrong in the original collection.

> **EXAMPLE:** there seems to be little problem finding out that the waiting times in a clinic are going up, but getting information that would explain why that is, what is happening to referral rates, and what is happening to the productivity of clinicians is a lot more difficult.

33. One of the continuing debates is on timeliness *versus* completeness.  Current data will contain errors, but are sometimes needed because they are up-to-date: a compromise is needed.  This is why metadata are so important.  It can be appropriate to make data available that are not absolutely perfect, so long as the user understands that.

34. Information can be misleading if it is not of the right quality or if users do not understand the fitness for purpose issues.

35. Information must be of good quality but it must also be *perceived* to be of good quality and reliable, otherwise the public and professionals will not use it. Users need to be aware of whether the information they are looking at is reliable, how the data quality varies and how to assess the reliability of a website.  They may not be aware of the quality of data in some of the other (non GSS) websites.  Unless the original data are collected appropriately, there is a limit to what can be improved.

36.    Statisticians are sometimes concerned that indications of reliability, where appropriate, may actually shake confidence in the data. In fact it would probably reinforce confidence because users would then be assured that providers were aware of the various limitations. There is also a need to know about reliability as part of an input into allocating resources in the provision of statistics.

37.    It is also important to do more to get clinicians engaged. They are ultimately the authors of diagnostic information, whether in HES or in cancer registries. The more the data is used by the people who have influence and need to use it, the better the chances of improving the data.

# Uses of data

38.     The UK population has to be told what it can expect from its health services. However, finding out how much was spent at present on key disease areas, aggregating the spending, and looking at the impacts of demographics and technology is proving difficult.

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**Data uses**

- How to measure success is a key question. To know how much it would cost to run a high quality Health Service you need to first answer the question about how quality would be defined. What are the implications of changes to either demography or developments in medical technologies? An evidence-based and information-based solution is needed. There is a need to know what the future statistical base of the UK population will be in terms of ethnicity because there is a need to know the health-related needs of those groups.

- How much of the spending growth in the Health Service over the last 10 years was attributable to changes in medical technologies? There is a need for help in terms of working out precisely how much the Health Service is spending on technology and how that has worked over recent years. Analysis in isolating technological change from other elements is not only important in terms of knowing how much the UK spent historically but also the UK's position relative to the rest of the world.

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39.     Disaggregating blocks of spending across the UK by age, sex, disease category, and whether or not people died in the year after treatment, is a significant component of forecasting the cost base. However, some of the areas of hospital spend, such as in A&E, are difficult to disaggregate in terms of how much of that cost base was spent, even by age and sex.

40.     The measurement of productivity is difficult and is being considered by the Treasury and DH at present. Changes in quality are very often even more difficult to measure and to disentangle from productivity measures. It is an important area because it is crucial to public understanding of what has been achieved in the Health Service. It is crucial to public engagement, and ultimately it will be crucial to public willingness to fund health services.

41.     The right targets have a place in driving improvement. At the moment some targets are used in a naïve or political way, for point scoring rather than the management of resources.

42.     A balanced scorecard would be useful. This is essentially a framework for putting the different measures together in a way that actually gives users not just a description of what has happened, but a real feel for what is happening in between those statistics. One suggestion of four sources of information that

could be put together into a balanced scorecard is: outcomes and cost effectiveness; user experience; process efficiency; capacity and capability.

43.     At the moment information tends to flow up and down within organisations, rather than between them; the information that is released at the end does not necessarily reflect the experience of people.  As many of the statistics are developed from management information they tend to be what is reflected at management level.

44.     Websites and search facilities are improving all the time but are still not at a stage where a general user, or even a specialist user, can get what is needed.

45.     Many different groups have different priorities for different types of information, however, the need for accountability uses up resources, sets priorities and becomes the focus for the information producing machinery.

46.     It is important for some public health data to be in the public domain, for the people themselves to see how the health of the nation is improving.

## Issues for the Statistics Commission

It was suggested in discussion that the Commission might want to consider the following points:

47.     To what extent is it the Commission's role to look at public health information? The Commission should use its influence to ensure that the right sort of data are gathered.

48.     The Commission might try to generate a more informed debate in the media on the issues involved than there has been hitherto and play a role in terms of how numbers are used by Government.

49.     The Commission might do more to inform the public and professionals about the meaning of 'National Statistics'.  The Code of Practice and various protocols would help the ONS, DH and the Commission to ensure that, once standards are set for data, they then continue to be collected and managed in a particular way.

50.    The Commission should think about whether the issues regarding confidentiality are affecting some of the ways in which numbers are capable of being produced.

51.    One of the big inhibitors to good health statistics is access to good IT.  There might be an opportunity for the Statistics Commission to engage with that issue.

52.    There is already a National Statistics theme group which has a work programme to improve health and care statistics.  The Statistics Commission should examine the theme group programme and determine whether it is tackling the right issues and whether it is likely to produce significant benefits in a reasonable sort of timescale.


Secretariat
Statistics Commission
November 2003


**Abbreviations**


CHAI      Commission for Healthcare Audit and Inspection

COPD      Chronic Obstructive Pulmonary Disease

DH          Department of Health

HES        Hospital Episode Statistics

NPRAS    National Patient Record Analytic Service

PCT        Primary Care Trust

**HEALTH STATISTICS SEMINAR ATTENDANCE LIST**

**29 JULY 2003**

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|---|---|
| **Paul Aylin** | Imperial College |
| **Jon Billings** | Audit Commission |
| **Nick Black** | London School of Hygiene and Tropical Medicine. |
| **Colette Bowe** | Statistics Commission |
| **Sir Ken Calman** | Statistics Commission |
| **Pieter Degeling** | University of Durham |
| **Gill Eastabrook** | Statistics Commission |
| **John Fox** | Department of Health |
| **Michael Goldacre** | Institute of Health Sciences, University of Oxford. |
| **Deana Leadbeter** | Health Statistics Users' Group |
| **Alison Macfarlane** | City University |
| **Alan Maynard** | Department of Health Sciences, University of York. |
| **Carolyn Sinclair** | Consultant |
| **Lovedeep Vaid** | Statistics Commission |
| **Derek Wanless** | Statistics Commission |
| **Martin Weale** | Statistics Commission (Meeting Chairman) |
| **John Wyn Owen** | The Nuffield Trust |