



# The use of national registries data in three European countries in order to improve health care quality

National  
registries

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## Abstract

**Purpose** – The purpose of this paper is to highlight the role of national health registries in three European countries in order to improve patient care.

**Design/methodology/approach** – The methodology used was a literature review of databases in Sweden, the UK and Portugal, and a search on Medline and Pubmed as well. In addition case studies from the three countries are included.

**Findings** – In Sweden registries encompassing cardiac intensive care, hip-fractures and stroke are the most developed. In the UK, the collection of information on healthcare performance, both specific to particular specialties and general hospital performance, is widespread. There are some national and regional registries in Portugal, but the most developed areas are the Cardiovascular and the Oncology areas. The collection of information on health quality/performance indicators, based on administrative and clinical data is an important tool for quality improvement.

**Originality/value** – This paper showed differences and similarities between the three countries with a common aim; to improve quality of care, delivered on equal terms for the whole populations, and in an effective and efficient way and will be useful to those in the field of patient care.

**Keywords** Quality improvement, National Health Service, Benchmarking, Sweden, Portugal, United Kingdom

**Paper type** General review

## Introduction

Quality of care is considered a multidimensional concept that has been given different meanings and definitions in the literature, all over time.

There was a time, not so long ago, when quality could be defined by saying “I know it when I see it”. Not today. The public is concerned. They want to know that the medical care they receive is safe, effective, and accessible to them (Marshall, 2001).

In today’s world, the rapid diffusion of information, the growing level of knowledge and the greater requirements of patients, the strong financial constraints and the need



to introduce criteria and quality/performance indicators in the health care given, have contributed to change some of the dynamics of health institutions (Biscaia, 2002; World Health Organization, 2003). These dynamics have evolved in the direction of giving greater value to the collection and treatment of credible standardized information thus making possible the evaluation and monitoring of services in terms of the volume of activity and results achieved (Weitraub *et al.*, 1997; Cheng and Song, 2004; Cavalli *et al.*, 2004).

There is an emphasis on patient-centred care in most health systems in Europe. The consumer of today is more informed and demanding than ever, and calls for a description of the recommended treatment and its advantages and risks. For that reason there is a pressing and increasing need for information.

Several authors highlight this issue, the increasing need for information, in different perspectives: patient perspective, in order to make informed choices, for instance; professional perspective, to measure and improve clinical and economic costs, and to help to develop performance and quality indicators, and political perspective, to compare performances and results among providers, and to plan health care, based on solid knowledge of needs and demands, and to draw effectiveness strategies based on either trends of the population characteristics and of the health care delivered (Larsson *et al.*, 2005).

Additionally, the publication of such information could drive up the overall quality of care.

Public reporting of comparative information on health care quality of physicians, hospitals, and health plans through "report cards" is hailed as a plausible way to improve health care. Without publicly reported comparative information on health care quality, patients may choose their physicians based on more measurable characteristics, such as cost, or by word-of-mouth or other informal referral practice not obviously related to their needs (Werner and Asch, 2005).

Reporting quality information publicly is presumed to motivate quality improvement through two main mechanisms. First, public quality information allows patients, referring physicians, and health care purchasers to preferentially select high quality services (physicians and institutions). Second, public report cards may motivate physicians to compete on quality and, by providing feedback and by identifying areas for quality improvement initiatives, help physicians to do so (Werner and Asch, 2005; Spiegelhalter, 2005).

We tend to think ourselves unusually enlightened in examining outcomes of care. In fact, historical precedents for this are noteworthy, not only because of the compilation and comparison of outcomes and other data but also because of vigorous efforts to discover the causes of variations and use this knowledge to improve care (Iezzoni, 2003).

For example, English hospitals, which were primarily charitable institutions serving the poor, had independent accumulated patient statistics since the 1600s. For centuries, Great Britain gathered data on population death rates, primarily to track epidemic illness and later as a mean of encouraging new subscribers and donation to the hospitals (Iezzoni, 2003).

In 1863, Florence Nightingale published the third edition of her book entitled "Notes on Hospital", recommending fundamental changes in the configuration, location, and operation of hospital, as well highlight the role of collecting patient data, to reduce

deaths caused by unsanitary conditions. Nightingale continued to argue that compiling and disseminating patient data and outcome statistics for hospitals were critical to understanding and improving quality of care (Iezzoni, 2003).

In the last decade, the development of new policy orientations, such as the demand for accountability and quality improvement strategies, or a growing interest in patient satisfaction assessment, are incentives for developing, throughout the world, health care registries on a local, regional, national, or international level.

There is a strong commitment today to quality issues, including support in establishing system for continuous follow-up of quality and results. It is emphasised in this paper that supply of information and follow-up of activities in health care should be strengthened so that the public receive good information about care and so that efficient health care is promoted (Ovretveit, 2003).

Conditions in health care are changing constantly. New methods of investigation and treatment affect the structure, contents, quality and results of the care provided. Quality indicators are important so that this process of change can be discerned and must be capable of being reviewed and completely replaced.

Quality indicators can be used for internal and/or external reasons. Internal reasons are related to the various management functions of the hospitals as a health service delivery organization and the indicators are used as management information to monitor, evaluate and improve the functions in the short- or in the long-term (strategy). External reasons are related to accountability questions asked by other stakeholders such as the financier (insurer, state, or other), patients/consumers and the public at large (World Health Organization, 2003).

The purpose of this paper is to describe and highlight the role of health care registries and the use of quality/performance indicators, in three European countries, Portugal, Sweden and the UK, in order to improve patient care.

### **Portugal – first steps in the right direction . . .**

Good care, of high quality and on equal terms for the whole population, is the ultimate quality goal for all health care and medical services. There is a need for systems that support planning, implementing, following and continuously developing quality in activities.

The establishment and expansion of national registries in Portugal, could be seen as a response to rapid changes in society and the health services, as well as to increasing demands for improvements when it comes to patient focus, effectiveness and efficiency (Observatório Português dos Sistemas de Saúde, 2003).

In the last decade, we assist an ambitious reform to increase efficiency and improve quality of health care system in Portugal. The need to improve the health care system has been clearly identified by the authorities for several years but attempts of reform did not survive the political cycle and were never fully implemented.

A comprehensive reform of the health care system was undertaken in 2002. According the report of OECD (2004, p. 16), "In contrast with past reform programmes, which were rather gradual, the strategy now was to create a big ban in health sector, making efforts essentially irreversible." The reform has two main aims: to deliver better-quality public health services than at present but at no higher cost; and to reduce the underlying growth rate of public health care spending over the medium term.

New legislation has been approved separating functions of regulation, financing and provision of health care, setting up new models of financing and management for the hospitals, and introducing incentives towards productivity and quality improvement.

In addition, the authorities have been preparing a ten-year framework aimed at continuing to improve the health status of the population, by integrating the health strategic factors of health that are not linked to the health care system and defining quality indicators which allow us to measure quality (OECD, 2004).

It is consensus among all stakeholders that this kind of reforms needs a good information system to monitor and evaluate the results.

Besides that, and according the same report, in Portugal "Quality control was absent. There were no standardized information systems that could have enabled the monitoring of the performance of managers and institutions" (OECD, 2004, p. 24).

In our opinion this is the most important barrier, at the same time, the biggest challenge in the short time, for Portuguese authorities; develop an integrate and homogeneous data system for all health care institutions which allows comparisons and share clinical and administrative information among the system. The reality now, in the major part of the health care institutions in Portugal is that there are a set of databases without connection and non-communicable between them, which means that we have lots of information diffuse, sometimes duplicate, but with a poor reliability and utility.

Although, we have some good examples, in the clinical field, with the implementation and management of registries, on regional and national level, like the oncology and cardiovascular area.

The regional oncology registry is community-based registry, with clinical and administrative data, which allows monitoring the performance indicators of the prevention programmes in this area, and to assessment quality, in the efficiency and efficacy dimensions, of those programmes. Recently, it was implemented the INetROR, which is an important IT tool, like an intranet site, where all participants could access, any time, to send data, share information and to compare results (Observatório Português de Sistemas de Saúde, 2004).

In the area of cardiology are four National Registries: Acute Coronary Syndrome (Ferreira *et al.*, 2004) Percutaneous Coronary Intervention (Pereira *et al.*, 2004), Clinical Electrophysiology (Morais *et al.*, 2005), and the Cardiac Surgery National Survey (Uva *et al.*, 2003). All these Registries collect clinical and administrative data of all procedures performed.

Systematic registration of data from clinical practice in cardiology using local, national and international registries has assumed increasing importance for quality assurance in the management of cardiovascular disease throughout Europe.

In 2005 the Ministries of Health of all EU Members state accepted the Cardiology Audit and Registration Data Standards (CARDS) project, which is a minimum core standard data set with definitions and coding for each of the three modules of cardiovascular health information systems: ACS, PCI and Clinical Electrophysiology.

In the beginning of 2005 systematic registration of data, from the clinical practice settings of these three modules, especially in the PCI registry, have used the CARDS standards witch ensure that comparable data will be collected throughout Europe.

With this methodology it's possible to define quality indicators and, consequent, assess quality and improve cardiac care in Europe, based on large populations and international multicenter studies.

### **Sweden – the masterpiece of registries and quality culture . . .**

A strong ambition of politicians in Sweden is to improve quality of care, strengthen the position of the patients, and offer them freedom of choice within specified limits, mostly due to economic constraints.

The different professional organizations in the Swedish health care system have, in recent years, done extensive work to develop models for quality improvement. As an important complement to these directions, a system of national quality registries has been established in the Swedish health and medical services in the last 15 years or so (National Health Care Quality Registries Report, 1999).

The registries contain individual-based data on diagnoses, treatment and outcomes. Statistical compilations are made at an aggregate level and are presented both for each department and for the country as a whole. The registries provide a unique means of promoting and monitoring quality improvement efforts in the Swedish health service.

Today, there are over 50 voluntary national health quality registries, which either have achieved or are in the process of achieving nationwide coverage. They were started up by representatives of the medical profession and established to support efforts to improve quality. Their purpose is to support learning and development and they are not intended for supervisory or similar purpose. The registry managers are distributed among a variety of hospital departments administered by many different health authorities. In most cases, the development from a local to a national registry has taken place gradually.

The Federation of Swedish County Councils, the National Board of Health and Welfare (NBHW), and the Swedish Society of Medicine collaborate at the national level in providing financial and other kind of active support for the creation and development of the national quality registries.

Since 1990 resources have been allocated within the framework of the “Dagmar Agreement” between the Government and the health authorities to support the development and operation of the registries (Synnerman, 2000).

The establishment of a national registry is a result of a consensus in the medical speciality concerned on important concepts and quality indicators and a conviction that the registry provides a quality measurement tool based on these indicators. These tools may be developed and refined from year-to-year. These national registries cover different diagnoses and treatments. Each quality register has chosen a number of quality indicators concerning procedure and outcome data important for its own objectives. The intention of using these registries is to make comparisons over time, among hospitals, and with national results – Benchmarking.

The contemporary policy of quality improvement is based on a directive from the NBHW (the Government's central expert and supervisory authority for the social, health and medical services in Sweden) with the title “Quality Improvement Systems for Health Care and Medical Services”. These directions require that the patient's needs and expectations, a well as all health care, should be addressed by systems for planning, implementing, evaluating and improving the quality of the health services provided (National Board Health and Welfare, 2001).

By combining performance indicators from national or regional registries together with experienced quality-of-health patient data, the processes can be quality-assured from different perspectives. For example a model comprising of data from the national hip-fracture registry, the cost-per-patient registry and DRG registry together with health-profile-data, makes it possible to quality assure the hip-fracture process out of four perspectives namely: Functional health-status, The clinical perspective, Patient satisfaction and Health economy.

This quality improvement tool is called the clinical value compass, named to reflect its similarity in layout to a directional compass, has at its four cardinal points. These points refer to:

- (1) functional status, risk status, and wellbeing;
- (2) costs;
- (3) satisfaction with healthcare and perceived benefit (using the eq-5d instrument); and
- (4) clinical outcomes.

To manage and improve the value of health care services, providers will need to measure the value of care for similar patient populations, analyse the internal delivery process, and determine if these changes lead to better outcomes and lower costs (Nelson *et al.*, 1996; Swedish National Hip Arthroplasty Register, 2005).

Unlike a traditional compass, the points on the clinical value compass are not used to navigate in one particular direction versus another. Rather, the compass as a whole serves as a guide to maintain perspective on the entire care process. A specific improvement initiative can focus on one quadrant of the compass, the clinical outcomes for instance, however, the overall project must consider all four quadrants, and analyse the health care process as a whole (Stegmayr *et al.*, 2003).

The National Health Registries have attracted great international attention, and represent a unique resource, in quality improvement perspective, for the Swedish Health and Medical Services.

### **United Kingdom – moving fast toward the key point ...**

Florence Nightingale was one of the first in the UK to promote the collection, statistical analysis and public release of institutional surgical outcome data. When she published her league tables of London Hospitals in the mid 19<sup>th</sup> century she received acclaim in some quarters but was ostracised in others (Spiegelhalter, 1999).

Times have changed, however. Medical science and technology are advancing. Improvements in information technology have seen an explosion in the amount of medical information available to all citizens through a multitude of sources. Combined with growing concern over clinical and administrative standards in the wider National Health Service, open benchmarking of clinical outcomes and institutional performance became a high profile issue contributing to the introduction of the concept of clinical governance outlined in the white paper *A First Class Service* published by Department of Health (1997). This document set out a package of proposals to support the delivery of more consistent and higher quality care to patients. The aim was to drive performance improvement by setting measurable national standards, through National Service Frameworks and the National Institute for Clinical Excellence and providing

an environment for improving local clinical care through clinical governance. This would be underpinned by improved professional self-regulation and development and monitoring of standards through the Commission for Health Improvement (CHI), the NHS Performance Assessment Framework and the National Survey of Patient and User Experience.

These were wide ranging proposals and represented the first attempt to understand and measure the quality of service offered by the NHS since its inception 50 years previously – a remarkable deficiency of the biggest organization in the UK.

The Society of Cardiothoracic Surgeons has a 25-year history of voluntary data collection and analysis. Its most recent incarnation is the UK Cardiac Surgical Register. The Society established the Register in 1977 to collect activity and mortality data on all cardiac surgical procedures performed in each NHS cardiac surgical centre, amounting now to 35,000 procedures a year. The process represented the first attempt in Britain by any specialty group to collect national activity and outcome data.

The measurement of outcomes from medical or surgical interventions is now seen as good practice, but publication of individual doctors' results remains controversial.

After the General Medical Council hearings and the subsequent Bristol Royal Infirmary Inquiry into paediatric cardiac deaths, cardiac surgeons expected a stinging attack on British cardiac surgical practice. What emerged instead, in 2001, was a comprehensive report highlighting many of the difficulties facing frontline clinicians and managers in the NHS (available at: [www.bristolinquiry.org.uk/finalreport/index/htm](http://www.bristolinquiry.org.uk/finalreport/index/htm)) (Learning from Bristol, 2004).

The report included 198 recommendations, of which two stated that patients must be able to obtain information on the relative performance of the trust and of consultant units within the trust. This led to an increasing belief that the interests of the public and patients would be served by publication of individual's surgical performance in the form of postoperative mortality.

A precedent for this existed in the USA, where in 1990, the New York Department of Health published mortality statistics for coronary surgery for all hospitals in the state, and has published comparable data each year since (Chassin *et al.*, 1996). A newspaper, *Newsday*, successfully sued the department under the state's Freedom of Information Law to gain access to surgeon specific data on mortality, which the newspaper published in December 1991, evoking a hostile response from surgeons. New Jersey and Pennsylvania states have also started publishing mortality data, but the practice has not yet spread to any other state or country.

Cardiac surgeons had seen this coming, so during the Bristol Royal Infirmary Inquiry the Society of Cardiothoracic Surgeons of Great Britain and Ireland tried to redress perceived deficiencies in surgeons' approach to national data collection and audit by producing unambiguous guidelines on data collection and clinical audit in cardiac surgical units (available at: [www.scts.org](http://www.scts.org)) and by debating how to measure their clinical performance.

A detailed analysis by the Nuffield Trust has shown that the arguments for and against publication are finely balanced (Marshall *et al.*, 2000). The reason for publication determines the way such data are presented. The two key reasons are either to facilitate patient choice or to demonstrate safety. Publishing for patient choice requires detailed, risk adjusted tables of outcome published in a comparative fashion. Publishing to indicate whether a surgeon is safe or not requires agreeing a threshold of

unacceptable mortality and then showing where each individual surgeon's results lie relative to that threshold.

The national service framework for coronary heart disease, launched in early 2000, included clear recommendations for comparative audit based on the Society of Cardiothoracic Surgeons' clinical dataset (Keogh *et al.*, 1998). As part of this framework, data collection in England would shift from the Society of Cardiothoracic Surgeons to the central cardiac audit database, part of the National Clinical Audit Support Programme in the NHS Information Authority.

The price the surgical community had to pay for these long term benefits was the publication of individual surgeon's results: the first set of results would be released in some form by the end of 2004. But to retain the confidence of all parties – surgeons, the public, and the healthcare regulators – the project would be overseen jointly by the surgical community, the then Commission for Health Improvement, and the Department of Health (2000).

Now these results are published, mostly through requests based on the UK's Freedom of Information Act, medicine in the United Kingdom has crossed a threshold into a new era. Cardiothoracic surgeons will have shown that it is possible for a surgical specialty to review its own performance at an individual clinician level by professional consensus. This system is not perfect; it is a first step, which, in the words of Alan Milburn in 2003, when he was secretary of state for health, "has opened a door which other branches of medicine will need to enter" (Department of Health, 2000, p. 17). Most importantly, cardiac surgeons will have opened a more general debate that will revolve around the balance between the relative influence of individual physicians and institutional influences on patient outcomes and how this relation translates to transparent public accountability.

The final question is whether, with transparent systems in place to maintain standards, it is necessary to publish a list of names, or can the public good can be served just as well by the knowledge that appropriate mechanisms are in place and independently regulated.

### Conclusion

The purpose of this paper was to present a general view of the quality improvement strategies, based on national and regional health care registries in Portugal, Sweden and the UK. It was also our intention to highlight the role of those registries in these three European countries in order to improve patient care.

To improve care for their citizens and to realise the potential efficiency gains, policymakers are looking for the methods and tools to measure and benchmark the performance, and quality of their health care systems. In this way, the implementation of national health registries, and the effective use of this data, assumes a central point in the agenda of the politicians in most European countries, and in other countries all over the world.

The National Health Registries have attracted great international attention, and represent a unique resource, in quality improvement perspective, for the Swedish Health and Medical Services.

In both countries, Portugal and the UK, the imperatives of accountability and quality improvement make the wider development and implementation of national quality registries inevitable.



In this paper we could see some differences and similarities between these three countries with a common aim; to improve quality of care, delivered on equal terms for the whole populations, and in an effective and efficient way.

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