

3. PUBLIC DISCLOSURE IN THE CONTEXT OF HEALTH CARE SYSTEMS

3.1 Structure of the United States (US) health system

The following brief overview describes US health care and the history and context that has promoted public disclosure of measures of performance.

The US health system has been described as bewildering not only to international observers but to Americans as well (Reinhardt, 1998). The system is driven by market forces and is based more on temporary compromises between powerful vested interests than on any agreed national policy. The end result is a system characterised by marked contradictions. America leads the world in technological innovations yet over 40 million citizens have no health insurance coverage at any one time. The US spends almost twice as much of its gross domestic product on health care as does the UK and yet for some sectors of the population, health status measures are worse than those in some developing countries (Anderson, 1998). In addition, the satisfaction of the American people with its health care system is lower than for most English-speaking countries (Blendon, 1998).

A mixture of public and private health insurance supports the 84 percent of the population with coverage. The largest public systems are Medicare and Medicaid. Medicare is a social insurance programme for the elderly, some of the disabled under 65, and those with end-stage renal failure. It is administered by the federal government and financed through a combination of payroll taxes, general federal revenues and premiums. It covers 13 percent of the population and accounts for 20 percent of total health care expenditure. Medicaid is an entitlement programme for the poor, administered by the states within broad federal guidelines. It covers 12 percent of the population and accounts for 14 percent of total health care expenditure. Private health insurance, provided by

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more than 1200 for-profit and not-for-profit insurance companies (regulated by state insurance commissioners), is purchased by individuals or employers. In the latter case it is funded by voluntary premium contributions shared by employers and employees on a company-specific basis. Private insurance covers 58 percent of the population and accounts for 33 percent of total health expenditure. Individuals may be covered by a combination of public and private insurance policies and cost sharing is common. Some policies may cover basic care but out-of-pocket expenses can be significant – estimated at about 17 percent of national health expenditure.

Concern about costs has resulted in the rapid expansion of Managed Care. This is an imprecise term. Managed care was introduced with the aim of improving quality, accountability and controlling costs by creating health plans to assume responsibility for individual and population health needs on a pre-paid or capitation basis. In practice it usually involves methods to influence clinical decisions made by the providers and users of health services in order to achieve greater adherence to standards and congruence with cost-effective decision making. Practice guidelines and disease management programs may be a key part of the way that services are provided. Plans that contract with independent providers may impose constraints by refusal to pay for health services that they judge to be inappropriate. There is controversy as to whether the introduction of managed care has started to focus the debate not only about costs but also about quality (Brook, 1997) or whether intrusive constraints on clinical decision making are unwarranted.

Concerns about the quality of health care in the United States have been expressed for decades and numerous studies have demonstrated

significant deficiencies (Winslow et al, 1988; Bernstein et al, 1993). Recent attempts to address the problem have focused on the use of market forces. The argument goes that if individuals or group purchasers are provided with evidence that quality varies among health plans, they will take this information into account, alongside cost and other factors, when they purchase their coverage and therefore drive improvement in the health care market. For the market to work, information about quality will need to be made public. This fits in with the belief in the impact of public opinion and the consumer-oriented model that predominates in the US. Antagonists argue that buying health coverage is not the same as buying a car or loaf of bread and that the power of health care purchasers is small in comparison with that of provider interest groups who might resist or attempt to modify the purchaser demands. Furthermore, the ability of consumers to choose their health plan, hospital or physician is sometimes limited.

3.2 Historical development of US reporting systems

Publication of data about performance in the US is not a new phenomenon. In 1754 a Pennsylvania hospital released mortality data tabulated by diagnostic groups (Lansky, 1998) and in 1917 the senior surgeon of Massachusetts General Hospital stated:

“Our charitable hospitals do not consider it their duty to see that good results are obtained in their treatment of patients ... It is against the individual interests of the medical and surgical staff of hospitals to follow up, compare, analyse, and standardise all their results”
(Codman, 1917)

He claimed that this was because of concern that the public would not be impressed with poor results, that the process was difficult

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and time-consuming and because no one was willing to pay for the data to be produced.

Information about quality has been collected by US health care organisations for many years but it has usually been for internal use and has rarely been made available to the general public. According to Longo and colleagues (1997), the first modern call for greater openness was made in 1982 (Anderson and Shields, 1982). The authors reviewed methods of changing physician behaviour and concluded that neither clinical audit nor utilisation review had much impact. Their call to make the process and outcomes of care more explicit was answered in 1987 when the HCFA started publishing annual mortality rates for hospitalised Medicare patients. The report studied all causes of hospitalisation, used administrative data and made minimal case mix adjustments. The lack of a sophisticated risk-adjustment system ultimately led to the demise of the report in 1992.

Subsequent attempts to publish valid, reliable and useful information about quality have become increasingly more sophisticated. The following account briefly summarises the historical development of four high profile examples: the New York State Cardiac Surgery Reporting System (CSRS), the Pennsylvania Health Care Cost Containment Council (PHC4), the Health Plan Employer Data Information Set (HEDIS) and the California Hospitals Outcomes Project (CHOP).

New York State Cardiac Surgery Reporting System (CSRS)

In 1989 the New York Department of Health highlighted mortality after coronary artery bypass graft operations (CABG) as a focus for quality improvement. In conjunction with a group of cardiac surgeons, cardiologists, internists and consumers, the health

department developed a register to collect clinical data on patients undergoing coronary artery bypass surgery in New York State hospitals. Data on age, gender, type of coronary artery disease, presence of myocardial ischaemia, level of ventricular function, presence of cardiac or non-cardiac diagnoses, severity of the atherosclerotic process, previous heart operations and whether the procedure was elective or an emergency, were collected prospectively. A multivariate risk-adjustment model was constructed to compare mortality rates amongst hospitals and surgeons. The actual number of deaths for each hospital was divided by the expected number, given the hospital's patients' risk factors, as compared with the risk factors present in the state as a whole.

In 1990 the anonymised 1989 data were made available to the public but a newspaper, *Newsday*, sued them under the state's Freedom of Information Act to gain access to named surgeon-specific data. The state resisted the action on the grounds that low numbers would invalidate the data but it lost the case and published surgeon-specific results in December 1991. Initial press accounts were alarmist and misleading and clinicians were furious. They agreed only to submit data to the Department that could not identify individual surgeons. After detailed discussions, an agreement was reached whereby operative mortality data from the previous three years would be released only for surgeons performing at least 200 operations during that period. The Department made considerable efforts to educate journalists and recent press reports have been more balanced. In subsequent years the risk-adjustment procedure and systems to ensure data reliability have been improved. The CSRS is now regarded as one of the foremost examples of public data disclosure and is the most evaluated system in the US. The risk-adjusted mortality rate is provided to hospitals and surgeons on a regular basis to allow them

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to compare levels of performance. The data have been cited as a significant factor in a dramatic reduction in post operative mortality following CABG in the state of New York (Chassin et al, 1996).

Pennsylvania Health Care Cost Containment Council (PHC4)

PHC4 was created by the legislature to constrain costs and improve quality by producing public information about the performance of health care providers (Sirio and McGee, 1996). It was based on the premise that current and accurate data about the costs and quality of care would encourage group and individual purchasers to drive down costs and improve quality through the use of market forces. It was also thought that the data would help shape health-related policies and programmes. The original motivation behind publication of data by the PHC4 was therefore broader than that of the New York CSRS.

PHC4 produced a report card *A consumer guide to coronary artery bypass graft surgery* in 1992. It listed, by surgeon and hospital, the number of CABG procedures performed per year and the risk-adjusted inpatient hospital mortality, compared with expected rates drawn from the risk-adjustment model. The risk-adjustment system, called Medisgroups, includes seven risk adjusters, including presence of a myocardial infarction, age, type of bypass (artery versus vein), presence of cardiogenic shock, presence of congestive heart failure, gender, and severity of illness at the time of admission. It has been patented and is marketed by a for-profit company. A grade is assigned to hospitals according to whether the actual mortality is higher than expected (i.e. is greater than two standard deviations away from the expected value), lower or within the normal range. In addition, the report publishes data on the costs charged by each hospital and compares charges with outcomes. The guide is distributed free to hospitals, surgeons,

public libraries, business groups, legislature, the media and any individual who requests it (Schneider and Epstein, 1996; Schneider and Epstein, 1998). Regular updates have been published since 1992 and the risk-adjustment mechanism has been modified. The PHC4 initiative has also been evaluated but not in as much detail as the New York State CSRS.

Health Plan Employer Data Information Set (HEDIS)

HEDIS is the most commonly used database for assessing performance at the level of the health plan. It is managed by the National Committee for Quality Assurance (NCQA), a not-for-profit accreditation organisation. HEDIS represents an attempt to standardise how plans measure and report performance data and is based on both administrative and clinical data. Since its introduction in 1991, the first set of indicators has become larger. The 1995 version, HEDIS 2.5, contained nine measures directly related to quality whilst the current version, HEDIS 3.0 contains 14 measures and a pilot set of new indicators contains a further 25 measures of quality.

Comparative HEDIS data from volunteering health plans are published as the *Quality Compass*. The second edition published in 1997 contains information from over 330 plans, representing three quarters of all Health Maintenance Organisation enrollees.

The HEDIS indicators have not escaped criticism. They represent a considerable cost and administrative burden to health plans and because participation is voluntary, concern has been expressed that only plans with above average performance would be willing to provide information. Concern has been expressed that the NCQA may be subject to conflicts of interest because of the nature of the organisations contributing to indicator development (Epstein,

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1995). The data are not risk adjusted, emphasise process over outcome measures of quality, preventative over curative indicators, and the data collection methods are not standardised (Epstein, 1998). The NCQA has taken a pragmatic approach to indicator development and the data set is going through a process of refinement, attempting to address many of the criticisms that have been levelled against it (Corrigan, 1995).

California Hospitals Outcomes Project (CHOP)

CHOP was established by a state law that was passed in 1991 in response to purchaser demands for lower cost and higher quality health care. The project analysed and disseminated data on risk-adjusted hospital outcomes. It differs from the New York CSRS and PHC4 in that it is based on routinely collected data extracted from hospital discharge summaries. Three years of debate prior to 1991 led to impasse between the state and hospital association and a threat by the state to impose the Pennsylvania proprietary risk-adjustment system unless an alternative was found. The cost of collecting and reporting data for the Pennsylvania system was considerable, so agreement was reached to use existing data and make prospective incremental improvements in the quality of the data (Romano et al, 1995). For each hospital discharge, hospitals are obliged to code procedures, diagnostic categories and basic demographic data and send this information to the state.

The first report was released in 1993 and included inpatient mortality rates for acute myocardial infarction and complication rates for cervical and lumbar discectomy. Results were published in two categories, better or not better than expected. A second report, released in 1996, classified acute myocardial infarction mortality rates as better, worse or not significantly different from expected. Proposals to include discectomy complication rates and

postpartum readmission rates were dropped because of concerns about their validity. A third report on acute myocardial infarction mortality was published in December 1997. All reports are sent to the providers prior to publication and their comments are appended to the final report.

Each CHOP contains different sections. The *Users Guide* contains details about the methods used to produce the data and numerical and graphical comparative results by hospital. The *Technical Guide* provides greater methodological detail and *Detailed Statistical Tables* provide results in depth. A *Hospital Guide* explains to providers how to use the spreadsheet and interpret the results. The timeliness of the data release has been criticised – the 1996 report contained data derived from 1990-92 (Rainwater et al, 1998). The impact of CHOP has not been evaluated to the same degree as had the New York State CSRS or the PHC4.

3.3 Public disclosure in the United Kingdom.

Perhaps the first systematic reporting of comparative performance data in the world took place in England in the 1860s, when Florence Nightingale highlighted differences in mortality rates of patients in London hospitals (Nightingale, 1863). Since that time, a variety of methods and tools has been used to improve quality in the UK but there has been little emphasis on the public disclosure of performance data.

In the last decade clinical audit has been a central component of the drive to improve quality. When introduced in 1990, it was accepted and in many areas implemented by the medical profession, in part because it was unthreatening – the process was confidential and the data was used for internal purposes only. In addition to conventional medically-led audit, isolated examples

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exist of using specific performance indicators to promote quality improvement. The Maryland Hospital Quality Indicator Project, started in the United States but now operational in several countries including the UK, is one such example of using explicit indicators to make comparisons among voluntarily participating hospitals (Thomson et al, 1997). Despite the enthusiasm for audit, recent evidence suggests that the expected improvements in clinical care resulting from audit activity have not materialised, at least in terms of value for money (Davis et al, 1995; Bero et al, 1998).

Alternative mechanisms are now being considered and the use of public disclosure of performance data is one option. One of the stated objectives for the NHS in 1996/7 was “to improve the quality and quantity of information given to enable patient choice about treatment options” (NHS Executive, 1995). Outcomes data have been available in some limited fields for many years in the form of the Confidential Inquiries, but the detail of these inquiries has not been made public and there has been no rigorous evaluation of their impact. Throughout the 1990s the NHS has been encouraged to become more accountable to the public and more open with information. Initially the information provided had minimal direct relevance to quality. It included the provision of largely structural data on services available, the description of some processes and outcomes in annual reports, which in theory are public documents but in practice are not widely disseminated and did not encourage comparisons among different providers. There have been only a small number of examples of public disclosure of performance information in the UK in recent years. Most of these have attracted only minimal public interest, in part because they addressed very specialised areas of expertise, such as *in-vitro* fertilisation or renal transplant success rates. Perhaps the best example of a more generic system for public disclosure is the Clinical Outcomes

Working Group project that compares hospital outcomes data across different hospitals and health areas in Scotland (Dillner, 1994). The project was established by the Clinical Resource and Audit Group which is responsible to the Scottish NHS Management Executive. Thirty indicators have been published in four reports since 1994. Outcomes, including rates of teenage conception, suicide, cancer survival and postoperative emergency readmission are published for hospitals treating a minimum number of patients in each category. There is minimal risk adjustment of the data and the emphasis of the reports is very much on raising awareness of variation, rather than making judgements about performance. Waiting list data are also published widely and used to pursue government policy to reduce waiting times. Neither the impact of the Scottish outcomes data nor the waiting list data has yet been rigorously evaluated, though the Centre for Health Economics, University of York, is currently conducting such a study which is funded by the Department of Health.

The UK government intends to use the publication of quantitative information on performance as a key tool to improve quality (NHS Executive, 1998). Public disclosure will therefore become an integral part of a coordinated and systematic approach to quality improvement in the NHS, including the following initiatives:

The National Institute for Clinical Excellence (NICE).

NICE is responsible for identifying new and existing health technologies that would benefit from appraisal, collecting evidence to assess the clinical and cost-effectiveness of the interventions, producing and disseminating guidelines and coordinating a national strategy to ensure equitable and effective health interventions across the NHS. Explicit indicators of performance will be an integral part of the guidelines produced.

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National Service Frameworks (NSF)

The NSFs set national standards and define service models for specific diseases, services or care groups. In addition, they are responsible for ensuring that the models are implemented in a coordinated fashion across the different sections of the NHS and for establishing performance measures against which progress can be measured. The Calman-Hine NSF for cancer services is already established and a NSF for mental health services was published recently. Service frameworks for coronary heart disease and diabetes will be published in the near future. Again, explicit performance indicators will be a key component of each of the frameworks.

Clinical Governance

Clinical governance is a framework through which health care organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care. The aim is to create an environment in which excellence can flourish. The process is led in the main by health professionals but includes all relevant stakeholders. A variety of mechanisms can be used to implement and monitor clinical governance and the explicit use of performance indicators is likely to be one important tool.

The Commission for Health Improvement (CHI)

CHI is an independent 'watch-dog' which will be used to monitor the performance of health care provider organisations. It is proposed that the Commission will combine the roles of inspection and regulation with consultation and guidance. CHI will ensure that clinical governance processes are in place, carry out a rolling programme of inspections of NHS organisations and intervene if local quality assurance mechanisms have not been effective. Public performance data will be used, alongside other types of evidence, to make judgements about performance.

The National Performance Assessment Framework (NPAF)

The NPAF sets targets for six different areas suitable for performance measurement:

- Health improvement.
- Fair access.
- Effective delivery of appropriate health care.
- Efficiency.
- Patient/carer experience.
- Health outcomes of NHS care.

Any designated clinical topic chosen for the framework should include all six areas for performance measurement. Standards for each of the specific indicators within these areas are agreed between the NHS Executive Regional Offices and Health Authorities, between Health Authorities and Primary Care Groups and between Primary Care Groups and Trusts. In addition, Local Health Improvement Programmes will have to take them into consideration. Following a period of consultation and in response to some specific criticisms (Thomson, 1998; McColl et al, 1998), the framework was revised and the first effectiveness indicators for hospital outcomes were published for Wales and England in the spring of 1999. The results of the first patient experience survey were published later in 1999. The hospital outcome data showed wide variations among geographical regions and specific hospitals but the public response was relatively balanced and somewhat muted. At this stage it is too early to make judgements about the

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impact of the data release on the various stakeholders, or on quality of care.

Revalidation and appraisal of doctors

The final part of the UK government strategy for quality improvement in the NHS is the revalidation and appraisal of doctors. Recent high profile examples of failure of self-policing by the medical profession have resulted in demands for an explicit link between fitness to practice and the maintenance of a doctor's name on the medical register. Formal mechanisms for three yearly revalidation of all doctors are being developed by the specialist societies, adapting a structure devised by the General Medical Council (GMC, 1998). Use of explicit performance indicators might well be part of the revalidation process. It is likely that a formal process for revalidation will be in place by 2002. In addition, an annual appraisal for doctors has been recommended by the Secretary of State for Health.

In conclusion, there is no significant history or culture of public disclosure in health care in the UK. However, the government's quality agenda for the NHS incorporates a number of different initiatives which are all likely to use public reporting of performance data as a tool to inform, promote regulation and accountability and encourage quality improvement.