

# Data matters

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## Abstract

Data underlie all service development and quality improvement initiatives in healthcare. This article describes the myriad potential benefits for improving current disjointed data systems through the creation of truly comprehensive electronic records. These will allow both real-time recording of the patient–doctor interaction and the ongoing process of care, as well as compatibility across healthcare settings and international boundaries.

An important step is to implement a common clinical terminology to allow capture and sharing of clinical information with sufficient precision. SNOMED CT is the only system currently available with the potential to be healthcare data's universal language. As with all data systems, the technology infrastructure is simply a means to improve health information delivery for clinicians, commissioners and policymakers. Its ultimate value to patients will depend on how healthcare professionals collect and use the information. It is a professional responsibility to ensure accurate and timely data collection through a thorough knowledge of health informatics as it applies at the doctor–patient interface.

**Keywords** electronic health record; electronic patient record; health informatics; hospital episode statistics; quality improvement; SNOMED CT

## Introduction

It is a truly shocking statistic that children in the UK are more likely to die in childhood than in almost any other developed country. This is known, only because of the diligence with which deaths are recorded in the developed world. But improvement requires more detailed information about the causes and circumstances surrounding these deaths. Is there a failure to prevent the causes of death, to provide adequate treatment, or both? Quality of healthcare cannot be measured solely by death rates. There have been various attempts across Europe and in the UK to develop outcome frameworks which rely heavily on the collection of healthcare statistics.

The present system of collecting clinical data is designed on the basis that the information is spread across a paper record.

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The advent of electronic patient records provides an opportunity to record data in a structured way that can give useful clinical information back to the clinician. This article aims to provide an understanding of how data recording takes place at the doctor–patient interface, and how data can be used to inform quality improvement. The difference between disease classification and terminology will be explained, as will the move towards “collecting once and using many times”. The advantages for clinicians and patients of improved data collection through the use of a single clinical terminology, The Systematised Nomenclature of Medicine Clinical Terms (SNOMED CT) will be demonstrated.

## Administrative healthcare data in England

Most healthcare systems lack the NHS's unified organisational responsibility for data, the infrastructure for collection, or the analytical capability for interpretation and use. As a result, healthcare data in England provides a rich source of information which is the envy of healthcare systems across the world. NHS data consists of millions of healthcare episodes over decades, from purely administrative data to richly detailed clinical information on diagnosis, procedures and treatments in many different healthcare settings. Despite this, healthcare information is currently created by an administrative process away from the point of patient care and clinicians have often felt detached from the process and frustrated when they wish to get involved.

The current system is based on extraction of data from paper records. Inpatient diagnoses and treatments are extracted from unstructured notes by clinical coders and classified using the International Classification of Disease v 10 (ICD-10) and the Office of Population Census and Surveys Classification of Interventions and Procedures v 4 (OPCS-4) respectively. This data, along with a great deal of administrative detail relating to the admission, is submitted according to the requirements defined by the Clinical Data Set (CDS6.2) to an online database entitled Secondary User Services (SUS). The composite data is processed by the Health and Social Care Information Service (HSCIC) and subsequently published in various formats, most particularly as the Hospital Episode Statistics (HES). Currently, outpatient activity is not routinely coded for clinical information, including presenting symptoms, diagnosis or treatment.

This same data underlies many different measures of healthcare performance. This includes Dr Foster's “My Hospital Guide”, which published the Hospital Standardised Mortality Ratio (HSMR) that first drew attention to problems in Mid-Staffordshire NHS Trust, and ultimately to the publication of the Francis report. Hospital statistics are also used to calculate Standardised Hospital Mortality Index (SHMI) and to publish the recent surgical outcome data on NHS Choices showing mortality rates by surgeon.

Secondary care coding was not designed to capture patient-specific detail at the doctor–patient interface – rather, it was based on diseases (and specific diagnostic or therapeutic interventions), and designed to give population-level epidemiological data for healthcare researchers and policymakers to plan services.

By contrast, primary care data use different sets of clinical coding terminology to facilitate data collection at the doctor–patient interface - most commonly Read Codes Version 2,

developed by James Read, a General Practitioner from Loughborough. This is the basis of primary care monitoring, including the Quality Outcomes Framework (QOF) by which a significant proportion of GP remuneration is managed. Although these data are collected routinely by all practices, several non-compatible electronic systems are in use. Therefore comprehensive data for primary care services in England are laborious to analyse retrospectively, except for relatively small, curated research databases such as The Health Improvement Network (THIN) or Clinical Practice Research Datalink (CPRD). Lack of interoperability between primary care and hospital data means patient-level data linkage is not routinely possible.

### Healthcare data for quality improvement

It was Don Berwick, a paediatrician working in North America, who first drew attention to variations in patient safety across healthcare systems. Collection and use of good quality data is the key to making hospitals and clinical care better and safer.

*".....it is clear that only what can be measured can be improved"* - Lord Darzi

Given the clear importance of data, the involvement of clinicians in collecting and reviewing data about the care of patients would be expected. When the current system was first launched in 1989 following the report by Edith Korner in 1982 the president of the Royal College of Physicians said:

*"The recommendation that diagnostic data should be collected on all patients covered by the system is to be welcomed; its omission would make the scheme even more obviously a management exercise, thereby lessening its appeal to the active clinician. Both for the sake of analysing the use of his own unit and for the sake of colleagues in epidemiology, however, he should accept the responsibility of making the diagnostic coding as accurate as possible"* - Douglas Black

Sadly clinical involvement with national data collection has never been strong. A national survey of consultants found that only 22% had regular involvement with clinical coding and 36% thought it was important but did not involve them. The situation is entirely different where clinicians have led the development of bespoke data collection systems, such as the Badger System in neonatology, or have worked with national data collection, as in diabetes care. These enterprises highlight the potential for improvement when clinical interest is evoked. However successful, these systems are expensive and will never capture more than a tiny portion of NHS encounters.

One of the reasons clinicians have been reluctant to involve themselves in the current system of national data collection is that they often find it difficult to access the data on their own patients.

*"...there are no immediate benefits for those who use them [clinical data]."* - Audit Commission Report

When clinicians have accessed hospital data they have often been disappointed because the diagnostic and procedure data are aggregated for coding purposes into groups of similar (or not so similar) conditions. This is often interpreted as inaccurate data, whereas it is actually a result of aggregating data in a way that is

not helpful to their purpose. An analogy can be made with other classification systems, such as zoological taxonomy. For example, it would be perfectly logical to group together Lions, Tigers and Domestic Cats because they all belong to the same family. However in an international comparison of the outcome from injuries caused by cats, countries dealing mainly with injuries from big cats would inevitably have worse outcomes that could be attributed unfairly to the quality of care. Unless the system is detailed enough to allow analysis of the data using more meaningful criteria (in this case, species of Cat) the data cannot be retrospectively tooled for other purposes. Creating meaningful clinical datasets for improvement and research requires the recording of multiple levels of information, representing the multiple taxonomies for each individual diagnosis or symptom. SNOMED CT is a system which makes this possible.

### SNOMED CT

Quality improvement and audit require very specific information about diagnosis and treatment. Using a disease classification such as ICD-10 to group similar conditions makes the data more manageable for large scale analysis, but a great deal of important detail is lost. Conversely most clinicians are very specific when writing in free text. In fact the medical profession has a long history of eloquent descriptions of disease which helped to take forward medicine before the pathophysiology of many conditions was understood. The description by Sir Frederic Still of Pyloric Stenosis is a prime example and review of the notes in such a case would leave no doubt about the surety of the diagnosis.

*"Since the vomiting began the bowels have been costive, perhaps only opened with enemata. And now the infant is wasting to a marked degree and perhaps it is this wasting rather than any alarm at the vomiting which leads the parents to seek medical advice. Such is the history which leads one to examine specially for the two characteristic signs – visible and very marked peristalsis of the stomach and a palpable thickening of the pylorus – upon which the diagnosis rests."*

The same issue exists for procedures where OPCS-4 is used to classify procedures, which are further grouped into Human Resource Groups (HRGs) for the purpose of commissioning and payment. Clinicians in highly technical specialties may get heavily involved in the coding of their procedures because even small changes in the classification can result in a large increase in departmental income. However, frustration exists as the classification does not support the detail that many clinicians require to record the complexity of their work, especially where these data are used to report outcomes linked to individual teams or clinicians.

In preparation for electronic patient records, the NHS has been developing a structured terminology that is suitable for clinicians to record the details of every aspect of their clinical work. SNOMED CT was born in 1999 from an amalgamation of an American Pathology set of terms (SNOMED-RT) and Read Clinical Terms v3.

SNOMED CT has been mandated for use for a number of years and is part of all secondary care electronic patient records (EPR) deployed through the National Programme for IT. It has been in use in a number of hospitals for well over 4 years. Since the

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