How might information improve quality of care in the English NHS?

Gwyn Bevan

The Labour Government elected in 1997 observed that they had “24 hours to save the National Health Service (NHS)” and sought to make it once again “the envy of the world”. There was good evidence of serious problems over quality of care in the NHS: with high mortality from major diseases, excessively long waiting times, and a series of scandals that highlighted appalling failures of governance. Currently, the main policy driver of improving quality is in a market driven by patient choice in which hospitals are paid a fixed tariff by types of case.* This overview begins by examining evidence of answers to two fundamental questions about patient choice: Do patients want choice? And, do they act on information to exercise choice? It then considers evidence on the impacts that quality of care information has on providers, and concludes by examining the information that is currently available, and ought to be available.

Do patients want choice?

When patients are asked what they want most, the consistent finding is that they do not want choice but ‘a good local hospital’. A recent study,¹ as part of the national patient survey programme in England overseen by the Healthcare Commission, sought to identify the aspects of care that patients discharged from hospitals in England were most important to them. This study found

* The system is known as ‘Payment by Results’.

Do patients act on information?

There is one striking example of patients using information to choose to go to another hospital, namely the London Patient Choice Project (LPCP), which began in 2002. The LPCP was established to improve choices for patients who were clinically eligible for treatment and who had been waiting for treatment at an NHS London hospital beyond some target waiting time (initially six months, which was later reduced). The scheme was introduced on a pilot basis for types of elective surgery in south east London only. Eligible patients were first informed about the scheme and then contacted by a Patient Care Adviser (PCA) who offered them the option of going to an alternative hospital, answered their questions, and, if the patient

* The Observatory is a partnership between the WHO Regional Office for Europe, the Governments of Belgium, Finland, Greece, Norway, Spain, Slovenia and Sweden, the Veneto Region of Italy, the European Investment Bank, Open Society Institute, the London School of Economics and Political Science and the London School of Hygiene & Tropical Medicine.
agreed to accept the offer of an alternative, booked an appointment, supported the patient and kept the patient’s GP informed. Patients valued the PCA’s support and the provision of free transport. A study of its operation in 2004 found that although only a third of patients apparently eligible for the scheme were actually offered a choice of hospital, of those who were offered the opportunity to go to an alternative hospital, two-thirds chose to do so, and this was influenced by whether patients were in pain or dissatisfied with the reputation of their local hospital. Of those choosing to go to another hospital, a third wanted to know more about these hospitals’ arrangements for follow-up care, quality of care, qualification and experience of surgeons, operation success rates, standards of hygiene and safety record. And nearly all of those who had opted to go to an alternative hospital said they would recommend the scheme to others. The LPCP, although recent, is a world away from how things were previously because of the reductions in waiting times: by 2008, the target in England is to reduce waiting times from GP referral to elective admission to 18 weeks for all providers. The next question is: when patients were given information on quality of care, as they say they wanted in the LPCP, did they use this information?

In the early 1990s, the United States pioneered the publication of intelligence systems on health care performance through annual reports of clinical outcome indicators for use by the public and doctors. This broke away from the traditional approach of secrecy and anonymity over data on clinical outcomes. Studies of patients’ use of this information highlighted several things: when this information was published only a minority were aware of it; of those, most did not understand the information (including whether high or low rates of an indicator reflect good performance); nor did they trust it or use it (with problems of timely access, and lack of genuine choice). Moreover, evaluations of later developments that addressed many of these potential barriers failed to demonstrate significant or sustained public interest. A review concluded, “most experts do not believe that consumer pressure will be an important mechanism to stimulate quality improvements for the foreseeable future.” Whereas the LCPC showed that most patients, when asked if they would like to go to another hospital to avoid long waits for treatment, did so, there is no evidence of an equivalent effect in patients’ responses to information on variations in quality of hospital services. Perhaps patient choice on the basis of information on quality is an idea which is valued in the abstract by people who are well, but when people are ill, they take little notice of such information and see choice as unimportant?

Does information on quality impact on hospitals?

Three studies of the impact of publishing information on quality of hospitals – in New York, Scotland and Wisconsin – are instructive.

The most famous and studied attempt to use information to improve quality of care began when the New York State Department of Health, in 1989, developed methods to collect and analyse data to report comparative crude, expected and risk-adjusted 30-day mortality rates by hospital and surgeon from coronary artery bypass grafting (CABG). As Mark Chassin, who was Commissioner of the State Department of Health from 1992 to 1994 observes:

“The improvements in New York happened because individual hospitals and cardiac surgery programs used the data to make specific changes in the way they provided care to CABG patients. Market forces played no role. Managed care companies did not use the data in any way to reward better performing hospitals or to drive patients toward them. Nor did patients avoid high-mortality hospitals or seek out those with low mortality.”

Scotland’s Clinical Resource and Audit Group (CRAG) pioneered in the UK (and Europe), in 1994, the publication of annual reports of clinical outcomes. The main conclusion of the evaluation by Mannion and Goddard was that in Scottish trusts these indicators “had a low profile … and were rarely cited as informing internal quality improvement or used externally to identify best practice.” The identified reasons for this were that the reports had low credibility (for example, because there was no risk rating and the information was seen to be out of date), few people were aware of them, and the information was difficult to interpret.

A study of a controlled experiment in Wisconsin provided information on indices of adverse events (deaths and complications) across three areas of care: cardiac, obstetric, and hip and knee. Hospitals were divided into three groups:

Public report – where considerable effort was made to publicise the results by mailing, a supplement in the local newspaper, publishing information online and in hard copy for libraries and community groups;

Private report – where hospital staff only were given a private confidential report (with no publicity); and

No report – where no information was provided to hospital staff or the public.

The key findings from the Wisconsin study were that the public report hospitals were significantly more negative than the other two groups about the public reporting of information, but their efforts to improve quality efforts were significantly greater than in hospitals given only private reports or those provided with no information. None of the hospitals saw such information as having an impact on their market share (or ‘one like it’ in the case of the private and no-report hospitals), and this belief was confirmed by analysis. As in New York, for the public report group of hospitals, there was no significant change in market shares: there were no shifts away from low-rated hospitals nor toward higher-rated hospitals. The public-report hospitals, however, saw this information as having an impact on their public image. Hence the key driver of change in New York and Wisconsin appears to be concerns by providers of damage to hospitals’ reputation. This factor also was cited by patients in the LPCP. In Scotland it appears that CRAG reports lost their impact over time and hence their
potential to cause reputational damage. The key issue thus seems to be producing reliable information on quality, which is robust to criticism from providers, and making this information comprehensible and known to the public. It is unclear whether pressure on providers to respond to information indicating poor quality requires a system in which reputational damage threatens market share.

Information requirements on the quality of hospital care

To assess the information that is, and ought to be, provided on the quality of hospital care it is essential to appreciate three crucial facts.

1. Studies of quality typically find significant variations and that some hospitals provide poor quality care. Hence, we are likely to be quite wrong in assuming that where clinical care has not yet been measured, that there is no variation which ought to concern us. In quality of care, ignorance ought not to be bliss.

2. As a general acute hospital is a highly complex organization, to assess the quality of hospital care, we need to go below the level of the hospital: by specialty, sub-specialty, medical condition or surgical procedure. In England, the Commission for Health Improvement, in its inspections of the implementation of systems and processes to assure and improve quality of care for acute hospitals, found that single-specialty hospitals tended to do best, and that within multi-specialty hospitals performance varied greatly, often with a dysfunctional clinical team being identified.

3. There are massive gaps in the data that are routinely collected below the level of the hospital on key dimensions of quality of care. The only data on clinical outcomes the NHS routinely collects after discharge are from the local collection of data in hospitals, but collecting these data are not organized or funded on a coherent basis: they rely on the enthusiasm of charismatic clinicians and opportunistic sources of funding. Nor is the information that is available from the various national clinical audits easily accessible for patients. National surveys on patients do collect data on satisfaction of patients from national patient surveys on the processes of care: for example, catering, cleaning, and being treated with dignity and respect. But these are organized to give information on average performance for each hospital.

There are two ways of simplifying assessment of quality of a hospital and each aims to give a global indicator of hospital performance and hence of all its services. First, the synecdoche assumption that the part we can measure will act as a good proxy for all services in the hospital: for example, using the outcomes measures we have of mortality and readmission rates and assuming that these give good indicators of outcomes where these either do not apply or good indicators do not exist. Second, taking estimates at the level of the hospital, as in measuring satisfaction of patients from national patient surveys on the processes of care: for example, catering, cleaning, and being treated with dignity and respect. For multi-specialty hospitals, generic indicators are valid for those services that are organized at the level of the hospital (for example, catering, cleaning, diagnostic services), but not for those that vary between specialties and individual doctors. Thus, for example, to know that a hospital has low mortality rates for medical and surgical admissions tells us nothing about subspecialties within surgery. Nor do hospital mortality rates tell us anything about specialties where mortality is irrelevant, for example, dermatology. And an average hospital rate for being treated with dignity and respect may conceal important variations between specialties.

The gaps in information identified above suggest that the following developments need to be pursued:

- securing funding of a coherent programme of national clinical audits to cover common medical conditions and surgical procedures;
- extending the national surveys of patients to generate estimates of different specialties within hospitals;
- piloting systems to collect data on outcomes of patients after discharge from hospitals; and
- publishing all this information and making it easily accessible.

Although each development would require extra resources, there is no need for all the necessary data to be collected all the time. Some national clinical audits and the patient surveys are organized to take samples at different times. The national patient survey programme might be organized to, for example, rotate through different specialties (although there may be advantages in choosing these at random and not having a programme announced long in advance). And the collection of data on outcomes of patients after discharge could be organized similarly. There would, of course, be costs from the design and collection of new data for new national clinical audits and on outcomes of patients after discharge. But the central costs of organization would be low: the organization of a national clinical audit, for example, costs about GBP £100,000 (€148,000). The main costs of these audits are from the local collection of data in hospitals, but collecting these data are vital to knowing whether care is, or is not, being delivered properly, and this information ought to be seen as integral to the proper delivery of health services.

References

Health Quality Information in Norway

Michaela Schiøtz and Sherry Merkur

A systematic framework to improve health care services in Norway began with the National Strategy for Quality Development in the Health Service 1995–2001 which set a target for all health care providers to establish comprehensive and effective quality improvement systems by the year 2000. The introduction of ‘internal control’ by health care institutions for quality assurance purposes was a central component of the strategy.

Health-related registries

At the national level, health-related registries cover the entire population and include data over several decades. Many of these are medical databases containing information related to outcomes and specific treatments or diagnoses, which are used to assess the effects of different treatments on patients’ health in primary and specialized care. These databases have been set up through initiatives by individuals, hospitals or educational institutions, and provide valuable information for assessing the effects of different treatments and benchmarking production units down to the ward level.

The Norwegian Institute of Public Health is responsible for ensuring good utilization, high quality and simple access to registry data, as well as ensuring that health information is treated in accordance with privacy protection rules. Seven central health registers have been established: Cause of Death Register; Norwegian Cancer Register; Medical Birth Register of Norway; Norwegian Surveillance System for Communicable Diseases (MSIS); Tuberculosis Register; Childhood Vaccination Register (SYSVAK); and the Norwegian Prescription Database.

Quality registries

There are many regional and national quality registries in Norway, most of which began as initiatives within medical professional environments. The registries do not have a stable framework with regard to operation and financing. Ownership and responsibility for data management lies with the regions, while the National Board of Welfare and Health is responsible for national coordination in establishing new registries and the continuing operation of existing registries. The registries cover different disease areas and regions but currently do not cover all professional areas; 10 of them are related to cancer. The National


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National quality indicators

National quality indicators for specialized health care services were introduced in Norway in 2003. In 2006, data for 21 indicators were registered (11 for health care and 10 for psychiatric care), as well as patient experience surveys. The reporting of data is compulsory and information is published on the web page www.sykehusvalg.no together with information about hospital waiting times for different treatments and initiatives. Data is presented at an organizational (hospital) level and can be compared with national averages.

National quality indicators for care services supplied by municipalities were introduced in 2005. In 2006, six indicators were published on the web page www.bedreikommune.no. Data are presented at the municipality and county level together with national averages for each year. While the system is designed to compare results, it does not perform rankings. The first complete data set from all municipalities will be available in 2008 while quality indicators for public dental care, social services and municipal health care services are under development.

* These are out-of-hospital services for the elderly and people with disabilities, including people with mental health needs.
Information for patients

In Norway, the national indicators for specialized health care services are published on the web page www.sykehusvalg.no and the indicators for municipality health care services (and social services) are published on the web pages www.ssb.no/kostra and www.bedrekommenue.no.

The web sites provide the following information and features:

- Information about public and private hospitals (those that have an agreement with public hospitals to perform selected treatments).
- Comparison of waiting times for the selected hospitals on 139 different treatments.
- Information about patient rights, laws, free choice of hospitals, news, help with using the web site, FAQ and more.
- View quality indicators for each of the participating hospitals.
- Administrators and patient advisors have access to online administration tools, which allow waiting times, quality indicators and other factors to be updated on a daily basis.

Patient surveys and patient satisfaction

The Knowledge Centre for Health Services (Nasjonalt kunnskapsenter for helsetjenesten) has carried out several national surveys on patient/users experience. The surveys have provided feedback to health care providers on patients’ experiences in different areas and have been used to provide information for quality improvement work and for management and leadership purposes. The surveys also have provided the basis for the development of national indicators, available at www.sykehusvalg.no.

In 2006, two national surveys were carried out: (1) A national survey of the experiences of adults who have been admitted as patients to hospitals, and (2) A survey among the relatives of children and adolescents receiving health care services at psychiatric outpatient clinics.

In 2007, a national survey is being carried out among cancer patients in hospitals, and outpatient clinics for adults in psychiatric health care service. Norway also participates in the Nordic Ministers Council for Quality Measurement initiative, including surveys of patients’ experience of the health care system (See Box on Nordic Collaboration on page 8).

References


Health Quality Information in Sweden

Michaela Schiøtz and Sherry Merkur

Sweden has a well-developed system to monitor economic and human resource activities within health care. Corresponding systems have not yet been developed for working with patients, although provider organizations are aiming towards this goal. In particular, traditional patient record systems have not facilitated the collection of the data needed for quality improvement, and although electronic records are becoming increasingly prevalent, currently many providers continue to use notepads for memory support in treating patients. Swedish regulations require that health care quality systems contain mechanisms to aid the coordination of quality improvements, and that adverse incidents are reported and prevented.

The National Board of Health and Welfare (NBHW) monitors and evaluates health services to determine if they correspond to the goals laid down by the central government. All staff working in health services is formally required to participate in quality assurance programmes.

National Quality Registries

For over a decade the Swedish Association of Local Authorities and Regions (SALAR) and the NBHW have joined forces to support the development and use of National Quality Registries in health care. This collaboration takes place within the Executive Committee for National Quality Registries, which also includes representatives from the associations for Swedish doctors and nurses.

The registries are developed and managed by representatives of the professional groups that use them, and the databases are spread out among different hospital clinical departments throughout the country. Starting with approximately 15 registries in the early 1990s, Sweden now has 57 registries, covering a wide range of disease categories and conditions, which receive economic support through the Executive Committee.
The competence centres also enter into special agreements, for example, to define the limits of treatment indications or to develop national guidelines. Therefore, competence centres have expertise along two main dimensions: (1) one or more specialty areas, for example, orthopaedics or cardiovascular disease; and (2) ‘registry know-how’, that covers everything from technical operation, to scientific analysis, to methodologies for quality improvement. Despite the emergence of competence centres, the registries continue to be managed independently by their own managers. However, increasingly, registries have turned to a competence centre for collaboration on operational and analytical work, such as using a common IT-platform.

Health data registries

Unlike the national quality registries, which are voluntary initiatives, the national health data registries are regulated by law, and consequently coverage is high. Although the information contained in these registries is somewhat limited, particularly regarding treatment interventions, they play an important role in validating the data in the national quality registries. The Epidemiological Centre at the NBHW is responsible for the following health data registries:

The Patient Registry, covers all admissions to hospitals, and in recent years also data from some outpatient services;

The Medical Birth Registry, includes all deliveries and information about mother and child;

The Cancer Registry, contains information on people registered as living in Sweden and diagnosed with a tumour or tumour-like condition;

The Pharmaceutical Registry, started in October 2005, contains information on all prescriptions filled in Sweden;

The Cause of Death Registry, provides official cause of death statistics and maintains data on cause-specific mortality to describe the health of the population.

Quality data and indicators

The NBHW is responsible for the development and reporting of national indicators for ‘good care’ through a number of initiatives, including the project Public Evaluations. The 2006 report presented 57 indicators which are used to evaluate the health care services of county councils; and 19 of these are from the inventory of the national quality registries. The indicators fall under several headings: medical results (35 indicators), patient experiences (9 indicators; see Box 1), access (4 indicators) and cost (9 indicators).

Information dissemination

In Sweden, quality information is published primarily by the NBHW (www.socialstyrelsen.se) and through the web site of the Swedish municipalities and county councils (www.skl.se). The NBHW provides statistics on public health, the health care system, health security, disease control and social security in a variety of formats (reports, databases, tables and diagrams). From its databases it is possible to access data on abortion, cancer, diagnosis at the end of care, DRGs, causes of death, financial support, family counselling, births, myocardial-infarction, substance abuse, surgery at the end of care, health care personnel and care for the elderly. The ‘How does Sweden feel?’ database contains information on public health status, morbidity and mortality, social circumstances, lifestyle and health care utilization, available at the municipality level.

The Swedish municipalities and the county councils publish statistics on health care professionals as well as financial and organizational data for the county councils.
The 'Hospital data in focus' database contains statistics on several areas relevant to the county councils, such as information on patients, diagnoses, hospital beds, the financial situation of county councils, pharmaceuticals and health care professionals.

**References**


**Health Quality Information in Denmark**

Michaela Schiøtz and Sherry Merkur

Quality development projects were initiated in the Danish health care system from the middle of the 1980s. The projects were primarily implemented in the hospital system, in general practice and in public sector research institutions. In 1992, the National Board of Health set up a national council that published the first national strategy for quality improvement.1

From 1999–2000, a systematic and formalized quality development process at the national level was introduced with the establishment of the National Board of Quality Development and a number of nationwide quality initiatives, including the National Indicator Project (NIP), The Secretariat for Reference Programmes and Competence Centres for Clinical Databases and the Nationwide Survey of Patients’ Experiences (NSPE). In 2002, the Ministry of the Interior and Health and the National Board of Health published a new strategy for quality development. One of its main initiatives was the Danish Quality Model which focuses on coordinating national quality development activities.

The Danish Institute of Quality and Accreditation in Healthcare was established in 2005 to develop and implement the Danish Quality Model and to take over responsibility for the accreditation of all health care institutions (in both primary and secondary care).

**The National Indicator Project**

NIP is a nationwide, interdisciplinary quality development project established in 2000. In the period 2000–2007, diseasespecific, evidence-based standards and indicators for eight disease categories have been developed: hemorrhage, hip fractures, heart insufficiency, lung cancer, acute gastrointestinal surgery, schizophrenia, diabetes and chronic obstructive pulmonary disease.

The project is implemented in hospitals and participation is compulsory for all hospital wards that manage the treatment of the listed diseases. Information is collected from patients’ medical records with respect to treatment, severity of illness, and results of treatment. NIP data are made available to doctors, nurses and other health professionals involved in treating patients, with the aim of assessing which areas within the care pathway are of adequate quality and which require improvements. NIP results also have been used to identify hospital departments with poor performance. In some cases, this has led to additional funding from the regions, which finance hospital care in Denmark, to the identified departments to improve quality.

The results of NIP are published online through the health care portal financed by the regions: www.sundhed.dk.

**Clinical quality databases**

There are about 50 publicly financed, nationwide clinical databases relating to the major diseases treated in the Danish health care system. Of these, 32 contain clinical quality data. The aim of these databases is to measure the quality of the health services provided to a number of patient groups, and they also feed into the National Quality Project. For all diseases with a nationwide clinical database, patient information from hospital wards is collected and reported by health care professionals to the relevant national database, where it is analysed and used to monitor the quality of the services provided. The regions finance and support the dissemination of the clinical databases. All the databases are attached to one of three competence centres and quality data is published regularly online through the www.sundhed.dk website.*

**Health registries**

The National Board of Health is responsible for the operation and development of a number of health registries which are used for monitoring and planning, as well as for research and administration. Examples of registries related to quality of care include the National Patient Registry, the Cancer Registry, and the Registry on Births and Birth Complications. The website www.sundhedsdata.sst.dk makes available extensive health statistics from the registries in flexible formats.

* However, the information published is primarily for the use of health care professionals and is often difficult for the lay public to understand.
The Nationwide Survey of Patients’ Experiences

The Nationwide Survey of Patients’ Experiences (NSPE) is carried out every two years. Around 500 patients from each of the country’s 54 hospitals are asked to answer a questionnaire about their experiences within the health care system. The results are published at www.sundhed.dk.

The Danish Quality Model (DQM)

DQM, managed by the Danish Institute for Quality and Accreditation in Healthcare since 2005, is a joint quality development and accreditation system for the entire Danish health care system that is based on a common set of standards and indicators. DQM focuses on patient care across the different sectors of the health care system, between institutions and internally within institutions.

The DQM’s basis for evaluation (standards with associated indicators) includes 37 themes that are described within three main areas:

1. General activities
2. Disease specific activities
3. Organizational activities

The evaluation framework for the DQM (developed in 2006) is based on national quality initiatives and the national clinical quality databases. In relation to each of the 37 themes, two to four standards have been developed and for each standard, two to four indicators specified.

The Health Quality initiative

Sundhedskvalitet (Health Quality) is a collaboration between the National Board of Health and the Ministry of the Interior and Health that focuses on free hospital choice and the promotion of patients’ involvement in their own treatment. It uses existing and published data from, among others, the National Patient Registry, the NIP and the NSPE.

Through the website www.sundhed-skvalitet.dk, patients have access to relevant hospital information, including length of stay, number of readmissions, waiting times and hygiene. For a number of treatments, it is possible to compare hospitals with each other and the national average.

Sundhedskvalitet provides two sets of key figures with scores: hospital key figures and treatment-specific key figures (currently a treatment score is available for 12 different treatments). However, experience so far has shown that few patients use the website.

REFERENCES

2. National Indicator Project at www.nip.dk

Nordic collaboration

The Nordic Ministers Council Working Group for Quality Measurement* was established in 2000 to develop quality indicators and to create a foundation for evaluations.

The working group consists of 3–9 representatives from each of the participating countries – Sweden, Norway, Finland, Denmark, Iceland and Greenland. Six sub-groups work on selecting generic and disease-specific indicators as well as indicators related to patient safety, psychiatry, primary health care, acute hospital care, public health and preventive health care and patients’ experience of health care. So far, the selected joint quality indicators for the Nordic countries also include, among others:

Patient safety:
- Births – proportion of perinatal fissures, grade III/IV in relation to vaginal births;
- General hospital mortality – proportion of patients who die during hospitalization

Patient experienced quality:
- Patient satisfaction with hospitalizations – validation through a questionnaire