

# The Quest for Quality in the NHS

A mid-term evaluation of the ten-year  
quality agenda

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## FOREWORD

In 1997, The Nuffield Trust commissioned Sheila Leatherman and Kim Sutherland to conduct a review of the quality agenda as articulated by the newly elected Labour Government. The proposals for quality described in *The New NHS – Modern, Dependable* (1997) and *A First Class Service: Quality in the New NHS* (1998) envisioned a ten-year plan for securing quality improvement in the health care system.

The resulting report, *Evolving Quality in the New NHS* (1998), sought to assess the potential impact across the NHS. It was necessarily speculative in nature, because most of the policy initiatives were at an early stage of design and development, so could not have been expected to demonstrate effects in health care delivery.

Five years on, in 2002/03, the Nuffield Trust commissioned the authors to conduct a follow-up, mid-term appraisal of the quality agenda in the NHS. The mid-term evaluation has been designed and performed to accomplish four objectives:

- a review of the vision, strategy and structural changes that underpin the quality agenda;
- a synthesis and presentation of data to evaluate quality in multiple domains;
- an in-depth analysis of key components of the quality agenda, including the role and contribution of organisational culture, primary care, patient engagement initiatives, information technology, and public reporting for accountability; and
- summary analysis and recommendations.

As with any undertaking of this kind, however well-intentioned and designed, a mid-course evaluation allows for responsible inventory of achievements to date, and identification of prudent mid-course corrections to best attain further successes and sustain gains.

*John Wyn Owen C.B.*

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We thank the Nuffield Trust for the invitation to do this work, and John Wyn Owen for the recognition that a mid-term evaluation of the Quality Agenda offered a unique opportunity to support the ongoing reforms in England, as well as to provide a case study for countries worldwide that are undertaking systemic initiatives to improve quality in the health sector. We thank the School of Public Health at the University of North Carolina for their support in producing this book – in particular Sara Massie who has worked many hours on many drafts, tirelessly and enthusiastically.

It has been our privilege to study the NHS and to observe the serious and intensive efforts not only to preserve the NHS, but to provide a consistently first-class health system.

*Sheila Leatherman*

*Kim Sutherland*

## ABBREVIATIONS AND ACRONYMS

A&E	Accident and Emergency
AHRQ	Agency for Healthcare Research and Quality
CCHI	Compendium of Clinical and Health Indicators
CHAI	Commission for Healthcare Audit and Inspection
CHC	Community Health Councils
CHD	Coronary Heart Disease
CHI	Commission for Health Improvement
CHIME	Centre for Health Informatics and Multi-professional Education
CMO	Chief Medical Officer
CPPIH	Commission for Patient and Public Involvement in Health
CQI	Continuous Quality Improvement
CT	Computerised Tomography
DOH	Department of Health
EHR	Electronic Health Record
EPR	Electronic Patient Record
ERDIP	Electronic Record Development and Implementation Programme
ETP	Electronic Transfer of Prescriptions
GMC	General Medical Council
GP	General Practitioner
GPASS	General Practitioner Administrative System for Scotland
HA	Health Authority
HAZ	Health Action Zone
HES	Hospital Episode Statistics

ICAS	Independent Complaints Advisory Service
ICRS	Integrated Care Records Services
IOM	Institute of Medicine
IT	Information Technology
MA	Modernisation Agency
MI	Myocardial Infarction
MMR	Measles, Mumps, Rubella
MRI	Magnetic Resonance Imaging
MRSA	Methicillin- (or Multiple-)Resistant Staphylococcus aureus
NAO	National Audit Office
NCAA	National Clinical Assessment Authority
NCEPOD	National Confidential Enquiry into Perioperative Deaths
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NPCC	National Primary Care Collaborative
NPCDT	National Primary Care Development Team
NPCRDC	National Primary Care Research and Development Centre
NPfIT	National Programme for IT
NPSA	National Patient Safety Agency
NSF	National Service Frameworks
OECD	Organisation for Economic Co-operation and Development
OSC	Overview and Scrutiny Committee
PAF	Performance Assessment Framework
PALS	Patient Advice and Liaison Service
PCA	Patient Care Advisor
PCG	Primary Care Group
PCT	Primary Care Trust
PEAT	Patient Environment Action Team

PFI	Private Finance Initiative
PMS	Personal Medical Services
QuIC	Quality Information Centre
R & D	Research and Development
SHA	Special Health Authority
StHA	Strategic Health Authority
TQM	Total Quality Management





## SECTION I

# The NHS Agenda for Quality

Section I describes the research project that formed the basis for this report; examines the organisational and political context in which the work was undertaken; and outlines in broad terms the Government's Ten-Year Quality Agenda for the NHS.



# 1. Introduction

In recent years, the subject of quality has attracted increasing attention and investment across health care systems internationally. In the UK, the New Labour Government, upon taking power in 1997, asserted that modernising the NHS was a crucial task in improving public services generally, and in ensuring the continued existence of the NHS. Quality of care was placed at the heart of the modernisation programme for the NHS. The Quality Agenda in England is likely to be the world's most ambitious, comprehensive, systemic and intentionally funded effort to create predictable and sustainable capacity for improving the quality of a nation's health care system.

This book, resulting from an 18-month research project, is a mid-term appraisal of the Ten-year Quality Agenda that the New Labour Government first articulated in 1997–98. The term “Quality Agenda”, as used in this report, applies to the long list of legislative and regulatory initiatives, improvement programmes, new organisations and evaluation capabilities designed and implemented to improve quality in health care and performance of the health care delivery system. The subject of this evaluation, “quality of care”, is broadly defined to include issues of access, effectiveness, equity, responsiveness, safety and capacity. It encompasses a number of different perspectives, drawing on a wide range of available data, both quantitative and qualitative.

Realising a quality agenda of such scope, in an organisation of the scale and complexity of the NHS, represents a task of enormous magnitude. Judgements about progress should be formed in light of the significant constraints imposed by organisational and historical context. Some may argue that it is too early to tell whether the Quality Agenda is delivering real improvement. However, we believe that such an evaluation is timely. It provides an opportunity to catalogue and encourage progress and, most importantly, to responsibly identify constructive mid-course corrections. Moving beyond the domestic arena, the Quality Agenda, as conceptualised and implemented in England, will be instructive to countries around the world that face parallel challenges and aspire to goals similar to those of the NHS.

Let us be clear. This evaluation is about reforms to the health services sector, namely, the NHS in England, with specific regard to improving quality of care. It is not an evaluation of national progress on health status, which has many more determinants than the health care system. The NHS is not exclusively responsible for the country's health relative to other countries' health. A nation's health is the result of a multitude of factors, including, but not limited to, comparative standards of living, educational attainment, the welfare system as a whole and the environment.

Though not part of the apparatus affecting these changes, we as authors are nonetheless more than just interested bystanders, as we share a great respect both for the NHS as an institution, and for the UK leaders and NHS employees engaged in the fight for improvement and survival. It is in this spirit of support and high regard that we have conducted this evaluation of the Ten-year Quality Agenda. In the body of this report, we intend to address four key questions.

- Is the development of new organisational, regulatory, monitoring, change management and evaluation capacity reasonable for accomplishing a multi-year improvement agenda?
- What is the evidence of impact to date?
- Is the Quality Agenda sustainable?
- What are reasonable mid-course corrections to increase likelihood of success?

## 2. The State of the NHS: Background and Context

*The NHS has a severe shortage of capacity, directly costing the lives of tens of thousands of patients a year. We have fewer doctors per head of population than any European country apart from Albania. We import nurses and doctors from the world's poorest countries, and export sick people to some of the richest. More than one million people – one in sixty of the population – are waiting for treatment. They are waiting far too long, every step of the way – for the first appointment with a GP, for initial consultation with a specialist, for diagnosis and for treatment. Patients needing heart bypasses often have to wait over a year for treatment. One in four cardiac patients die while waiting and one in five lung cancer patients wait so long they go from being treatable to untreatable. The cancer survival rate in Britain is lower than in almost all other developed nations. World Health Organisation figures show that if the UK had the same cancer survival rates as the European average, it would save 10,000 lives a year; if we had the best in Europe, it would save 25,000 lives a year.*

(Browne & Young 2002)

*The NHS of the 21st century is still evolving. The 10-year strategy for NHS reform is still not three years old, but our conclusions are these. The NHS Plan is on schedule. The resources going into the NHS are paying dividends for patients but there is still a long way to go. Capacity problems remain. The building blocks are there and the culture of the NHS is changing. With extra resources about to come on stream, we feel confident that fast and effective progress can be made. The patient-centred NHS, once a distant ambition, is now drawing visibly closer.*

Excerpt from the Modernisation Board's Annual Report ([DOH 2003], p. i)

The NHS, when founded in 1948 post-war Britain, was a testament of the Government's social contract with its population. It remains so today. The NHS is an icon of national health care systems, with an international audience watching whether it can modernise, to be competitive with other 21st-century health systems in industrialised countries, or indeed survive at all.

Any evaluation of the Quality Agenda, if it is to be balanced and meaningful, must be underpinned by an understanding of the scale and scope of the NHS. Measures of capacity and productivity give some idea of the complexity and volume of this massive enterprise. On

any typical day in the NHS, almost one million patients visit their primary care doctor, about 1.5 million prescriptions are dispensed and some 25,000 operations are performed (DOH 2000). *The Times* newspaper described the NHS – at 1.2 million employees – as on the “scale of the Red Army and the Indian State railway”, and projected that “by 2008, the NHS will be granted £105.6 billion a year to spend on hospitals, doctors, nurses and medicines, a sum equal to the combined gross domestic products of Iceland, Hungary, New Zealand and the Slovak Republic” (Doran 2002, p. 9).

Within this huge organisation, the publications *The New NHS – Modern, Dependable* (DOH 1997) and *The New NHS – A First Class Service* (DOH 1998) asserted that quality was to be an explicit and fundamental design principle. These documents signalled that quality was no longer discretionary, and that securing and delivering quality care was the responsibility of all NHS employees. The growing emphasis on quality was reinforced by a rash of highly visible cases that were collectively so egregious as to constitute an indictment of the NHS by any definition of quality. These included the high mortality rates among paediatric cardiology cases in the Bristol Royal Infirmary, cancer-screening failures in the south-east of England and the unchecked activities of the murderous GP, Harold Shipman. Whilst encouraging reform, these infamous cases also undercut the ability of entrenched interests to fight the new quality-related initiatives. In response, the Labour Government was spurred on in its NHS reforms, creating an inspectorate capability, embarking on widespread modernisation of the infrastructure and initiating system-wide efforts to monitor quality at the individual clinician and hospital level. The Government was politically driven and time-pressured to act decisively and expediently, with the professions largely in a reactive state.

At the same time as a few particularly dramatic cases of poor performance were riveting, the general state of quality throughout the NHS was also of concern. There were widespread concerns about a range of issues, such as access to care and waiting lists, the equitable provision of services, the unjustified variation in clinical care processes, the structural condition of health care facilities and the need for more active patient involvement in decision-making. All of these topics speak to the issue of quality, an inherently amorphous term, with varying attributes as defined through the eyes of the beholder. The Department of Health defined quality in *The New NHS – Modern, Dependable* as “doing the right things, at the right time, for the right people, and doing them right – first time . . . measured in terms of prompt access, good relationships and efficient administration” (DOH 1997, p. 17).

The range of perspectives inherent in the term “quality” notwithstanding, the technical field of quality measurement and advancement is reaching international consensus in defining its scope. It typically includes the domains of effectiveness, equity, access, responsiveness/patient-centredness and safety. Across the many countries placing a high priority on quality, the issues are quite consistent. Lack of adherence to the evidence base means that many effective health care interventions with proven value for improving health outcomes are not performed at acceptable levels. In a recently published article in the *New*

*England Journal of Medicine*, researchers document that patients receive just 55% of recommended health care services across acute, chronic and preventive care in the US (McGlynn et al. 2003). Conversely, over-utilisation of ineffective therapeutic interventions is also problematic. Clinicians themselves acknowledge problems in quality, as a survey of physicians in five countries illustrates: when asked how their ability to provide quality care had changed over the past five years, significant numbers of physicians reported that it had worsened – 46% in the UK, compared with 57% in the US and 38% in Australia (Blendon et al. 2001, see section 9.36 in chapter 9).

Safety, too, has become an international concern in recent years, with NHS data estimating that 850,000 incidents and medical errors occur annually (NPSA 2003), with up to 10% of hospital admissions resulting in some kind of adverse event (CMO 2003). Should the data on quality deficiencies not be sufficiently motivating in and of itself, a cogent argument can be made that quality is inextricably linked to sustainable financing. In 2001, the National Audit Office estimated the net value of outstanding claims against the NHS at £2.6 billion in England alone, having doubled from just three years earlier (NAO 2001).

The NHS, like many health systems, also suffers from unjustified variation in care. This may be due to a lack of adherence by clinicians to the available evidence base, or sometimes simply to a lack of knowledge of what constitutes effective care in particular areas of medicine. In the UK, this phenomenon is compounded by what is sometimes called “postcode lottery”, the result of explicit choices made by different purchasers and different health authorities variably prioritising health services for delivery – an inevitable consequence of devolving power and decision-making. Another fundamental cause is the historical underfunding of the NHS relative to other westernised countries. In 1998, UK total health care expenditures were 6.8% of GDP, compared with an (income-weighted) average of 8.4 % in EU countries. The UK’s total health care spending per capita was then about 25–30% lower than in Australia, France and the Netherlands, and around 35% lower than in Canada and Germany (OECD Health Data 2001; Wanless 2002).

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### 3. NHS Modernisation and the Ten-year Quality Agenda

The NHS was founded on explicit values of fairness and public service that remain critically important to the institution today. Together with the originally established objective of equity, issues of efficiency and economy have dominated health policy and NHS reforms for decades, joined by an explicit policy emphasis on clinical effectiveness in 1996 (Hood 1991; Farnham & Horton 1993; NHS Executive 1996). In the early 1990s, the publication of the *Patient's Charter* (DOH 1992) attempted to move the system from an admittedly singular population focus to include attention to individual patient experience.

No one in England is denied access to essential treatment simply because of an inability to pay. This distinguishes the NHS from the health systems of many other countries. Yet equity, the very principle on which the NHS was founded, and that which makes it a beacon for supporters of universal health systems, may be in danger. The word “rationing”, although often avoided in health policy documents, has been apparent in the form of the “5Ds” – delay, defer, deter, dissuade and decline. Critics and friends alike now worry that the NHS may be moving to a two-tier system based on the ability to pay a premium for improved service. There is a risk that there may develop a system that has one level of care for those who must solely depend on provision of services “free at the point of delivery”, and a different level of care for those willing and able to pay out-of-pocket, or who have supplementary private insurance.

The bold reforms undertaken in the NHS should be viewed within the broader political context. In his February 2003 speech, *A Modern Agenda for Prosperity and Social Reform*, Chancellor of the Exchequer Gordon Brown declared that central government’s task is to produce “opportunity and security for all”, noting that this requires “the courage to push forward with all radical long-term reforms necessary to enhance productivity and to improve public services, health being in that basket along with transportation, higher education, utilities and others.” He further stated that “the respective role of markets and the public sector has been the underlying, even sometimes the unspoken, divide at the heart of British political arguments for nearly a century” (Brown 2003). This is a very incisive description of the macro environment, both political and economic, in which health care exists.

Another critical part of the backdrop is the apparent tension between centralisation of services with national accountability, and the intent for greater decentralisation with devolution of power, control and authority. This issue is now playing out through the restructuring of the NHS, pushing the locus of control into Primary Care Trusts, and

purporting to give hospitals more autonomy in decision-making and financial management. This devolution in health care management resonates with the political devolution that is also occurring at the level of whole countries, with power shifting to the Scottish Parliament, the Welsh Assembly and the Northern Ireland Office.

Early in its first term, the Labour Government acknowledged a wide range of shortcomings within the NHS, and used the term “modernisation” to describe the process that would seek to secure the ambitions of the “New NHS”. The term has taken on a life of its own by spawning what appears to be the largest and most expansive set of reforms, structural changes and investments in infrastructure in NHS history. A “Modernisation Board” to oversee reforms and a “Modernisation Agency” to support and catalyse change have been created. The NHS Plan (DOH 2000) laid out an implementation strategy to realise the vision and objectives posited in 1997–98. In addition, acknowledging the historic pattern of relative underfunding, the Government infused significant new monies into the NHS, beginning in 2001, to support actualisation of the vision and operational goals.

The Labour Government inherited an NHS that had been historically under-resourced compared with other Western European countries. The Organisation for Economic Co-operation and Development (OECD) health economics indicators revealed expenditures for the UK comparable to the Czech Republic, Poland and South Korea. The OECD statistics showed that the UK spent £863 per person on health in 1999, while Norway spent £1,484 on each person (Wanless 2002). The five-year funding infusion of £40 billion, as Chancellor Gordon Brown announced in April 2002, means an extra 7.4% expenditure in real terms each fiscal year over the period 2003–04 to 2007–08. This increase in the NHS budget represents a rise in the share of gross domestic product spent on health care from 7.7% to 9.4%. If these increases are achieved, the next five years will more than double the historical rate of annual increases, which averaged just 3.7% over the period of 1954–2000 (Robinson 2002).

Despite the Government’s ostensible rejection of an internal market model in *The New NHS* (DOH 1997), the direction of initiatives over the past five years has been to develop or foster dynamics commonly associated with a market environment. These methods include selective commissioning of services and making performance information available to the public to guide their new, albeit modest, set of choices. Furthermore, the Government is diligently trying to structure institutional and individual provider contracts to include explicit performance standards, accompanied by clear incentives and sanctions. In a book (Enthoven 1999) drawing on his re-examination of market models within the NHS, Alain Enthoven asserts that the key challenge facing the NHS is to capture the best of both central planning and market forces through the mechanism of quasi-markets. This accords with the general NHS reforms and, more specifically, the dynamics being put in place to drive the Quality Agenda.

The Government's approach to modernising the NHS has been predicated on a clear and comprehensive initiative to improve health care quality through a Ten-year Quality Agenda, announced in *A First Class Service* in 1998. It is a very broad and ambitious policy initiative, driven by legislation and supported by regulation, implementing a plethora of new organisations, programmes and capabilities. Table 3.1 shows a chronology of the unfolding of the Quality Agenda. Admittedly, selecting the key events in this chronology required discretionary judgement on the part of the authors – a statement that applies to many analyses within this evaluation – but it is meant to illustrate the intensity, rapidity and volume of actions taken in pursuit of the Modernisation and Quality Agendas.

**TABLE 3.1 Chronology of key events in the Ten-year Quality Agenda**

<b>1997</b>	
<b>May</b>	Labour wins General Election.
<b>July</b>	Chancellor announces extra £1.2bn for NHS in the UK.
	A review of health inequalities to be conducted by Sir Donald Acheson is announced.
<b>October</b>	Review of <i>Patient's Charter</i> announced.
<b>November</b>	Waiting list action team appointed.
<b>December</b>	<i>The New NHS – Modern, Dependable</i> is published. It announces the intention to establish NICE, CHI, NSFs and PCGs, and introduces the concept of clinical governance.
<b>1998</b>	
<b>January</b>	Consultation paper, <i>A National Framework for Assessing Performance</i> published.
<b>March</b>	Pilots for NHS Direct launched in three areas.
	First round of Health Action Zones announced.
<b>July</b>	Consultation paper, <i>A First Class Service – Quality in the New NHS</i> , published.
<b>August</b>	Formation of 480 Primary Care Groups announced.

<b>1999</b>	
<b>April</b>	Announcement of 20 fast access walk-in centres.
<b>June</b>	Publication of first set of clinical indicators and high-level performance indicators.
<b>July</b>	White Paper, <i>Saving Lives: Our Healthier Nation</i> published.
<b>September</b>	Publication of consultation document <i>Patient and Public Involvement in the New NHS</i> .
<b>2000</b>	
<b>January</b>	<i>Revalidation for Clinical General Practice and Good Medical Practice for General Practitioners</i> published by Royal College of GPs and BMA.
	First 13 Primary Care Trusts announced.
	Prime Minister announces that NHS spending will be brought up to EU average.
<b>February</b>	National Primary Care Development Team announced.
<b>June</b>	Health Development Agency launched to tackle health inequalities and ill health due to poverty.
	<i>An Organisation with a Memory</i> published.
<b>July</b>	<i>The NHS Plan: a Plan for Investment, a Plan for Reform</i> is published. It announces, amongst other things, the Modernisation Agency, Modernisation Board, new incentives, clinical priorities and patient focus.
<b>September</b>	NHS Cancer Plan launched.
<b>October</b>	Annual appraisals for consultants introduced.
<b>2001</b>	
<b>January</b>	Review of Harold Shipman's clinical practice published.
	<i>Assuring the Quality of Medical Practice</i> , guidance for implementing the proposals in <i>Supporting Doctors, Protecting Patients</i> , is issued. It announces the NCAA.
	<i>Your Guide to the NHS</i> published, replacing the <i>Patient's Charter</i> .
	<i>Report of the Inquiry into Organ Retention at Royal Liverpool Children's Hospital</i> published.
<b>April</b>	<i>Building a Safer NHS for Patients</i> published. National Patient Safety Agency announced.
<b>July</b>	<i>Learning from Bristol – the report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995</i> published.
<b>September</b>	<i>The Expert Patient: a new approach to chronic disease management</i> published.
	First set of Acute Trust Performance ratings published.

2002	
<b>January</b>	First Modernisation Board Annual Report published.
<b>April</b>	Wanless Report published.
	Chancellor announces 40% (£40bn) boost to NHS funds over 5 years.
	<i>Delivering the NHS Plan</i> published.
	Commission for Healthcare Audit and Inspection announced.
<b>May</b>	Proposals for establishing foundation hospitals published.
2003	
<b>February</b>	Announcement that Community Health Councils are to be abolished following launch of Commission for Patient and Public Involvement in Health.
<b>April</b>	Health Protection Agency established.
<b>May</b>	CHI publishes <i>Getting Better? A Report on the NHS</i> .
<b>June</b>	Publication of <i>NHS Complaints Reform – making things right</i> .
<b>July</b>	Agreement reached over the introduction of new consultant/GP contracts.
	CHI publishes NHS star ratings.

As stated earlier, England may well be unique in the nature of its comprehensive conceptualisation and implementation of a systemic quality agenda. The Ten-year Quality Agenda is clearly backed up by resources, and the Labour Government has made significant investment in its implementation. Though it is not easy to parse out those NHS expenditures that are specific to the goals and objectives of improving quality of care, we have attempted to construct an illustrative portfolio of the investments in the Quality Agenda (see Table 3.2).

This serves two purposes. First, it is entirely too common for lofty goals to be set with quality as part of the rhetoric of health care policy, but not part of the explicit budget; so delineating financial allocations allows us to develop a picture of the extent to which rhetoric is matched by action. Here, credit is due to the Government for their investments.

Second, in the conduct of responsible fiscal stewardship it is important to associate monies spent with tangible achievements. It is still too early to make definitive judgements about the cost-benefit of most of the new structures and functions. However, it is timely to understand in explicit terms the financial implications at present and for the future. Table 3.2 is an admittedly partial budget for the Quality Agenda, and is certainly an understatement of costs, as our assumptions of what should be included are almost wholly line-budget items of direct costs, with no indirect costs included.

The NHS has increased not only its overall spending for the delivery of health care services, but also its investment in institutional capacity. It has done so principally through the development of new organisations with varying improvement missions. For example, the Commission for Health Improvement (and subsequently the Commission for Healthcare Audit and Inspection [CHAI]) provides an arm's-length inspectorate function. The National Institute for Clinical Excellence (NICE) builds the capability for more transparent, evidence-based guidance on the appropriate use of health care resources. The National Patient Safety Agency (NPSA) addresses both the reporting of errors and the promulgation of systemic safety schemes.

More diffusely across the NHS, and beyond the structural investments, the National Service Frameworks (NSFs) have started to provide a standardised template for describing optimal care. They are marshalling the necessary resources and redesigning care processes in clinical conditions such as cancer, coronary heart disease and diabetes, as well as for targeted populations such as children and the elderly. Overall, major changes in General Practice have been made in control of NHS monies, influence over consultant usage and referral patterns, use of acute facilities and accountability for the quality of patient care. Finally, the stated value of "patient-centredness" is being actualised through such programmes as NHS Direct and walk-in centres, which are proving popular with users.

**Table 3.2 Investments in quality***Part A: Explicit investments in quality-related organisations and initiatives (in '000s of ££)*

<b>ENTRY</b>	<b>1999/00</b>	<b>2000/01</b>	<b>2001/02</b>	<b>2002/03</b>
<b>Clinical Effectiveness</b> This initiative sought to help clinicians, patients and managers to make informed choices about the provision and delivery of health care services, with the aim of improving quality of care and making maximum use of limited resources.	722	355		
<b>Clinical Governance</b> Facilitates the implementation of clinical governance through the establishment of a national support team (NCGST). Also includes the development, maintenance and management of clinical governance and appraisal tools.		1,300	1,650	1,000
<b>Clinical Standards Advisory Group</b> Set up to advise on standards of clinical care and access and availability of services to NHS patients.	199			
<b>CHI</b> See Chapter 5.		11,300	23,950	33,950
<b>Health Action Zones</b> HAZ initiative brings together organisations within and beyond the NHS to develop and implement a locally agreed strategy for improving the health of local people.	49,000	49,172	1,807	51,586
<b>HImP Performance Scheme</b> The Health Improvement Modernisation Programme (HImP) rewards Health Authorities (HAs) that have made best progress in meeting their targets and objectives. In particular, funding must be used for local and community-based initiatives to tackle heart disease, entrenched problems of ill health, deprivation and poor or fragmented services.		10,000	10,000	10,000
<b>Implementing An Organisation with a Memory / NPSA</b> See Chapter 5.			11,000	15,000
<b>Independent Complaints and Advocacy Services</b> To help individuals to pursue complaints about the NHS.				13,190

**Table 3.2 Investments in quality** (*continued*)

<b>ENTRY</b>	<b>1999/00</b>	<b>2000/01</b>	<b>2001/02</b>	<b>2002/03</b>
<b>Modernisation Initiatives &amp; MA programmes</b> <sup>†</sup> Includes modernisation fund entries; special assistance fund to HAs to facilitate strategic change; and initiatives such as: <ul style="list-style-type: none"> <li>● achieving spread and sustaining service improvements;</li> <li>● creating a service culture that supports leadership, openness and accountability;</li> <li>● enhancing the internal capability of the NHS to deliver improvement;</li> <li>● modernising the workforce; and</li> <li>● supporting underperforming organisations</li> </ul> See Chapter 5.	344,761	40,000		69,011
<b>NCAA</b> See Chapter 5.			14,309	13,299
<b>NICE</b> See Chapter 5.		9,957	12,457	14,457
<b>Safety &amp; Efficacy Register of New International Procedures</b> To identify new interventions and insure their safety and efficacy are monitored.	95	95	95	300
<b>Health Outcomes</b> To promote and support the use of health outcomes assessment and information in health policy making and the planning and monitoring of interventions to improve health.	1,650	1,650	1,650	1,650
<b>National Patient Survey</b> See Chapter 12.		2,000	2,000	2,500
<b>Patient Advocate Liaison Service</b> See Chapter 12.			10,000	
<b>Controls Assurance</b> To improve NHS internal control and risk management. Underpins clinical governance.			833	
<b>Explicit Funding for Quality TOTAL</b>	<b>396,427</b>	<b>125,829</b>	<b>89,751</b>	<b>225,943</b>
<b>TOTAL Explicit Funding for Quality</b> Financial years 1999–2000 to 2002–03: <b>837,950</b>				



**Table 3.2 Investments in quality** (continued)*Part B: Contributory initiatives to improve quality in the NHS (in '000s of ££)*

<b>ENTRY</b>	<b>1999/00</b>	<b>2000/01</b>	<b>2001/02</b>	<b>2002/03</b>
<b>Primary Care Development &amp; Improvement*</b> Includes funding for: PCG/PCT development; primary care act pilots; improving infrastructure and out-of-hours services; walk-in pilots; improving infrastructure and out-of-hours services; walk-in centres; National Primary Care Development Team; extending access to primary care; and GP incentives to promote new ideas and improve patient services.	36,000	171,919	117,075	113,146
<b>Cancer*</b> Includes funding for: Implementation of Calman–Hine report; colorectal cancer service development; quality assurance and co-ordination of breast and cervical screening; training for screening; national screening quality management; for implementation of NSF; cancer action team; cancer plan implementation.	16,810	14,938	32,125	46,784
<b>CHD*</b> Includes funding for: Expansion of heart operations; rapid-access chest clinics; supporting NSF.		15,000	31,500	16,750
<b>Critical &amp; Emergency Care*</b> Includes funding for: Improving paediatric intensive care (following Ashworth Inquiry); national intensive care beds register; increasing capacity; neonatal critical care; improving ambulance response times.	10,090	183,090	167,790	58,090
<b>Mental Health</b> Includes funding for: Developing safe, sound supportive mental health services; establishing mental health primary care workers.	4,000	41,935	13,950	11,090
<b>NHS Direct</b> See Chapter 12.	40,000	80,000	82,447	82,447
<b>Sexual Health</b> Includes funding for: Research on chlamydia and gonorrhoea; screening (does not include specific HIV/AIDS funding).			2,000	5,000

**Table 3.2 Investments in quality** *(continued)*

<b>ENTRY</b>	<b>1999/00</b>	<b>2000/01</b>	<b>2001/02</b>	<b>2002/03</b>
<b>Improving access to care: Waiting List Initiatives*</b> Includes funding for: Investment in additional elective activity; National Patient Access Team; Action On projects, beacons; booked admissions, demand management.	60,000	67,500	67,300	67,200
<b>Delayed discharges:-addressing bed blocking</b> See Chapter 9, section 9.4.				100,000
<b>Flu vaccination programme</b> Supports extension of flu vaccination to all over 65 years of age.		60,000	58,000	27,000
<b>Hospital Cleanliness</b>			30,000	
<b>Hospital food:improvements and / or new menu</b>			10,000	10,000
<b>Hospital-Acquired Infection</b> To develop and support a national surveillance system for hospital-acquired infections.	268	280	300	300
<b>Community Health Councils</b> Two main functions: <ul style="list-style-type: none"> <li>● monitor the health service and assess quality by means of visits and surveys;</li> <li>● help and inform the public.</li> </ul> Now superseded by CPPIH.	22,561	23,324	23,324	23,324
<b>Ethnic Minority Health</b> To improve access and facilitate improvements in NHS services for ethnic minorities; Equality Strategy Unit.	907	607	407	557
<b>Medical Devices Agency</b> To evaluate medical devices for use in the NHS.		2,400	2,400	2,400
<b>Recruitment, retention and return to practice</b> To increase workforce.			79,000	63,800

**Table 3.2 Investments in quality** (*continued*)

<b>ENTRY</b>	<b>1999/00</b>	<b>2000/01</b>	<b>2001/02</b>	<b>2002/03</b>
<b>Contributory Items</b>				
<b>TOTALS</b>	<b>190,636</b>	<b>660,993</b>	<b>717,618</b>	<b>627,888</b>
<b>TOTAL Contributory Items</b> Financial years 1999–2000 to 2002–03:				<b>2,197,135</b>
<b>Explicit and Contributory Items</b>				
<b>TOTAL</b>	<b>587,063</b>	<b>786,822</b>	<b>807,369</b>	<b>853,831</b>
<b>TOTAL Funding for Quality Initiatives</b> Financial years 1999–2000 to 2002–03:				<b>3,035,085</b>

† In 1999–2000, this includes an allocation of 274,761 to a Modernisation Fund derived from the Comprehensive Spending Review (further details not available).

\* Includes funding allocated to MA for improvement.

Note: no allocations relating to IT investment or dental services are included in this table.

SOURCE: Centrally Funded Initiatives Services and Special Allocations ([www.doh.gov.uk/allocations/expositions.htm](http://www.doh.gov.uk/allocations/expositions.htm)).

This table is an illustrative compendium of investments made to improve the quality of care in the NHS. Items in Part A of the table are the least likely to be debatable as to whether the resources expended were explicitly to implement the Quality Agenda. Those in Part B are arguably part of the Ten-year Quality Agenda, but the authors judged them to be primarily designed to improve the patient experience of care and/or patient outcomes.

Inevitably, the NHS reforms have been plagued by major controversies between central and local control. Government asserts that devolution is necessary, but engages in paradoxical behaviour, including issuing a multitude of policy documents and nationally set performance targets, new laws and regulations, as well as establishing a bevy of new national institutions since 1997. Though critics charge that this is at best inconsistent, and at worst disingenuous, others could argue that this centralised infrastructure comprises the necessary instruments to allow for devolution in a nationally accountable health system. One unintended consequence of this centrally devised schema is that the Government is held responsible for everything that goes wrong, even as it tries to push accountability down to the localities and front lines.

The public appears to be equivocal about the health system and sceptical about the Government's Modernisation Agenda. In 2002 (of more than 10,000 voters surveyed), only 10% believed that Government targets for 15,000 more doctors and 10,000 more hospital beds by 2008 would be realised (Summerskill 2002). The same disbelief applied to Government performance targets for waiting times; 75% of those polled did not believe that the maximum wait for operations would fall to 6 months by the next election. However, respondents rated more positively their individual experiences as patients. Indeed, 75% of patients were either very satisfied or quite satisfied with their last visit to a GP or local hospital, and approval ratings for both nurses and doctors were above 80%. Yet, when asked to rate the NHS locally, only 41% described it as good or very good, and ratings fell to just

15% when asked about the NHS performance nationally. This paradox of high satisfaction with one's individual experience of care, accompanied by concern in respect to general performance of the health system, is also present in US surveys. It does represent, however, an opportunity to use recently emerging quality data to inform the public's view of general performance in the NHS.

Accepting that it is still early days for many of the initiatives and reforms of the Quality Agenda, it is nonetheless both fair, and in fact prudent, to conduct a mid-term evaluation to pinpoint the signs of progress, identify inevitable missteps and, most importantly, responsibly and energetically implement mid-course corrections. Box 3.1 lists some of the strengths and limitations of the Quality Agenda to date (as assessed in the conduct of this evaluation).

### **BOX 3.1**

#### **General accomplishments and limitations in first 5 years**

##### **Accomplishments/strengths**

- Quality is central to the “Modernisation Health Agenda”
- Significant additional multi-year funding for NHS
- Strong policy articulation
- Significant new organisational capacity – CHAI, NICE, NPSA, etc.
- “Clinical governance” legitimises attention to quality, not just throughput and costs, on both managerial and clinical fronts
- National Service Frameworks serve as templates to define population-specific quality
- National Performance Frameworks provide routine and standardised measurement
- External review and inspection of hospitals/Trusts initiated
- Advances in the field of performance monitoring and reporting
- Safety and medical mistakes identified as a critical issue; a national agency established
- Patient-centredness identified as a fundamental principle supported by innovations such as NHS Direct, walk-in centres, introduction of “choice” to ameliorate long queues
- New procedures for annual physician appraisal and revalidation (at 5 years)
- Progress in workforce supply

**Limitations/weaknesses**

- Difficulty in establishing whether Quality Agenda is succeeding – dearth of valid and reliable longitudinal data (standardised data points)
- Variation in care/postcode lottery
- Perception/reality of micromanagement from the “top down”, stifling initiative and “ownership” at the institutional level and front lines
- Medical profession attentive, but not yet sufficiently engaged and activated
- Data deficiencies are numerous and widespread; lacking a realistic, corrective plan
- Reliance on the PCTs to become the quality catalyst, despite insufficient experience, expertise, resources and basic performance data
- Uneven success in reducing waiting times, which are sentinel indicators for overall NHS performance – for example, the target of a maximum 6-month wait for inpatient admission
- Workforce shortages, especially among doctors
- Conflict of interest in DOH role as funder, provider and objective self-evaluator
- Ambiguity in co-regulation model; lacking clarity in complementary accountabilities of the professions and of government

Many disparate views exist as to whether the NHS is moving in the right direction. Countless lugubrious commentaries describe the formidability, if not impossibility, of changing this monolithic entity into a nimble, responsive and high-performing health system. Yet, if the self-reported numbers are accurate, the 2003 Modernisation Board Annual Report does show cause for optimism, as illustrated in Box 3.2.

**BOX 3.2****Positive quality results**

- 7.5% annual funding increases for the next 5 years
- Staffing increases between September 1999 and March 2002
  - 28,740 nurses
  - 388 GP registrars
  - 3,130 consultants
  - 3,400 more allied health professionals
  - 483 more GPs

***Clinical Quality Improvements***

- **Heart Disease**
  - Deaths from heart disease fell by 14% since 1997
  - Number of heart surgeries rose by 13% in 2001–02, and another 11% in first six months of 2002–03
- **Cancer**
  - Death rate from cancer reduced by 6.5% over 3-year period
  - Increase of 91% in suspected cancer patients being seen by specialist within 2 weeks of urgent referral by GP
  - In calendar year 2002, 94.4% of breast cancer patients received their first treatment within 1 month of diagnosis
- **Access and Choice**
  - Long waits (more than 15 months) for hospital operations; were radically reduced from 8,075 to 9 (Oct 2001–Sept 2002)
  - Reduction of 61% in waits for hospital admission (Oct 01–Oct 02)
  - By Sept 2002, 77% of people seen within 4 hours in A&E
  - Long waits for outpatient appointments (over 26 weeks) reduced by 99% from 92,800 to 716 (Sept 01–Sept 02)
- **Patient-centred environment**
  - Refurbishment of 1,325 GP premises by October 2002
  - Nine major new hospitals opened from October 2001–September 2002
  - 100,000 patients receiving improved food services daily

Evaluating the quality agenda is not simply an academic exercise. The ability to access health care predictably when needed, in a system that will provide safe and effective health care services routinely, is of the utmost importance. In this report, we aim to assess the logic and reason of the design and pursuit of investment and capacity building, by using multiple data sources to get a picture of the direction of performance. We conclude with an analysis of how to move forward in the second half of the Ten-year Quality Agenda, by providing a set of recommendations for the near term.

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## SECTION II

# Building Systemic Capacity for Quality in England

This section addresses the first of the four evaluation questions of this project: Is the development of new legal, organisational, regulatory, monitoring and evaluation and governance capacity reasonable for accomplishing a multi-year improvement agenda?

*The New NHS will have quality at its heart. Without it there is no fairness. Every part of the NHS and everyone who works for it should take responsibility for working to improve quality.*

*The New NHS – Modern, Dependable* [DOH 1997]



## 4. A Multi-tier Conceptual Model for Building Systemic Capacity

The development of the NHS Quality Agenda in England coincides with the evolution of a number of similar initiatives in various health care systems around the world. All have common objectives, seeking to document the extent of shortcomings in health care provision, and to implement interventions to address those deficiencies.

The UK Government and medical professions, in pursuit of these objectives, focused upon the organisational characteristics necessary for encouraging and nurturing the Quality Agenda. The resulting joint statement, issued in 2001, comprises a seven-point pledge that articulates a shared vision of what is necessary for fundamental quality improvement (see Box 4.1).

### **BOX 4.1**

#### **A seven-point pledge by Government and medical professions**

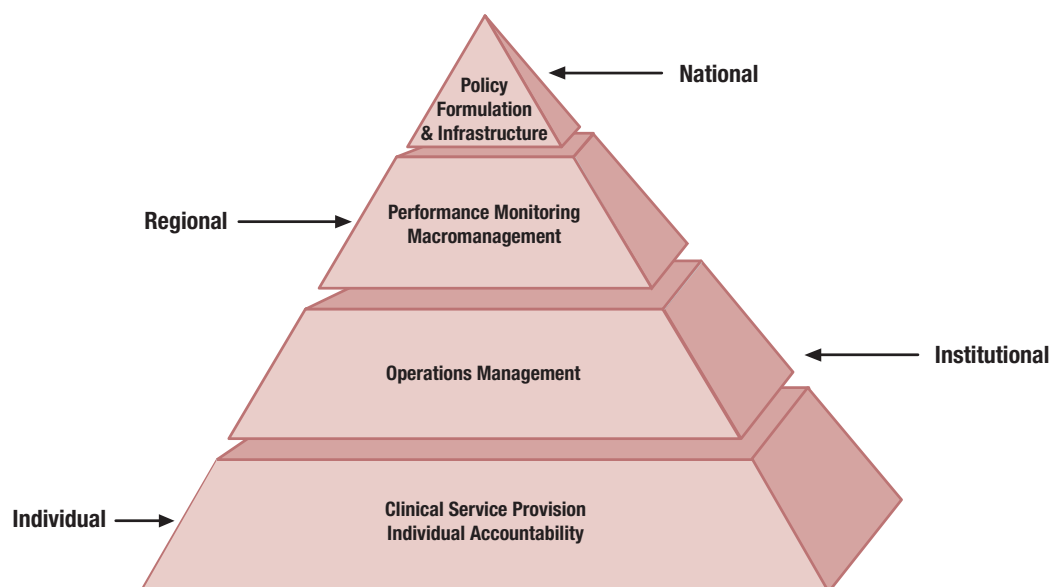
- To continue to show commitment from the top to implementing the programme of quality assurance and quality improvement;
- To take every opportunity to involve patients and their representatives in decisions about their own care and in the planning and design of services;
- To work towards providing valid, reliable, up-to-date information on the quality of health services;
- To work together in determining clinical priorities;
- To create a culture within the NHS which is open and participative, where learning and evaluation are prominent, and which recognises the safety and the needs of patients as paramount;
- To recognise that in a service as large and complex as the NHS, things will sometimes go wrong. Without lessening commitment to safety and public accountability of services, to recognise that honest failure should not be responded to by blame and retribution, but by learning and a drive to reduce risk for future patients; and
- To recognise that the professions, the Government and the public share a common interest and a commitment to improving the quality of services for patients.

SOURCE: DOH 2001.

Admirable as the intent of this joint pledge is, an understanding of how to realise the goals and operationalise the intent is elusive. Traditionally, discrete approaches have been adopted in order to secure such improvements. Waves of faddishness have been apparent, with enthusiastic reception for new ideas followed by abandonment and subsequent attraction to the next new technique. Approaches such as medical audit (and the more inclusive clinical audit), continuous quality improvement (CQI), total quality management (TQM) and “report cards” are all examples of techniques implemented in an attempt to bring about organisational change. Increasingly, research indicates that whilst these types of discrete methods may be effective in particular situations for particular audiences, a broad and multi-faceted approach that uses numerous interventions simultaneously is necessary to achieve systemic and sustainable quality improvement (Leatherman 2002). There are no “magic bullets” to secure significant quality improvement across a range of contexts in complex systems. Building systemic capacity for quality requires a multi-level, integrated strategy involving, at a minimum, national policy formulation, standard setting, monitoring of performance, regulation, institutional governance, patient engagement, tools for knowledge enhancement, payment reform and professional commitment (Hurst 2002).

Assessing a programme as sweeping and ambitious as the NHS Quality Agenda requires the development of a conceptual framework that provides a basis for evaluation. Such a framework should describe, in specific terms, what is necessary to create an environment where quality will be routinely defined, measured, monitored and improved. To some extent, this can be accomplished by relying on the published evidence base, and supplementing that relatively weak resource with expert opinion as to what capacity and configuration of will and skill must exist to improve quality predictably. We base our evaluation of policy coherence in

*Figure 4.1* A conceptual model for building systemic capacity



the NHS Quality Agenda on such a model (see Figure 4.1). We have used the model to examine whether the many investments, initiatives and infrastructure established to date constitute reasonable capacity building for systemic quality improvement.

For a nation to address the volume, diversity and seeming intransigence of quality problems, it is necessary to design and implement a comprehensive, multi-tiered approach to change – one that is systemic, evidence-based and transparent (Marshall et al. 2000, Ferlie & Shortell 2001, Leatherman 2002). Four levels may be conceptualised and operationalised, as depicted in Figure 4.1, a multi-tier model first articulated in the Nuffield Trust precursor study by the authors (Leatherman & Sutherland 1998) and used in the subsequent five years in a number of developed and developing countries. The model is based on an increasing body of evidence; hence, it is not only descriptive but also, to some extent, prescriptive. The design of any model has its limitations, not the least of which is the designer's temptation to select only those observations that meet the specifications of the model. In this case, we note that there is permeability between the levels – a feature that is not only real, but also desirable. We now describe each of the four tiers in terms of their potential contribution to, and effect on, building capacity for ongoing improvement of health care quality.

The four tiers represent different functional levels within a health care system or health sector.

Tier 1 generally encompasses the sphere of influence and responsibilities of a nation's central government. In the newly devolved UK, this would be the country level, such as Scotland or England. In addition, there are situations where a quasi-governmental entity or voluntary body performs the functions acting in the public interest or on behalf of, but outside of, government.

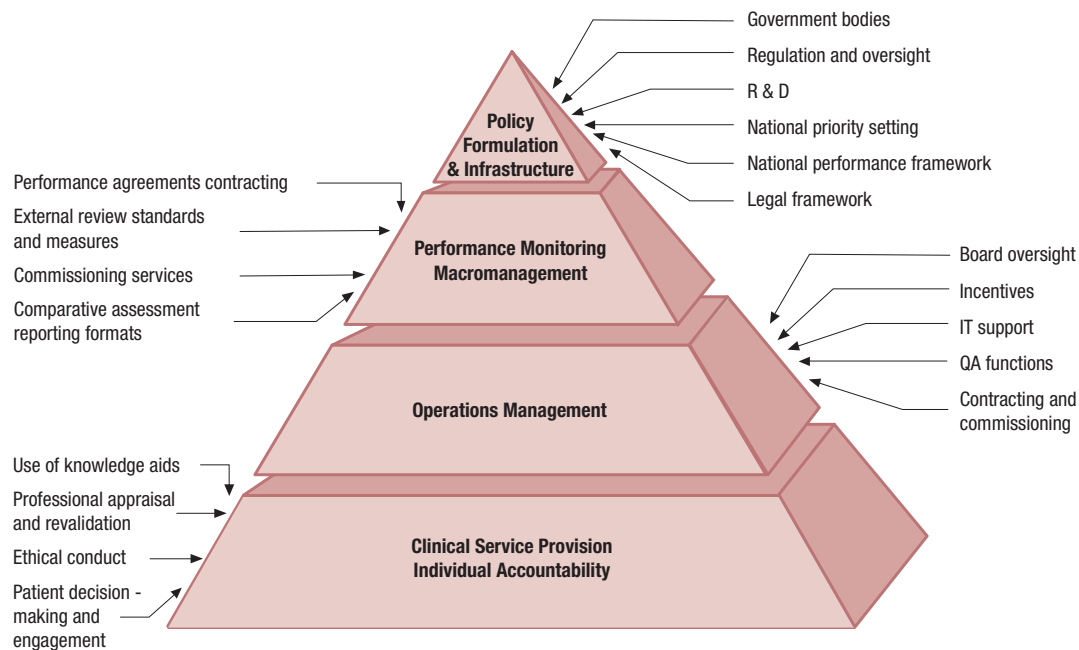
Tier 2 is regional, including geopolitically defined regions, population catchments and bureaucratic regions.

Tier 3, the institutional level, largely consists of organisations with discrete governance structures and defined accountability for services and results. It includes entities such as England's Trusts (or hospitals, clinics and health plans in other countries).

Tier 4, upon which the other three rely for actualisation, is the clinical care level, or the interfaces involving patients and health care professionals (often within teams and units).

A set of generic capabilities are ubiquitous features of the model, as portrayed in Figure 4.2. These capabilities are apparent across different health care systems, regardless of the particulars of funding, ownership and market orientation. The specific form and structure of these capabilities, however, are influenced by each country's unique policy environment, resources and ideological underpinning for the health care system.

Figure 4.2 Generic functions in the multi-tier conceptual model



Within Tier 1, the central or federal government level, reside a number of essential tasks in capacity building. They include:

- policy formulation;
- priority setting;
- creation of legal (including contractual) context;
- identification of performance targets or goals;
- establishment of essential infrastructure, including organisational structures and IT;
- design and implementation of regulation;
- monitoring of system performance; and
- research and development (R&D).

Based on continuing efforts to improve health system performance of member countries, the Organisation for Economic Co-operation and Development (OECD) asserts that “it is necessary to be clear about the objectives of the health care system and to measure relevant aspects of achievement against these objectives” (Hurst 2002, p. 37). Hence, it is critical to have policy formulation that articulates priorities and defines performance targets. Goals should derive from an evidence base that describes the gap between optimal and current functioning. This requires clinical and health services R&D capacity, the lack of which may have a high cost in both financial and health consequences, resulting in increased morbidity and avoidable deaths (Peckham 1999). Building infrastructure may include creating new organisations, as well as conditioning the environment by regulatory and legal frameworks. Research increasingly points to the vital role of adequate information infrastructure, which often requires diligent attention at the national level (Balas & Boren 2000; IOM 2001).

Within Tier 2, that of regional-level activity, key functions include macro-management and macro-monitoring of performance, through functions such as:

- refinement of nationally established goals;
- articulation of the regional implementation strategy;
- negotiation and agreement on performance parameters;
- aggregation of data for reports up to Tier 1; and
- monitoring performance and comparisons within and between regions.

Placing responsibility for macro-monitoring of performance at this intermediate level has several benefits. It permits the customising of centrally promulgated policy to reflect regional heterogeneity and justifiable variation in policy interpretation. Economies of scale are attainable, particularly where there is insufficient distribution of capacity, such as in data and analytic skills among institutions and providers. In the UK, the NHS has generally had well-defined regional offices, of which the number, geographical scale and scope of responsibilities have been subject to frequent alteration and reform. Over the last five years, the NHS has seen several permutations, the most recent being the introduction of 28 Strategic Health Authorities (StHAs). In other countries, regionalisation takes the form of geopolitically defined regions, such as provinces in Canada, county councils in Sweden and cantons in Switzerland – or, as in the US, bureaucratically defined regions for the Medicare program.

At Tier 3, individual institutions or organisations represent the locus of accountability for health services delivery, and act as the change agent for quality. In the UK, this would commonly be the “Trust” and its constituent parts. In acute care, this includes responsibilities for a single hospital, or for a collection of related hospitals, clinics and ancillary services

providing care within a defined catchment area. The fledgling Primary Care Trusts (PCTs) also populate this tier and are emerging as a linchpin of the Modernisation Agenda. Approximately 300 PCTs with a shared governance structure serve, on average, about 160,000 patients each. By 2004, PCTs will have control of 75% of the NHS budget and be responsible for arranging the provision of all primary and community care services, and commissioning the majority of specialist care (see Chapter 13). At this level, broadly articulated NHS policy and clinical governance must translate into practice. At a minimum, this requires:

- routine use of the evidence base and knowledge management methods;
- traditional quality assurance functions such as infection control and risk management;
- judicious resource utilisation;
- mechanisms to ensure professional competence and ethical conduct;
- practical application of information technologies;
- regular implementation of peer review processes;
- fair implementation of incentives; and
- achievement of specific, contractually agreed targets.

Finally, Tier 4 encompasses actual service delivery, the interaction between and among providers and patients. Some mechanisms to optimise quality of care at this level are:

- peer review;
- self-assessment and periodic revalidation or certification of professions;
- professionals' use of knowledge aids such as embedded protocols, guidelines and computerised prompts;
- patient engagement at an individual level, e.g. sharing decision-making about treatment options, or exercising provider choice (if it exists) based on performance data; and
- citizen involvement to influence the health care system, e.g. participation in governance or feedback mechanisms.



On the part of health service professionals, technical proficiency must augment clinical acumen, and be rooted in sensitivity to individual patient needs and preferences. Quality at the clinical interface also relies on professional ethos exercised through peer interactions to influence behaviour in a self-improvement feedback loop. In seeking to become “patient-centred” in the UK and “consumer-oriented” in the US, both countries grapple with the role of the patient as a judge of and catalyst for quality. Though public disclosure of data has had only limited effect to date in the US (the country with the most experience), there are signs that patients are increasingly becoming sophisticated “consumers” of services and are willing and able to act as evaluators (Coulter 2002).

In England, new tools such as the electronic health library and publicly reported performance data are increasingly available to the public. Another potentially important role is influencing the health care system through community involvement in the governance of institutions (such as Trusts). The emerging concept of “expert patient” points toward a role beyond “informed consumer” to a co-producer of health, requiring shared knowledge of one’s own clinical profile and appropriate treatment options mediated by individual preferences.

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## 5. Applying the Model: The NHS Quality Agenda

Since 1997, the NHS has undergone an impressive overhaul from top to bottom, including the implementation of a strategy consistent with the multi-tiered model. At the national level, published documents introduced dramatic policies encoded by new health law, denoting quality as a principal design factor that would explicitly join efficiency, effectiveness and equity – values long articulated as the pillars of the NHS.

The massive changes in the NHS include the establishment of new organisations and capabilities for external oversight and inspection, as well as the development of new approaches in areas such as performance evaluation and public reporting, payment reform and patient engagement. A pivotal new concept, “clinical governance”, was introduced to define professional and institutional accountabilities, including statutory duties for optimising quality.

The accomplishments in the first half of the Quality Agenda fall into three main categories:

- conditioning the environment through mechanisms such as law and technological capabilities;
- creating new organisations to develop essential functionality; and
- developing new programmatic initiatives.

Although these three types of action are all interactive and interrelated, we will discuss them separately. In this chapter, we address conditioning the environment and organisational capacity. In Chapter 6, we turn our attention to a number of sentinel programmes and approaches.

Given the multitude of possible topics, we focus on only some of the key contributors, briefly describing the history and purpose of each, then discussing its contributions and limitations, using the multi-tiered theoretical model as an evaluation tool. Much of the first half of the Quality Agenda has focused on creating core competencies and capacity at the national level; hence, the relatively larger set of organisations listed under Tier 1. The next five years should focus on creating the requisite infrastructure and functionality at Tiers 2, 3 and 4.

## **TIER 1: NATIONAL INFRASTRUCTURE AND CAPACITY**

### ***National Institute for Clinical Excellence***

The National Institute for Clinical Excellence (NICE), created in 1999 as one of the first manifestations of the Ten-year Quality Agenda, is a Special Health Authority that develops and publishes cost-benefit analyses for specific technologies and pharmaceuticals (NICE 2003).

NICE was established in order to fill a perceived vacuum at the national level for providing evidence-based guidance on the value of health care interventions. It primarily focuses on new interventions, and aims to inform the development of clinical practice by providing advice in terms of appropriate context and degree of use.

The remit of NICE is to act as an authoritative guide on best practice to patients, health professionals and the public. This requires the development of credible and defensible evidence-based appraisal of selected health care interventions when, for example, drugs are first marketed, when local policies are varied, and when unproven interventions enter routine use (Dent & Hawke 1997). Its general operating procedures entail collating technology assessment by independent researchers, along with submissions from manufacturer(s) and patient and professional groups. The appraisals committee then reviews the evidence, consults various stakeholders, and advises NICE on how it should guide the NHS. Inevitably, controversy has surrounded the methodology for making judgements about drugs and treatments, with concerns about the transparency of the decision-making process. Also inevitable, particularly within the NHS, is the suspicion held by charities and patient groups that banning or limiting drug use is a means to reduce NHS costs, rather than to improve appropriate use.

NICE has made significant progress in changing the NHS environment by establishing and embedding a defined evaluation process and, in so doing, setting the terms of debate about the value and cost-effectiveness of interventions. Most importantly, and notwithstanding continuing controversy about methods and judgement criteria, there is now a recognised legitimacy for centrally provided guidance on controversial issues of resource and service availability.

The long-term effectiveness of NICE will be predicated on a number of factors, including the general acceptance of its appraisal process and decision criteria. The status of NICE guidance needs urgent clarity: is it discretionary information or does it represent a legal obligation to fund and provide care adherent to NICE “guidance” (Dent & Sadler 2002)? NICE would provide further influence if it had a broader outlook; instead of only being concerned with adopting effective innovations, it should also be concerned with discontinuing ineffective interventions and providing guidance on existing, well-established treatments, medical devices and procedures. Incorporating selective NICE guidance into the newly developing Commission for Healthcare Audit and Inspection standards is another cogent method to amplify impact and embed evidence into practice (see the recommendation in Chapter 16).

The House of Commons Health Select Committee's Report (HoC 2002), while commending NICE for its achievements, recommended a broader portfolio that includes evaluating all therapeutics of interest for specific clinical conditions, or advising on a whole class of drugs rather than a subset. It reinforced the Kennedy Report's view (BRI Inquiry 2001) that NICE should develop guidelines for all major causes of mortality and morbidity, with clearer links to National Service Frameworks (NSFs) (Burke 2002).

### ***The Commission for Health Improvement 1999–2004 and the Commission for Healthcare Audit and Inspection 2004–***

The Commission for Health Improvement (CHI) is currently the independent regulator of NHS performance. In 2004, as part of a merger, a newly established organisation, the Commission for Healthcare Audit and Inspection (CHAI) will replace CHI. This section briefly discusses the history and intentions of both organisations by identifying key functions and issues.

Of all initiatives put into place during the first five years, CHI has perhaps played the most compelling role in drawing attention to and influencing performance (at least among Acute Care Trusts). Established in November 1999, CHI's mission was to improve quality through routine external standards-based reviews of all health institutions (CHI 2000). The Government set national priorities and targets, naming CHI as the independent NHS performance regulator. Its original broad remit encompassed four statutory functions:

- to conduct clinical governance reviews;
- to study how the NHS is meeting NSF and NICE guidelines;
- to investigate areas where serious deficiencies are suspected; and
- to assume a leadership role in quality improvement through identifying and disseminating knowledge of excellent performance.

Regular inspection, accompanied by publication of “star ratings”, has garnered the rapt attention of Trusts, owing to their fear of becoming “zero-rated” hospitals (with the pursuant consequences including the possible imminent removal of the chief executive), and the aspiration to attain “earned autonomy” if awarded a three-star hospital status. The star ratings incorporate key targets purported to measure Government priority areas, as well as a broader set of important indicators, including clinical governance reviews. In 2003, CHI published the star rating methodology in advance, including the list of indicators, which were previously unavailable to Trusts under inspection.

Star ratings, explained in CHI's language, are summarised in Box 5.1. They are unsurprisingly a subject of heated controversy. Because of the perception that there is insufficient rigour in the methodology to date, the meaning of star ratings is frequently contested. A sampling of the news headlines contained in the July 2003 online *Health Services Journal* indicates the vagaries of interpreting the star ratings. One article explained that “star ratings reveal north–south split” (HSJ 2003a), meaning that a line of differentiation exists across the middle of England, with high-performing Trusts in the north and low-performing Trusts in the south. Another controversy related to star ratings is over the consequences facing the highest-rated hospitals that slip from three-star status, thus losing a major role in the Government's flagship policy of “foundation-status hospitals”, as well as up to £1m in Department of Health bonus payments and “earned autonomy” from Whitehall (HSJ 2003b).

### **BOX 5.1**

#### **NHS star ratings system**

The NHS performance ratings system places NHS Trusts in England into one of four categories.

- Trusts with the highest levels of performance are awarded a performance rating of three stars.
- Trusts that are performing well overall, but that have not quite reached the same consistently high standards, are awarded a performance rating of two stars.
- Trusts where there is some cause for concern regarding particular areas of performance are awarded a performance rating of one star.
- Trusts that have shown the poorest levels of performance against the indicators or little progress in implementing clinical governance are awarded a performance rating of zero stars.

SOURCE: CHI 2003

In 2002, the Office of Information on Health Care Performance within CHI took over collating and reporting the star ratings for Acute Trusts; since 2002, it has added star ratings for Primary Care, Mental Health and Ambulance Trusts. The same office will also be responsible for publishing an annual “State of the NHS Report”, and for conducting routine national clinical audits and national surveys of patients and staff.

Our interview data showed considerable confluence towards the opinion that CHI was a critical, perhaps even the primary, engine of change for the Quality Agenda in the last several years. CHI adopted a developmental approach to its work and described its reviews as a “learning process”. Despite its widely acknowledged impact on the health service, CHI was charged with a number of criticisms, including methodological weaknesses in the inspection process, a lack of consistency across review reports and a lack of focus on clinical processes and outcomes (Day & Klein 2001; Klein 2002). A fair appraisal would surely recognise the pressures under which CHI emerged, including the expectation that it would perform complex inspections across large numbers of heterogeneous NHS entities in a relatively short timeframe.

In 2002, *Delivering the NHS Plan* (DOH 2002a) outlined new NHS structures and responsibilities, and the establishment of a new independent inspectorate, CHAI. CHAI will subsume the existing CHI and absorb the Audit Commission’s value-for-money studies in health as well as undertake the inspection and licensing of private health care organisations. Owing to the need for independence, both perceived and real, CHAI will report directly to Parliament when it “goes live” in April 2004. The NHS Reform and Health Professions Act 2002 expanded the remit of the Commission and gave it more teeth. A partial listing of CHAI functions as set out by the draft Health and Social Care (Community Services and Health) Bill is in Box 5.2.

### **BOX 5.2**

#### **CHAI functions**

- Inspect the management, provision and quality of NHS health care.
- Inspect arrangements for clinical governance.
- Register, inspect and regulate providers of health care in the independent sector.
- Inspect NHS Foundation Trusts.
- Identify where and how public resources are used to provide health care.
- Investigate serious failures in health care.
- Report to the Secretary of State for Health where serious concerns arise about quality.
- Publish annual ratings of the performance of all NHS organisations in England.
- Produce an annual report to Parliament on the state of health care.
- Conduct an independent review of complaints about NHS services.
- Act as the leading inspectorate in relation to health care, coordinating other bodies involved in inspection.

SOURCE: Adapted from CHAI 2003.

CHAI will adopt a role in the Quality Agenda that is even broader and more challenging than that of its predecessors. Clarity in purpose and approach is imperative. Firstly, at a conceptual level, it needs to define its fundamental task. Secondly, it must build an organisation with the managerial, intellectual and technical capacity to accomplish the many and disparate objectives. Data and information must play a critical role in achieving the many responsibilities in the CHAI portfolio.

Key questions remain. Is the model to be used one of inspection or accreditation? Inspection would seek to assure the adequacy of the health system using “floor” standards, or minimum standards. Accreditation would seek to develop and employ standards that describe a well-functioning health care system, not a minimally adequate one. Future models of inspection should move to a continuous assessment model incorporating remote surveillance of performance based on managerially and clinically relevant data. Over time, if successful, this will replace excessive dependence on “one-off”, resource-intensive, site-based inspection processes, and will foster important skills and processes of self-monitoring against relevant standards within the organisations.

### ***Modernisation Agency***

The Modernisation Agency (MA), as announced in *The NHS Plan – A Plan for Investment, A Plan for Reform*, was formed to “help local clinicians and managers redesign local services around the needs and convenience of patients” (DOH 2000b, p. 60). As such, it represents national capacity (Tier 1), but primarily acts at an institutional level (Tier 3) to effect change. The MA’s strategy appears to be to support change in a focused area, concentrating on the spread and dissemination of learning in the hope of reaching a “tipping point” (Gladwell 2000) for catalysing positive change. At its inception, it encompassed a range of programmes, as shown in Box 5.3

#### **BOX 5.3**

##### **Key programmes of the Modernisation Agency in 2000**

- National Patients’ Access Team
- Primary Care Development Team
- Collaborative Programmes
- Clinical Governance Support Unit
- NHS Leadership Centre
- Beacon Programme
- Annual Awards Programmes
- Action On Programmes
- Development and application of national protocols for specific care pathways (in partnership with NICE)



Since it was announced (2000) and operationalised (April 2001), the MA has burgeoned. As of 2002–03, it had some 150 programmes and an annual budget of around £120m. A significant portion of the MA's work in terms of patient outcomes and impact remains unquantified or unpublished. Box 5.4 contains data available on individual programmes as self-reported by the MA (Section III contains further data).

#### **BOX 5.4**

##### **Modernisation Agency self-reported quality improvement results**

###### **National Primary Care Collaborative**

The NPCC had four national waves, involving 80 PCTs and over 400 practices. Results include:

- a fourfold reduction in mortality for CHD patients in NPCC PCTs;
- a reduction of over 60% in average waiting time to see a GP in NPCC practice sites; and
- an increase in the proportion of CHD patients prescribed with aspirin: 91–100% of patients in ~43% of practices in June 2002, compared with ~8% of practices in July 2000.

###### **Cancer Collaborative**

- 95% of patients in the Northern Cancer Network and Mid-Anglia Network now receive treatment within 62 days of referral (NHS Plan target for 2005).
- 67% of patients with prostate cancer in the Black Country receive treatment within 62 days. Median waiting time has dropped from 203 to 55 days.

###### **Service Improvement Team**

- Derby – 90% of CHD patients have an echo-cardiogram within 1 day (down from 14 days).
- Queen Elizabeth Hospital, Woolwich – ultrasound waiting list has been reduced from up to 12 weeks to 11 days.
- Good Hope Hospital, Birmingham – the wait for a barium enema investigation has been reduced from up to 10 days, to 30 minutes.
- Chelsea & Westminster Hospital – ENT had almost 200 patients waiting more than 13 weeks for first appointment. Now, there is no waiting.
- Bolton – waiting time for routine gastroscopy fell from 12 months to a maximum of 6 weeks.
- Kettering Hospital – “See & Treat” in A&E – patients seen within 1 hour rose from 52% to 75%; patients seen within 30 minutes rose from 28% to 57%.

SOURCES: NPCDT 2002 (also refer to Dataset 9.21 in chapter 9); NHSMA 2002a, pp. 2-3; Scott, M. 2003, personal communication, March.

There are encouraging reports of positive results. Most often cited are the significant changes made in primary care (see Dataset 9.21) in terms of access and treatment of coronary heart disease (NPCDT 2002). Results such as these suggest that there exists in the NHS a significant capacity for change and improvement. Aside from self-reported data such as that in Box 5.4, there have been evaluations of specific programmes such as the Cancer Collaboratives. These are limited in terms of the extent to which they have collected comprehensive and validated data on improvement (Robert et al. 2002). There are also many descriptive accounts of individual team experiences – termed “case studies” and “eurekas” – used for idea dissemination, rather than outcomes reports. However, there remains little in the way of data on the overall impact of the MA. The lack of accessible and credible national evaluation data is, in part, a reflection of the fact that the MA is a relatively new organisation and seeks to work at a sub-institutional (team) level, based on the assumption that change should and will be measured locally. The paucity of easily accessed and objective data, in tandem with generous funding relative to other quality-related organisations, may result in a growing pressure on the MA to show results.

Controversy abounds as to whether centralising change capacity is a reasonable long-term model, a rational interim step or a distraction of precious resources from local distribution. The MA has played a valuable role in raising consciousness, conducting training and widely supporting change strategies throughout the NHS. It recognised the need to analyse limitations of the present design and implementation of initiatives; so, in October 2002, it produced *Healthcare Improvement Next Steps* (NHSMA 2002b), a review of current modernisation efforts with a view to the future. In a working paper, Helen Bevan and Paul Plesk (Bevan & Plesk 2003) report that some current issues facing the MA are the need to amplify focus from a team level to an institutional leadership level; to shift priority setting from a national to a local level; and to affect change at an organisational level, rather than concentrating on separate discrete problems.

The limitations in terms of tangible impact do not equate with failure; they are a consequence of the evolutionary process upon which the NHS has embarked, and are reflective of the entire Quality Agenda, not just of the MA. Realisation of this dilemma perhaps instigated the restructuring of the MA, in Spring 2003, towards a distributed capacity model in which particular programme capabilities such as the Primary Care Development Team become a freestanding consultancy engaged directly by Trusts to improve performance. To move from a largely quality-driven, top-down (Tier 1) approach to one that appropriately blends a bottom-up approach, it will be necessary to devolve change capacity into the institutional level (Tier 3) and the front lines of clinical service delivery (Tier 4). This shift in thinking and processing is already under way, owing to the wealth of experience of MA leaders who recognise the need to evolve the strategy by devolving the design and implementation.

### ***The Modernisation Board***

While not an organisation *per se*, the Modernisation Board has acted to inform the direction and monitor the progress of the Ten-year Quality Agenda. The aim of the NHS Modernisation Board has been to advise the Secretary of State for Health and his ministerial team on implementing the NHS Plan. It is comprised of senior health and social care professionals, managers and front-line staff. They meet quarterly to discuss progress, guide priorities and issue an annual report on the NHS. The Modernisation Board is groundbreaking; it is the first time in England that an independent group representing the many different interests involved in health and social services has had influence over health policy and its implementation (DOH 2003a). The Modernisation Board's Annual Report 2001–2002, released in March 2003, is summarised in Table 3.2. In order for it to play a constructive, ongoing role, the government may need to review and revise the process and composition of the Modernisation Board. Rightly or wrongly, it suffers from the perception that it is not, in fact, a truly independent board functioning in the public's interest; instead, it has become closely identified with the Department of Health, and even with political leadership.

### ***National Patient Safety Agency***

The National Patient Safety Agency (NPSA), created in July 2001, is a Special Health Authority that coordinates efforts to learn from and reduce adverse incidents throughout the NHS. The organisation was established as a result of the report, *An Organisation with a Memory* (DOH 2000a), produced by an expert group led by Sir Liam Donaldson, the Chief Medical Officer. It estimated that 850,000 incidents and errors occur every year in the NHS, with approximately a fifth of adverse incidents leading to disability or death. In June 2000, the Government accepted all the report's recommendations, including the development of a new national system encouraging staff to identify adverse events and near misses, without fear of reprisal. The new centralised system for recording, coding, classifying, analysing and providing feedback on adverse events has been tested through selective pilots around the country. Everyone, including patients, will be able to submit a report (NPSA 2003a).

The NPSA is operationalising its remit through a series of processes. First, it collects and analyses data on adverse incidents to reveal incident patterns and potential system problems. Second, it supports the development of pilots, informed through safety-related information from other industries/sectors, in order to test possible solutions. The approach of the NPSA appears to embrace an expert and cross-national evidence base. A principle tenet is that systemic change will be more predictable and productive in reducing medical errors than in identifying and punishing individual providers (AHRQ 2001).

Similarly to other NHS initiatives, it explicitly set performance targets from the outset. This is noteworthy and meritorious. Unfortunately, as is the case elsewhere in the NHS, the

performance targets may have been too bold and ambitious, not only for realising target levels, but also for reliable data collection to measure progress against performance targets. The target for a 40% reduction in serious medication errors by 2005 (DOH 2001a, 2001b) is an example; it is an admirable “stretch” goal, but one that is unlikely to be attainable. Data to measure progress against these goals was not available for this report.

The NPSA is still relatively new; hence, not much credible data regarding safety in the NHS is yet available. In the absence of good data, a case study can illustrate how the NPSA is performing in one important area – issuing safety alerts. In July 2002, the Potassium Chloride Safety Alert went to hospitals across the UK after maladministration of potassium chloride was identified as a serious patient safety risk in the UK and US. The Alert advised hospital staff to implement specific controls in the storage, handling, dilution and prescription of potassium chloride, and to review the storage and availability of potassium concentrate in clinical areas. According to the NPSA press release in July 2003, results of this first system-wide safety alert showed increased compliance with potassium chloride safety controls. The press release announced that an evaluation of 166 NHS Trusts in England and Wales found that the number of hospitals implementing formal safety controls on potassium chloride more than doubled after the alert issued in July 2002. NHS Trust compliance rose from 25% before the alert to 68% six months after the alert (NPSA 2003b).

### ***National Clinical Assessment Authority***

In April 2001, pursuant to a recommendation in the Chief Medical Officer’s Report, *Supporting Doctors, Protecting Patients* (DOH 1999), the National Clinical Assessment Authority (NCAA), a Special Health Authority, was formed. The NCAA’s mission is “to provide a support service to health authorities and hospital and community Trusts who are faced with concerns over the performance of an individual doctor” (NCAA 2003), and to focus on managing poorly performing doctors through assessment and recommendations for remediation (Donaldson 2002).

The NCAA is not a regulator as such; its remit is to advise the Trust or Strategic Health Authority (StHA) on appropriate courses of action. The establishment of the NCAA does not change long-standing arrangements whereby doctors accused of incompetence or underperformance are referred to the General Medical Council (GMC), nor does it change the threshold at which a referral should be made. The GMC investigates serious misconduct, health or performance issues of individual doctors that may call into question the doctor’s fitness to remain on the Medical Register. Lay involvement in the Authority is to ensure that the public has confidence in the organisation (NHS 2001).

In its first two years, the NCAA has received some 500 calls from Trusts wanting advice, and cases of more than 270 doctors have been referred to them (Smith 2003). The NCAA claims that in over 80% of cases where suspension was considered, they sought alternative ways of

resolving the problems. However, the NCAA has been criticised for conducting only a handful of formal assessments; most complainants receive telephone advice – a circumstance that has attracted the label “whitewashing” (Smith 2003).

The fundamental question of whether there is a long-term need for a separate “Special Health Authority” to deal with poorly performing individuals remains. Given the assumed remit and competency of both the GMC and CHAI to deal with poorly performing individual physicians and institutions, establishment of a separate SHA may be redundant in the long term. Furthermore, with the operationalisation of clinical governance, the responsibility of identifying and remediating individually underperforming doctors should rest with local institutions, under their statutory responsibility for quality. Like other national organisations that address a specific problem, NCAA may ultimately succeed by embedding the competencies needed to remediate poor performance in the appropriate NHS organisations. The price of, or reward for, success may be the redundancy and subsequent sunset of the organisation.

### ***The General Medical Council***

The 1858 Medical Act created the General Medical Council (GMC) as an organisation that would develop a professional code, systematise education and self-regulate any aberrant performers (Gray 2002). The GMC protects patients by maintaining a Register of doctors who are fit to practise. No doctor can practise in the UK unless he or she first registers with the GMC. Historically, the GMC relied on professionalism to assure quality: that is, doctors had to maintain independently the skills and knowledge necessary to be fully competent. However, the predictable inadequacy of this voluntary approach produced some notorious cases in the last decade.

It is important to assess whether the GMC, now sometimes referred to as “The New GMC”, is really an updated institution – itself “fit for purpose” – or an old organisation in new clothes. The problems in the Bristol Children’s Heart Surgery Service, which became a major national controversy, may have singlehandedly brought about the largest changes in the GMC in its nearly 150-year history. It caused a costly, extensive and highly visible public inquiry that addressed widespread deficiencies of the NHS, and made expansive recommendations for changes.

This set of circumstances, occurring contemporaneously with the unveiling of the Ten-year Quality Agenda and the introduction of clinical governance, converged to galvanise the emergence of new annual appraisal and revalidation procedures (see Chapter 6). The individual and tandem contributions of these two requisite processes, if rigorously implemented, could make the rhetoric of self-regulation real. Proper execution of the revalidation procedures could transform the GMC from its stereotype of being a sometimes “toothless” entity to being a major safeguard of clinical quality. Full implementation of the annual appraisal and revalidation procedures would further the cause of balancing a “top-down” quality approach with a “bottom-up” capability. Specifically, the routine conduct of physician evaluation would infuse a critical new tool at the level of Tier 4.

### ***Commission for Patient and Public Involvement in Health***

The Commission for Patient and Public Involvement in Health (CPPIH) began in January 2003. Sponsored by the Department of Health, it describes itself as an independent, non-departmental public body. Its aim is to ensure that the public is empowered to influence health-related decisions, and that citizen and patient opinions on health matters are heard. It aims to work at national, regional and local levels in England. Thus, it is an example of a nationally established organisation working throughout the entire scope of the four tiers. The CPPIH subsumes Community Health Councils, and will establish, fund, monitor and support Patient and Public Involvement Forums and the delivery of the Independent Complaints Advocacy Services (CPPIH 2003). Although it is too early to report on CPPIH's progress or impact, in Chapter 12 we describe some organisational concerns, such as the adequacy of its funding and whether it has sufficient independence to perform its stated role.

### ***Medical Royal Colleges***

Given the extent of their influence and voice, it would seem incontestable that the Royal Colleges could and should play a critical role in the Quality Agenda. "For over 450 years, the Royal College of Physicians (RCP) has played a pivotal role in maintaining standards of medical practice in hospitals in England, Wales and Northern Ireland, with the aim of assuring quality care for patients", according to the RCP's website (RCP 2003a). The Royal College of Surgeons, formed by Henry VIII in 1540 as the Company of the Barbers - Surgeons, has likewise had a wide scope of responsibilities, including training and education, examination, research and evaluation (RCSE 2003).

The key question here is not whether the Royal Colleges have a pivotal role in the Quality Agenda, but rather how to engage them most constructively in a set of critical tasks including standards setting; development of quality measures, data collection and analysis; peer review; and the design, based on evidence, of interventions to predictably improve patient care. This is the subject of a recommendation in Chapter 16.

A crucial role, unevenly adopted at the time of writing, is the development of routine data collection, analysis and reporting capability in order to monitor quality. Two examples, both within the Royal College of Physicians, amply serve as models for the type of initiatives that could be developed through the Royal Colleges.

- The National Audit of the Myocardial Infarction Audit Project began in 1998 in response to the audit requirements of the NSF for Coronary Heart Disease. The Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians of London, in collaboration with the British Cardiac Society, convened a working group of cardiologists, nurses, managers and representatives of the Department of Health. Its objective was to examine inpatient management of myocardial infarction against the

standards of the NSF for Coronary Heart Disease. These standards included targets such as delays from arrival in the hospital to treatment with a thrombolytic drug or, for eligible patients, a percutaneous intervention. It involved defining a core dataset for collection of standardised and comparable data across the country. Collaboration with the Central Cardiac Audit Database enabled collection and analyses of data online. Now, data is downloaded from computers on Cardiac Care Units to central servers for data analysis. Hospitals can compare their own analyses with the aggregate online. Analyses are refreshed every 24 hours, allowing Trusts up-to-date access to their own analyses (but not to those of other Trusts). Plans for expanding the system include providing outcomes measures and links to interventional cardiology and cardiothoracic surgery (Birkhead 2002; RCP 2003b). This initiative should serve as a model for similar work in a number of other clinical conditions.

- The Department of Health and the National Assembly for Wales are funding a pilot exercise to give the Royal College of Physicians (RCP) access to the Health Episode Statistics (HES) database and its Welsh equivalent, the Patient Episode Database for Wales (PEDW). The RCP intends to provide a service to individual clinicians by developing tailored analyses of HES and PEDW data. The aim is to support appraisal and revalidation by providing clinicians with analyses on their patients (and to improve data quality at the same time). A logical extension of this work is to invite professional groups to work with HES and other databases to identify clinically relevant information to support continuous quality improvement of clinical services – and the Department of Health is beginning to do this (Fletcher, A. 2003, personal communication 21 August).

As England's Quality Agenda matures, it must increasingly move from the current, legitimate and vital emphasis on national capacity building, led largely by Government, to professionally dominated initiatives of routine analyses of quality and the implementation of corrective actions to remediate deficiencies. It is in this body of work that the Royal Colleges should be close collaborators, if not leaders. A number of exemplary activities exist, including the work of the CEEU at the RCP, the development of quality measures at the Royal College of General Practitioners, post-surgical mortality rates developed by the Cardiovascular Surgeons, and the Intensive Care National Audit and Research Centre.

## **TIER 2: REGIONAL INFRASTRUCTURE AND CAPACITY**

### ***Strategic Health Authorities***

The 28 Strategic Health Authorities (StHAs), established in April 2002, will assume responsibility for executing critical functions at the regional level, Tier 2. Covering an average population of 1.5 million, StHAs will support PCTs and NHS Trusts in delivering the NHS Plan regionally, and will build capacity for performance improvement across all the local health agencies (DOH 2002b). These tasks are consistent with those of macro-monitoring and

macro management as set out in the multi-tier model, including agreeing to performance parameters and monitoring actual performance. In *Shifting the Balance of Power: The Next Steps* (DOH 2002b), it is clear that the StHAs are responsible for managing all local NHS performance on behalf of the Department of Health, thereby fulfilling the Department of Health's intention to make the NHS less bureaucratic by creating a more devolved management. Strategic Health Authorities should be "committed to service quality and patient safety [through] creating the environment where they are at the centre of decision-making" (DOH 2001a).

The role of StHAs is still evolving. It will be challenging to define, given their position in the pyramid, embedded between an arguably over-controlling central government and emerging institutional-level accountability.

### **TIER 3: INSTITUTIONAL INFRASTRUCTURE AND CAPACITY**

#### ***Acute Care and Primary Care Trusts***

At Tier 3, the institutional/organisational level, the Trusts become pivotal catalysts of quality improvement if they perform the duties specified within the framework of "clinical governance". Clinical governance is a new statutory duty, established by law, requiring Acute Care Trusts and PCTs to monitor and improve quality; and is subject to regular review by CHI (and CHAI, as it emerges in 2004). Thus, Trusts become the linchpin for actualisation of the broad Quality Agenda. It is at this level that "the rubber hits the road".

All of the policy goals and targets set from the top must be actualised at Tiers 3 and 4, the levels of institutional and individual providers. The Trusts are expected to deal with a multitude of new responsibilities and accountabilities, including performance goals set nationally, inspection by regulatory organisations, incident reporting for NPSA, compliance with CPPIH, clinical governance duties, adherence to the latest advice from NICE, and securing culture change in their institutions. Even when they are willing, there is a question of whether sufficient capacity is well distributed at Tier 3 to accomplish the aims and objectives of the Quality Agenda.

All these newly defined responsibilities require changes in the governing boards and management who, prior to the Quality Agenda, were primarily occupied with managing operations, coping with pressured budgets and maximising "throughput". Now, quality is a primary responsibility. The governing boards possess inadequate data, and suffer from a dearth of analytic capability and experience. Consequently much will depend on central government's abilities to construct specific tools, data and methods for individual institutions to adopt and adapt within their own settings.



## **TIER 4: INDIVIDUAL LEVEL CAPACITY**

### ***Patients and professionals as individuals***

At the level of Tier 4 it is the conduct of individuals – health care workers and patients (and their families or caregivers) – that will foster or inhibit changes to improve quality. Although operating within organisations and other groupings, at this level individuals act as sole agents or in tandem with others. New behaviours on the part of the professions and patients, increasingly technology-facilitated, will be necessary to predictably improve the processes of clinical care. These include shared decision-making methods, patient and professional shared use of e-health capabilities, and the use of computerised knowledge aids such as prompts or reminders and flags for risk management in drug prescribing.

A principal responsibility for the health care professional is ethical conduct, including first and foremost the maintenance of up-to-date knowledge and proficiency in requisite skills. The Government has openly challenged the professions to make self-regulation more responsive, reliable and transparent. In the wake of several notorious failures to identify and remediate poor performance, new national organisations will provide the capacity to identify and intervene with poor performers (NCAA), while additional motivation will arise from the statutory responsibility established in law and the integration of performance-based pay into contractual arrangements. For the average physician, purportedly overworked and underpaid, the required routine participation in peer review and annual performance appraisal may appear onerous (Dent & Sadler 2002), but the Government is applying appropriate pressure for this to soon be a reality.

We explore more fully the multiple roles of the citizen and patient in the health care environment in Chapter 13. The relationship between the health care professional and patient is being substantially redefined all over the world, including in the UK. Citizen engagement is arising through new roles in governance arrangements and advocacy. Recently introduced technology-supported tools, such as the 24-hour NHS Direct (telephone line) and a shared electronic health education database available to both professionals and patients, facilitate active patient participation in health care. In the meantime, a newly established structure in all NHS Acute Trusts and PCTs, the Patient Advice and Liaison Service, will be responsible for liaising with patients to resolve problems quickly, advising on any formal complaint, collecting feedback to monitor concerns and addressing the issues raised (DOH 2003b). This is another example of how national policies set in Tier 1 are implemented at Tier 4, the ground level.

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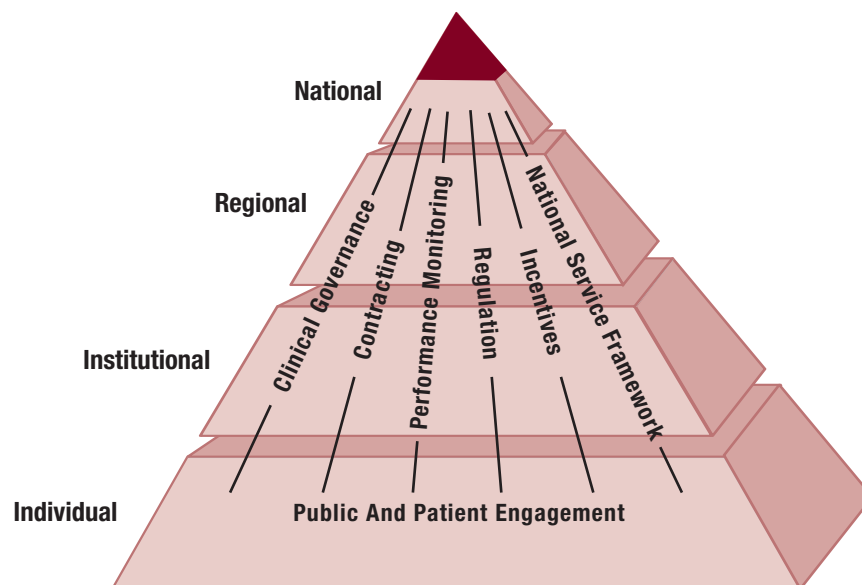
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## 6. Assessing Capacity Building: New Methods and Approaches of the Quality Agenda

The NHS, as a national health care system, has the advantage of being able to align policy, resources and operational management for the pursuit of an explicit agenda – in this case, quality improvement. Organisational capacity building, such as that described in Chapter 5, is a necessary but not a sufficient step in achieving sustained and meaningful quality improvements. The system as a whole must be conditioned to support – adequately at least, optimally at best – the investment in organisations, allowing them to realise their potential. Figure 6.1 shows a number of broad initiatives and approaches that link the national, regional, institutional and clinical levels of quality-related endeavours. It is initiatives and approaches such as these that will be essential in developing a common, but well-distributed set of commitments and capabilities across the four tiers. The list of what might be included here is long; however, we focus here on a limited number of key approaches.

**Figure 6.1** The NHS Quality Agenda: initiatives, functions and tools



## Clinical governance

In its White Paper, *The New NHS – Modern, Dependable* (DOH 1997), the Government proposed new policies, structures and initiatives to develop a comprehensive approach for improving clinical service quality. “Clinical governance” was named as central to this goal, establishing a statutory duty of quality for all NHS organisations. It was embedded in the 1999 Health Act, and implementation began in 1999–2000. Clinical governance is “the system through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish” (Scally & Donaldson 1998, p. 61; NHS Executive 1999).

In the interviews we conducted for this evaluation, there was general accord regarding several aspects of clinical governance. First, interviewees credited clinical governance with giving physicians, managers and governance bodies the legitimacy needed to focus on quality concerns in 1998, at the outset of the new Quality Agenda. Most interviewees also thought that the professions, hospitals and Trusts were struggling with how to operationalise clinical governance effectively. Many reported they were unclear as to what should be done differently from in previous eras, which implemented precursor methods such as audit, total quality management, clinical effectiveness and risk management.

By January 2003, more than 870 teams from the NHS had been through the clinical governance programmes run by the National Clinical Governance Support Team, based in Leicester. A team of researchers<sup>†</sup> at the Judge Institute of Management, University of Cambridge, conducted an evaluation of the Clinical Governance Roll-out Programme, covering 2000–2003 (to be published in autumn 2003). The team has discussed a number of preliminary observations with the Department of Health. We summarise the interim report briefly here (Cambridge University Health, 2002).

Clinical governance is understood in many different ways and cannot be assumed to be a one-size-fits-all, ready-made platform for implementation. Currently, clinical governance is pushed from the centre out and from the top down. Senior management must implement policy expectations for clinical governance. The strength of this is that managers are encouraged to contribute to and take responsibility for the entire patient care experience, not delegating clinical care to the physicians. The weakness is that clinicians may fail to engage, if they perceive clinical governance as the managers’ domain.

Clinical governance has been useful in reorienting quality to a necessary and not a discretionary topic. Most importantly, it has repositioned quality as a statutory duty, alongside fiscal stewardship. Extensive training and counselling is aimed at changing the culture (see Chapter 11) and acquiring new skills in problem identification and solution. Moving forward constructively will require significant strides in the use of information, which CHI identifies as the least effective component of clinical governance (CHI 2003a).

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<sup>†</sup> Leatherman involved as research advisor.

### **NHS contracts and incentives for institutions and individuals**

One of the most vexing aspects of quality is resolving the philosophical and methodological issues of implementing incentives, both financial and non-financial. Though intuitively appealing to some, and increasingly acceptable to most, there remains considerable confusion and angst regarding health care incentives.

Contracts and incentives are potential tools to maintain central policy control and conduct macro-management (Tiers 1 and 2) at the same time as devolving resources to the institutional and individual levels (Tiers 3 and 4). In a system as massive as the NHS, specification of performance standards backed by incentives represents an efficient way of delivering a message from “the centre”, aligning policy directives with the delivery of care at the front lines.

A critical feature of the Quality Agenda is, and should be, the twinning of performance-oriented contracts and explicit incentives. Increasingly, it appears prudent, perhaps even necessary, for specification and agreement of contractual terms to precede any implementation of incentives (Leatherman 2002). The contractual terms constitute an agreement of performance parameters, which then provide the objective basis for incentives. They may also be multi-levelled. For example, in the UK, financial incentives are hierarchical: that is, they flow from national to regional levels (Strategic Health Authorities), then to Trusts and small groups of clinicians.

In the UK context, performance-based contracting requires a mix of old and new approaches. It involves undertaking some bold actions, as well as building on long-existing practices, which were either poorly known or unrecognised as incentives. When conducting interviews during the initial evaluation of 1997–1998, we were repeatedly told that the NHS did not use incentives, sometimes with the implication that it was unworthy of the NHS to do so. That is simply untrue. For example, the NHS has long used a “bonus” incentive to encourage GPs to perform well in providing preventive services such as immunisations and cervical screening.

The use of performance-based contracting with explicit incentives (and sanctions) incites a range of responses. Those who just want to know the “rules of the game” receive it reasonably well; those who value their independence and view the approach as micro-management may be predisposed to resist. The Government has encountered considerable difficulty and been in protracted, even acrimonious, negotiations with consultants and GPs to sign new performance-based contracts as part of the Quality Agenda. However, the GPs have recently signed a new contract specifying that part of the performance evaluation, as well as compensation, will be based on a set of quality measures. The new contract, finally signed after 18 months of negotiations, is a bold departure from the model of practitioners with individual contracts to one founded on group-practice contracts based on a new quality

framework. The contract offers an increase in primary care expenditures, rising to 33% over three years. Two-thirds of this increased investment will be linked to new quality payments. In February 2003, the NHS Confederation, which took the lead in negotiations on behalf of the Department of Health, described this as “the first time any health care system will systematically resource GPs on the basis of how well they care for patients rather than simply the number of patients they treat” (NHS Confederation 2003).

Although financial incentives have existed for a number of years, the notion of pay for performance is relatively new, and research into the effects of financial incentives is still scant. The US National Health Care Purchasing Institute wrote several reports on payment incentives in 2002 (Bailit 2002a, 2002b), providing a useful categorisation of various approaches (see Box 6.1).

### **BOX 6.1**

#### **Pay-for-performance options**

- Quality bonuses – additional payments of usually 5–10% of total compensation, depending on achievement of an absolute improvement threshold – for example, that 90% of enrolled children are immunised.
- Quality grants – given by a sponsoring organisation (e.g. either the DOH or StHAs) to support a specific quality intervention by a provider (e.g. an Acute Trust or a PCT).
- Extra reimbursement for care planning – incremental earmarked payments for specific programme design and planning beyond the day-to-day patient care – for example, payment for design and implementation of a diabetes management or congestive health failure programme.
- At-risk compensation – a percentage of pay withheld from the provider and returned (in part or in full), conditional upon attaining pre-set targets.
- Relative fee schedules – differential fee rates paid depending upon normative performance (i.e. those performing better than average get more than 100% of the usual fee).

SOURCE: Adapted from Bailit 2002a



The first three of these payment incentives may be the most culturally acceptable and compelling in the UK. The latter two are more difficult to conceive of in England, and perhaps more importantly, have caused the most antipathy in the US.

Experience with non-financial incentives seems to be even less well researched and annotated. England's innovation of naming "foundation hospitals" is an interesting case of creating a non-financial reward that, in effect, offers "earned autonomy" for achieving the highest performance rating in an inspection process. Though controversial and likely to be resisted and possibly diluted in Parliament, hospitals with foundation status are rewarded with access to additional funds and greater independence in decision-making, the latter being a potentially powerful non-financial incentive. There remain a number of questions about the initiative, including whether the star ratings are an appropriate basis on which to grant foundation status, and the consequences of the apparent irreversibility of the process. Notwithstanding legitimate controversies, the notion of earned autonomy as an incentive is one of the best aspects of the Quality Agenda, both in its innovation and in its recognition that financial rewards are not the only powerful motivator (McGauran 2002).

### **Performance monitoring and reporting**

Any serious effort to improve clinical care and systems behaviour requires performance measurement and reporting tools. A well-defined, evidence-based performance strategy, with a coherent set of goals and indicators, is one of the most transparent and potentially cogent ways of integrating the Quality Agenda from the policy level through the front lines of patient care (Tiers 1 through 4) (Hurst 2002). It is increasingly recognised that building systemic capacity requires the use of fair and salient rewards and sanctions that reflect national priorities and performance targets (Institute of Medicine 2001; Hurst 2002). Now, this requirement is particularly pressing in the NHS. As central government aims to devolve power while maintaining accountability, it must exercise indirect control through various means such as indicators and targets.

Setting performance targets, measuring performance and reporting results to the public in a meaningful and comprehensible manner has been a central part of the Quality Agenda. To date, much work has led to mixed success. In an attempt to use Government-published performance targets as the fair and transparent basis for this evaluation, we sought to collect and compile what has been published over the past five years in an assortment of Government documents. Our initial findings are shown in Table 6.1. It is an incomplete listing, but it demonstrates dramatically the large numbers of commitments and targets set forth. The volume of pledges in combination with limited data availability, precluded the use of target and commitment achievements as our primary evaluative approach.

**Table 6.1****Government commitments and performance targets published in the first half of the Quality Agenda (partial)****The New NHS – Modern, Dependable (1997)**

- Set up NHS Direct
- By 2002, connect every GP surgery and hospital to NHSnet
- Anyone with suspected cancer will be able to see a specialist within 2 weeks of GP request [breast cancer by April 1999; other cancers by 2000]
- Produce new NHS charter
- Reduce costs by £1bn over current Parliament
- Set up local Health Improvement Programmes to integrate health and social care services
- Establish mechanisms to share best practice
- Develop National Performance Framework
- Replace the Purchaser Efficiency Index with National Reference Costs [as an indicator of efficiency]
- Cut commissioning bodies from 3,600 to 500
- Implement 3- or 5-year contracts, rather than 1-year
- All NHS Trusts to open board meetings to public
- Comparative information on NHS Trust performance will be published
- NSFs will help ensure consistent access to services and quality of care
- Establish NICE
- Establish PCGs
- Local service agreements between HAs, PCGs & NHS Trusts
- New system of clinical governance to ensure clinical standards are met
- Establish CHI
- Develop a national schedule of reference costs
- Establish clear incentives and sanctions to influence performance
- Introduce Performance Assessment Frameworks
- Publish a new Information Management and Technology Strategy for the NHS
- Introduce Health Action Zones

### **Our Healthier Nation (1999)**

- By 2010, reduce death rate from cancer in people <75 by at least a fifth
- By 2010, reduce the death rate from coronary heart disease and stroke in people <75 by at least two-fifths
- By 2010, reduce the death rate from accidents by at least a fifth and serious injury by at least a tenth
- By 2010, reduce the death rate from suicide by at least a fifth

### **The NHS Cancer Plan (2000)**

- Reduce smoking in adults to 24% by 2010
- Reduce smoking rates among manual groups from 32% (1998) to 26% (2010)
- By 2005, a maximum 1-month wait from diagnosis to treatment for all cancers
- By 2005, a maximum 2-month wait from urgent GP referral to treatment for all cancers
- By 2004, extra £50m investment in hospices and specialist palliative care
- Maximum 1-month wait from urgent GP referral to treatment guaranteed for children's and testicular cancers and acute leukaemia by 2001
- Maximum 1-month wait from diagnosis to treatment for breast cancer by 2001
- Maximum 1-month wait from diagnosis to treatment for all cancers by 2005
- Maximum 2-month wait from urgent GP referral to treatment for breast cancer by 2002
- Maximum 2-month wait from urgent GP referral to treatment for all cancers by 2005
- By 2006 almost 1,000 extra cancer specialists [120 more urologists; 200 more gastroenterologists; 257 more general surgeons]
- 50 new MRI scanners
- 45 new linear accelerators

### **NSF for Coronary Heart Disease (2000)**

- By 2001, health authorities will introduce specialist smoking cessation clinics, helping 150,000 people
- By April 2001, 50 rapid-access chest pain clinics, so that people who develop new symptoms which their GP thinks may be angina can be assessed by a specialist within

2 weeks. A hundred rapid-access chest pain clinics by April 2002 and nationwide rollout thereafter

- By April 2001, reducing “call-to-needle” time for thrombolysis for heart attacks. Involves improving ambulance response times so that 75% of category A calls receive a response within 8 minutes; and increasing the proportion of A&E departments able to provide thrombolysis to 75%. Should lead to 75% of eligible patients receiving thrombolysis within 30 minutes of hospital arrival by April 2002 and within 20 minutes by April 2003
- By April 2002, improving the use of effective medicine after heart attack (aspirin, beta-blockers and statins) so that 80–90% of people discharged from hospital after heart attack will be prescribed these drugs
- By April 2002, increasing by 3,000 the number of revascularisation procedures, performed

### **The NHS Plan (2000)**

- 7,000 extra beds by 2004
- 30% increase in adult critical care beds by 2003
- 100 new hospital schemes [buildings] between 2000 and 2010
- 20 Diagnostic & Treatment Centres by 2004
- £7bn new capital investment through PFI by 2010
- Up to £1bn invested in primary care facilities
- 500 one-stop primary care centres by 2004
- 50 new MRI scanners
- 200 new CT scanners
- 80 new liquid cytology units
- 45 new linear accelerators
- 3,000 new automated defibrillators in public places
- 450 new and replacement haemodialysis stations
- £30m allocated directly to Trusts to improve hospital cleaning
- 24-hr catering service with new menu by 2001 [£10m per year]
- Bedside telephones & televisions in each major hospital by 2004
- Extra £250m invested in IT in 2003/4
- Electronic booking of appointments by 2005
- Access to electronic personal medical records for patients by 2004

- Electronic prescribing of medicines by 2004
- All GP practices connected to NHSnet by 2002
- All local health services have facilities for telemedicine by 2005
- By 2004: 7,500 more consultants; 2,000 more GPs; 20,000 more nurses; 6,500 more therapists and other health professionals
- 5,500 more nurses, midwives and health visitors trained each year by 2004
- 1,000 more specialist registrars by 2004
- 450 more doctors training for general practice by 2004
- 1,000 more places at medical school by 2005
- By April 2003, all NHS employers are expected to be accredited as putting the Improving Working Lives (IWL) standard into practice
- £30m by 2004 on childcare provision
- On-site nurseries at 100 hospitals by 2004
- Extend Performance Assessment Frameworks (PAFs) from health authority focus to NHS Trusts and primary care
- By April 2001, every GP practice must have systems in place to monitor referral rates
- From 2001, CHI to inspect 100 hospitals each year
- From April 2001, a new system of incentives in place
- From April 2001, a National Health Performance Fund established, building up to £500m per year by 2003/4
- Change the consultant contract
- By 2004, most NHS staff will work under agreed protocols that identify how to handle common conditions and which staff can best handle them
- An extra £140m for training and staff development by 2003/4
- Access to individual learning accounts (£150yr) or NVQ for non-professional staff by 2003
- Letters between clinicians copied to patient
- Smart cards introduced
- By 2005, patients may book every hospital appointment and elective admission, letting them choose a convenient date and time, rather than the hospital assigning a time
- All doctors to participate in annual appraisal and clinical audit from 2001 [GMC's 5-yearly revalidation process to start in 2002]
- National Clinical Assessment Authority to be established by April 2001
- UK Council of Health Regulators will be established

- By 2002, a NHS-wide Patient Advocacy and Liaison Service will be established in every Trust with an annual national budget of £10m
- From 2002, if an operation is cancelled for non-clinical reasons, the hospital must offer another binding date within at most 28 days or fund patient's treatment at the time and hospital of patient's choice
- By 2001, an NHS charter will replace the Patients' Charter
- All NHS Trusts and PCGs will have to ask patients and carers for their views on services they have received
- All patients leaving hospital will be given the opportunity to record their views about the standards of care they have received
- Every local NHS organisation must publish, in a Patient Prospectus, an annual account of the views received from patients – and action taken as a result
- Financial rewards for Trusts will be linked to results of the National Patients Survey
- A Patients' Forum will be set up in every NHS Trust
- Changes to membership on various committees/panels/boards
- By 2004, NHS Direct will be providing information via digital TV as well as by telephone and Internet
- By 2004, over 500 NHS Direct information points
- From 2001, authoritative information in leaflets etc., provided by NHSplus
- By 2004, a single phone call to NHS Direct will be a one-stop gateway to out-of-hours health care
- By 2002, all NHS Direct sites will refer people where appropriate to help from their local pharmacy
- By 2004, patients will be able to see a primary care professional within 24 hours and a GP within 48 hours
- By 2004, patients who currently have to go to hospital will have tests and treatment in primary care centres
- By 2004, hospital consultants will be delivering 4 million outpatient consultations in primary care and community settings
- Up to 1,000 specialist GPs will take referrals from fellow GPs for ophthalmology, orthopaedics, dermatology, ENT surgery and endoscopy
- By 2004, end bed blocking
- By 2004, no one waiting more than 4 hrs in A&E. Average wait times will fall to 75 minutes. By then, no inappropriate "trolley waits"
- By end 2005, waiting lists for hospital appointments and admission will be abolished
- By end 2005, maximum wait for routine outpatient appointment halved from 6 to 3 months

- By end 2005, maximum wait for inpatient treatment cut from 18 to 6 months
- Set national health inequality targets
- By 2002, develop a new health poverty index [combines data about health status, access to health services, uptake of preventative services, and opportunities to pursue and maintain good health]
- By 2003, following review of existing weighted capitation formula to distribute NHS funding, reduce inequalities through resource allocation
- Medical Education Standards Board will track the number and distribution of doctors in primary care
- 200 new Personal Medical Services schemes in disadvantaged communities by 2004
- By 2001, local NHS action on tackling health inequalities managed and measured through the NHS Performance Assessment Framework
- By 2003, a free and nationally available translation service will be available from every NHS premises
- By 2004, expand Sure Start programme; spending will rise to £500m
- Creation of children's fund worth £450m over 3 years
- Reform of welfare foods programme
- 15% reduction in rate of teenage conceptions
- Screening programme for haemoglobinopathy and sickle cell disease
- New sexual health strategy
- By 2001, NHS will provide a comprehensive smoking cessation service
- By 2010, at least 1.5m smokers will have given up smoking
- By 2004, start new National School Fruit Scheme – every child at nursery and aged 4–6 at school will be entitled to a free piece of fruit each school day
- Reducing the proportion of people <25 years of age reporting the use of Class A drugs, by 25% by 2005 and 50% by 2008
- Increasing the number of problem drug users in treatment by 66% by 2005, and 100% by 2008
- By 2002 there will be new single, integrated public health groups across NHS regional offices
- By 2002, there will be a Health Communities Collaborative to spread best practice through the aegis of the Modernisation Agency
- By 2003, there will be a leadership programme for health visitors and community nurses
- Cut the death rate from cancer in people <75 by at least a fifth by 2010
- Invest an extra £570m a year in cancer services by 2003/4

- NHS breast screening programme extended from ages 50–64 to 65–70
- New Cancer Research Network will be fully implemented by 2004
- End postcode prescribing for cancer treatment
- Coronary Heart Disease National Service Framework – a 10-year programme – will save 20,000 lives per year
- Extra £230m per year in heart disease services by 2003/4
- Extra £120m capital funding over the 2 years to March 2002
- By 2003, rapid-access chest pain clinics established across the country to assess patients within 2 weeks; 50 clinics by April 2001; 100 by April 2002; national roll-out by 2003
- By 2001, ambulance service should achieve a first response to 75% of Category A calls within 8 minutes
- By 2003, 75% of eligible people will receive thrombolysis within 20 minutes of arrival at hospital
- The NSF pledged 3,000 extra heart operations in the 2 years to March 2002 – and a further 3,000 by 2003
- Maximum 3-month waiting time for cardiac surgery by 2008
- In mental health – by April 2001: 500 extra secure beds, over 320 24-hr staffed beds, 170 assertive outreach teams; and access to services 24/7 for those with complex mental health needs
- Extra annual investment in mental health of over £300m by 2003/4
- 1,000 new primary care mental health workers
- 500 more community mental health workers
- By 2004, all young people who experience a first episode of psychosis will receive the early and intensive support they need
- 335 crisis resolution teams established by 2003
- A further 50 assertive outreach teams by 2003
- By 2004, women-only day centres in every health authority
- By 2004, 700 more staff recruited to increase breaks available for carers and to strengthen the carer support networks
- By 2004, up to 400 patients should have moved from high-security hospitals to more appropriate accommodation
- By 2004, 5,000 prisoners at any time should be getting more comprehensive health services in prison
- Mental Health Act will be reformed



- By 2004, 140 additional secure new places and 75 specialist rehabilitation hostel places provided for those with severe personality disorder [400 staff]
- By 2004, an additional £1.4bn annually for investment in health and social services for older people
- New National Care Standards Commission start work in 2002
- From 2001, implementation of NSF for older people
- By 2001, pilot an NHS retirement health check
- By 2002, a single assessment process introduced for health and social care
- During 2002, development of personal care plans for each older person
- An extra £900m by 2003/4 for investment in intermediate care to promote independence and improved quality of care for older people

#### **Building a Safer NHS for Patients (2001)**

- Establish the National Patient Safety Agency
- Reduce to zero the number of patients dying or being paralysed by maladministered spinal injections by the end of 2001
- By 2005, reduce by 25% the number of instances of harm in Obstetrics & Gynaecology that result in litigation
- By 2005, reduce the number of serious errors in use of prescribed drugs by 40%
- Reduce to zero the number of suicides by mental health patients as a result of hanging from non-collapsible bed or shower curtain rails on wards by 2002

#### **Delivering the NHS Plan (2002)**

- Spend 9.4% of GDP on health by 2008
- Waiting times for operations will fall from a maximum of 15 months now to 6 months by 2005 and 3 months by 2008
- By 2008, there “are likely to be” net increases of at least 15,000 more GPs and consultants, 30,000 more therapists and scientists, and 35,000 more nurses, midwives and health visitors
- By 2008, hospital capacity likely to grow by at least 10,000 more general and acute beds
- Use of incentives – the hospital payment system will switch to payment by results using a regional tariff system
- Introduce incentives with explicit patient choice. By 2005, all patients and GPs may book appointments at a time and place convenient to the patient
- Promote diversity in supply

- Development of NHS foundation hospitals
- Independent health care inspectorate/regulator to be established

#### **Public Service Agreements Targets for the Department of Health (2002)<sup>†</sup>**

- Reduce the maximum wait for an outpatient appointment to 3 months and maximum wait for inpatient treatment to 6 months by the end of 2005, and achieve progressive further cuts with the aim of reducing the maximum inpatient and day-case waiting time to 3 months by 2008
- By the end of 2004, reduce to 4 hours the maximum wait in A&E from arrival to admission, transfer or discharge; and reduce the proportion waiting over 1 hour
- From 2004, guarantee access to a primary care professional within 24 hours and to a primary care doctor within 48 hours
- Ensure that by the end of 2005, every hospital appointment will be booked for the convenience of the patient, making it easier for patients and their GPs to choose the hospital and consultant that best suits their needs
- Enhance accountability to patients and the public, and secure national improvements in patient experience as measured by independently validated surveys
- Reduce mortality rates for major killer diseases by 2010: heart disease by at least 40% in people <75; cancer by at least 20% in people <75
- Improve life outcomes of adults and children with mental health problems through year-on-year improvements in access to crisis and CAMHS services, and reduce the mortality rate from suicide and undetermined injury by at least 20% by 2010
- Improve quality of life and independence of older people so that they can live at home wherever possible, by increasing by March 2006 the number of those supported intensively to live at home to 30% of the total being supported by social services at home or in residential care
- Improve life chances for children by:
  - improving level of education, training and employment outcomes for care-leavers aged 19
  - narrowing the gap between the proportions of children in care and their peers who are cautioned and convicted
  - reducing the under-18 conception rate by 50% by 2010
- Increase problem drug users' participation in drug treatment programmes by 55% (by 2004) and by 100% (by 2008). Increase year-on-year proportion of users sustaining or completing treatment programmes
- By 2010, reduce inequalities in health outcomes by 10% as measured by infant mortality and life expectancy at birth
- Value for money in the NHS and personal social services will improve by at least 2% per annum, with annual improvements of 1% in both cost efficiency and service effectiveness

<sup>†</sup> See also HM Treasury's website at [www.hm-treasury.gov.uk](http://www.hm-treasury.gov.uk)

Inarguably, the enthusiasm for defining performance targets greatly exceeded the plausible capacity to produce the necessary and valid data in the NHS. The excess is now acknowledged by the Government, and some remedial steps have been taken. The Priorities and Planning Framework 2003–2006 announced that a culling and re-ordering of performance targets would take place, lessening the reporting burden on Trusts, and allowing for discretion in selecting relevant indicators at the local level. Box 6.2 shows the list of performance indicators for 2003 that will apply to acute and specialist Trusts. This list contains indicators that have face validity in their salience and potential usefulness for improving patient care.

Another significant deficiency of the Quality Agenda concerns the validity (or lack thereof) of performance data. Sometimes performance indicators lack face validity when lined up with other data. Inpatient waiting lists are an example of one performance indicator that commands attention within the NHS. It is closely monitored and reported as an indicator of access and performance. Whilst important, such access measures provide only a fraction of the quality picture. Performance measures must be focused across the different domains of quality, if fair and accurate assessments are to be made. For example, the Department of Health's NHS Performance Indicators show alarming death rates among babies in the most deprived parts of the Midlands, which has maintained good performance on waiting lists, with Birmingham, Sandwell, Walsall and Dudley all in the top ten for inpatient hospital admission. Walsall has the highest infant death rates in the country, at just below nine deaths per 1,000 live births; the proportion of children dying within 1 year has risen by more than 16% (Walker 2002). This points up the inherent complexity in prudently selecting performance indicators that are individually defensible and collectively coherent.

The Department of Health has acknowledged that there remains a significant amount of work to refine the approach to performance measurement and reporting. In the long run, a stable and mutually agreed-upon approach to defining ambitious, yet realistic, quality improvements must be accomplished, accompanied by a stable and comprehensible performance measurement system. The National Performance Framework (NPF) developed early in the Quality Agenda held promise to be such a tool; however, it seems to have been eclipsed recently by the attention and resources focused on the star rating system, which draws on the NPF data. The NPF had a number of developmental weaknesses such as changing data definitions and unstable indicator sets, making it difficult in these early years to produce meaningful longitudinal analysis. However, it did provide an aggregated national dataset that reported on performance in the NHS, and we would argue that, in terms of data presentation, the NPF was well conceptualised and will better serve the long-term needs for defensible, evidence-based evaluation. Development and refinement should be ongoing.

**BOX 6.2****Performance indicators for Acute & Specialist Trusts for 2003****Key targets**

- Number of inpatients waiting longer than the standard
- Number of outpatients waiting longer than the standard
- A&E emergency admission waits (12 hours)
- Total time in A&E
- Cancelled operations
- 2-week cancer waits
- Improving working lives
- Hospital cleanliness
- Financial management

**Clinical focus**

- Clinical negligence
- Deaths within 30 days of a heart bypass operation
- Deaths within 30 days of selected surgical procedures
- Emergency readmission to hospital following discharge
- Emergency readmission to hospital following discharge for children
- Emergency readmission to hospital following treatment for a stroke
- Emergency readmission to hospital following treatment for a fractured hip
- Infection control procedures
- Methicillin-Resistant *Staphylococcus aureus* (MRSA) bacteraemia: improvement score
- Thrombolysis treatment time

**Patient focus**

- 6-month inpatient waits
- Total inpatient waits
- 13-week outpatient waits

- Day case booking
- A&E emergency admission waits (4 hours)
- Cancelled operations not admitted within 28 days
- 9-month heart operation waits
- Waiting times for Rapid-Access Chest Pain Clinic
- Breast cancer treatment
- Delayed transfers of care
- Outpatient/A&E survey – Better information, more choice
- Outpatient/A&E survey – Clean, comfortable, friendly place to be
- Outpatient/A&E survey – Building relationships
- Outpatient/A&E survey – Safe, high quality, co-ordinated care
- Outpatient/A&E survey – Access and waiting
- “Paediatric outpatient did not attend” rates
- Patient complaints procedure
- Better hospital food
- Privacy and dignity

### **Capacity and capability**

- Data quality
- Staff opinion survey
- Junior doctors’ hours
- Consultant appraisal
- Sickness absence rate
- Information governance
- Fire, health and safety

The visible mis-steps in the publication of performance targets and indicators have given ammunition to those who wish to annihilate all performance measurement and reporting. However, this is a mistake. Performance targets and indicators are a vital tool in creating systemic capacity for quality. As the Conservatives point out in their March 2003 document *Setting the NHS Free* (Conservative Party 2003), the Government's insistence that health care professionals' work must be oriented to the fulfilment of its targets has produced rampant target-oriented behaviour. The Conservatives at the same time argue that there is a greater need "to develop a more standardised methodology of determining clinical outcomes".

We cannot overstate the value of getting the overall performance reporting strategy and the performance indicators right. To do so is important because of the specific functions that they serve, such as incentives, and for their generally symbolic value within the NHS culture. NHS performance measurement and reporting is often maligned, mistrusted and relegated to a status of perfunctory and begrudging compliance. Far from being a constructive and powerful lever for change, it appears to be one of demotivation and disregard. The NHS needs to address this issue head-on and alter it. The June 2000 Audit Commission management paper, *On Target: The Practice of Performance Indicators*, recommended a number of actions for "Making Indicators Work" (see Box 6.3).

### **BOX 6.3**

#### **Making performance indicators work**

- Control the number of indicators
- Develop action-focused indicators
- Report only indicators relevant to the user
- Use composite or illustrative indicators
- Refine indicators regularly

SOURCE: Adapted from Audit Commission 2000

Although we are supportive of performance reporting, we also know that it can create unintended consequences. The dangers include tunnel vision, gaming, avoidance of adverse risk selection and other perverse but explainable and predictable behaviours (Leatherman & McCarthy 1999; Marshall et al. 2000). In spite of having made considerable advances, the science is still deficient in many areas, including risk adjustment limitations, problems of statistical power and sample size, establishing comparability of numerators and denominators, and general statistical difficulties with standardisation (Theofilopoulos 2002).

Moving from population-level reporting to a greater focus on specific clinical teams and/or individual providers is a likely direction for performance measurement. This evolution will be driven by the need specifically to investigate problems identified at higher levels of analysis. Such analysis and intervention requires measurement at a level disaggregated from the regional performance reporting.

Pressure for individual physician-level data is growing; however, this is highly controversial. A number of reservations regarding the use and limitations of physician-specific performance data have been reported in the US literature, including a concern that physicians will avoid high-risk patients for fear of causing poor outcome-data reports; thus, seriously ill patients may have decreased access to health care (Omoigui et al. 1996; Schneider & Epstein 1996). Complicated methodological issues also arise at a micro-reporting level, such as case-mix adjustment and determining causal attribution. For example, operative mortality attributed to the surgeon is likely to be influenced by other factors, such as consultant management and referral, anaesthetic care and intensive care resources (Pace 2002).

The potential for perverse effects of performance measurement at an institutional level in the UK could occur in the area of waiting times, arguably the most visible and actionable performance indicator. Rather than indicating suboptimal performance, it may very well be the case that the best hospitals, with expert surgeons possessing the most experience in a particular procedure, could attract more referrals, resulting in a comparatively longer list of patients than in less experienced hospitals.

The lessons are twofold: be circumspect about selected measures, and be careful in interpreting the results, lest the system end up rewarding the wrong thing. A name-and-blame strategy is not fair, useful or accurate in representing the fact that quality problems are often attributable to system deficiencies, not solely to the individuals' performance (Reason 2000).

### **National Service Frameworks**

A first-order task in establishing systemic capacity for predictable improvement in quality of care is the specification of national priorities (Cassel et al. 2003). This is clearly a strength of the UK's Quality Agenda, accomplished in part through a well-researched and articulated set of National Service Frameworks (NSFs). They are exemplary templates for developing guidelines for organising and delivering clinical care, covering a wide range of clinical conditions and sub-populations, as illustrated in Box 6.4.

Within selected priority areas, NSFs specify national standards, define service delivery models, establish resources and strategies to support implementation, and set performance milestones to accomplish progress within an agreed time-scale (Coulter 2001; NICE 2003). Thus, the NSFs have become an explicit and constructive method for defining the process and outcome measures of quality for specific conditions and/or target populations. Available data indicates

improvements in patient outcomes and compliance with cancer and cardiovascular care standards as laid out in NSFs (see Chapter 9). They are powerful tools for articulating policy and standards, influencing the resource allocation, organisational compliance and individual behaviours throughout the four tiers of the model.

#### **BOX 6.4**

##### **The scope of National Service Frameworks, developed 1998–2003**

- Paediatric intensive care (1998)
- Mental health (1999)
- Coronary heart disease (2000)
- The National Cancer Plan (2000)
- Older people (2001)
- Diabetes (2001)
- Children (2003)
- Renal (in development)
- Long-term conditions – neurological focus (in development)

SOURCE: CHI 2003b

### **Regulation**

Establishing a regulatory framework and building organisational capacity has been a major part of the Quality Agenda. This encompasses self-regulation by the professions as well as regulation by, or on behalf of, the Government, and spans the public (NHS) and private sector of health care delivery.

#### ***Professional self-regulation***

One of the most critical elements of building predictable, systemic capacity for improving quality is the will and skill of the professions to self-regulate. The medical profession in the UK first emerged through the Medical Royal Colleges in 1505 (Gray 2002). Self-regulation and a uniform educational approach were strengthened in the 19th century with the establishment of the General Medical Council (GMC) and the introduction of Royal College examinations.

Given this long history in England, it is possible to argue that the professions will never effectively self-regulate, since they have not done so in half a millennium of organised capacity. On the other hand, it is also possible to argue that throughout history, until recent decades,



quality was assumed and standards were implicit. Government and the public awarded autonomy to the professions and willingly placed their trust in the medical profession to act in the public's interest. Now, however, the public's confidence is faltering. It is no longer in the Government's self-interest to allow such a degree of professional autonomy; in fact, it may have become a political liability.

In the final analysis, it is the professions' intent and ability to self-regulate that offers the best promise of embedding quality in everyday medical practice. Will is not enough; quality requires the adoption and implementation of routine practices of standard setting, measurement and evaluation. New methods, such as the recently introduced annual appraisal and 5-year revalidation requirement, are essential guarantors of quality. The reasons for revalidation are at least threefold: to bolster waning trust in the professions; to identify egregious performers; and to ensure that all doctors are "fit for practice". Revalidation is not required until 2005, but the NHS appraisal process required by contracts has undergone "patchy" implementation (Watts 2003, p. 183). Now is a pivotal time to assess whether history has so entrapped the medical professions in tradition that their organisations, the Medical Royal Colleges and the General Medical Council, are unable to metamorphose nimbly into 21st-century institutions and whether they are willing to do so.

### ***Institutional regulation through an inspection model: moving forward with CHAI***

External inspection for quality is now mandatory, which is a significant accomplishment. Though the Audit Commission has done excellent reviews over recent years, quality was not an explicit part of its remit. The new CHI /CHAI inspection processes encompass the quality of clinical service delivery and the patient's experience of care, as well as financial performance. As a result of CHI's endeavours, the public has access to performance data for the first time. Now, careful work is needed to evaluate and validate the integrity of the process, the reliability of the ratings and the salience of the review criteria. The intention to do so is well reflected in the planning documents of the new CHAI transition team (CHAI 2003).

Improvements in the transparency and rigour of the inspection process are essential. This is not an indictment of efforts to date, but simply a statement of a predictable evolutionary process. Star ratings have riveted the attention of the NHS, but they need refinement. The system is open to significant misinterpretation, or even politicisation, as demonstrated in two public releases concerning the 2002 ratings.

- Labour Ministers said the increased number of hospitals achieving three-star ratings shows that standards improved in 2002 (68 of England's 304 Trusts received the top mark), whilst the Opposition highlighted the 36 Acute Trusts that deteriorated in performance (BBC News 2002).

- In July 2002, the second year of published ratings, two out of three hospitals failed to improve, despite cash injections of approximately £5 billion. One year later, 43 hospitals received one star or zero stars, whereas 35 did so the previous year, on targets ranging from “time spent waiting for surgery” to the “level of respect shown by staff”. As expected, this resulted in wide media coverage, with various interpretations and positioning by politicians on both sides. Little to no dispassionate analysis attempted to understand whether this was indeed a demonstration of sliding performance, or, in fact, due to the improved rigour of the newly established and evolving inspection process.

Star ratings have inherent problems. They are simply not multi-dimensional enough to reflect reality; hospitals that might warrant a three-star rating for paediatrics are likely to have lower performance ratings on some other wards. If the objective is not only to get the attention of hospital governance structures, but also to communicate meaningful information for patient choice, the star ratings need to be refined and amplified.

The newly emerging CHAI is responsible for developing the strengths and assets of forerunning organisations. It also has a valuable opportunity to optimise its contributions to the second half of the Quality Agenda by conducting a full review of its intellectual underpinnings and operations.

### **Physician licensing, appraisal and validation**

Professional self-regulation is a collective and individual pursuit, occurring through policy-setting bodies at the national level, and implemented by both institutions and individuals. If pursued energetically and fairly, it may be one of the greatest contributors to the goal of optimising the delivery of health services. Strengthening the methods and tools the professions will use is no longer a choice – it is a mandate. The work needs to occur in the public eye, according to the Department of Health’s consultation paper *Reform of the General Medical Council* (DOH 2002b), which proposed that 40% of the GMC’s Central Council should be lay members, instead of the current 25%.

Annual appraisal is a newly defined professional process for NHS doctors, designed to give them regular feedback on performance, and to identify educational and professional development needs. The drive for formal appraisals came from the introduction of clinical governance, outlined in the 1998 consultation document *A First Class Service – Quality in the New NHS* (DOH 1998). In 1999, the consultation document *Supporting Doctors, Protecting Patients* (DOH 1999) set out a wide range of proposals, to which appraisal was central.

The GMC, the regulatory body for doctors, was severely criticised in the wake of the Bristol Royal Infirmary and Alder Hey Hospital scandals. In response, there are plans to reform the

GMC and make it more open and accountable by implementing revalidation. Revalidation requires that, in order to obtain a licence, all doctors must demonstrate to the GMC that they are up to date and fit to practise. At five-year intervals, every practising doctor will have to submit evidence that their practice meets licensure standards. Doctors will have to collect evidence in numerous categories, including clinical care, teaching, relationships with patients, collegial relationships, “probity” and individual health. These areas are all part of the annual appraisal, so the processes can dovetail. The GMC is now working with the Government to obtain legislation to make participation in revalidation mandatory. Pilots of the revalidation process are underway, which will be followed by a large-scale test of the system (GMC & DOH 2003).

### **Public and patient engagement**

Engaging individual citizens and patients (Tier 4) as part of the Quality Agenda has been addressed in part during the last five years, but much remains as unfinished business. Historically, the NHS has adopted a population perspective, rather than a perspective that concentrates on the individual recipient of NHS services. The reasons for this approach include the founding principle of equity, which implies a community ethos rather than an individual focus. The very real resource constraints, coupled with an explicit value of efficiency, may also have reinforced the population perspective. This means that the task of engaging patients and citizens is one that is breaking new ground.

However, intentions to emphasise responsiveness to the individual are not entirely new. A number of policy initiatives over the past decade have attempted to move the NHS to focus more on the individual. Recent Government papers explicitly acknowledge the “hierarchical and paternalistic culture” of the NHS, and admit that such an orientation is outdated (DOH 2002a). Research demonstrates that the public, engaged as citizens and patients, can improve the appropriateness of care, safety practices and clinical outcomes (Coulter 2001). These findings should be tempered by an acceptance that policy should not be driven simply by populist values, important as they are, but also be rooted in the published evidence-base.

In some cases, Government’s efforts have been innovative and successful. One illustrative success is NHS Direct, established to provide the public with a source of professional clinical advice and access to comprehensive health information 24 hours a day. It is now the largest functioning telephonic health information service in the world. Access is available via Internet or touch-screens in libraries, post offices and health centres. The satisfaction rate among users has been consistently greater than 90% (NAO 2002). Even with this kind of success, nay-sayers exist. “NHS Direct is in danger of becoming a victim of its own success”, according to a 2002 House of Commons Public Accounts Committee report, which reported high public popularity and a good safety record, but cautioned that careful planning for sustainability and growth is warranted (Eaton 2002).

The role of the public, both collectively and individually, is not limited to active participation as a patient. As Angela Coulter describes in Chapter 12, there are four overlapping but discrete functions: care manager, decision maker, evaluator and active citizen. It is the actualisation and facilitation of these functions that must become high priority as the Quality Agenda moves forward.

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## 7. Assessing Capacity Building for the Quality Agenda in England

We have presented a conceptual model to assess capacity building, and have described key aspects of conditioning the environment, building the organisational capacity and creating new approaches and tools that have characterised the quality agenda. Over the past five years, the capacity-building enterprise has grown in complexity, size and resource consumption, making it an easy target for critics. However, policy articulation, infrastructure design and the inarguable importance of new organisations to embody necessary functions are all consistent with the Labour Government's ambitious aim to modernise the NHS and optimise quality of care. In summary, the first five years of the Ten-year Quality Agenda have accomplished a great deal.

Building capacity at the national level is well advanced. However, several areas, aside from those discussed so far, must join the list of priorities if predictable and systemic quality improvement is to be achieved. Those areas include assuring an adequate workforce, developing a 21st-century information infrastructure and informatics expertise, and making the firm commitment to embed the functions necessary for bringing quality improvement into NHS operations and professional organisations.

### **Assuring an adequate workforce**

Firstly, an absolutely essential component to a sustainable and productive Quality Agenda is an adequate workforce. In the UK, quality is hampered by inadequate and suboptimal resource distribution; whereas in the US, uneven distribution may be part of a quality problem, but rarely, if ever, are insufficient resources expended in total. This historical underfunding relative to peer countries has resulted in critical personnel shortages (including nurses, GPs and consultants), hospital resource shortages (such as intensive care beds and stroke units) and eroding infrastructure.

The 2003 Modernisation Board's Annual Report identified the shortage of health care professionals as the biggest challenge facing the NHS (DOH 2003a). This is a very real problem for quality of care, as illustrated in the case of cardiovascular care. The Organisation for Economic Co-operation and Development ranked the UK 10th out of 11 countries assessed for their levels of heart surgery. The report named a shortage of cardiologists, nursing staff and intensive care beds as contributors to the poor performance (OECD 2001a; 2001b). In the last few years there have, however, been improvements in this area, as shown in Box 7.1.

**BOX 7.1****Improving capacity for the care of cardiovascular disease**

<b>Performance indicator</b>	<b>Then</b>	<b>Now</b>
Number of patients waiting over 12 months for heart surgery	1,093 (Mar 2000)	Zero (Dec 2002)
Number of patients waiting over 9 months for heart surgery	2,694 (Mar 2000)	212 (Dec 2002)
Consultant cardiologists	467 (1999)	590 (2002)

SOURCE: DOH 2003b

The Government's record against its own published targets for recruiting is mixed. For nursing, there has been considerable success in recruitment, with retention becoming more important (see section 9.22 in chapter 9). Increasing the numbers of doctors and surgeons has been harder to achieve. Not only is it difficult to add GPs, but supply may diminish further because of the significant number of GPs who are approaching retirement.

Health care worker shortages are a real problem. However, it is critical to diagnose correctly the root cause of the many resource problems associated with deficiencies in quality of care. Detailed analysis is necessary to isolate the nature of quality problems, which many automatically assume to be due to resource shortages. That which masquerades as a problem of insufficient resources may be, in fact, a problem of inadequate knowledge, skill or proficiency, as illustrated in the following example.

Research carried out at King's College Hospital in London indicated that NHS hospitals are failing to treat women with breast cancer quickly enough, and the delays are putting lives at risk. This is not a problem of inadequate resources; rather, it is a problem of inappropriate diagnosis and triage. Women with suspected breast cancer have waited up to 3 months to see specialists, because GPs have wrongly identified some women as non-urgent cases, meaning they have to wait longer than 2 weeks for treatment, even when access during that time may have been possible (BBC News 2002).

### **Information technology and data**

The Government describes the current status of NHS information technology in *Delivering 21st Century IT Support for the NHS* (DOH 2002). It acknowledges a number of strategic



problems that need immediate attention to support the needs of a modern and integrated health care system. These problems include the historical lack of a cohesive and nationally led IT architecture, the slow pace of IT implementation and low levels of investment in IT at the Trust level. These issues are addressed in Chapter 15.

Beyond infrastructure, the NHS data environment is stifled by two issues of frank concern. The first issue is attitudes, and the second is skills. Unfortunately, attitudes towards data collection and use range from antipathy and indifference, to an appropriate regard for data's importance, coupled with resignation to the lack of valid data. In terms of skills, there is a shortage and poor distribution of individuals with sufficient data fluency and analytic skills to support the scope and ambition of the Quality Agenda.

Even in the most critical areas, there are widely acknowledged data flaws. An Audit Commission report, released in March 2003, reported on the accuracy of NHS waiting lists. The report selected 41 hospitals where problems were most likely to occur, and found that 93% of the Trusts were weak in their information systems for reporting and measuring waits. Most problems were due to complex procedures, unclear guidance and poor systems, rather than to deliberate manipulation of the figures. In this particular area, the new system of booked admissions for all patients by 2005 may help overcome these flaws, but the point is that the most basic of statistical reporting is vulnerable because of historical inadequacies compromising essential data practices (Audit Commission 2003). At the programmatic level, even in the most pivotal improvement engines of the Ten-year Quality Agenda (such as the clinical governance initiatives and the Modernisation Agency collaboratives), there is insufficient data allowing for comprehensive evaluation.

### **Organisational capacity and leadership in quality improvement**

A widely noted weakness of the Quality Agenda, as well as of the NHS itself, is its perennial reorganisation. This is not just “around the edges” change; it is often large enough an overhaul to displace functions significantly, affect people by role changes and significantly shift operating budgets. In other words, disruptive and distracting changes are par for the course. It is only with due circumspection and some misgiving that we raise the topic of further organisational change. However, we do not suggest any near-term organisational changes; rather, we aim to address the issue of how to plan for the future.

In conducting a mid-term appraisal and pursuing prudent mid-course corrections for the Quality Agenda, it would be remiss not to consider organisational issues. In fact, the Government should be given credit for having already done so. For example, the newly defined Commission for Healthcare Audit and Inspection (CHAI) will subsume the predecessor Commission for Health Improvement, the former health function of the Audit Commission and the National Care Standards Commission (barely announced before the

merger). This has been greeted by some disparaging comments: change “does not inspire confidence in the depth or maturity of official thinking on this subject” (Robinson 2002, p.987). However, a different perspective applauds the integration of organisations with complementary functions and congruent missions. In fact, the second half of the Quality Agenda may warrant more of this type of exploration. Given the magnitude of direct spending, indirect costs (not fully captured and accounted for) and the complexity of the entire enterprise, careful and dispassionate analysis is necessary to determine whether additional opportunities exist for rationalising organisational capacity for the long term.

Analysis of organisations – individually and collectively – should aim to reduce redundancy and unwarranted costs, improve integration, and create efficiency. Of the many initiatives, supported by significant direct and indirect resources, some must more clearly catalyse the Quality Agenda and contribute to constructive change. A routine part of the ongoing Quality Agenda should be programme evaluation to identify the initiatives and entities that, based on the available evidence of impact, are most likely to improve performance for the second half of the Ten-year Agenda. This will, and should, mean the elimination of some activities and the merger or downscaling of others. It may very well mean a planned “sunset” of some organisations when functions are naturally absorbed within the NHS or into other appropriate settings such as the professional organisations. It is likely to lead to increased or sustained resources for selected entities that have realised demonstrable impact to date.

Most importantly, it is essential to remember the *raison d'être* for the organisations created within the first half of the Quality Agenda. The value is not the organisational unit *per se*: it is its specific functions and capabilities. In some cases, such as CHAI, there will be a clear and ongoing need for an external review and oversight body. In other situations, the functions and capabilities may be more suitable in the NHS or professional groups. Examples of such competencies include setting clinical service standards, dealing with poor performing professionals and change-management in organisations.

In general, government's role is – and should be – changing. Inevitably, with such a large task, both strengths and weaknesses arise; that which some see as a positive accomplishment, others may see as a deficiency. For example, the prevailing role of design and implementation from the central government might objectively be seen as both a strength and a limitation. For the first half of the Quality Agenda, it has been a strength in that the nationally driven health care system has the unique advantage of being directly responsible for the vision, policy and resources to mount this large-scale endeavour. Now entering the second half of the Quality Agenda, during the next five years, government must loosen the reins, allowing for the capacity building and ownership to move to the NHS delivery system, the professions and patients.

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## SECTION III

# The “So What?” Question – Where is the Evidence?

This section addresses the second of the four evaluation questions of this project: What is the evidence of impact to date? Existing data has been gathered to reflect the current state of quality in the NHS and, where possible, to look at trends over time.

*The government is committed to giving the people of this country the best health care system in the world. At its best, the National Health Service is the envy of the world. But often it takes too long for patients to get treated. Quality is variable ... . The NHS has stood the test of time for fifty years. But the government was elected with a mandate to change the NHS for the better.*

*(The New NHS – Modern, Dependable [DOH 1997], pp. 4-5)*



## 8. Evaluating Quality: Definitions and Data Issues

Evaluating the quality of care in the NHS is challenging. Although a plethora of data exists, there is a shortage of easily accessible, validated datasets and analyses that portray quality in a fully credible and defensible manner. An authoritative, coherent and integrated set of analyses based on consensual standards with well-presented charts and graphs is needed to present a common understanding of quality in the NHS. In the absence of such, and for the purposes of compiling data for this project, we have attempted to pull together a very preliminary prototype. We selected the data based on these criteria:

- *Clinically meaningful*: reflective of care that is evidence-based, where wide consensus exists on standards and appropriateness, and provision of effective care makes a difference;
- *Scope*: affects large segments of the population;
- *Representative*: a range of types of care and care settings; and
- *Multidimensional*: portrays care through multiple measures, inclusive of policy, practitioner and patient perspectives.

### **Defining quality**

The ability to measure and report quality in health care systems in meaningful, useful terms is growing rapidly worldwide. This growing capability has been catalysed and driven by four main factors. Firstly, there is a growing demand to hold professions, managers and governments accountable for their performance. Secondly, increasing agreement on clinical standards, protocols and clinical pathways has facilitated the identification of key and consensual process and outcome measures. Thirdly, there have been advances in research to validate data and develop analytic methods. Finally, there is greater utilisation of quasi-market mechanisms that explicitly call for publicly available information to be used by the public, purchasers, regulators and other stakeholders.

The technical quality-of-care field has an emerging shared perspective on which key domains of quality are important to measure, as well as an increasingly common view of essential data elements, definitions of measures and reporting conventions. Similar frameworks for assessing and reporting quality of care are being used in nations such as Australia, Canada, England and the US, as well as in international organisations such as the Organisation for Economic

Co-operation and Development (OECD 2001; McLoughlin & Leatherman 2003). These frameworks, although containing slight differences in terminology, generally include measurement in at least five domains: access; effectiveness and appropriateness; responsiveness; safety; and equity. Confusion abounds as to the definitional differences between “performance” and “quality”. These are largely semantic and can be argued many ways. For the purposes of this study, we are using a conceptual framework of health care quality that does not explicitly include efficiency and other economic indicators. A broader definition of performance would typically include both quality and economic/financial measures.

Quality is kaleidoscopic. The picture one sees varies across stakeholder audiences, who define and prioritise differing attributes of quality. For example, the physician will almost certainly rate technical proficiency and effectiveness at the top, whilst the patient is likely to judge the health care encounter through its outcome and other factors such as the art of communication and degree of empathy demonstrated by the provider (Leatherman & McCarthy 2002). Defining quality broadly and measuring multiple dimensions are particularly important, given the legitimate variability in perceptions of quality.

For this study, we adopted six domains of quality to organise data scanning and collection. We used available data drawn from a wide range of data sources. These included the Department of Health (DOH) data, discrete health datasets such as the Myocardial Infarction National Audit Project at the Royal College of Physicians, Hospital Episodes Statistics (HES), surveys of public attitudes, published clinical literature, data from the Office of National Statistics, patient survey data commissioned by the DOH and international benchmarks.

Though often not included in frameworks for quality (for example, it is rarely used in the US), we have added another dimension for portraying quality in the UK – system capacity. This addition is important because of a number of factors in the UK that make capacity a central concern: historical underfunding, the widely acknowledged issue of resource constraints, queuing, and shortages of nurses and medically-trained staff, all occurring within an environment where private insurance to access care outside the NHS is still relatively uncommon.

Our data collection and presentation employs the three widely recognised types of quality measures: process measures, outcomes measures and structural measures (Kerr et al. 2000).

*Process measures* reflect appropriateness of patient health care services, the interaction between patients and providers and the performance of the health care system. This includes preventive health (e.g. timely and complete immunisations), acute care (e.g. receipt of appropriate drugs) and chronic care (e.g. integrated primary and secondary care). Process measures may also focus on the overutilisation and underutilisation of health care services, and variation in care that is unjustified by the medical needs of patients. In England, the National



Service Frameworks provide useful templates for defining standards of care that could serve as process measures.

*Outcomes measures* include changes in current and future health status (such as mortality), functional status (such as rehabilitation post-stroke), health-related quality of life and satisfaction with care.

*Structural measures* include characteristics of organisations (e.g. staffing levels or the existence of a stroke unit), clinicians (e.g., qualifications and years of experience) and health care systems (e.g., numbers of nurses in the NHS).

It is important to note that suboptimal performance on quality measures does not necessarily mean deficient performance on the part of the health care provider or the health care system. Predisposing factors such as patient co-morbidities and other demographic variables can explain differences in comparative performance among providers and institutions, requiring the application of rigorous methods such as case mix and risk adjustment for fair comparisons against “gold standards” and peer comparisons.

Another mitigating factor of performance is patient compliance. For example, England’s declining rate of measles, mumps and rubella (MMR) immunisation is largely due to parental failure to comply with medically recommended practices.

The selection of indicators and measures displayed here was constrained by available robust and relevant datasets across the key quality domains. The data was gathered opportunistically rather than according to a predefined deliberate schema. The displayed data, therefore, does not represent an ideal set of indicators on which to judge quality in the NHS. Instead, it provides an exemplar of how data, gathered from different sources, can measure and communicate changes in quality across a range of perspectives and over time.

A final caveat before we present the data: within the scope of this research project, no attempt is made (nor would such an attempt be appropriate) to establish direct causal links between aspects of the Quality Agenda and performance on specific parameters. We note associations between formally established programmes and explicitly announced performance priorities.

### ***Access***

Of foremost importance in the Quality Agenda through the eyes of patients, and hence of policymakers and politicians, is predictable and appropriate access to NHS services. Access describes the ability to obtain effective health care services in a timely fashion, when medically needed. Access problems are many and diverse. Factors that hinder appropriate access are capacity restraints, geographic limitations, inequitable treatment, patient behaviour and inability to pay. (Inability to pay is problematic in many countries, but less so in the UK.)

The Government has targeted certain priority areas of problematic access such as cardiovascular care. Prompted by mounting pressures to deliver on reduced waiting lists, and by data that links poorer outcomes with access problems, the Government announced in July 2002 that access for prospective heart surgery patients waiting for more than 6 months would be increased by providing alternative hospital choices. Over the subsequent 6 months in London, two-thirds chose treatment at an alternative hospital (DOH 2003a).

In February 2003, the Secretary of State laid out plans for securing major improvements in additional clinical conditions. For example, starting in mid-2003, more than 50,000 patients in London waiting over 6 months would be able to opt for treatment in an alternative hospital for orthopaedic surgery; ear, nose and throat surgery; urology; gynaecology; plastic surgery; oral surgery; and general surgery. At the same time, it was announced that over the next two years, different plans would be phased in, recognising unique regional needs such as West Yorkshire prioritising eye surgery patients for improved access, while the South of England would prioritise dermatology, urology and MRI scans. By December 2005, Government plans to offer all patients multiple (4–5) choices, including the NHS and private sector, when a GP refers them to a hospital (DOH 2003a). These are, yet, only pronouncements and should form the basis for future performance monitoring.

Improving access is critically important. New menus, improved ward amenities, even infusions of cash and staff are not going to allay misgivings about the state of the NHS unless the public experiences actual improvements in access. This may be where some of the hardest policy choices have to be made, one of which requires facing the reality that “patient-centredness is not a cheap option, in terms of either staffing time or resources” (Dunn 2002, p. 651). For example, in June 2002, *The Independent* reported that each call to the popular and easy-to-access NHS Direct (the 24-hour helpline) costs approximately £18, about 25% more than an office visit to a GP costs at £14 (Russell 2002). This, however, may reflect initial start-up costs that will be defrayed over time.

Numerous access targets have been published, and initiatives implemented to meet the goals. Unless the access targets are met, the Quality Agenda runs the risk of being labelled a failure, even if notable successes are achieved in measures such as cancer survival and improvement of cardiac surgery outcomes.

### ***Effectiveness***

Effectiveness means “providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit” (IOM 2001a, p. 223). Another way of defining effectiveness is as the congruence of care provided to patients with the available scientific evidence base, or, in the absence of such, consistency with consensual professional guidelines. Effectiveness can be measured in preventive services such as influenza immunisation for vulnerable adults (Dataset 9.10) and breast cancer screening for women

(Dataset 9.16). Examples of effectiveness include appropriate prescribing of drugs such as beta-blockers and statins, after myocardial infarction (see Section 9.12 in chapter 9).

### **Equity**

Equity, a founding value of the NHS, remains an explicit priority 50 years later. It can be described operationally as “availability of care and quality of services...based on individuals’ particular needs and not on personal characteristics unrelated to the patient’s conditions... [T]he quality of care should not differ because of such characteristics as gender, race, age, ethnicity, income, education, disability, sexual orientation or location of residence” (IOM 2001b, p. 56). For example, in the US, several research studies have demonstrated that African-Americans are worse off than are white Americans in access and process indicators that determine health outcomes (Collins et al. 1999; Fiscella et al. 2000; Gan et al. 2000). In the UK, a recent study suggests that South Asians with heart disease are less likely to get the same standard of treatment as white patients (BBC News 2002).

Equity cuts across the other domains of quality. For example, inequities based on socio-economic differences may affect access: in deprived areas such as Sunderland, there are 45 GPs per 100,000 persons, whereas in the more affluent North Yorkshire there are 69 GPs per 100,000 persons (DOH 2003b). Race may play a role in patient perceptions of respect and sensitivity of care (see Dataset 9.46). Discrimination based on age may influence effectiveness, for example, in a small study, Dudley et al. (2002) found that there is a significant level of suboptimal treatment of myocardial infarction amongst the elderly population.

### **Responsiveness and patient-centredness**

*The NHS Plan* (DOH 2000a) asserted that health care should be more responsive to the convenience and concerns of patients. *Crossing the Quality Chasm*, the groundbreaking study of quality by the US Institute of Medicine, states, “both technical care and interpersonal interactions should be shaped to meet the needs and preferences of individual patients” (IOM 2001b, p. 53). This entails a wide scope of variables. One important aspect is the care process, which includes, but is not limited to, communication, education, demonstrations of compassion and empathy and the opportunity for shared decision-making. Patient-centredness also encompasses convenience, such as providing evening hours for primary care visits, and facilitating family visiting in hospitals. It incorporates structural attributes, such as cleanliness and attractiveness of facilities and amenities, including a variety of inpatient food options. Patient surveys, which the DOH routinely conducts, are important for collecting the patient’s perspective.

Improving responsiveness to patients has been a goal of UK health policy for several decades. System pressures, including resource constraints, are common explanations for the rather modest progress toward this objective. The Labour Government has now placed high priority on attaining a more patient-centred NHS.

## **Safety**

A fundamental attribute of quality is safe care, avoiding medical error and reducing unnecessary risk to patients. Current systems to reduce and prevent health care errors have tended to focus too much on individual practitioners and not enough on system problems (President's Advisory Commission 1998). *An Organisation with a Memory* (2000b) provides statistics on the scope and magnitude of safety issues, reporting an estimated 850,000 adverse events, or 10% of admissions, occur in a year, costing hospitals approximately £2 billion. US data shows that deaths associated with medical mistakes in hospitals rank among the top ten leading causes of death in the country (IOM 2000; Kramarow et al. 1999).

*An Organisation with a Memory* (DOH 2000b) identifies the Government's four goals in increasing patient safety. They are:

- to reduce to zero the number of patients dying or paralysed from maladministered spinal injections by 2001;
- to reduce by 25% the instances of harm in obstetrics and gynaecology by the end of 2005;
- to reduce by 40% the number of serious errors in the use of prescribed drugs by the end of 2005; and
- to reduce to zero the number of suicides of mental health patients as a result of hanging from non-collapsible beds or shower curtain stalls by March 2002.

## **System capacity: workforce and structure**

Including capacity measures as a key domain in quality recognises its particular importance in England. Capacity measures can include workforce numbers and expertise, as well as structural variables such as technologies and facilities.

Stroke care is a case study in why capacity matters. Every year, some 130,000 people in the UK have a stroke. Hospitals in the UK are struggling to meet the spiralling demand of caring for stroke patients, with only a third of patients ever entering a dedicated unit. The third National Sentinel Audit of Stroke for 2001–2 found that only 36% of patients receive care in a stroke unit, despite the fact that almost three-quarters (73%) of hospitals in England, Wales and Northern Ireland have a stroke unit. This is despite significant improvement in capacity: in 1998, only 45% of hospitals had a stroke unit, and in 1999 56% had one. However, as reported in the *British Medical Journal*, the audit warns that the “number of allocated beds remains inadequate and cannot meet the demand” (Gulland 2002, p. 179).

UK capacity issues received stark notice in the 2002 Wanless Report, as Box 8.1 illustrates. These capacity issues relate directly to UK health spending. Using 2001 OECD data, the Wanless Report shows that UK health expenditures were 6.8% of gross domestic product, compared to the European Union (EU) average of 7.9% and an income-weighted EU average of 8.4%. As noted previously in this report, the Labour Government has committed to a multi-year infusion of significant new levels of health spending, as well as to an aggressive recruitment and retention strategy to increase the workforce.

### **BOX 8.1**

#### **Workforce, technology and structural capacity issues in the UK**

- Fewer doctors and nurses employed per head than in most European countries, at 1.7 doctors and 4.5 nurses per 1,000 population. These figures were from 1997, when the Labour Government began its reforms of the NHS, including the Quality Agenda.
- Lags behind other countries in adopting and diffusing new technologies, in part explained by “cash-limited budgets and greater central control over technology-adoption decisions”.
- Less technology per capita. Number of CT (Computerised Tomography) and MRI (Magnetic Resonance Imaging) scanners below the EU average of 15 per million of the population.
- Uptake of new drugs is at most half of that in Germany, and a third of that in France.

SOURCE: Wanless 2002

### **Data issues and caveats**

This section of the report presents quantitative data. We present the data in both tables and charts, in part to illustrate the important issues in the content and format of dissemination and communication. To identify clearly the limitations of our research, we must explicitly admit to encountering numerous data and analytic problems. Enumeration of data issues not only provides appropriate caveats for data interpretation in this report, but also serves to describe the “state of the art” of quality-related data in England. Below is an abbreviated list of four key data issues.

- *Uncertainty regarding validity and reliability of data sources.* There is little agreement on the types of extant data that are valid, and for what purposes they are reliable. For example, Hospital Episode Statistics (HES), a large and important dataset, draws a range of

opinions about its accuracy and completeness. Data collected, analysed and reported on the DOH website will likewise incite a range of opinions as to its validity and reliability.

There are adverse and very serious consequences of this contestability of data.

Practically speaking, it allows for endless debate as to whether any analysis depicting quality performance is accurate. The controversy sometimes reflects a sincere concern for validity; at other times, it is a means of side-tracking the real issue of performance deficiencies.

- *Standardised definitions for quality measures.* Use of data for selected performance indicators is compromised because the definition of the measure changes over time. For instance, changes are made in the definition of the numerator and denominator populations for constructing a statistical measure.

Performance indicators also change over time. For example, one indicator for effective cardiovascular care was administration of thrombolytic therapy within 30 minutes of arrival at the hospital. In 2003, the time interval was changed to 20 minutes. Further difficulties are encountered because some data series are for England only, others for England and Wales, and still others for the entire UK. These various datasets and the targets set against them are often poorly integrated and disparate.

- *Use of longitudinal trending and time series.* The Quality Agenda faces serious consequences because of unstable definitions in data and quantification of measures. A fundamental analytic tool for quality measurement and improvement is the identification of baseline performance and longitudinal trending across time to track progress or lack of progress. The rigour and credibility of time analyses or series analyses in England are undermined by the unstable data and quality measures.
- *“Compromises” in data entry and reporting.* There are both intentional and unintentional distortions in data entry and collection. Honest errors or gaps in data entry and reporting occur for a number of reasons. One problem is that the front-line staff, upon whom data reporting depends, lack an understanding or credence that the task is important enough to “get right”, which is compounded by their lack of training on the proper processes for accuracy.

The second type of “compromise”, sometimes called “gaming”, is intentional. It is an inherent vulnerability in any endeavour related to data submission, where positive or negative consequences are perceived. By widespread anecdote, and through some data validation performed in the DOH, we know that inaccuracies or distortions are present, particularly in areas such as waiting times (both inpatient and outpatient).

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## 9. What Picture of Quality is Emerging?

In order to provide as rounded a picture of quality as possible, the data presented draws on different aspects of quality, and different methodologies or types of data collection. Data is presented within five dimensions of quality<sup>†</sup>: access; effectiveness; system capacity; public perceptions and patient experience; and disparities and equity.

Within each dimension, data of three different types is generally presented:

1. *Snapshot* – a look at a particular quality measure at one point in time;
2. *Trend data* – data measured at two or more time points, presented longitudinally to indicate the presence or absence of progress; and
3. *International benchmarks* making comparisons between countries. We present benchmark data that is both snapshot and longitudinal in form.

For each measure or chart, relevant contextual information is provided. Generally, this includes:

- specification of the quality measure or indicator;
- identification of the data source(s);
- inclusion of a publicly stated goal or performance target to provide perspective on progress, if feasible; and
- background information to help clarify the importance of the indicator, and caveats that should be considered in interpreting the data.

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<sup>†</sup> Safety is an important dimension of quality. A section of data on safety has not been included, as it is a relatively new focus and insufficient validated data was available to the authors.

## **ACCESS**

Measures were selected in order to capture:

- access to health care in hospitals;
- access to health care in outpatient clinics;
- access to primary health care professionals; and
- access to health care advice.

Data displays:

- 9.1 Access problems due to cost
- 9.2 Inpatient waits over 12 months
- 9.3 Rescheduling of operations after cancellation (for non-clinical reasons)
- 9.4 Bed blocking
- 9.5 Waiting in Accident & Emergency
- 9.6 Waiting time from GP referral to specialist or hospital
- 9.7 Waiting time for GP appointment – two perspectives
- 9.8 Use of NHS Direct

### 9.1 Access problems due to cost

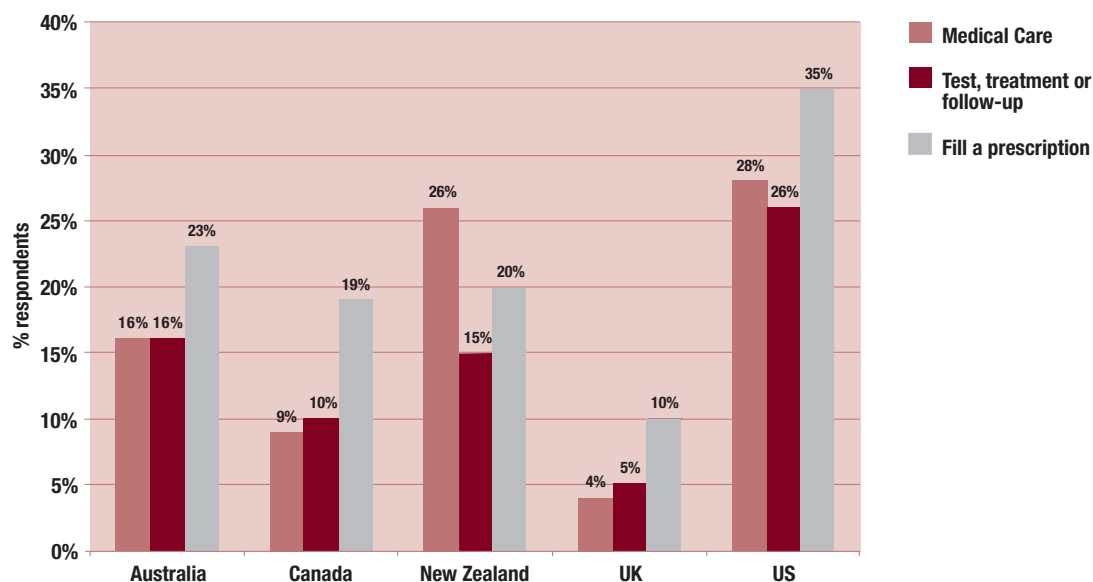
*Data source:* Commonwealth Fund International Health Policy Survey 2002 (www.cmfwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of four criteria:

- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

**Figure 9.1a** Percentage of adults with health problems in past 2 years not getting needed care because of cost



SOURCE: Commonwealth Fund

## 9.2 Inpatient waits

*Data source:* Commissioner-based data from the Department of Health (www.doh.gov.uk/waitingtimes)

*Target:* By end of 2005, maximum wait for inpatient treatment will be cut from 18 to 6 months (*The NHS Plan* 12.20).

*Background:* This chart contains commissioner-based data. Commissioner-based data excludes all patients living outside England and all privately funded patients waiting for treatment in NHS hospitals. However, it does include NHS funded patients living in England, who are waiting for treatment in Scotland, Wales and Northern Ireland, abroad and at private hospitals. These patients are not included in the corresponding provider-based data. Historically there has been a 1% to 3% difference in the overall size of the waiting lists reported for NHS hospital trusts and English residents, the trust-based figure being the larger.

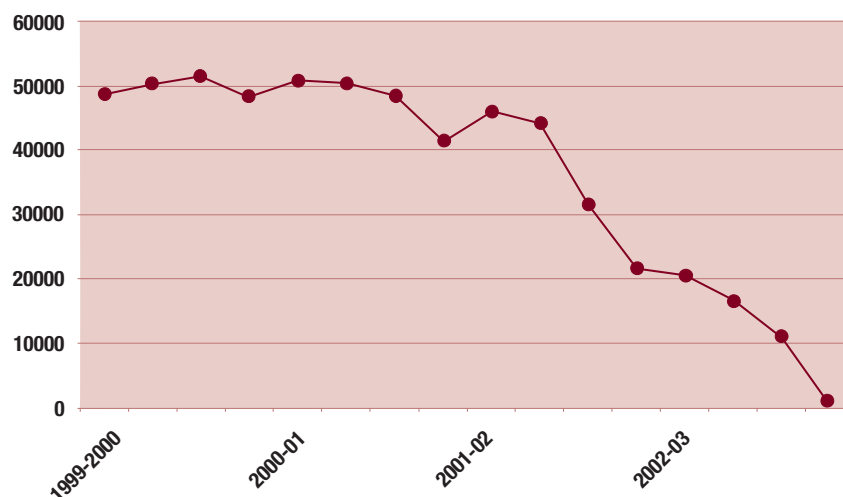
**Table 9.2a Number of patients waiting 12 months or more for admission to hospital (with % of total number of patients waiting in each quarter)**

	1999–2000	2000–01	2001–02	2002–03
<b>Q1</b>	48687 (4.5%)	50703 (4.9%)	46038 (4.5%)	20483 (2.0%)
<b>Q2</b>	50165 (4.7%)	50269 (4.9%)	44132 (4.3%)	16689 (1.6%)
<b>Q3</b>	51343 (4.7%)	48433 (4.7%)	31356 (3.0%)	10902 (1.0%)
<b>Q4</b>	48145 (4.7%)	41389 (4.1%)	21604 (2.1%)	73 (0.0%)

SOURCE: DOH, based on Commissioner Data

The same data, graphically presented:

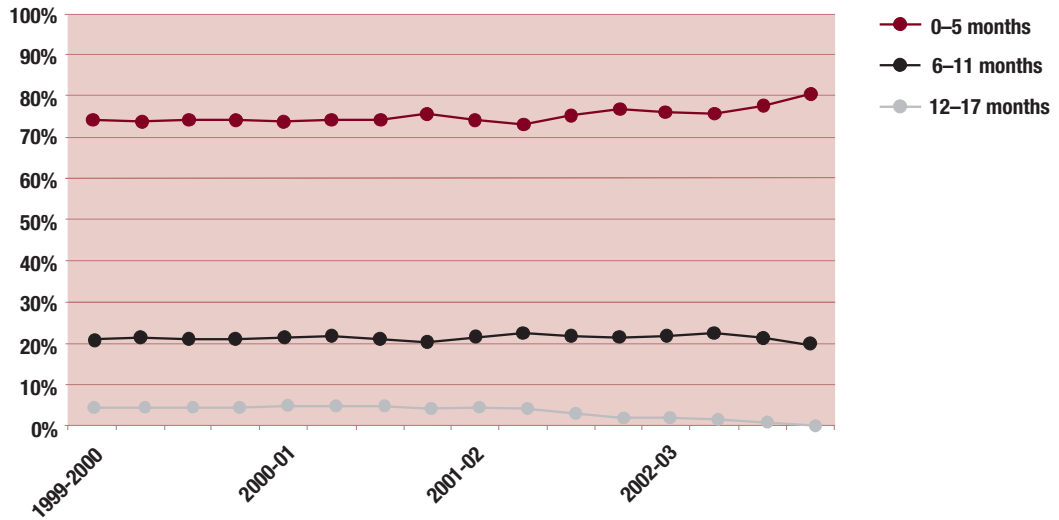
**Figure 9.2b** Graph of number of patients waiting 12 months or more for admission to hospital



SOURCE: DOH

A broader perspective is given when we chart the length of waits experienced by all patients per quarter. As can be seen from the graph, recent figures indicate that over 80% of patients are waiting less than 6 months for hospital (inpatient) care:

**Figure 9.2c** Inpatient waiting times – commissioner-based data



SOURCE: DOH

### 9.3 Rescheduling of operations after cancellation (for non-clinical reasons)

*Data source:* Department of Health  
([www.doh.gov.uk/hospitalactivity/data\\_requests/cancelled\\_operations.htm](http://www.doh.gov.uk/hospitalactivity/data_requests/cancelled_operations.htm))

*Target:* From 2002, when a patient's operation is cancelled, the hospital must offer another binding appointment within 28 days (*The NHS Plan* 10.20).

*Note:* In order to contextualise the scale, the numbers of last-minute cancellations are presented alongside data on the number of patients not admitted within 1 month/28 days of the cancellation.

<b>Table 9.3a Last-minute cancellations – non-clinical reasons</b>					
	<b>1998–99</b>	<b>1999–2000</b>	<b>2000–01</b>	<b>2001–02</b>	<b>2002–03</b>
<b>Q1</b>	12,384	12,313	17,033	20,833	14,808
<b>Q2</b>	11,470	12,017	16,965	20,901	14,826
<b>Q3</b>	14,611	15,769	18,844	20,036	17,706
<b>Q4</b>	17,685	20,143	24,976	19,973	19,914

SOURCE: DOH

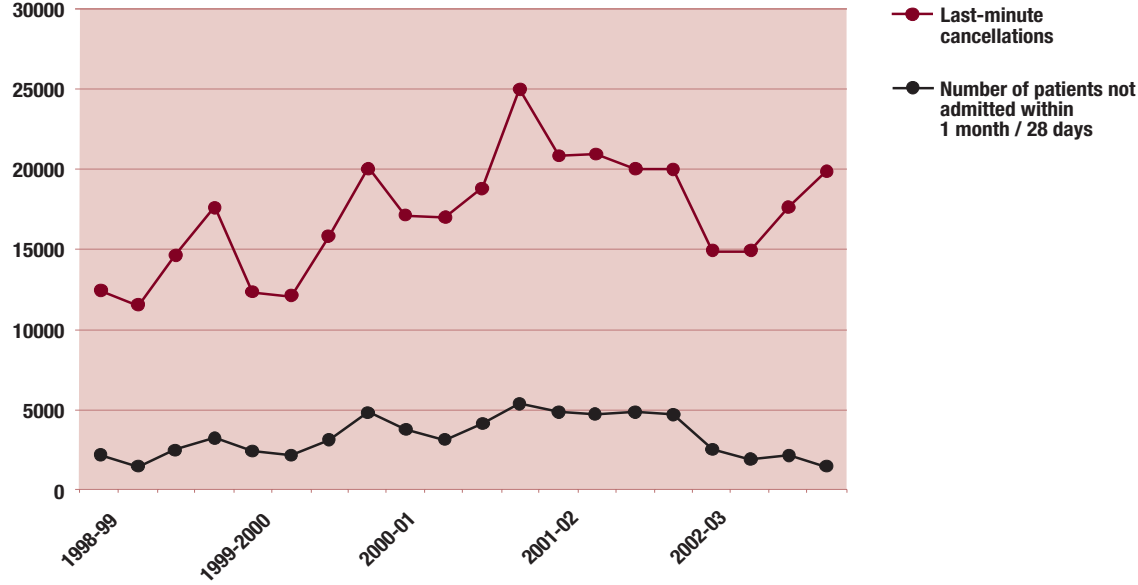
<b>Table 9.3b Number of patients not admitted within 1 month/28 days*</b>					
	<b>1998–99</b>	<b>1999–2000</b>	<b>2000–01</b>	<b>2001–02</b>	<b>2002–03</b>
<b>Q1</b>	2,174	2,384	3,733	4,881	2,443
<b>Q2</b>	1,495	2,186	3,116	4,684	1,926
<b>Q3</b>	2,472	3,042	4,168	4,810	2,119
<b>Q4</b>	3,239	4,809	5,437	4,712	1,484

\* For 1998–99 to 2001–02, data refers to the “Number of patients not admitted within one month of a last-minute cancellation”. This definition changed in 2002–03 to “Number of patients not admitted within 28 days of a cancellation on the day of surgery”. Therefore these two sets do not constitute a true time series.

SOURCE: DOH

The data contained in these tables, presented graphically:

**Figure 9.3c** Rescheduling of operations after last-minute cancellations



SOURCE: DOH

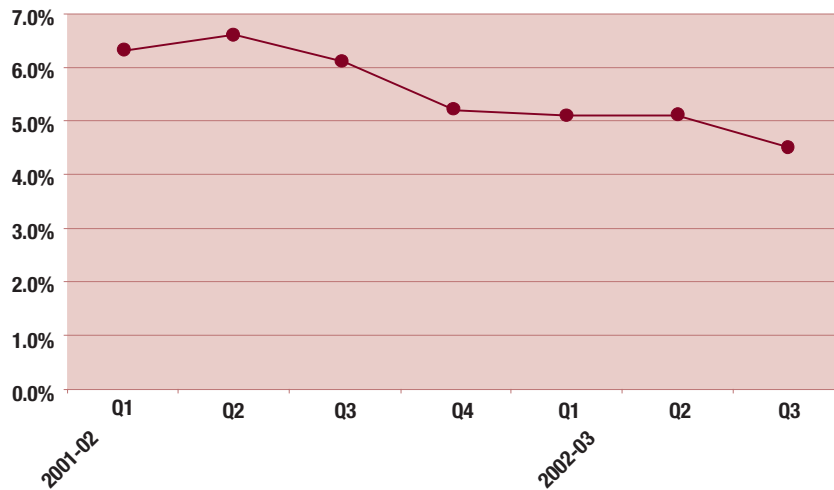
### 9.4 Bed blocking

*Data source:* Chief Executive's Report to the NHS 2002–03: statistical supplement [SaFFR] ([www.doh.gov.uk/nhsreport](http://www.doh.gov.uk/nhsreport))

*Target:* By 2004, widespread bed blocking will be eliminated (*The NHS Plan* 12.9)

*Background:* In order to improve access to inpatient care, it is necessary to minimise delays in hospital discharge that are caused by patients awaiting assessment, support at home or suitable intermediate or other NHS care. New standards were introduced for discharge plans, which included an assessment of care needs, and were to be developed from the beginning of each hospital admission.

**Figure 9.4** Percentage of patients occupying an acute bed with delayed discharge



Note restricted scale 0–7%.

SOURCE: DOH

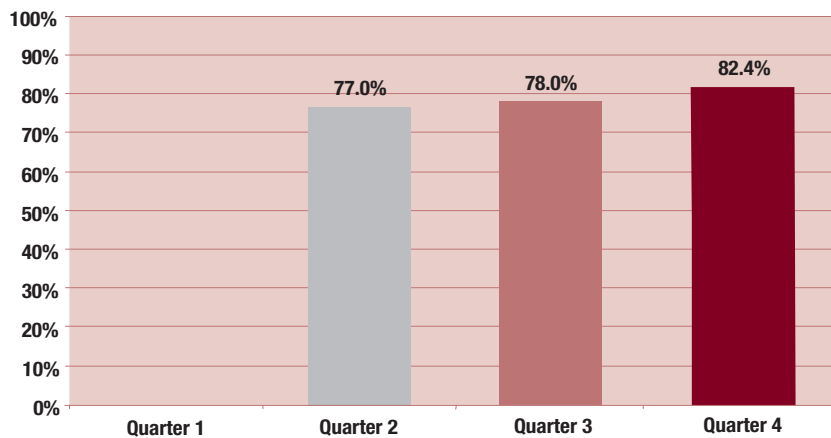


### 9.5 Waiting in Accident & Emergency

*Data source:* Department of Health ([www.doh.gov.uk/hospitalactivity](http://www.doh.gov.uk/hospitalactivity)) – no data collected before Q2 2002–03

*Target:* By 2004, no one should be waiting more than 4 hours in Accident and Emergency from arrival to admission, transfer or discharge. Average waiting times in Accident and Emergency will fall as a result to 75 minutes. By then, inappropriate trolley waits for assessment and admission will cease (*The NHS Plan* 12.10).<sup>†</sup>

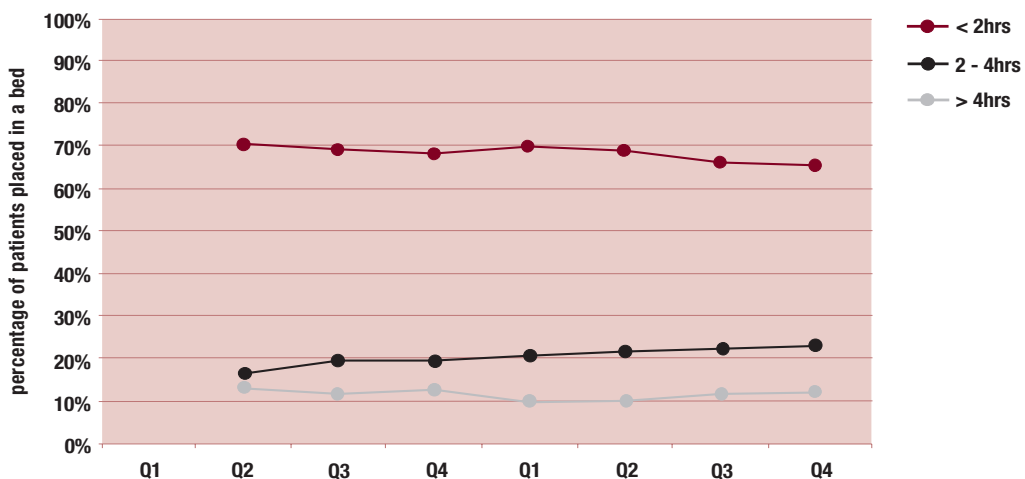
**Figure 9.5a** Percentage of patients spending less than 4 hours in A & E 2002–03



SOURCE: DOH No data collected prior to Quarter 2 2002–03.

A broader perspective is provided by charting the length of time patients wait in Accident and Emergency for admission. The majority of patients (around 65–70%) wait less than 2 hours, although this figure is trending negatively over time rather than showing improvement. The number of patients waiting less than 1 hour (as mentioned in the 2003 PPF target) are not currently provided on the Department of Health website.

**Figure 9.5b** Admission from A & E: time taken to place patients in a bed (2001/2 - 2002/3)



SOURCE: DOH

<sup>†</sup> This target was changed in *Priorities and Planning Framework 2003–2006* to “Reduce to 4 hours the maximum wait in A&E from arrival to admission, transfer or discharge, by the end of 2004; and reduce the proportion waiting over 1 hour.”

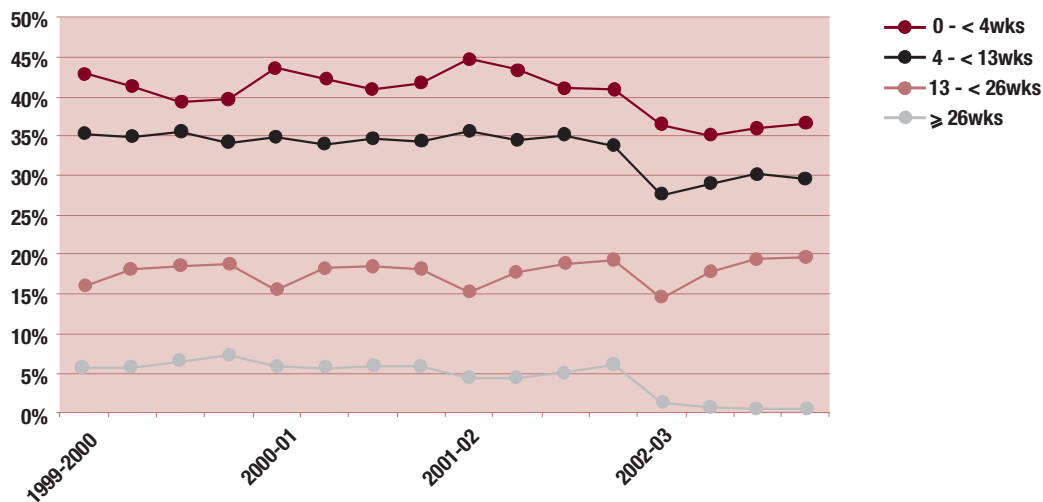
## 9.6 Waiting time from GP referral to specialist or hospital

*Data source:* Department of Health (provider data)([www.doh.gov.uk/waitingtimes](http://www.doh.gov.uk/waitingtimes))

*Target:* By the end of 2005, waiting lists for hospital appointments and admission will be abolished and replaced with booking systems, giving all patients a choice of convenient time within a maximum guaranteed waiting time. The maximum waiting time for a routine outpatient appointment will be halved from 6 months to 3 months. As a result of delivering this policy, we would expect the average time for an outpatient appointment to fall to 5 weeks (*The NHS Plan* 12.20).

*Background:* This dataset contains provider-based data, as collected by NHS Trusts. It differs from commissioner-based data in that it excludes NHS-funded patients, living in England, who are waiting for treatment in Scotland, Wales and Northern Ireland, abroad, and at private hospitals. Historically, there has been a 1–3% difference in the overall size of the waiting lists reported for NHS hospital Trusts and English residents, the Trust-based figure being the larger.

**Figure 9.6** Waiting times from GP referral to first outpatient attendance, as a percentage of total referrals (provider data)



SOURCE: DOH

Note: 2002/03 figures as given on DOH website do not total 100% of written GP referrals.

### 9.7 Waiting time for GP appointment – two perspectives

*Data source:* National Survey of NHS Patients: General Practice 1998; 2002; Primary Care Trusts, 2003 ([www.nhssurveys.org](http://www.nhssurveys.org)); Department of Health's Primary Care Access Survey (as quoted in Chief Executive's Report to the NHS 2002–03, [www.doh.gov.uk/nhsreport](http://www.doh.gov.uk/nhsreport))

*Target:* By 2004, patients will be able to see a primary care professional within 24 hours, and a GP within 48 hours (*The NHS Plan*, 12.6).

*Background:* Two perspectives on waiting time are displayed. The first is the patient perspective, drawn from patient-survey questions about how long respondents had to wait for their most recent appointment and the acceptability of that wait. The second perspective is provided by the Primary Care Access Survey, which is an administrative dataset, based on offers of an appointment with a GP.

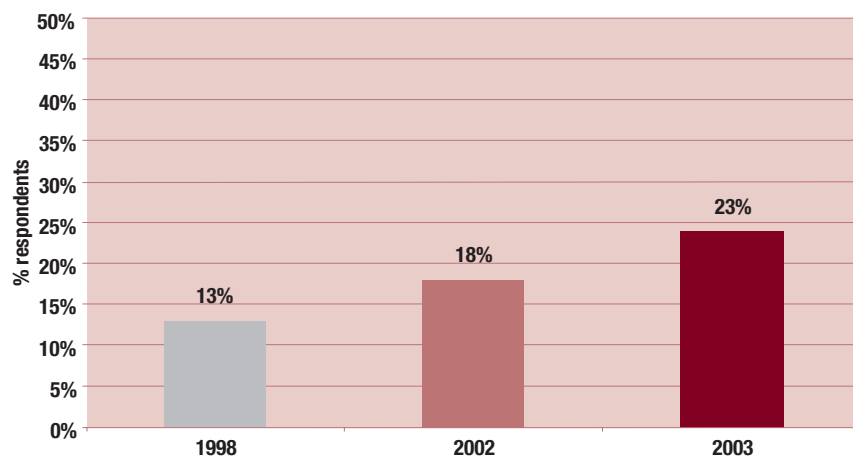
The general practice surveys were conducted for the Department of Health as part of the NHS Patient Survey Programme. Questionnaires were sent to individuals in England identified from the electoral register. In 1998, 100,000 questionnaires were sent, with over 61,000 returned; in 2002, 263,100 questionnaires were sent, with over 145,000 returned. In 2003, CHI conducted the PCT patient survey, and sent questionnaires to 250,000 individuals identified from PCT patient lists, with 123,833 returned. The PCT survey (2003) differed from the GP surveys (1998, 2002) in terms of questions about the length of wait for a GP appointment and response options.

**Table 9.7a Waiting for an appointment in primary care - patients' perspective**

Did you get an appointment on the day you wanted?	GP survey 1998	GP survey 2002	Did you have to wait for an appointment?	PCT survey 2003
yes	56%	52%	same working day	17%
waited 1 day longer	10%	8%	next working day	8%
waited 2 days longer	7%	7%	waited 2 working days	7%
waited 3 days longer	5%	5%	waited 2 days to a week	13%
waited 4–7 days longer	6%	9%	waited a week or longer	10%
waited 8 or more days longer	2%	4%	seen without an appointment	9%
did not mind which day it was	13%	13%	pre-booked appointment	36%
can't remember	2%	2%		
unweighted bases	43,082	106,277	unweighted base	102,152

SOURCE: nhssurveys

The differences in the questions, response options and sampling frames mean that these datasets do not constitute a true time series. However, in an attempt to develop an approximation of one, we have charted the percentage of patients reporting that they waited more than 2 extra days than they wanted for an appointment.

**Figure 9.7b** The patient's perspective: waiting more than 2 days for a GP appointment

SOURCE: nhssurveys

Respondents also reported their views on the length of time they had to wait for an appointment:

**Table 9.7c Patients' views on the length of time they had to wait for an appointment (1998 and 2002)**

Response	GP survey 1998	GP survey 2002
I was seen as soon as I thought was necessary	81%	77%
I should have been seen a bit sooner	15%	18%
I should have been seen a lot sooner	4%	6%
unweighted base	42,835	105,396

SOURCE: nhssurveys

The question and response option changed in the PCT 2003 survey:

**Table 9.7d Patients' views on the length of time they had to wait for an appointment (2003)**

Qn: Was that longer than you wanted to wait?	PCT survey 2003
yes	46%
no	42%
did not mind	12%
unweighted base	41,554

SOURCE: nhssurveys

In contrast to the most recent patient survey, which reports that 24% of patients indicated that they waited more than 2 days for an appointment, the Department of Health's Primary Care Access Survey (as quoted in Chief Executive's Report to the NHS 2002–03) reported that 90.5% of patients are offered an appointment within 2 working days.

**Table 9.7e Primary Care Access Survey on the length of time patients had to wait for an appointment (2002 and 2003)**

<b>% of patients offered an appointment with a:</b>	<b>March 2002</b>	<b>March 2003</b>
GP within 2 working days	74.6%	88.2%
primary care professional within 1 working day	71.7%	90.5%

SOURCE: PC Access Survey

### 9.8 Use of NHS Direct

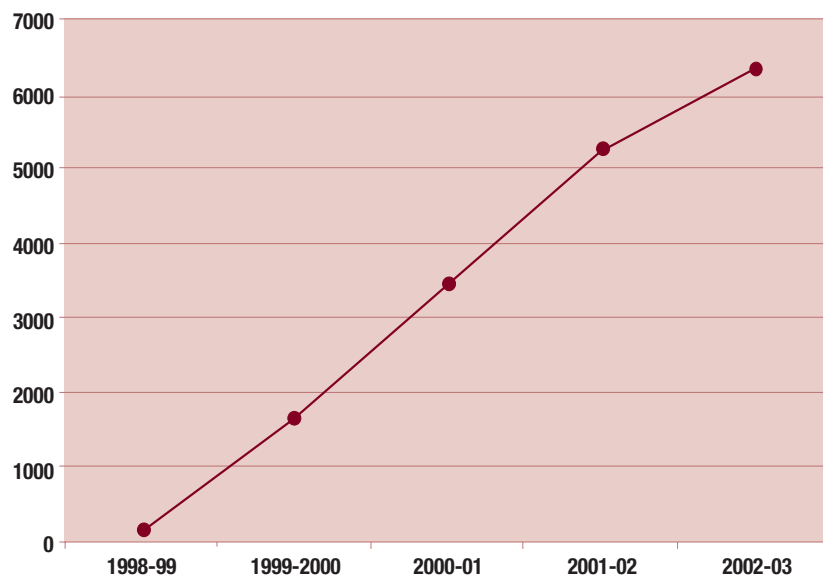
*Data source:* Health Intelligence Unit, NHS Direct.

*Background:* NHS Direct began taking calls in 1998, and since 2000 has provided a round-the-clock national confidential telephone advice line, staffed by nurses. By the end of 2006, it is anticipated that NHS Direct will provide a single point of access for out-of-hours care.

<b>Table 9.8a Calls received by NHS Direct</b>	
<b>Year</b>	<b>Calls received ('000s)</b>
1998–99	110
1999–2000	1,650
2000–01	3,420
2001–02	5,213
2002–03	6,319

SOURCE: DOH

**Figure 9.8b** Use of NHS Direct: calls received '000s



SOURCE: DOH

## **EFFECTIVENESS**

Effectiveness process and outcome measures include:

- preventive care;
- acute care;
- chronic care; and
- rehabilitative care.

Data displays:

- 9.9 Childhood immunisation
- 9.10 Influenza vaccinations for people  $\geq 65$  years
- 9.11 Thrombolysis post myocardial infarction
- 9.12 Secondary prevention of myocardial infarction
- 9.13 Mortality rates: circulatory diseases
- 9.14 Mortality rates: cancer
- 9.15 Breast cancer: time from diagnosis to treatment
- 9.16 Breast and cervical cancer screening rates
- 9.17 Five-year survival rates for major cancers
- 9.18 Waiting times for suspected cancer referrals
- 9.19 Hospital-acquired infections – *Staphylococcus aureus* bacteraemia
- 9.20 Stroke care
- 9.21 Capacity to improve quality: a case study for improving effectiveness

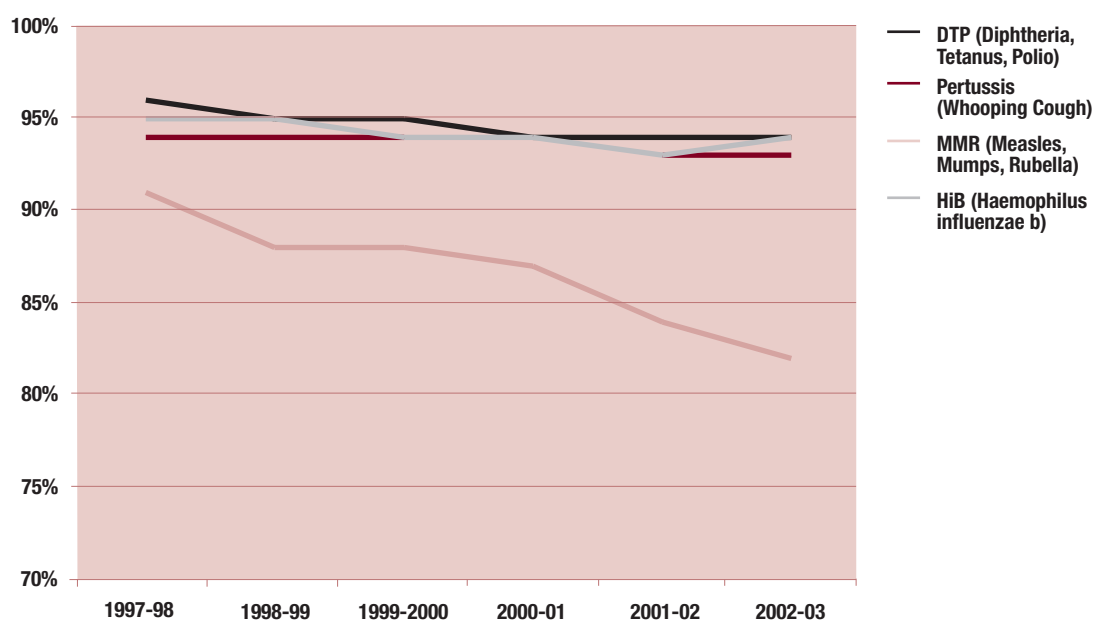
### 9.9 Childhood immunisation

*Data source:* Office for National Statistics (ONS) ([www.statistics.gov.uk](http://www.statistics.gov.uk))

*Target:* 95% coverage (World Health Organisation, [www.who.org](http://www.who.org)).

*Background:* Vaccination is one of the most cost-effective disease prevention strategies in public health. In the absence of natural infection, the acceptance of the risks of vaccination declines, and sustaining high coverage becomes a significant challenge.

**Figure 9.9a** Percentage of children immunised before their second birthday



Note restricted scale 70-100%

SOURCE: Office for National Statistics

The anticipated corollary of falling vaccination rates is an increase in cases and outbreaks of disease. The number of confirmed cases of measles and mumps is, as expected, displaying an upward trend following the drop in vaccination rates.

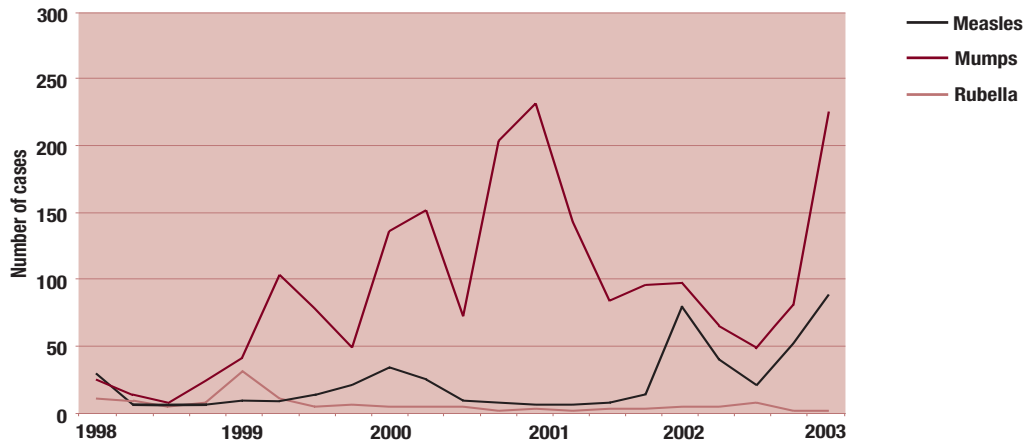
Confirmed cases of illness	Measles	Mumps	Rubella
1998	42	67	28
1999	47	280	49
2000	74	582	9
2001	28	574	7
2002	195	299	13

\* Confirmed by salivary antibody detection

SOURCE: Public Health Laboratory Service ([www.phls.co.uk](http://www.phls.co.uk))



**Figure 9.9c** Confirmed\* cases of measles, mumps and rubella per quarter in England and Wales



\* Confirmed by salivary antibody detection

SOURCE: Public Health Laboratory Service ([www.phls.co.uk](http://www.phls.co.uk))

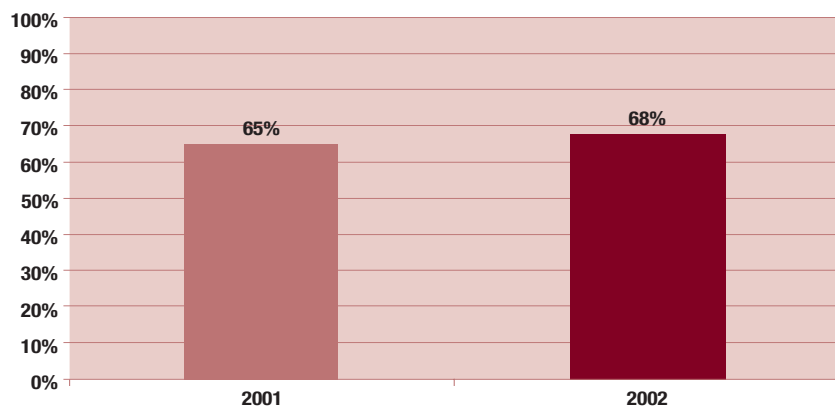
### 9.10 Influenza vaccinations for people $\geq 65$ years

*Data source:* Department of Health ([www.doh.gov.uk/cmo/progress/infdiseases.htm](http://www.doh.gov.uk/cmo/progress/infdiseases.htm))

*Target:* 60% of people  $\geq 65$  years (2001);  
65% of people  $\geq 65$  years (2002) (Chief Medical Officer);  
70% of people  $\geq 65$  years (2003) (Chief Medical Officer).

*Background:* Immunisation is one of the most effective health care interventions available. Influenza vaccines are highly effective at preventing illness and hospital admissions amongst high-risk groups (those aged 65 and over, and those with underlying respiratory or heart disease, diabetes or impaired immune systems). Up to 10–15% of the population may develop influenza in any one year. Even during a year when there is a low incidence, 3–4,000 deaths may be attributed to influenza. Mortality rates can rise much higher; for example, in 1993 there were 13,000 deaths, and in 1989–90 there were 29,000 deaths attributed to influenza.

**Figure 9.10** Influenza vaccine uptake in the population 65 years of age and over



SOURCE: DOH

### 9.11 Thrombolysis post myocardial infarction

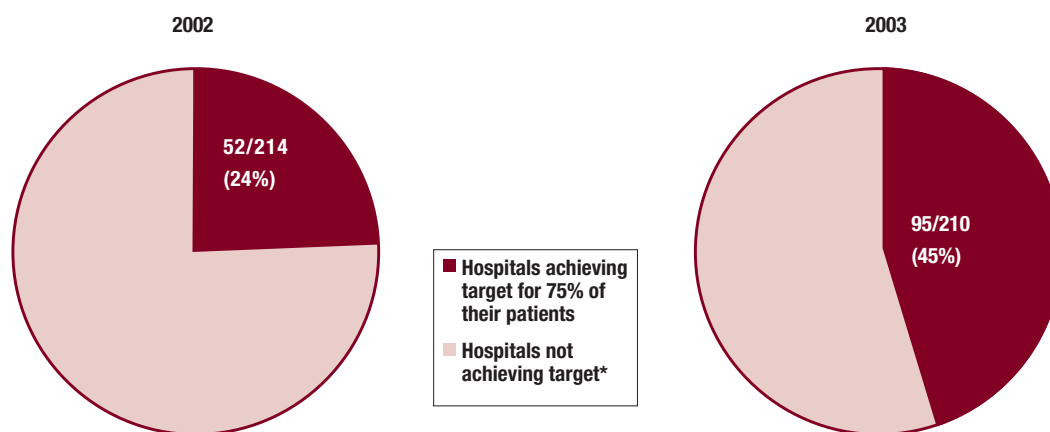
*Data source:* Myocardial Infarction National Audit Project (MINAP) – Royal College of Physicians (2002 and 2003) ([www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)).<sup>†</sup>

*Target:* By April 2002, 75% of eligible patients should receive thrombolytic drugs within 30 minutes of arriving at hospital the so-called Door-to-Needle Time (*National Service Framework*). The target was reduced in April 2003 to 20 minutes.

*Background:* A heart attack (myocardial infarction) occurs when a clot (thrombus) suddenly develops within a heart artery. The heart muscle that is supplied by the blocked artery suffers permanent damage if the blood supply is not restored quickly. Thrombolysis refers to the use of clot-dissolving drugs. Thrombolytic treatment is effective up to about 12 hours after the onset of symptoms, but is most effective when given very early. Thirty-six lives are saved per 1,000 patients treated in the first hour after symptoms occur, whereas 16 lives are saved per 1,000 treated after 7–12 hours have elapsed (Boersma et al. 1996).

<sup>†</sup> Data was collected in two tranches: 1 Jan 2003–30 June 2002 and 1 April 2002–31 March 2003. These time periods overlap so that this data does not constitute a true time series.

**Figure 9.11** Hospitals achieving NSF targets for thrombolysis



\* Includes hospitals with no data returns and those with <10 cases p.a.

SOURCE: Myocardial Infarction National Audit Project (MINAP) – Royal College of Physicians (2002 ; 2003)

### 9.12 Secondary prevention of myocardial infarction

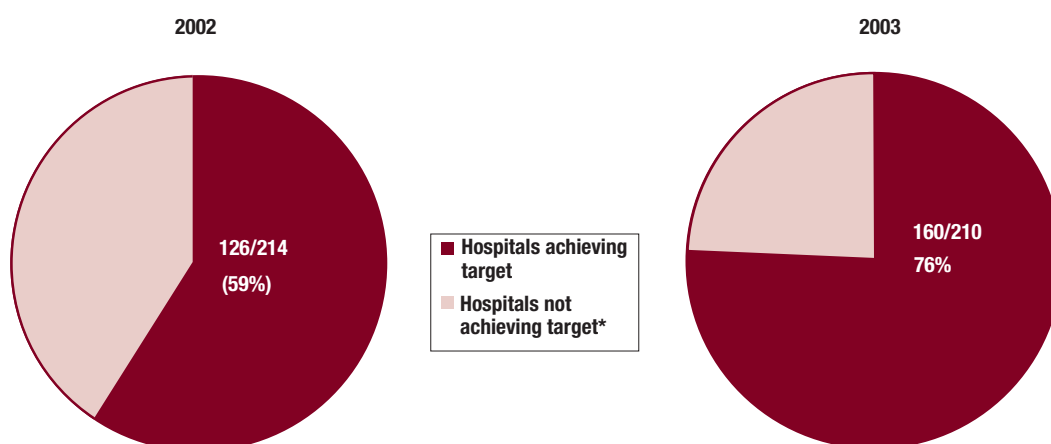
*Data source:* Myocardial Infarction National Audit Project (MINAP) – Royal College of Physicians (2002; 2003) ([www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)).<sup>†</sup>

*Target:* By April 2002, 80–90% of patients discharged from hospital following a heart attack should be given secondary prevention (*National Service Framework*).

*Background:* Secondary-prevention drugs have been shown in large clinical trials to reduce the risk of another heart attack. They include aspirin, beta-blockers and statins.

<sup>†</sup> Data was collected in two tranches: 1 Jan 2003–30 June 2002 and 1 April 2002–31 March 2003. These time periods overlap so that this data does not constitute a true time series.

**Figure 9.12** Hospitals achieving targets for aspirins, beta-blockers and statins



\*Includes hospitals with no data returns and those with <10 cases p.a.

SOURCE: Myocardial Infarction National Audit Project (MINAP) – Royal College of Physicians (2002 ; 2003)

### 9.13 Mortality rates: circulatory diseases

*Data source:* Office of National Statistics Mortality Statistics: *Health Statistics Quarterly* 18, Summer 2003 ([www.statistics.gov.uk](http://www.statistics.gov.uk))

*Target:* Reduction in death rate from heart disease and stroke and related illnesses amongst people aged < 75 by at least 40% by 2010 (*Our Healthier Nation*, 1999)

*Background:* Circulatory diseases accounted for around 60,000 out of 170,000 premature deaths (i.e. under 75) in England in 2001.

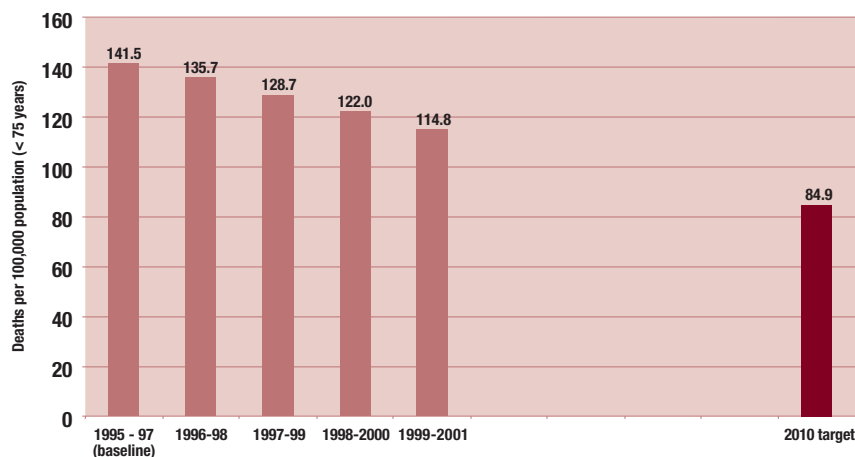
<b>Table 9.13a Mortality rate for circulatory disease (per 100,000 population)</b>	
<b>Date</b>	<b>Mortality rate*</b>
1995–97 (baseline)	141.5
1996–98	135.7
1997–99	128.7
1998–2000	122.0
1999–2001	114.8
2010 target	84.9

\*3-year rolling average mortality rates, age standardised (< 75 years)

SOURCE: Office for National Statistics

There have been improvements in mortality rates from circulatory illnesses such as heart disease and stroke, as is illustrated by a graphical presentation of the data.

**Figure 9.13b** Circulatory diseases – mortality rates



SOURCE: Office for National Statistics

### 9.14 Mortality rates: cancer

*Data source:* Office of National Statistics ([www.statistics.gov.uk](http://www.statistics.gov.uk))

*Target:* By 2010, a 20% reduction in deaths from cancer in people < 75 years (*Our Healthier Nation 1999*)

*Background:* Cancer is the cause of a quarter of all deaths in the UK. In those under the age of 65, more than one in three deaths are caused by cancer.

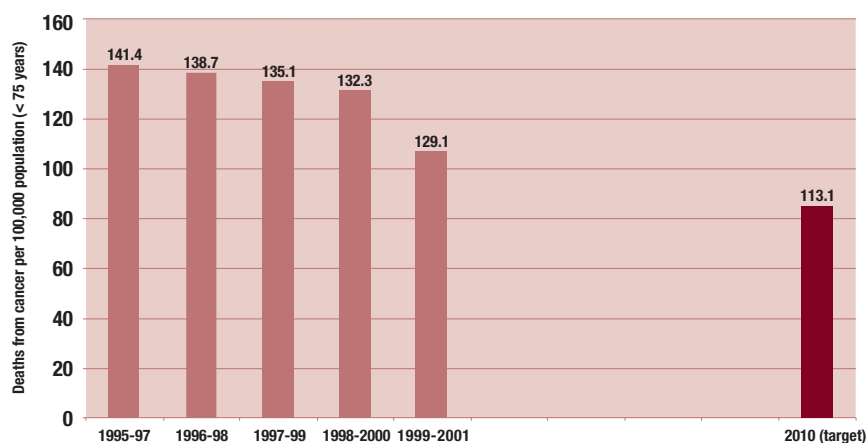
Date	Mortality rate*
1995–97	141.4
1996–98	138.7
1997–99	135.1
1998–2000	132.3
1999–2001	129.1
2010 (target)	113.1

\*3-year rolling averages; < 75 years, age standardised

SOURCE: Office for National Statistics

There have been improvements in mortality rates from cancer, as is illustrated by a graphical presentation of the data.

**Figure 9.14b** Cancer mortality rates



SOURCE: Office for National Statistics

### 9.15 Breast cancer: time from diagnosis to treatment

*Data source:* Department of Health ([www.doh.gov.uk/cancerwaits](http://www.doh.gov.uk/cancerwaits))

*Target:* By 2005, there will be a maximum of 1 month’s wait from diagnosis to treatment of all cancers (*NHS Cancer Plan*).

*Background:* Mortality rates for breast cancer reached a peak in the 1980s. Since 1990, there has been a steady fall in the mortality rates, which is attributed to earlier diagnosis (including screening) and prompt and more effective treatment.

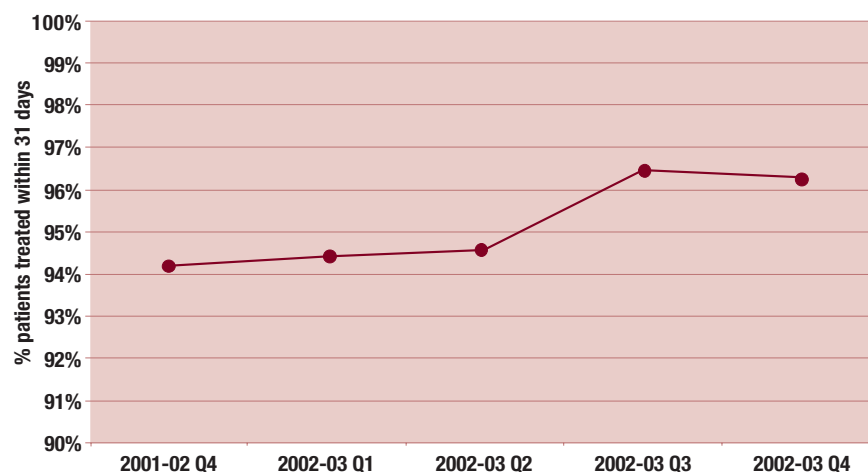
**Table 9.15a Breast cancer patients treated within a month of diagnosis**

Time period	% breast cancer patients treated within a month of diagnosis
2001–02 Q4	94.2
2002–03 Q1	94.4
2002–03 Q2	94.6
2002–03 Q3	96.5
2002–03 Q4	96.3

SOURCE: DOH

The same data presented graphically illustrates fairly steady progress.

**Figure 9.15b Breast cancer: time from diagnosis to treatment**



Note restricted scale 90–100%.

SOURCE: DOH

### 9.16 Breast and cervical cancer screening rates

*Data source:* Department of Health ([www.doh.gov.uk/public/sb0307.htm](http://www.doh.gov.uk/public/sb0307.htm) and [www.doh.gov.uk/public/sb0221.htm](http://www.doh.gov.uk/public/sb0221.htm))

*Background:* The Cervical Screening Programme was set up in 1988 and screens almost 4 million women every year in England. Cervical screening has been estimated to prevent between 1,100 and 3,900 cases of cervical cancer each year (Sasieni et al. 1996). Deaths from cervical cancer are falling by 7% per year.

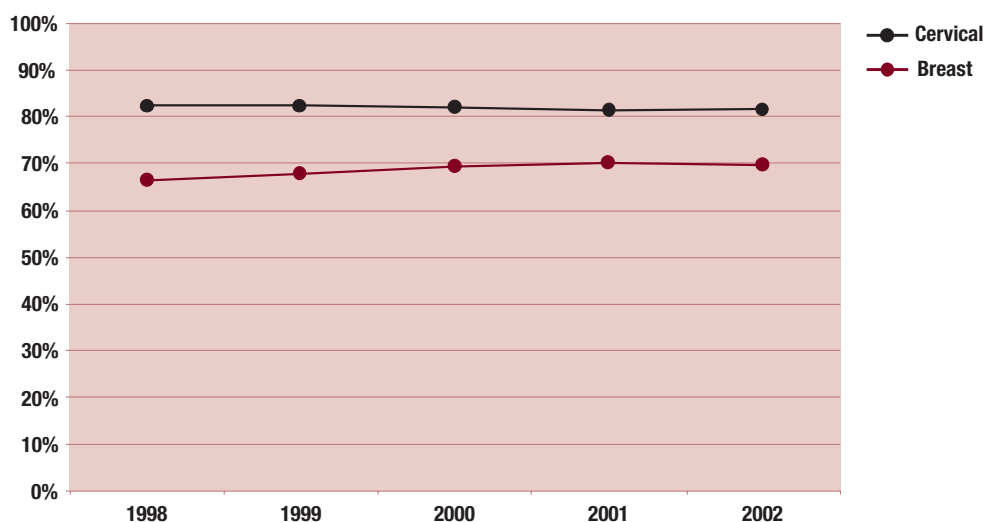
The Breast Screening Programme was set up in 1988. Women aged 50–64 are routinely screened every 3 years, and this is to be extended to those aged up to 70 by 2004. The programme has lowered breast cancer mortality rates in the 55–69 age group, with an estimated 300 lives per year saved. The Breast Screening programme projects a rise in lives saved to 1,250 lives/year by 2010 ([www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)).

	<b>Cervical screening coverage ages 25–64 (less than 5 years since last test)</b>	<b>Breast screening coverage ages 50–64 (less than 3 years since last test)</b>
1998	82.5	66.4
1999	82.3	67.7
2000	82.0	69.3
2001	81.3	70.2
2002	81.6	69.8

SOURCE: DOH

The same data, presented graphically, illustrates the slight deterioration in cervical screening coverage and the improvement in breast screening coverage.

**Figure 9.16b** Cancer screening coverage



SOURCE: DOH



### 9.17 Five-year survival rates for major cancers

*Data source:* Office of National Statistics ([www.statistics.gov.uk](http://www.statistics.gov.uk)); Cancer Research UK ([www.cancerresearchuk.org](http://www.cancerresearchuk.org))

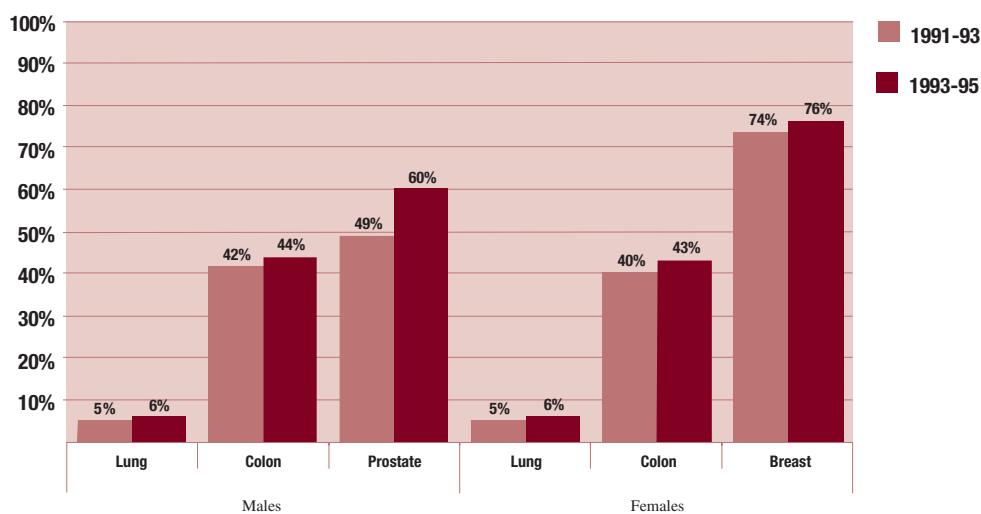
*Background:* Survival rates refer to the percentage of patients surviving 5 years after diagnosis. The headings 1991–93 and 1993–95 refer to the percentage of patients diagnosed during that time who are still alive 5 years later: e.g. patients diagnosed with the 1993–95 period still alive in 1998–2000.

<b>Table 9.17a Five-year survival rates for major cancers (%)</b>			
		<b>1991–93</b>	<b>1993–95</b>
Males	Lung	5	6
	Colon	42	44
	Prostate	49	60
Females	Lung	5	6
	Colon	40	43
	Breast	74	76

SOURCE: Office for National Statistics

The same data, presented graphically, illustrates the wide variation amongst the most prevalent cancers in terms of survival rates, and shows some general improvement over the last decade.

**Figure 9.17b** Five-year survival rates for major cancers



SOURCE: Office for National Statistics

### 9.18 Waiting times for suspected cancer referrals

*Data source:* Chief Executive's Report to the NHS 2002–03 ([www.doh.gov.uk/nhsreport](http://www.doh.gov.uk/nhsreport))

*Target:* Every patient with suspected cancer will be able to see a specialist within 2 weeks of a GP request (for breast cancer by April 1999; for other cancers by 2000)

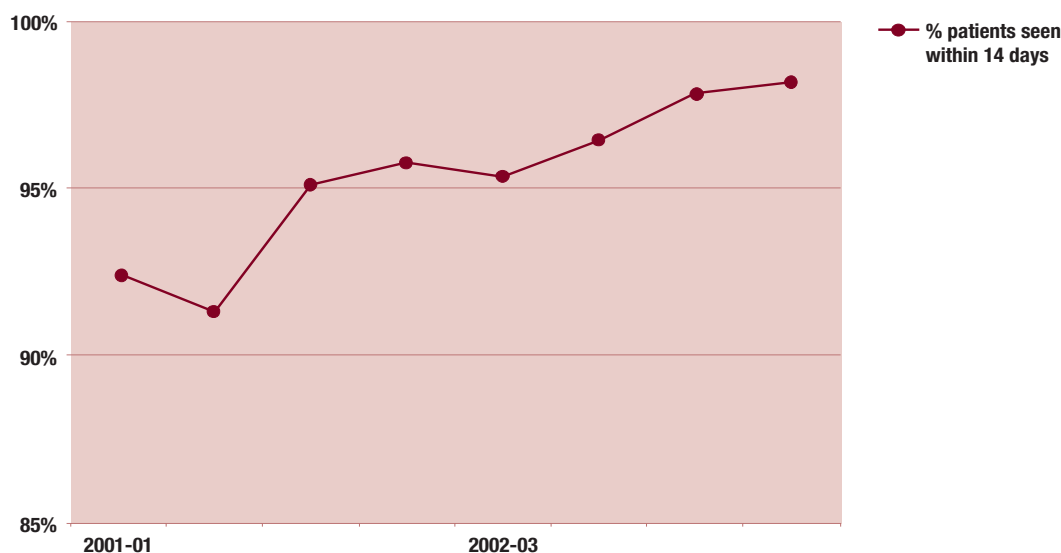
<b>Table 9.18a Patients seen within 14 days for a suspected cancer referral</b>				
		<b>Total patients seen</b>	<b>Patients seen within 14 days</b>	<b>% seen within 14 days*</b>
2001–01	Q1	65,398	60,458	92.4%
	Q2	74,104	67,650	91.3%
	Q3	77,609	73,813	95.1%
	Q4	79,591	76,243	95.8%
2002–03	Q1	85,416	81,466	95.4%
	Q2	94,954	91,551	96.4%
	Q3	97,284	95,190	97.8%
	Q4	92,886	91,241	98.2%

\* Of referrals received by NHS Trusts within 24 hrs

SOURCE: DOH

The following graph depicts some of this data: the percentage of patients with suspected cancer who waited 14 days or less to see a specialist. Although improvement is evident, the target has not yet been met.

**Figure 9.18b** Specialist referral for patients with suspected cancer



Note restricted scale 85–100%.

SOURCE: DOH

### 9.19 Hospital-acquired infections – *Staphylococcus aureus* bacteraemia

*Data source:* Health Protection Agency  
([www.phls.co.uk/topics\\_az/staphylo/lab\\_data\\_staphyl.htm](http://www.phls.co.uk/topics_az/staphylo/lab_data_staphyl.htm) and  
[www.phls.org.uk/publications/cdr/PDFfiles/2003/cdr1203.pdf](http://www.phls.org.uk/publications/cdr/PDFfiles/2003/cdr1203.pdf))

*Background:* *Staphylococcus aureus* is a bacterium that lives harmlessly on the skin of normal healthy people. It can cause problems when it invades the body. This is likely to happen in people who are already unwell. The bacteria can cause abscesses and boils and infect wounds – both accidental and deliberate (such as surgical incisions or catheter sites). It can then spread into the body and cause life-threatening illnesses such as bacteraemia (blood poisoning). MRSA is a variety of *Staphylococcus aureus* that is resistant to methicillin (a type of penicillin) and many other antibiotics, making it extremely difficult to treat. MRSA is one of the most prevalent micro-organisms associated with hospital-acquired infections.

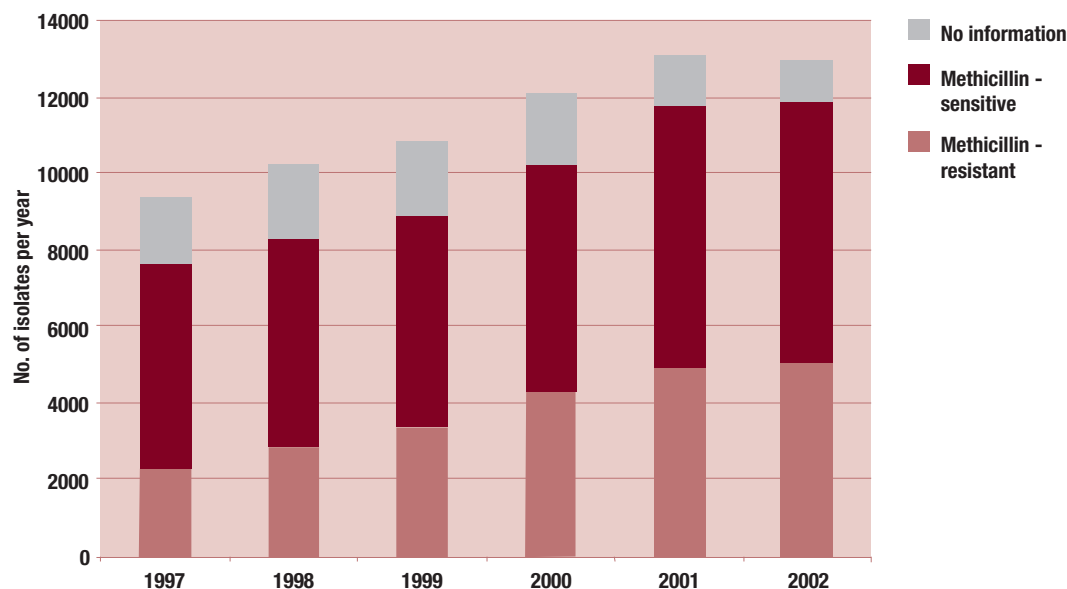
**Table 9.19a *Staphylococcus aureus* bacteraemia (England and Wales)**

	<b>Methicillin- resistant (MRSA)</b>	<b>Methicillin- sensitive</b>	<b>No information*</b>	<b>Total</b>
1997	2,290	5,325	1,763	9,378
1998	2,853	5,433	1,936	10,222
1999	3,338	5,590	1,896	10,824
2000	4,308	5,897	1,898	12,103
2001	4,904	6,864	1,316	13,084
2002	5,075	6,810	1,043	12,928

\* Returns to the PHLS which did not specify whether the isolate was sensitive or resistant to methicillin.

SOURCE: Public Health Laboratory Service

This data, presented graphically, illustrates how the incidence of bacteraemia caused by *Staph. aureus* increased by about 38% between 1997 and 2002. Of even greater concern is the proportion of those cases caused by MRSA. In 1997, 24% of *Staph. aureus* bacteraemias were found to be methicillin-resistant; in 2002, that figure increased to 40%.

**Figure 9.19b** *Staphylococcus aureus* blood poisoning (including MRSA)

SOURCE: Public Health Laboratory Service

The rise in MRSA bacteraemia prompted the Department of Health to introduce a mandatory MRSA bacteraemia surveillance scheme in Acute Trusts in England in April 2001. This ran concurrently with the voluntary surveillance as arrayed in the table and graph above. A comparison of the dual reporting raises questions about the accuracy of the results of the long-standing voluntary reporting programme:

**Table 9.19c** A comparison between voluntary and mandatory reporting rates (England only)

	Voluntary		Mandatory	
	<i>Staph. aureus</i> bacteraemias	MRSA (% of total)	<i>Staph. aureus</i> bacteraemias	MRSA (% of total)
2002	12,284	4,793 (42%)	18,075	7,227 (39%)

SOURCE: Public Health Laboratory Service

### 9.20 Stroke care

*Data source:* National Sentinel Audit of Stroke  
([www.rcplondon.ac.uk/college/ceeu/ceeu\\_stroke\\_audit\\_history.htm](http://www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_audit_history.htm))

*Background:* A stroke occurs when there is an interruption of the blood supply to the brain. Around 100,000 people in England and Wales have a first stroke each year. This dataset is based on three audits conducted in 1998, 1999 and 2001–02. The audit is based on a questionnaire regarding service organisation and retrospective analysis of case notes. In each Trust audited, up to 40 individual cases are analysed. Data is presented only for those Trusts that participated in all three audits. The number of Trusts participating in the audit were 197 in 1998 (80% of eligible sites); 174 in 1999 (72% of eligible sites); and 199 in 2002 (95% of eligible sites).

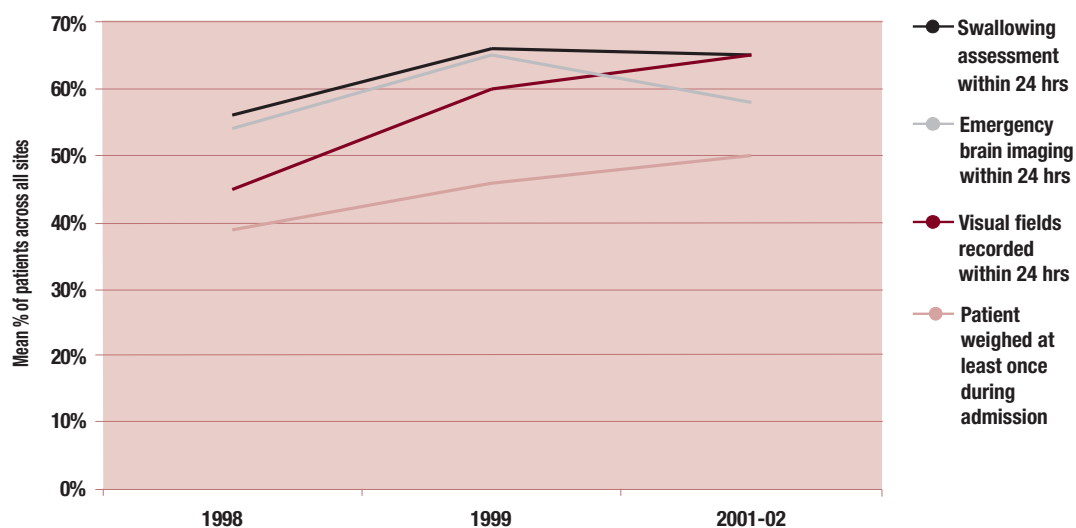
Table 9.20a Stroke care standards			
Standard	1998	1999	2002
Swallowing assessment within 24 hrs	56%	66%	65%
Visual fields recorded within 24 hrs	45%	60%	65%
Emergency brain imaging within 24 hrs	54%	65%	58%
Patient weighed at least once during the admission	39%	46%	50%
Data based on:	148 sites	145 sites	146 sites

\*Percentages are mean results of % compliance with the standards across the sites.

SOURCE: CEEU, Royal College of Physicians

This data, illustrated below, shows that the rate of improvement in meeting these process standards has slowed.

Figure 9.20b Stroke care processes



SOURCE: CEEU, Royal College of Physicians

### 9.21 Capacity to improve quality: a case study for improving effectiveness

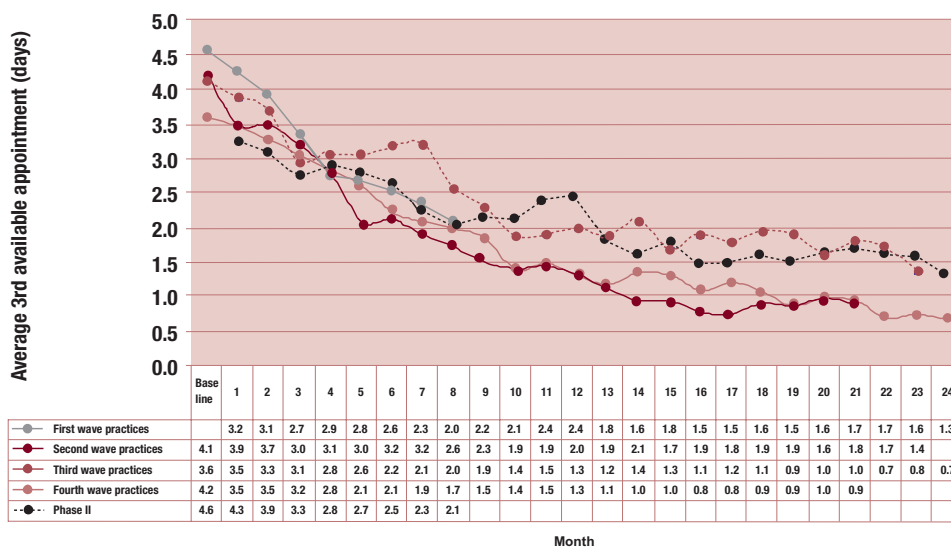
*Data source:* National Primary Care Development Team (www.npdt.org)

*Background:* The National Primary Care Development Team, launched in February 2000, established the National Primary Care Collaborative as a way of bringing about rapid improvement in patient care. There were four national waves of the NPCC, involving 80 PCTs and over 400 practices.

The data presented here is relevant in both access and effectiveness domains, and includes process and outcome measures:

- appointment scheduling with GP;
- prescribing practices; and
- blood pressure management.

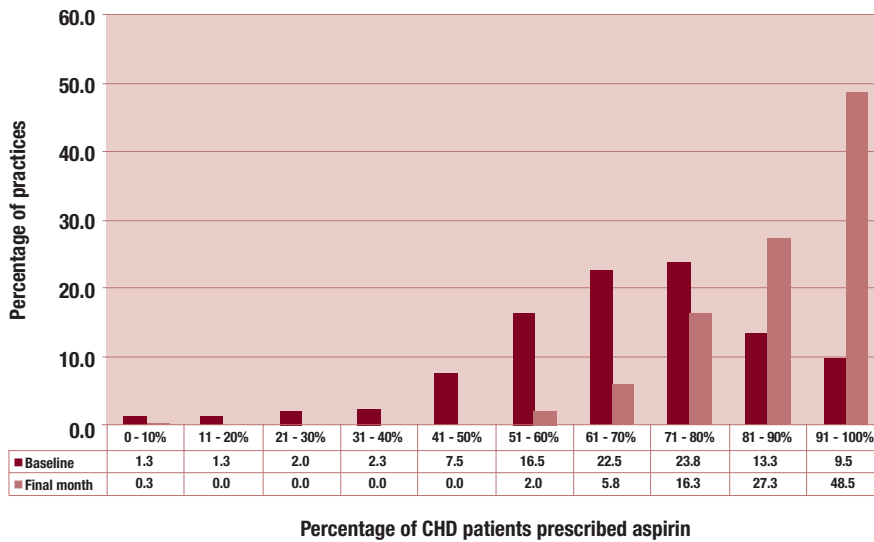
**Figure 9.21a** Trends in third available appointment with a GP: Phase I and early years of Phase II of the National Primary Care Collaborative (NPCC)



Collaborative practices use the measure of third available appointment to reflect the routine availability of clinicians. The measure is based on the number of days that a patient would have to wait for a routine appointment. The first and second free appointment are not counted, as they are more likely to be available because of cancellations.

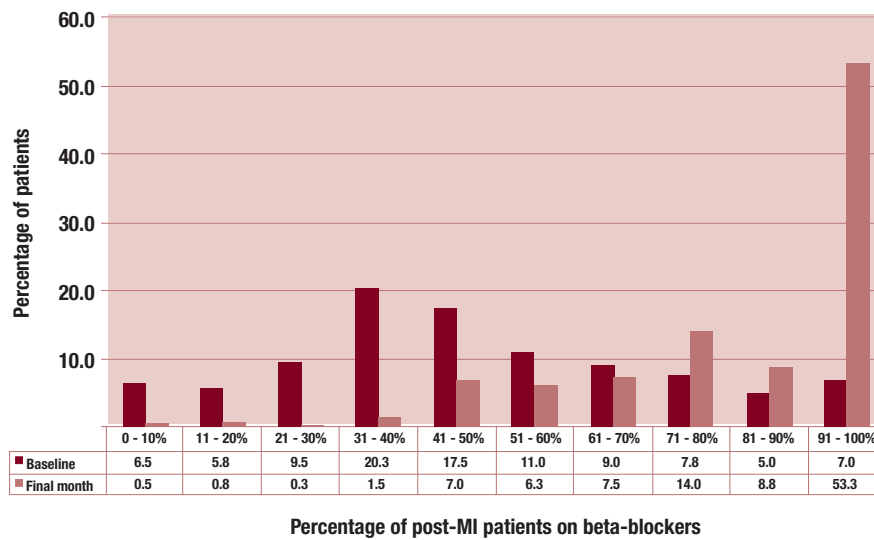
SOURCE: National Primary Care Development Team

**Figure 9.21b** Percentage of CHD patients prescribed aspirin: NPCC Phase I practices – baseline and final month



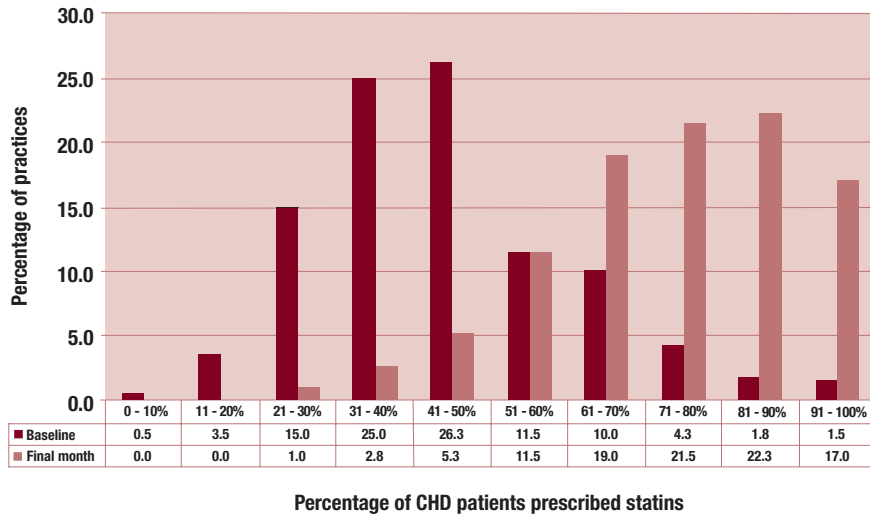
SOURCE: National Primary Care Development Team

**Figure 9.21c** Percentage of post-MI patients on beta-blockers: NPCC Phase I practices – baseline and final month



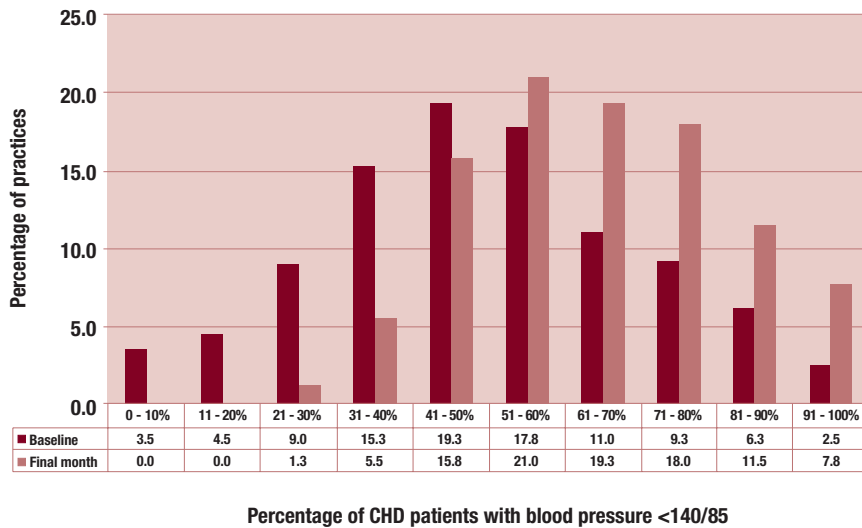
SOURCE: National Primary Care Development Team

**Figure 9.21d** Percentage of CHD patients (under 75) prescribed statins: NPCC Phase I practices – baseline and final month



SOURCE: National Primary Care Development Team

**Figure 9.21e** Percentage of CHD patients' blood pressure < 140/85: NPCC Phase I practices – baseline and final month



SOURCE: National Primary Care Development Team



**SYSTEM CAPACITY**

Capacity measures include data on:

- workforce;
- facilities; and
- technology.

Data displays:

9.22 Workforce

9.23 Critical care beds

9.24 Stroke care facilities

9.25 Technology: CT scanners, MRI scanners and linear accelerators

## 9.22 Workforce

*Data source:* Department of Health: Hospital, *Public Health Medicine and Community Health Services Medical and Dental Staff in England: 1992–2002*; ([www.doh.gov.uk/public/sb0304.htm](http://www.doh.gov.uk/public/sb0304.htm))

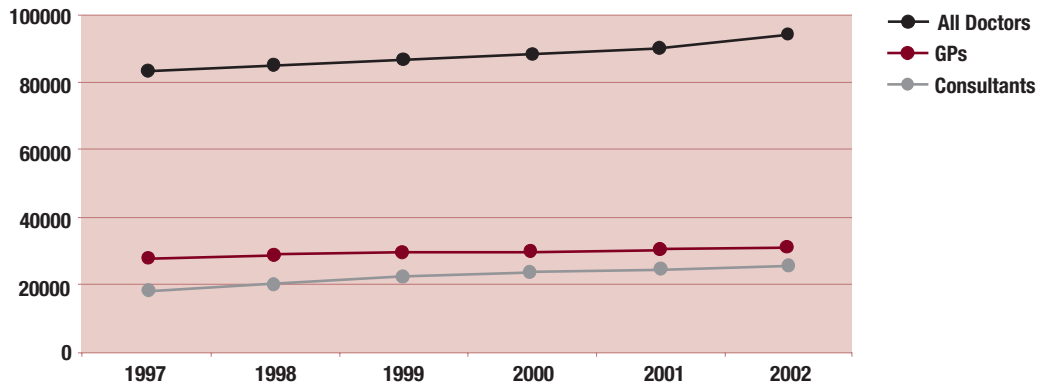
*Target:* By 2004, there will be 20,000 more nurses; 2,000 more GPs; and 7,500 more consultants (*The NHS Plan 2000*, 5.4).

<b>Table 9.22a Workforce numbers (whole-time equivalents)</b>				
	<b>All doctors (excluding GP retainers)</b>	<b>GPs (excluding retainers)</b>	<b>Consultants (including Directors of Public Health)</b>	<b>Nurses (including practice nurses)</b>
1997	82,789	27,660	19,661	256,093
1998	84,770	27,848	20,432	257,597
1999	86,679	28,033	21,410	261,340
2000	88,678	28,154	22,186	266,987
2001	90,868	28,439	23,064	277,334
2002	95,611	28,740	24,756	291,285

SOURCE: DOH

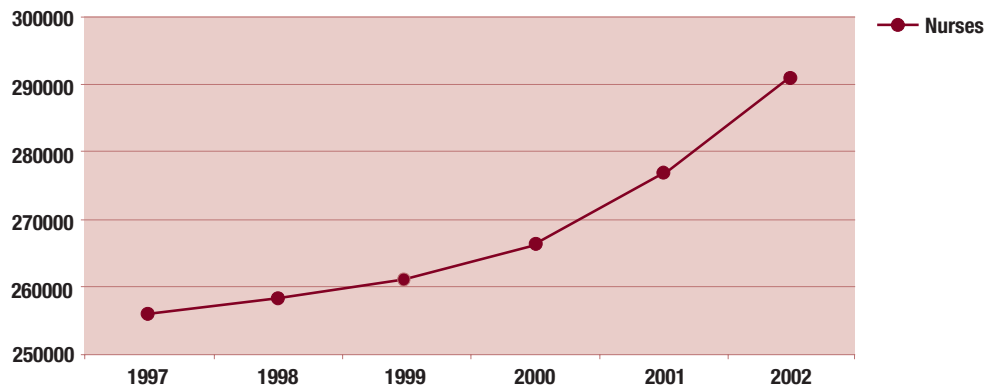
The same data, illustrated in the following figures, shows very significant progress with the nursing workforce; the Government's target has already been met. The progress is much slower with numbers of GPs and consultants, and goal attainment is uncertain.

**Figure 9.22b** Workforce numbers: whole-time equivalents - doctors



SOURCE: DOH

**Figure 9.22c** Workforce numbers: whole-time equivalents - nurses



SOURCE: DOH

### 9.23 Critical care beds

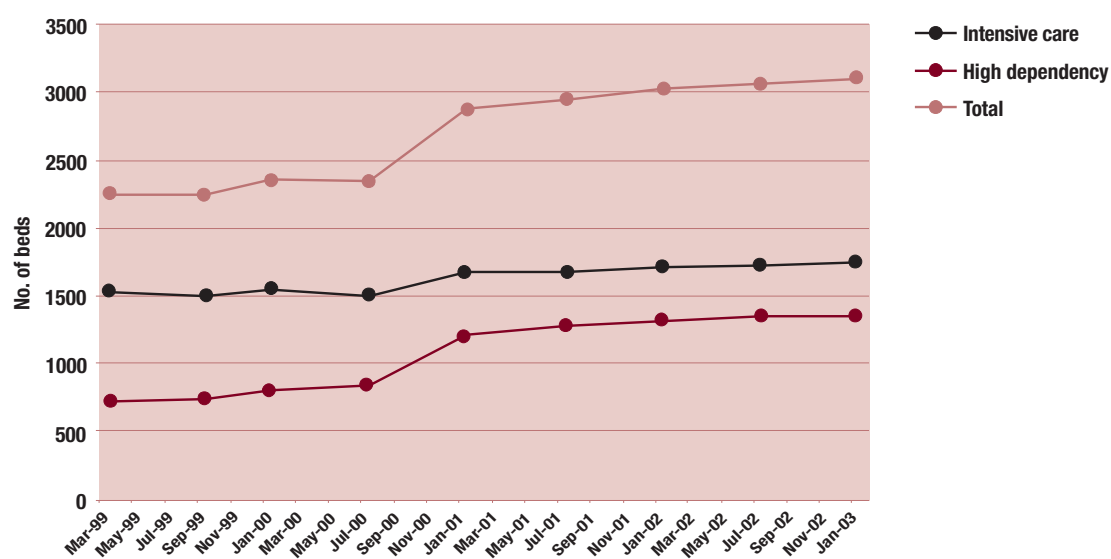
*Data source:* Department of Health: Chief Executive's Report to the NHS: statistical supplement [KH03a] ([www.doh.gov.uk/nhsreport](http://www.doh.gov.uk/nhsreport))

*Target:* By 2003, a 30% increase in the number of critical care beds (*The NHS Plan* 4.4).

Table 9.23a Critical care beds – open and staffed on census day			
Census date	Intensive care	High dependency	Total
31 Mar 1999	1,520	720	2,240
30 Sep 1999	1,501	740	2,241
15 Jan 2000	1,555	807	2,362
14 Jul 2000	1,496	847	2,343
15 Jan 2001	1,677	1,208	2,885
16 Jul 2001	1,670	1,270	2,940
15 Jan 2002	1,711	1,319	3,030
16 Jul 2002	1,718	1,352	3,070
15 Jan 2003	1,746	1,351	3,097
% growth from Jan 2000	12.3%	67.4%	31.1%

SOURCE: DOH

Figure 9.23b Critical care beds open and staffed on census day



SOURCE: DOH

### 9.24 Stroke care facilities

*Data source:* National Sentinel Audit of Stroke  
([www.rcplondon.ac.uk/college/ceeu/ceeu\\_stroke\\_audit\\_history.htm](http://www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_audit_history.htm))

*Target:* By 2004, every general hospital caring for people with stroke will have a specialised stroke service (*NSF for Older People*, p. 74).

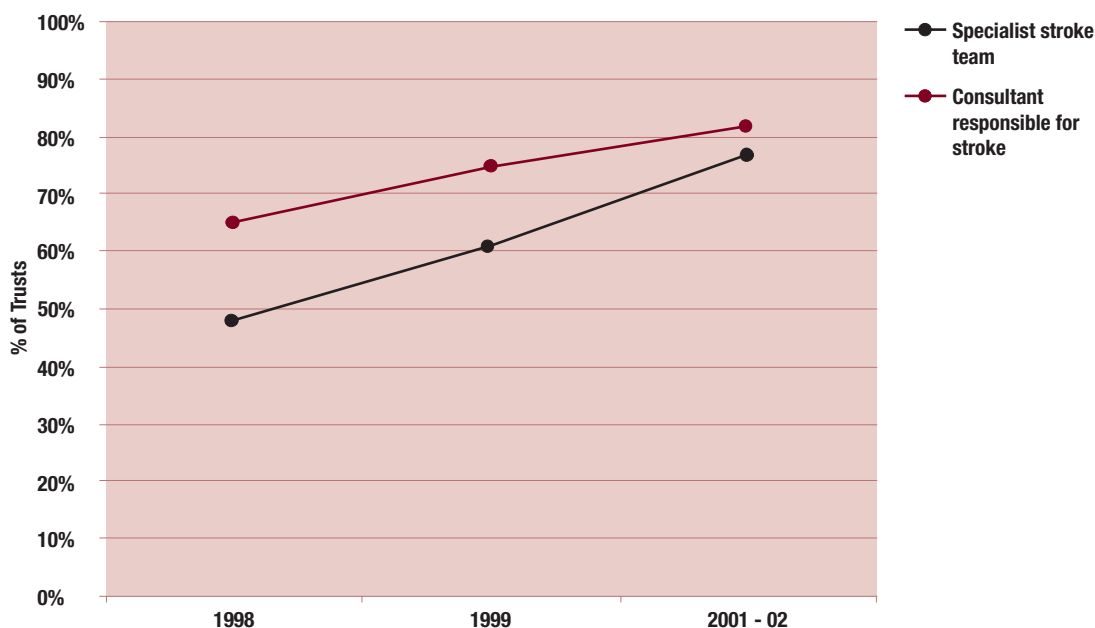
*Background:* A stroke occurs when there is an interruption of the blood supply to the brain. Around 100,000 people in England and Wales have a first stroke each year. This dataset is based on three audits conducted in 1998, 1999 and 2001–02. The audit is based on a questionnaire regarding service organisation and retrospective analysis of case notes. In each Trust audited, up to 40 individual cases are analysed. The number of Trusts participating in the audit were 197 in 1998 (80% of eligible sites); 174 in 1999 (72% of eligible sites); and 199 in 2002 (95% of eligible sites).

**Table 9.24a Stroke care facilities**

	1998	1999	2002
Data based on	147 sites	140 sites	145 sites
Number of Trusts with stroke team/unit (%)	71 (48%)	86 (61%)	111 (77%)
Number of Trusts with consultant responsible for stroke (%)	95(65%)	105 (75%)	119 (82%)
Proportion of cases that spend >50% time on stroke unit	17%	26%	27%

SOURCE: CEEU, Royal College of Physicians

**Figure 9.24b Capacity for stroke care**



SOURCE: CEEU, Royal College of Physicians

### 9.25 Technology: CT scanners, MRI scanners and linear accelerators

*Data source:* Department of Health ([www.doh.gov.uk/cancer/invest-facilities.htm](http://www.doh.gov.uk/cancer/invest-facilities.htm))

*Target:* By the end of 2004, there will be 50 new MRI scanners, 45 new Linear Accelerators and 200 new CT scanners (*The NHS Plan 4.13*).

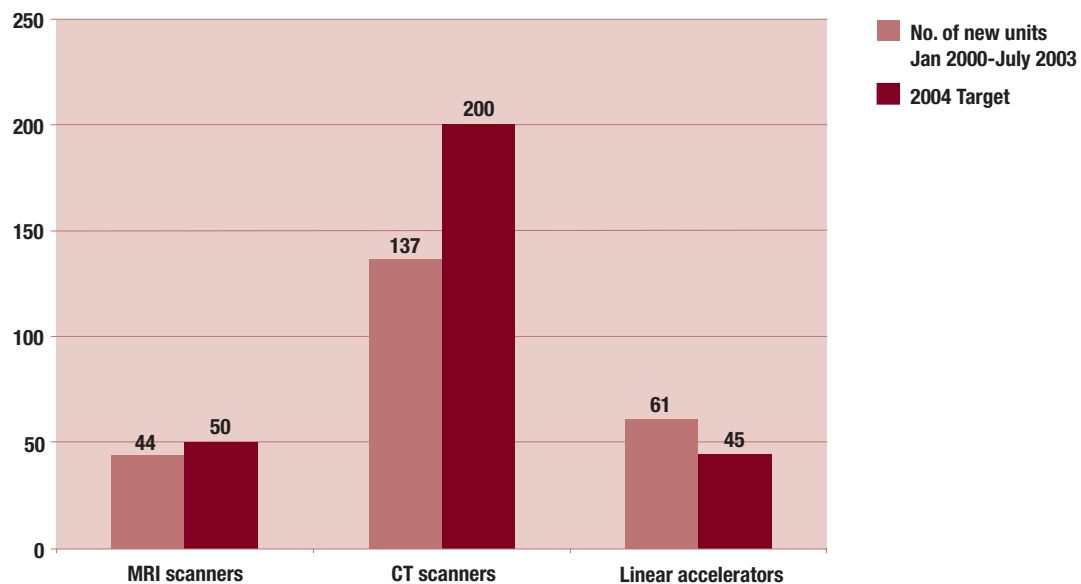
<b>Table 9.25a Investment in technology for cancer</b>			
	<b>No. of new units Jan 2000– July 2003</b>	<b>2004 Target</b>	<b>% units ≤ 3 yrs old (as of July 2003)</b>
MRI scanners	44	50	88%
CT scanners	137	200	68%
Linear accelerators	61	45	60%

Publicly available data to Jan 2003 was supplemented by personal communication - A. Fletcher Aug 2003.

SOURCE: DOH

This data, presented graphically below, shows that the target has been met for linear accelerators.

**Figure 9.25b** Technology – new equipment purchased since 2000



SOURCE: DOH

## **PUBLIC PERCEPTIONS AND PATIENT EXPERIENCE**

Perception and experience measures include:

- surveys of public attitudes to the health system;
- patient ratings of actual experience of care;
- international benchmarks from surveys of five countries; and
- trend data concerning patient complaints.

Data displays:

### *Time series*

- 9.26 Adults' health care system views: extent of change required
- 9.27 Complaints to the Health Service Ombudsman
- 9.28 General practice survey: complaint resolution

### *Snapshots from survey data*

- 9.29 Ratings of overall care
- 9.30 Inpatient ratings of cleanliness
- 9.31 Rating of the patient environment by inspection
- 9.32 Ratings of pain control
- 9.33 Patient counselling for aftercare
- 9.34 Ratings of respect and dignity in care
- 9.35 Patient involvement in care

### *International benchmarks – surveys of physicians and sicker adults*

- 9.36 Physicians' views on their ability to provide quality care
- 9.37 Patients' views of the health system
- 9.38 Patient ratings of physician care
- 9.39 Patient ratings of doctor-patient communication
- 9.40 Patient ratings of difficulty seeing a specialist
- 9.41 Patient accounts of medication and medical errors

### 9.26 Adults' health care system views: extent of change required

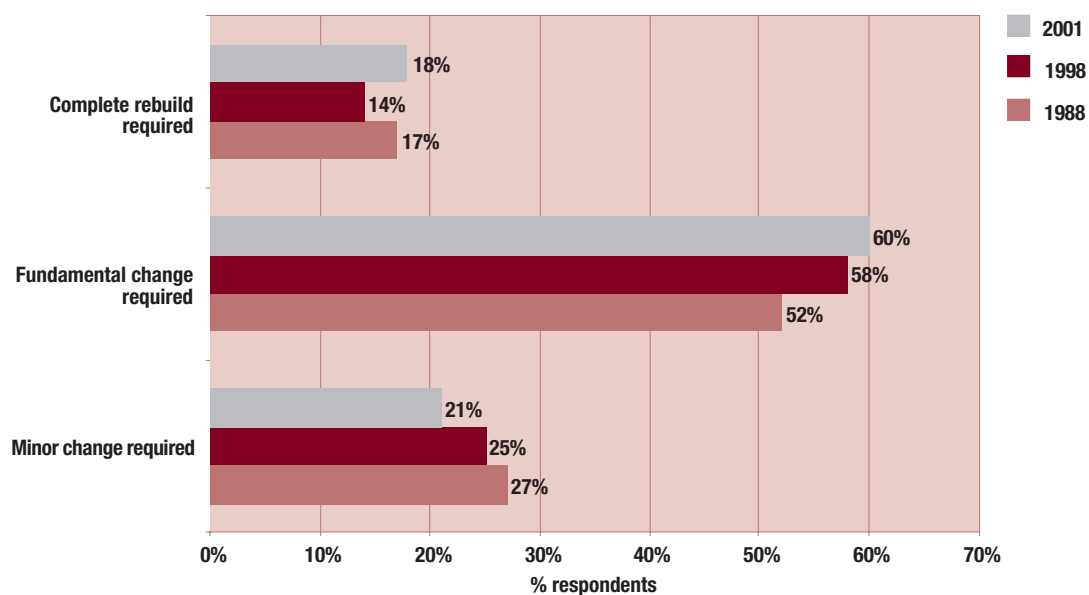
*Data source:* 2001 Commonwealth Fund International Health Policy Survey  
(www.cmwf.org)

*Background:* The 2001 Commonwealth Fund International Health Policy Survey consisted of telephone interviews with 1,400 adults in each of five countries: Australia, Canada, New Zealand, the UK and the US. One survey question asked what level of change was needed in the country's health system – only trend data for the UK is presented here.

<b>Table 9.26a Extent of change required in the health service – views of the UK public</b>			
<b>% of UK respondents who felt:</b>	<b>1988</b>	<b>1998</b>	<b>2001</b>
minor change required	27	25	21
fundamental change required	52	58	60
complete rebuild required	17	14	18

SOURCE: Commonwealth Fund

**Figure 9.26b** UK public perception of change required in the health system



SOURCE: Commonwealth Fund



### 9.27 Complaints to the Health Service Ombudsman

*Data source:* www.ombudsman.org.uk

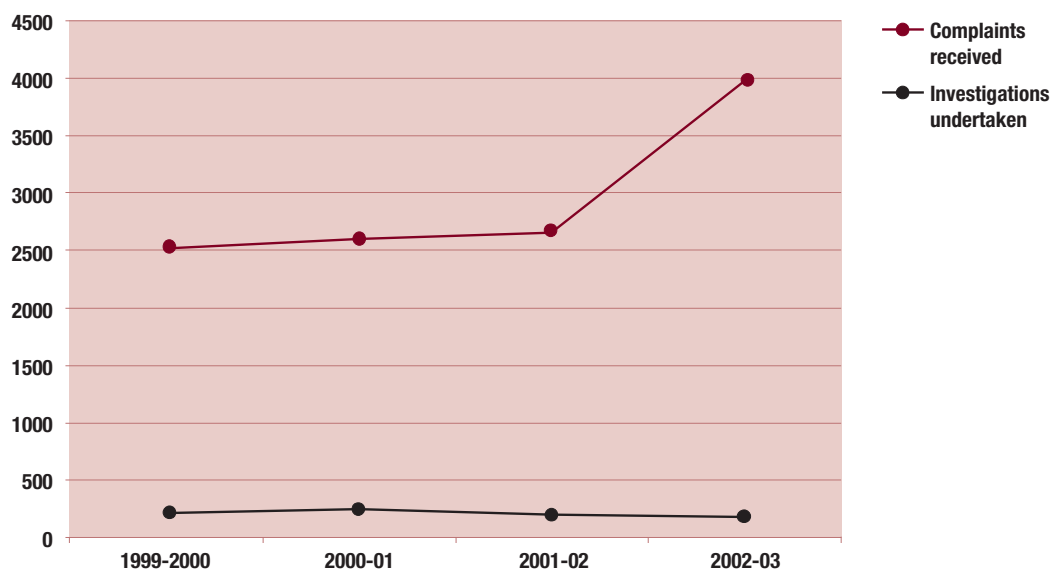
*Background:* The Health Service Ombudsman undertakes independent investigations into complaints about the NHS once local arrangements for resolution have been exhausted. The Ombudsman investigations include allegations that a hardship or injustice has been caused by the NHS’s failure to provide a service, by a failure in service, or by maladministration. The Ombudsman is an officer of the House of Commons, reporting to Parliament, and appointed by the Queen. The post is independent of government and is not within the Civil Service. Complaints are confidential and investigations are private.

<b>Table 9.27a Complaints made to the Health Service Ombudsman</b>				
	<b>1999–2000</b>	<b>2000–01</b>	<b>2001–02</b>	<b>2002–03</b>
Complaints received	2,526	2,595	2,660	3,994
Investigations undertaken	12	241	204	176

SOURCE: Health Service Ombudsman

This data, illustrated below, although showing an increase in the number of complaints received by the Ombudsman, may reflect greater awareness of the complaint mechanism or improved access to it, rather than increased incidents inciting more complaints. This interpretation is supported by the recent decrease in the number of investigations undertaken by the Ombudsman.

**Figure 9.27b** Complaints made to the Health Service Ombudsman



SOURCE: Health Service Ombudsman

### 9.28 General practice survey: complaint resolution

*Data source:* Department of Health: General Practice Survey 1998 and 2002 (Picker Institute Europe) ([www.nhssurveys.org](http://www.nhssurveys.org))

*Background:* The general practice surveys were conducted for the Department of Health as part of the NHS Patient Survey Programme. Questionnaires were sent to individuals in England identified from the electoral register. In 1998, 100,000 questionnaires were sent, with over 61,000 returned; in 2002, 263,100 questionnaires were sent, with over 145,000 returned.

This dataset presents responses to the question: *Was your complaint sorted out?*

Note only 1% of respondents in both 1998 and 2002 made at least one complaint (although 11% of respondents in 1998 and 12% in 2002 reported that they felt like making a complaint but did not).

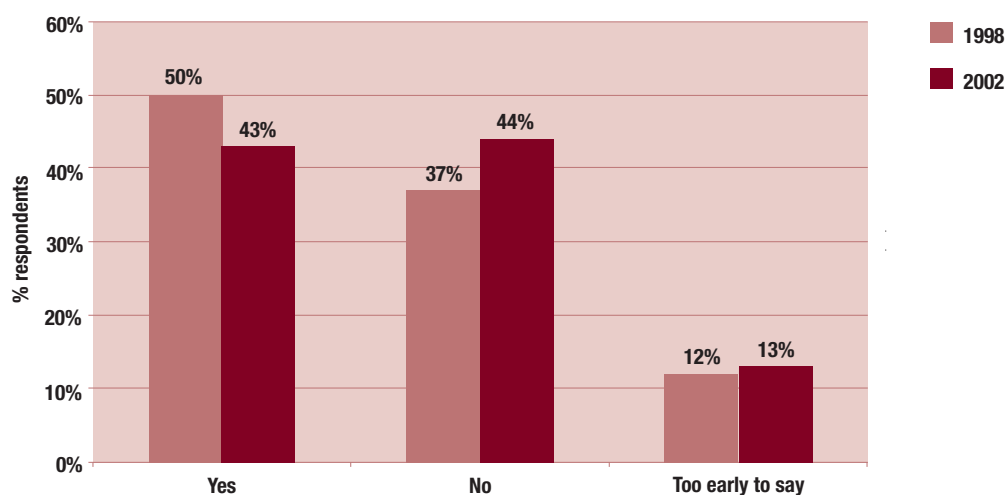
**Table 9.28a Respondents reporting that their complaint was “sorted out”, as a percentage of all those making a complaint**

	1998	2002
Yes	50%	43%
No	37%	44%
Too early to say	12%	13%
Unweighted bases (all who made complaint)	712	1,757

SOURCE: nhssurveys

This data, illustrated below, must be interpreted with care. The numbers of respondents making a complaint is extremely low (around 1% of the total). Furthermore, because the data is only from the patients' perspective, it is impossible to judge whether the complaints are reasonable. Nevertheless, the way in which complaints are handled is an important aspect of patient responsiveness.

**Figure 9.28b** Complaint resolution: was the complaint sorted out?



SOURCE: nhssurveys

### 9.29 Ratings of overall care

*Data source:* Department of Health: Acute Inpatient Survey 2001–02; A&E Patient survey 2003; Outpatient Survey 2003 (www.nhssurveys.org)

*Background:* Data from three patient surveys, commissioned by the DOH, is used.

- The Acute Inpatient Survey sampled at least 500 recently discharged patients from each of 176 Trusts – about 95,000 respondents in total.
- The A&E Patient Survey sampled over 131,000 patients, comprising 850 patients from each Acute Trust, with 59,155 questionnaires returned.
- The Outpatient Survey sampled over 143,000 patients, comprising 850 patients from each Acute Trust, with 90,552 questionnaires returned.

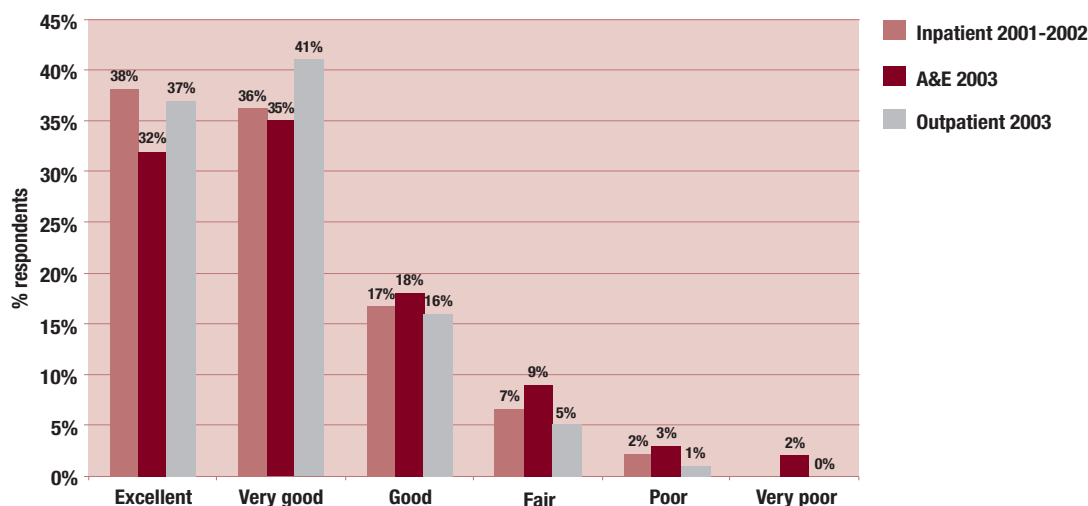
This dataset answers the question: *Overall, how would you rate the care you received?*

Rating	Acute inpatient 2001–02	A&E 2003	Outpatient 2003
Excellent	38%	32%	37%
Very Good	36%	35%	41%
Good	17%	18%	16%
Fair	7%	9%	5%
Poor	2%	3%	1%
Very Poor	N/A	2%	0%
Unweighted base	92,902	57,710	88,395

SOURCE: nhssurveys

This data, presented graphically below, shows that the majority of patients were pleased with the care they received in NHS Trusts. Overall, 74.4% of inpatients, 67% of A&E patients and 78% of outpatients surveyed rated their care as either excellent or very good.

**Figure 9.29b** Ratings of overall care



SOURCE: nhssurveys

### 9.30 Inpatient ratings of cleanliness

*Data source:* Department of Health: Acute Inpatient Survey 2001–02, (www.nhssurveys.org)

*Background:* The acute inpatient survey was carried out for the Department of Health as part of the NHS Patient Survey Programme. All NHS Acute Trusts were required to undertake the survey either in-house or using one of the approved survey contractors. The sample comprised at least 500 recently discharged patients from each of 176 Trusts – about 95,000 respondents.

This dataset presents the responses to two questions:

*In your opinion, how clean was the hospital room or ward you were in?* and

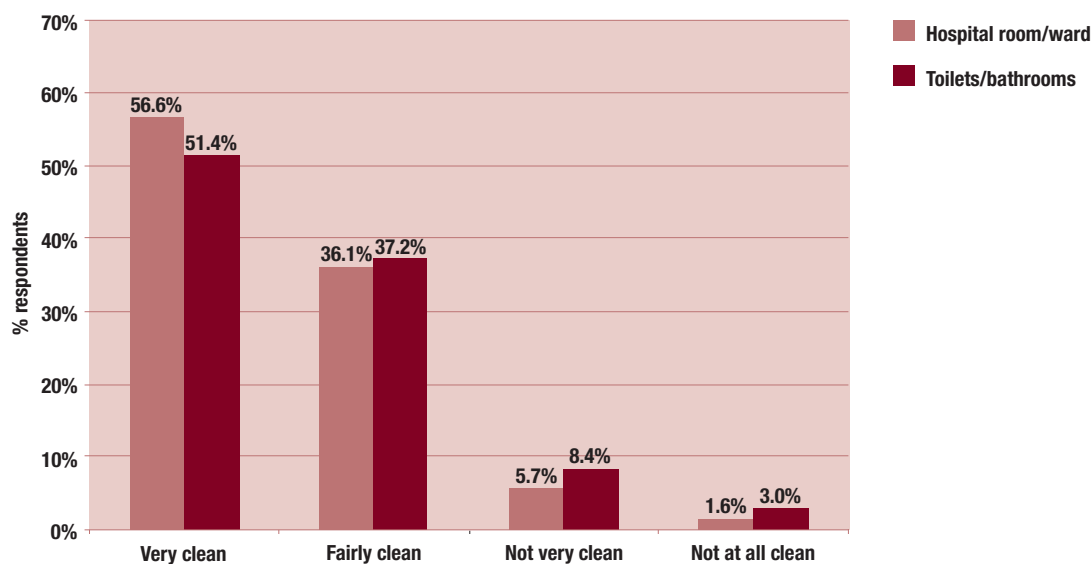
*How clean were the toilets and bathrooms that you used in hospital?*

Table 9.30a Patient perceptions of cleanliness		
	Cleanliness of room/ward	Cleanliness of toilets/bathrooms
Very clean	56.6%	51.4%
Fairly clean	36.1%	37.2%
Not very clean	5.7%	8.4%
Not at all clean	1.6%	3.0%
Unweighted bases	93,628	91,714

SOURCE: nhssurveys

This data, illustrated below, should be interpreted alongside the results in dataset 9.31, which show ratings of cleanliness in NHS Trusts as determined by dedicated inspection teams.

**Figure 9.30b** Inpatient ratings of cleanliness



SOURCE: nhssurveys

### 9.31 Ratings of the patient environment by inspection

*Data source:* Department of Health: NHS Estates (www.cleanhospitals.com and www.betterhospitalfood.com)

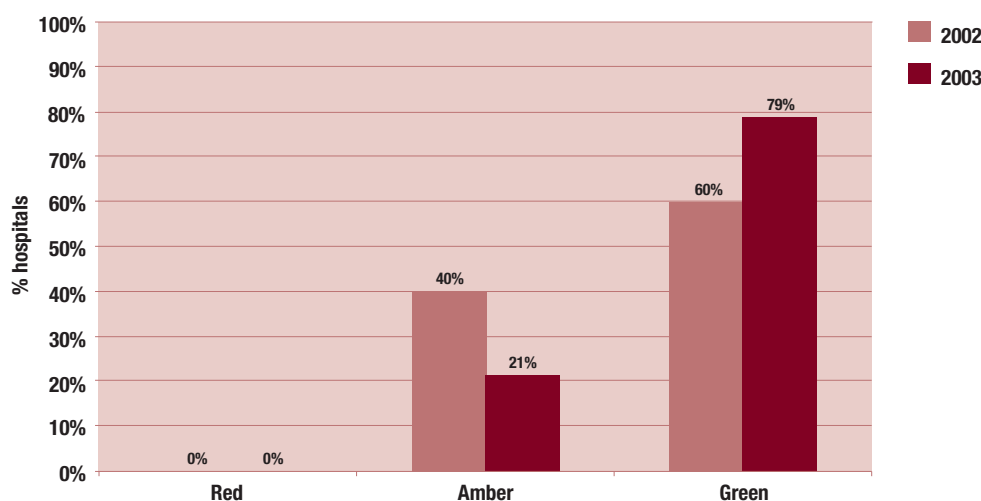
*Background:* Patient Environment Action Teams (PEATs) inspect hospitals and report on the patient environment (cleanliness and tidiness) and food services. PEAT visitors are volunteers, drawn from NHS managers, nurses, patients and patient representative organisations along with members of the general public. Based on PEAT reports, hospitals are awarded a ‘traffic light’ colour to denote a good (green), acceptable (amber) or poor (red) performance.

<b>Table 9.31a National cleanliness assessment results</b>			
	<b>Red (poor)</b>	<b>Amber (acceptable)</b>	<b>Green (good)</b>
Summer 2002	0 (0%)	317 (40%)	464 (60%)
Summer 2003	0 (0%)	186 (21%)	686 (79%)

SOURCE: NHS Estates

This data, illustrated below, is fairly consistent with the patient survey responses to questions about cleanliness; 56.6% of patients reported that their room or ward was very clean and 51.4% reported that the toilets and bathrooms were very clean.

**Figure 9.31b** National cleanliness assessment by Patient Environment Action Teams (PEATs)



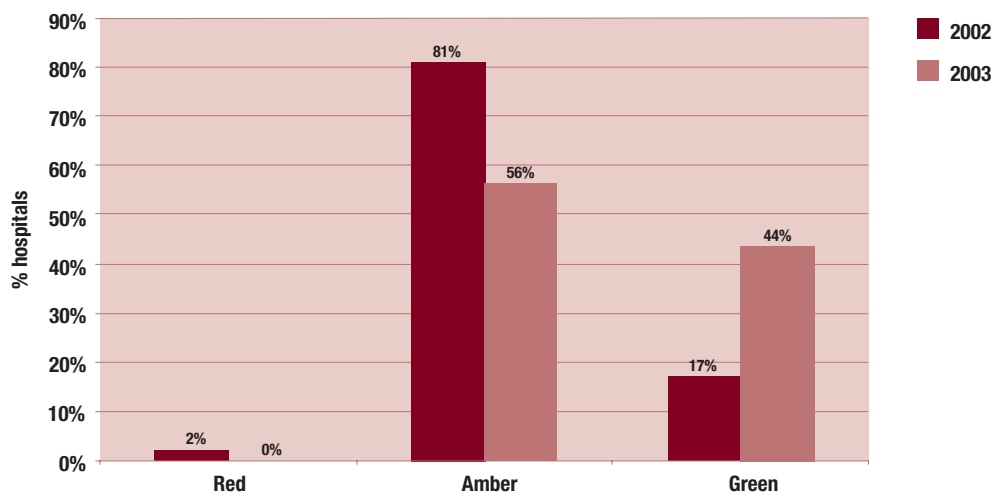
SOURCE: NHS Estates

The PEAT personnel also inspect food services provided to patients.

<b>Table 9.31c National food assessment results</b>			
	<b>Red (poor)</b>	<b>Amber (acceptable)</b>	<b>Green (good)</b>
PEAT Round 2002	14 (2%)	554 (81%)	118 (17%)
PEAT Round 2003	0 (0%)	479 (56%)	372 (44%)

SOURCE: NHS Estates

**Figure 9.31d** National food assessment by PEATs



SOURCE: NHS Estates

### 9.32 Ratings of pain control

*Data source:* Department of Health, Acute Inpatient Survey 2001–02, (www.nhssurveys.org)

*Background:* The acute inpatient survey was conducted for the Department of Health as part of the NHS Patient Survey Programme. All Acute NHS Trusts were required to undertake the survey either in-house or using one of the approved survey contractors. The sample comprised at least 500 recently discharged patients from each of 176 Trusts, about 95,000 respondents.

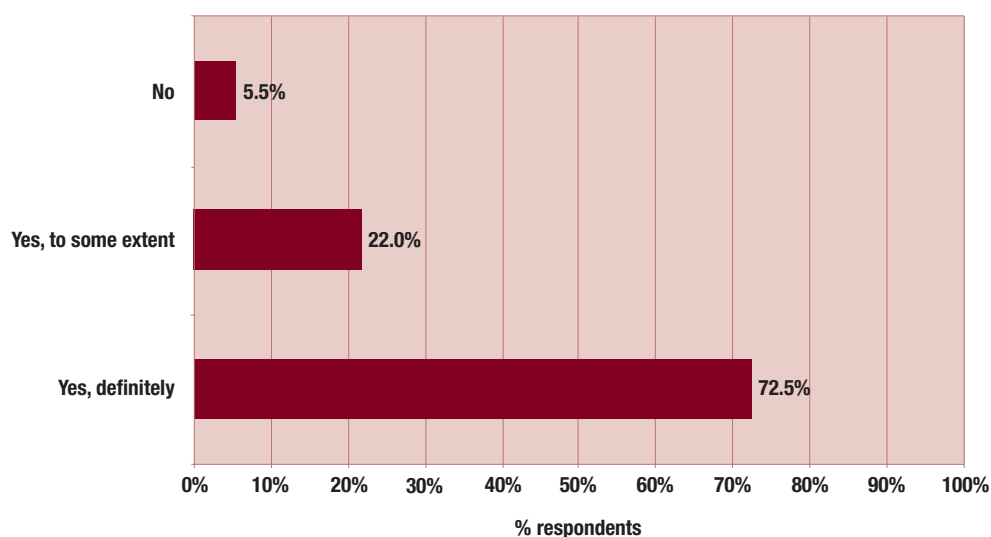
This dataset presents the responses to the question: *Did hospital staff do everything they could do to control pain?*

<b>Table 9.32a Did hospital staff do everything they could do to control pain?</b>	
<b>Response</b>	<b>% respondents*</b>
Yes, definitely	72.5
Yes, to some extent	22.0
No	5.5

\*Unweighted base = 61,128 (only those respondents who experienced pain whilst in hospital answered this question)

SOURCE: nhssurveys

**Figure 9.32b** Did hospital staff do everything they could do to control pain?



SOURCE: nhssurveys

### 9.33 Patient counselling for aftercare

*Data source:* Department of Health: Acute Inpatient Survey 2001–02, (www.nhssurveys.org)

*Background:* The acute inpatient survey was carried out for the Department of Health as part of the NHS Patient Survey Programme. All NHS Acute Trusts were required to undertake the survey either in-house or using one of the approved survey contractors. The sample comprised at least 500 recently discharged patients from each of 176 Trusts – about 95,000 respondents.

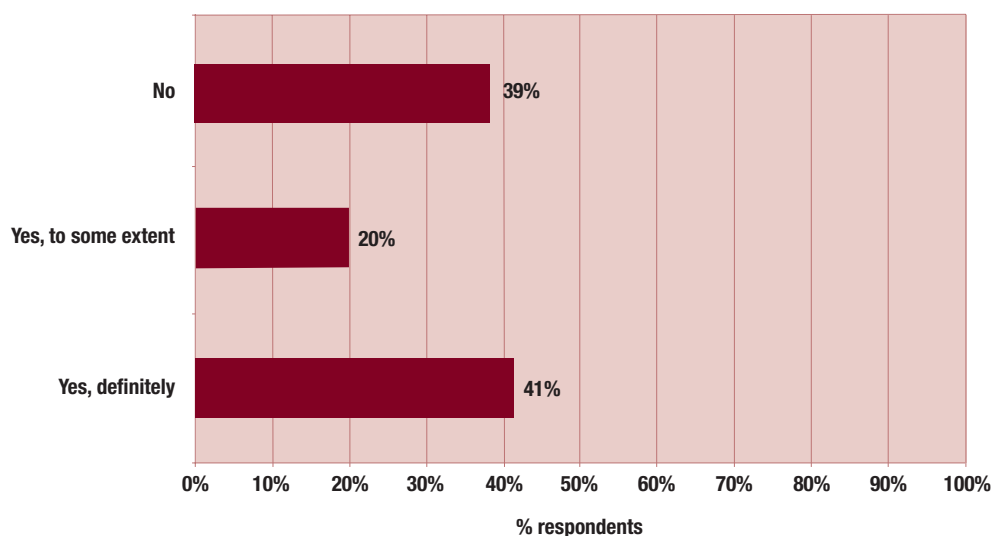
This dataset presents the responses to the question: *Did someone tell you about what danger signals regarding your illness or treatment to watch for after you went home?*

**Table 9.33a Did someone tell you about what danger signals regarding your illness or treatment to watch for after you went home?**

Response	% respondents
Yes, completely	41%
Yes, to some extent	20%
No	39%
Unweighted base	89,670

SOURCE: nhssurveys

**Figure 9.33b** Did someone tell you about what danger signals regarding your illness or treatment to watch for after you went home?



SOURCE: nhssurveys



### 9.34 Ratings of respect and dignity in care

*Data source:* Department of Health: General Practice Surveys 1998, 2002; Acute Inpatient Survey 2001–02; PCT survey 2003; A&E Patient survey 2003; Outpatient Survey 2003 ([www.nhssurveys.org](http://www.nhssurveys.org))

*Background:* The data is collected and collated from six separate patient surveys.

- Two general practice surveys were conducted. In 1998, 100,000 questionnaires were distributed with over 61,000 returned; in 2002, 263,100 questionnaires were sent, with over 145,000 returned. Subjects were identified from the electoral register.
- The Acute Inpatient Survey sampled at least 500 recently discharged patients from each of 176 Trusts – about 95,000 respondents in total.
- The A&E Patient Survey sampled over 131,000 patients, comprising 850 patients from each Acute Trust, with 59,155 questionnaires returned.
- The Outpatient Survey sampled over 143,000 patients, comprising 850 patients from each Acute Trust, with 90,552 questionnaires returned.
- In 2003, CHI conducted the PCT Patient Survey, and sent questionnaires to 250,000 individuals identified from PCT patient lists, with 123,833 returned.

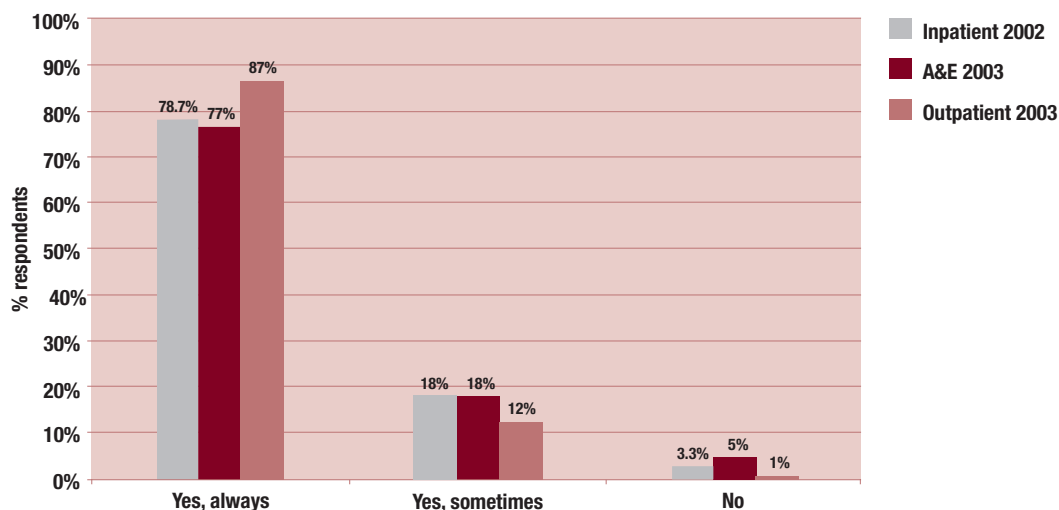
There were slight differences in the wording of the questions, and in the sampling frames, so these datasets do not constitute true time series and cannot be directly compared.

**Table 9.34a Overall, did you feel you were treated with respect and dignity while you were in hospital?**

	<b>Inpatient 2002</b>	<b>A&amp;E 2003</b>	<b>Outpatient 2003</b>
Yes, always	78.7%	77%	87%
Yes, sometimes	18%	18%	12%
No	3.3%	5%	1%
Unweighted base	92,961	57,596	88,353

SOURCE: [nhssurveys.org](http://nhssurveys.org)

**Figure 9.34a** Overall, did you feel you were treated with respect and dignity while you were in hospital?



SOURCE: nhssurveys.org

Table 9.34b How often does your GP treat you with courtesy and respect?		
	1998	2002
All of the time	78%	80%
Most of the time	15%	13%
Some of the time	4%	4%
Never, or hardly ever	1%	1%
Can't say	2%	2%
Unweighted bases	60,046	141,028

SOURCE: GP surveys 1998, 2002

Table 9.34c Did the person you saw treat you with courtesy and respect?	
	2003
All of the time	93%
Some of the time	6%
No	1%
	106,858

SOURCE: PCT survey 2003

### 9.35 Patient involvement in care

*Data source:* Department of Health: PCT Patient Survey 2003; A&E Patient Survey 2003; Outpatient Survey 2003 (www.nhssurveys.org)

*Background:* Data is presented from three patient surveys.

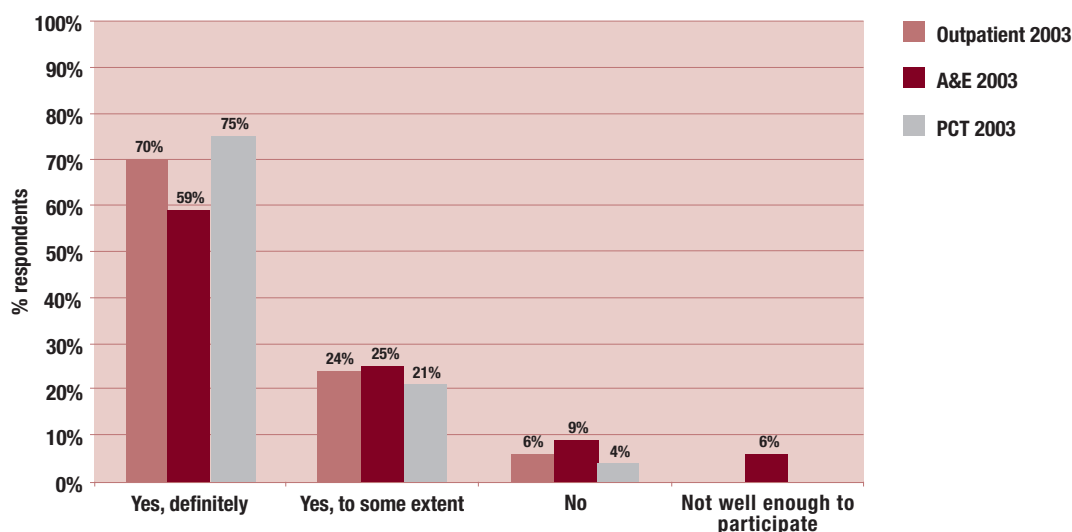
- The Outpatient Survey sampled over 143,000 patients, comprising 850 patients from each Acute Trust, with 90,552 questionnaires returned.
- The A&E Patient Survey sampled over 131,000 patients, comprising 850 patients from each Acute Trust, with 59,155 questionnaires returned.
- The PCT Survey sampled 250,000 individuals identified from PCT patient lists, with 123,833 questionnaires returned.

**Table 9.35a Were you involved as much as you wanted to be in decisions about your care and treatment?**

	Outpatient 2003	A&E 2003	PCT 2003
Yes, definitely	70%	59%	75%
Yes, to some extent	24%	25%	21%
No	6%	9%	4%
Too unwell	–	6%	–
Unweighted bases	86,905	56,843	105,881

SOURCE: nhssurveys

**Figure 9.35b Were you involved as much as you wanted to be in decisions about your care and treatment?**



SOURCE: nhssurveys

### 9.36 Physicians' views on their ability to provide quality care

*Data source:* Commonwealth Fund International Health Policy Survey of Physicians (2000) ([www.cmfw.org](http://www.cmfw.org))

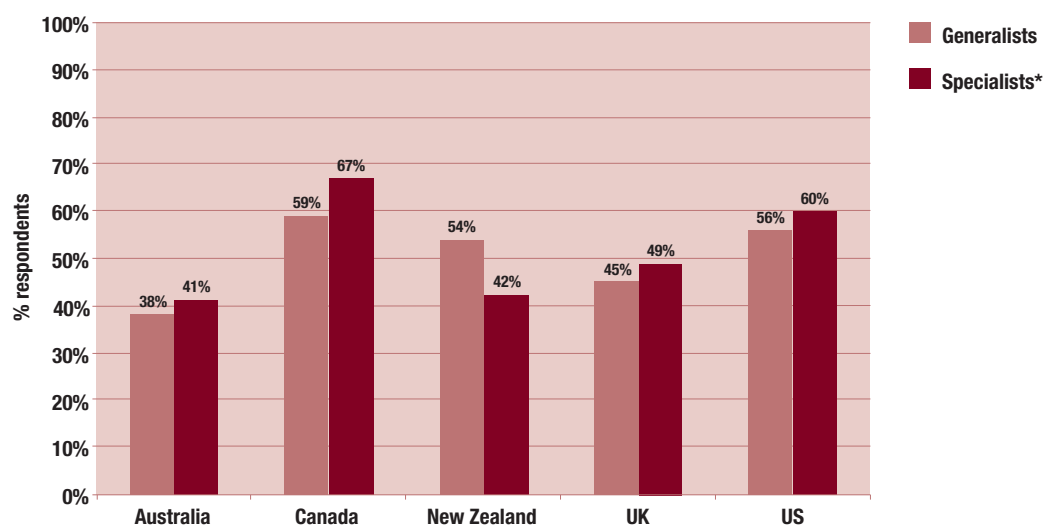
*Background:* The 2000 Commonwealth Fund International Health Policy Survey consisted of interviews with physicians in five countries. The sample size in each country was: Australia, 517; Canada, 533; New Zealand, 493; the UK, 500; and the US, 528. Generalist and specialist physicians were interviewed. Specialists were restricted to cardiologists, gastroenterologists and oncologists.

**Table 9.36a Percentage of physicians who think that their ability to provide quality care has worsened in the past 5 years**

	AUS	CAN	NZ	UK	US
Generalists	38	59	54	45	56
Specialists	41	67	42	49	60

SOURCE: Commonwealth Fund

**Figure 9.36b** Percentage of physicians who think that their ability to provide quality care has worsened in the past 5 years



\* Cardiologists, gastroenterologists and oncologists.

SOURCE: Commonwealth Fund

### 9.37 Patients' views of the health system

*Data source:* 2002 Commonwealth Fund International Health Policy Survey (www.cmwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of these four criteria:

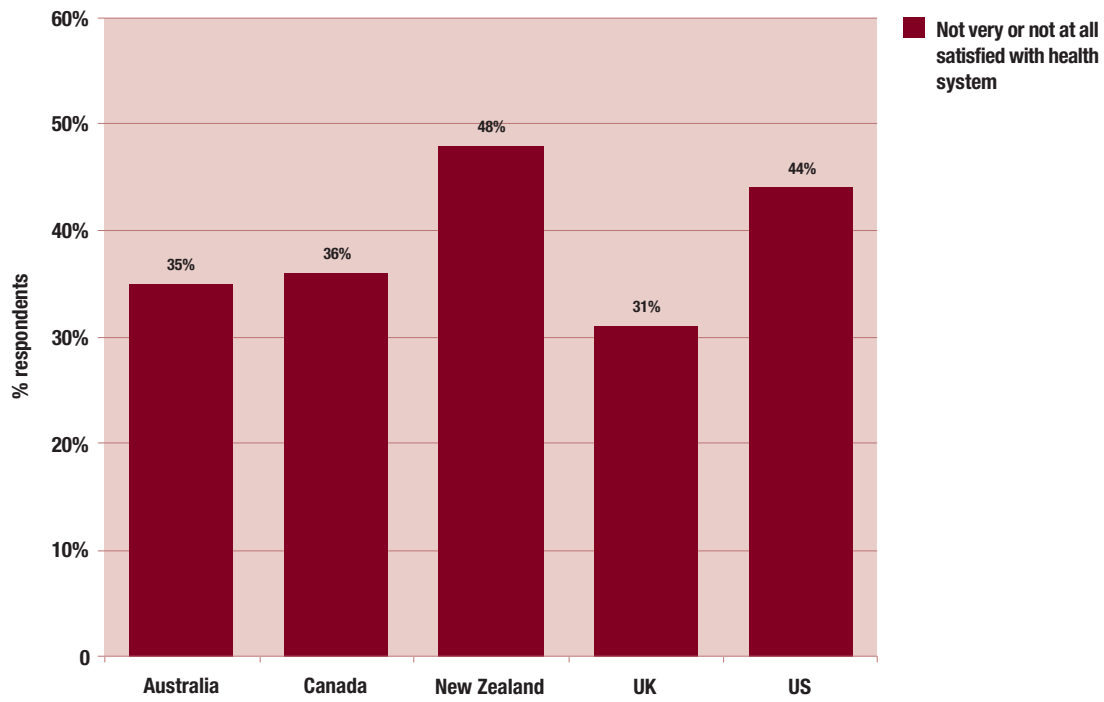
- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

**Table 9.37a Patients' views of the health system**

	AUS	CAN	NZ	UK	US
Satisfaction with the health system (% respondents)					
Very satisfied	15	21	14	25	18
Fairly satisfied	48	41	36	41	36
Not very satisfied	21	23	32	21	25
Not at all satisfied	14	13	16	10	19
Change in quality of care in past 2 years (% respondents)					
Worse than 2 years ago	15	24	11	13	13
About the same as 2 years ago	70	64	69	67	70
Better than 2 years ago	12	7	15	13	15

SOURCE: Commonwealth Fund

**Figure 9.37b** Dissatisfaction with the health system

SOURCE: Commonwealth Fund

### 9.38 Patient ratings of physician care

*Data source:* 2002 Commonwealth Fund International Health Policy Survey, (www.cmwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of these four criteria:

- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

<b>Table 9.38 Patient ratings of physician care</b>					
<b>% rating physician as excellent or very good in terms of:</b>	<b>AUS</b>	<b>CAN</b>	<b>NZ</b>	<b>UK</b>	<b>US</b>
How well he or she diagnosed your problem	67	62	68	57	58
Spending enough time with you	64	57	72	55	52
Being accessible by phone or in person	57	52	68	50	51
Listening carefully to your health concerns	72	66	76	65	62

SOURCE: Commonwealth Fund

### 9.39 Patient ratings of doctor-patient communication

*Data source:* 2002 Commonwealth Fund International Health Policy Survey (www.cmwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of these four criteria:

- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

**Table 9.39 Missed opportunities in patient discussions with regular doctor (% respondents)**

<b>Regular doctor does NOT:</b>	<b>AUS</b>	<b>CAN</b>	<b>NZ</b>	<b>UK</b>	<b>US</b>
Ask for your ideas and opinions about treatment and care	51	49	47	67	47
Keep you motivated to do the things you need to do	29	28	34	43	30
Make clear, specific goals for treatment	23	21	25	38	20
Help you to understand what you need to do for your health	12	14	17	26	14

SOURCE: Commonwealth Fund



#### 9.40 Patient ratings of difficulty seeing a specialist

*Data source:* 2002 Commonwealth Fund International Health Policy Survey, (www.cmwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of these four criteria:

- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

**Table 9.40 Difficulty seeing a specialist, and waiting problems**

<b>% reporting:</b>	<b>AUS</b>	<b>CAN</b>	<b>NZ</b>	<b>UK</b>	<b>US</b>
Very or somewhat difficult to see specialist	41	53	36	38	40
The following were “big problems” in the past 2 years:					
Long waits for hospital admission	20	28	21	19	13
Long waits for doctor’s appointments	17	24	5	21	14
Delay of scheduled surgery or procedure, because of cancellation	10	16	9	10	5

SOURCE: Commonwealth Fund

### 9.41 Patient accounts of medication and medical errors

*Data source:* 2002 Commonwealth Fund International Health Policy Survey  
(www.cmwf.org)

*Background:* The 2002 Commonwealth Fund International Health Policy Survey consisted of interviews with adults with health problems in five countries. The sample size in each country was: Australia, 844; Canada, 750; New Zealand, 750; the UK, 750; and the US, 755. The samples consisted of people who met at least one of these four criteria:

- they reported that their health was fair or poor;
- they had serious illness, injury or disability that required intensive medical care in the past 2 years;
- they had major surgery in the last 2 years; or
- they had been hospitalised for something other than a normal uncomplicated delivery of a baby in the last 2 years.

These sicker adults are among the most intensive users of the health care system, and are particularly vulnerable to variations in quality and outcomes of care.

**Table 9.41 Medication and medical errors reported by adults with health problems**

<b>% of adults with health problems who in the past two years:</b>	<b>AUS</b>	<b>CAN</b>	<b>NZ</b>	<b>UK</b>	<b>US</b>
Were given the wrong medication or wrong dose by a doctor, hospital or pharmacist	11	11	13	10	12
Believed either a medication error or a medical mistake was made	23	25	23	18	28
Believed an error or mistake caused serious health problems	13	15	14	9	18

SOURCE: Commonwealth Fund

**DISPARITIES AND EQUITY**

Disparities and equity measures include:

- affordability of health care;
- access;
- differences in process of clinical care;
- differences in experience of care; and
- outcomes; mortality rates.

Data displays:

9.42 Concerns about affordability – an international comparison

9.43 Infant mortality rates, by social class

9.44 Ease of attending GP surgery for those with disabilities

9.45 Quality indicators for older patients – a case study

9.46 Respect for patients – different perceptions between ethnic groups

### 9.42 Concerns about affordability – an international comparison

*Data source:* 2001 Commonwealth Fund International Health Policy Survey  
(www.cmwf.org)

*Background:* The 2001 Commonwealth Fund International Health Policy Survey consisted of telephone interviews with 1,400 adults in each of five countries: Australia, Canada, New Zealand, the UK and the US.

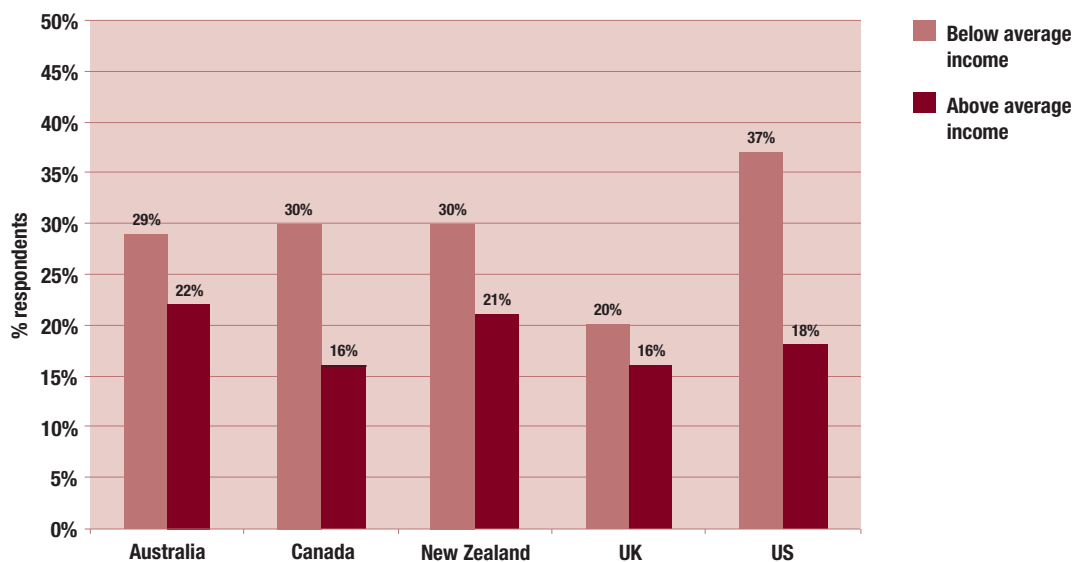
**Table 9.42a Percentages of people concerned about their ability to afford health care\***

	AUS	CAN	NZ	UK	US
Below average income	29	30	30	20	37
Above average income	22	16	21	16	18

\* Country averages of people questioned who were very worried that they would not be able to get the most advanced care if seriously ill; would not be able to afford treatment if seriously ill; would not be able to pay for long-term care; or would wait too long for non-emergency care.

SOURCE: Commonwealth Fund

**Figure 9.42b Percentages very worried about future ability to get health care (survey in five countries)**



SOURCE: Commonwealth Fund

### 9.43 Infant mortality rates, by social class

*Data source:* Office for National Statistics Mortality and Birth Statistics: *Health Statistics Quarterly* 17, Spring 2003 ([www.statistics.gov.uk](http://www.statistics.gov.uk))

*Target:* By 2010, to reduce by at least 10% the gap in infant mortality between routine and manual groups and the population as a whole (Public Service Agreement, 2001; Spending Review 2002 Public Service Agreement; *Tackling Health Inequalities – A Programme for Action*, 2003: p.7).

**Table 9.43a Deaths per 1,000 live births**

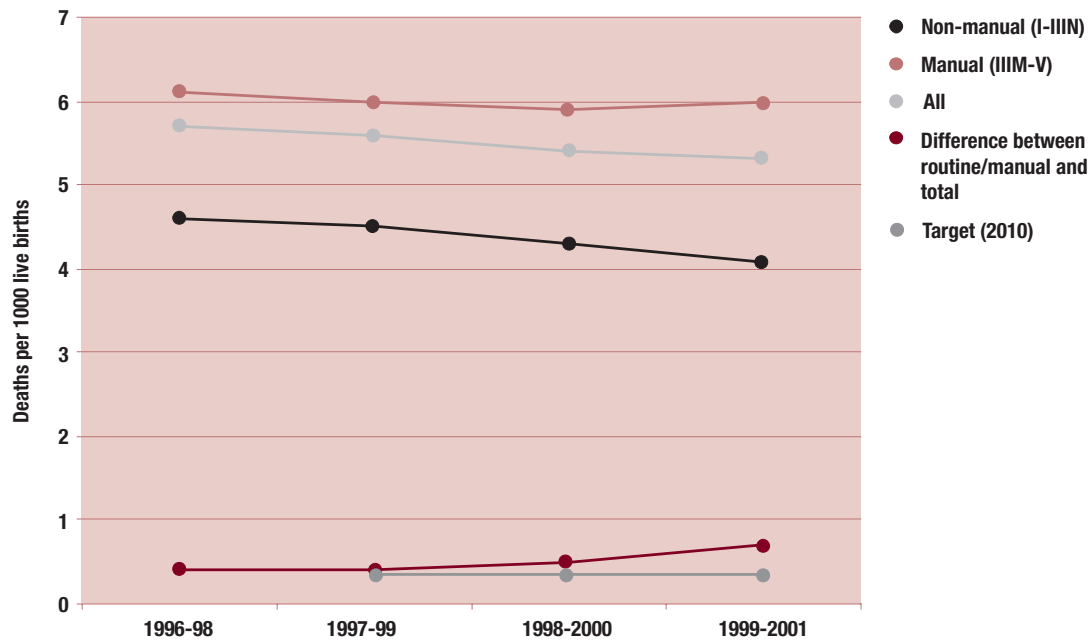
<b>Social class</b>	<b>1996–98</b>	<b>1997–99</b>	<b>1998–2000</b>	<b>1999–2001</b>
I Professionals	4.1	4.2	4.0	3.8
II Managerial and technical	4.4	4.2	4.1	3.8
IIIN Skilled non-manual	5.4	5.3	5.3	5.3
IIIM Skilled manual	5.6	5.5	5.4	5.4
IV Partly skilled manual	6.4	6.4	6.2	6.4
V Unskilled manual	7.9	7.8	8.1	8.0
Non-manual (I–IIIN)	4.6	4.5	4.3	4.1
Routine and manual (IIIM–V)	6.1	6.0	5.9	6.0
All (within marriage or outside marriage, jointly registered by both parents)*	5.7	5.6	5.4	5.3
Difference between routine/manual and total	0.4	0.4	0.5	0.7

England and Wales – 3-year averages

\* Dataset does not include sole registrations, as social class is defined by the father's occupation.

SOURCE: Office for National Statistics

The baseline for the target is 1997–99, when there was a difference of 0.4 between infant mortality rates in routine/manual groups and the population as a whole. A 10% reduction equates to a target difference for 2010 of 0.36 deaths/1,000 live births. To date, there has been a deterioration rather than an improvement.

**Figure 9.43b** Infant mortality rates by social class

SOURCE: Office for National Statistics

### 9.44 Ease of attending GP surgery for those with disabilities

*Data source:* Department of Health, General Practice Survey 1998 and 2002 (www.nhssurveys.org)

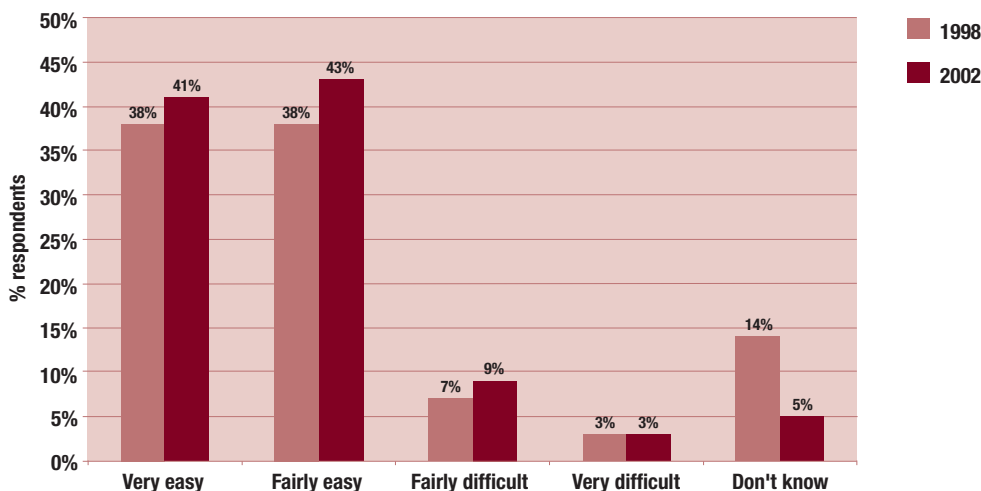
*Background:* The general practice surveys were carried out for the Department of Health as part of the NHS Patient Survey Programme. Questionnaires were sent to individuals in England identified from the electoral register. In 1998, 100,000 questionnaires were sent, with over 61,000 returned; in 2002, 263,100 questionnaires were sent, with over 145,000 returned.

**Table 9.44a Patient perceptions of ease of attending surgery for those with disabilities**

	1998	2002
Very easy	38%	41%
Fairly easy	38%	43%
Fairly difficult	7%	9%
Very difficult	3%	3%
Don't know	14%	5%
Unweighted bases	60,112	141,977

SOURCE: nhssurveys

**Figure 9.44b** Ease of attending GP's surgery for those with disabilities



SOURCE: nhssurveys

### 9.45 Quality indicators for older patients – a case study

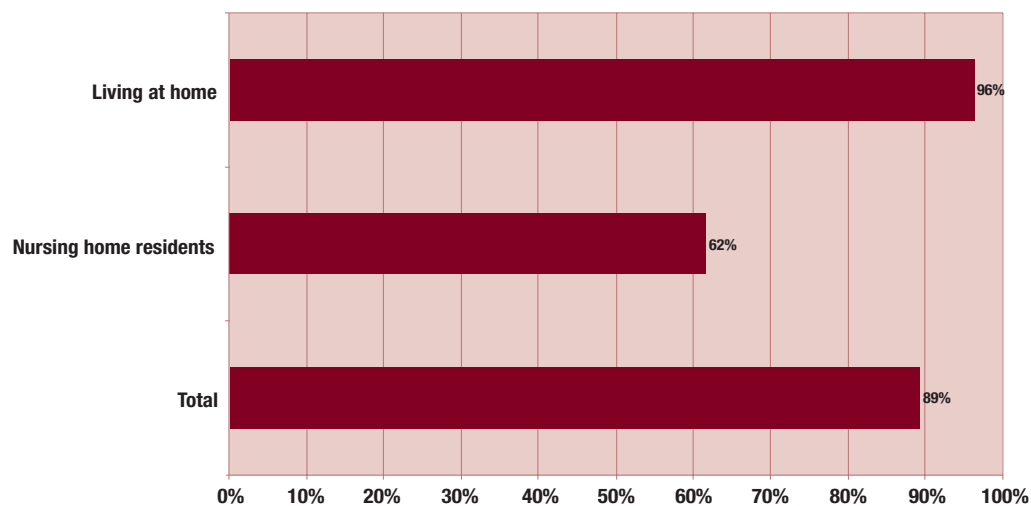
*Data source:* Fahey, T., et al. 2003 'Quality of care for elderly residents in nursing homes and elderly people living at home: controlled observational study', *British Medical Journal*, vol. 326, pp580-585.

*Background:* This data is drawn from three general practices in Bristol. The medical records of all patients > 65 years were examined. The sample size was 698, comprising 172 nursing-home residents and 526 people living at home. Although this is a small data set and the findings must be interpreted with care, it represents a useful example, and raises questions about equity of care for the elderly across the country.

Table 9.45a Quality indicators for older patients			
Quality indicators	Nursing-home residents (%)	Patients living at home (%)	P-value
Offered influenza vaccine	74	78	0.36
If diagnosis of coronary heart disease:			
Prescribed aspirin (unless contraindicated)	70	60	0.29
Blood pressure recorded in past 2 years	74	96	0.018
Prescribed beta-blockers after MI (unless contraindicated)	40	38	0.54
If diagnosis of hypertension:			
Blood pressure recorded in past year	53	85	< 0.001
If diagnosis of diabetes:			
HbA1C recorded in past year	54	85	0.07
Blood pressure recorded in past year	62	96	0.004
Offered pneumococcal vaccine	23	63	0.02

We present one of these indicators graphically:

**Fig 9.45b** Percentage of elderly patients with diabetes who had their blood pressure recorded in the past year



SOURCE: Fahey et al (2003)



### 9.46 Respect for patients – different perceptions between ethnic groups

*Data source:* Department of Health, Acute Inpatient Survey 2001–02, (www.nhssurveys.org)

*Background:* The acute inpatient survey was carried out for the Department of Health as part of the NHS Patient Survey Programme. All NHS Acute Trusts were required to undertake the survey either in-house or using one of the approved survey contractors. The sample comprised at least 500 recently discharged patients from each of 176 Trusts – about 95,000 respondents.

This dataset presents the answer to the question: *Did doctors/nurses often talk in front of you as if you weren't there?*

Overall, 71.3% of respondents answered that doctors did **not** often talk in front of them as if they were not there. The equivalent figure concerning nurses was 81.2%.

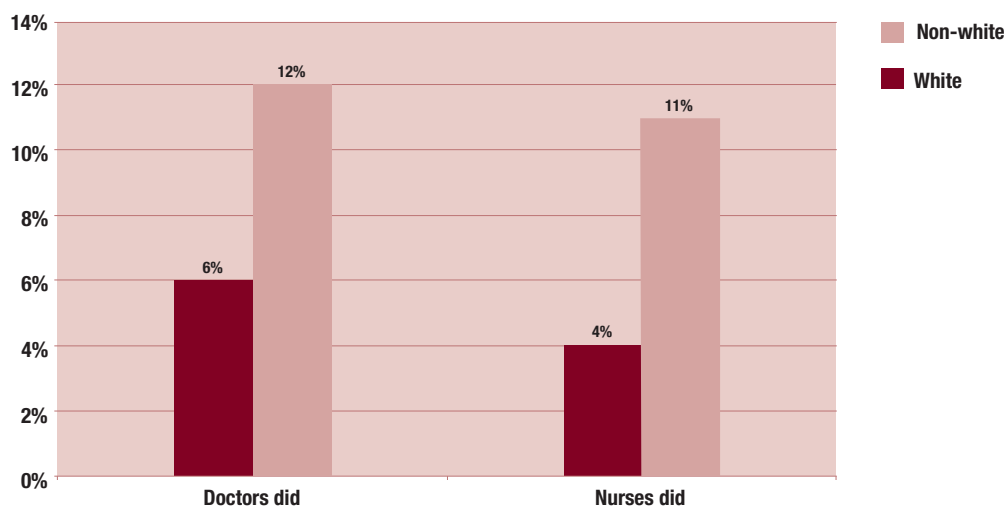
However, there were differences in the responses of white and non-white respondents:

**Table 9.46a Perceptions about whether doctors and nurses spoke in front of patients as if they weren't there, by ethnic group**

	White respondents	Non-white respondents
Doctors did	6%	12%
Nurses did	4%	11%

SOURCE: nhssurveys

**Figure 9.46b** Perceptions about whether doctors and nurses spoke in front of patients as if they weren't there, by ethnic group



SOURCE: nhssurveys

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## SECTION IV

# Essential Building Blocks for the Quality Agenda

This section of the book addresses the third evaluation question of this project: is the Quality Agenda sustainable? It will examine a number of critical issues and tasks that will influence the future impact of the Quality Agenda as well as its durability.

In the article ‘Evolving quality in the NHS: Policy, process and pragmatic considerations’ (Leatherman & Sutherland 1998), a number of discrete tasks were named as critical to the future effectiveness and sustainability of the Quality Agenda. They included:

- clarifying the underlying assumptions regarding the regulatory framework for performance improvement and accountability;
- influencing NHS organisational culture;
- engaging the public;
- optimising the role of primary care in all quality initiatives;
- advancing the state of the art of public performance reporting; and
- developing capabilities of information technology, including data and analysis.

These particular topics are as salient today as they were five years ago. Progress has been made in each area, but much work remains to be done. In this section of the book, we address these critical areas individually by assessing their current status and future needs.

We are indebted to five colleagues who generously devoted their wealth of expertise in authoring four of the six chapters on the building blocks of the Quality Agenda: *Angela Coulter, Martin Roland, Judith Smith, Martin Marshall and Don Detmer.*

## 10. Clarifying the Big Picture: Policy Assumptions for Improving Quality and Accountability

*Overall, it appears that the Government is travelling in the right direction – that is, towards a more robustly funded NHS, improved standards of health and social care, more patient-centred services and a system that is trying to reduce health inequalities. Some adjustments in style and emphasis could help to consolidate progress made so far... the Government must prepare the public for the long haul. It is time to stop making heroic promises and buckle down to the unglamorous detail of building a good-enough health system for the 21st century.*

(Appleby & Coote 2002; Coote 2002)

The “unglamorous” work referred to above should be founded upon a clear definition of the overall strategy for quality in the NHS and an explicit articulation of the assumptions and models underlying that strategy. This task may not be as satisfying as establishing new organisations to tackle Herculean jobs, such as the inspection of the entire health care service delivery apparatus. However, it may have the same or greater impact, if it results in a common understanding of, and concurrence with, the decision-making processes for the regulatory models being implemented.

Much of the first five years of the Quality Agenda has focused on tasks such as developing policy, enacting legislation, building organisational capacity and creating regulatory capabilities. The next half of the Ten-year Agenda should focus on devolution, emphasising capacity building at the institutional and individual levels of the health care system. This will require clarity regarding the assumptions underlying policy and strategy. Clear and public articulation is needed in order to explain the reasoning that underpins the overall strategy; to justify the selection of particular methods to catalyse change; and to justify the means through which coherent and effective accountability will be provided.

Looking across the Quality Agenda at a strategic level, there are three fundamental questions that require clarification.

- What does “accountability” mean in the context of the UK health care system, and how is it to be operationalised?
- Is the introduction of a quasi-market model to be a significant mechanism in stimulating quality improvement?
- How much will quality of care be managed top-down as against bottom-up?

### Accountability and performance improvement

Accountability has become a rallying cry for quality worldwide. It is frequently invoked, but rarely defined. The absence of operational definitions complicates actualisation. Table 10.1 shows three conceptual models of accountability and performance improvement in health care – governmental, professional and economic. Each model adopts a different perspective of the primary role of the patient within the system; as a passive recipient of services, a discerning consumer, or a member of a community with access to health care as a public good. Each model uses different approaches to providing accountability for performance. In the professional model, a patient receives services from a physician who is held accountable to professional norms by ethical standards, using instruments such as licensing, appraisal and revalidation. This contrasts sharply with the economic or market model, which conceptualises health care as a commodity purchased within a regulated market. In this model, performance and accountability are driven by choice within the competitive market, and in the case of unsatisfactory performance, the patient exercises “exit”. In the governmental or political model, the patient receives health care as an entitlement of citizenship or residency, and performance of the health care system is galvanised by government reforms, in response to the public voice (Emanuel & Emanuel 1996).

<b>Table 10.1 Three theoretical models of performance and accountability</b>			
	<b>Conception</b>	<b>Domain of patients</b>	<b>Methods of accountability</b>
<b>Professional</b>	Recipient of professional services	Patient, physician, professional association	Licensure, certification, peer review, liability
<b>Economic</b>	Consumer of health care commodity	Marketplace and regulation	Choice and “exit”
<b>Political</b>	Citizen receiving, a public good	Government reforms and actions	“Voice” and government pressure

SOURCE: Adapted from Emanuel & Emanuel 1996

The US and UK can be contrasted in terms of their historical pathways. Although with dramatically different health care systems in mission, resources and structures, the two countries are moving towards each other in adopting a blended model of accountability. Each has reduced its historical reliance on professionalism as a robust mechanism for affecting improved performance. For the past several decades, the US has relied heavily on the market model, in contrast to England, where the NHS has moved from depending on the professional model to, more recently, emphasising the political model. As the US is forced to face the issues of universality and social equity, which underpin health systems in many countries, greater government intervention will be needed. In contrast, the UK is now introducing market dynamics as a way of actualising the rhetoric of patient-centredness to facilitate choice and stimulate efficiency (Glennister 1998).

### **Introducing market dynamics**

One could argue that a quasi-market model of health care is being introduced in England. The use of such language as “markets” incites great debate in England; however, many of the newly introduced levers for change are founded on what one might describe as “market dynamics”. These include the notion of patient choice, performance-based contracts, provision of performance information to patients, facilitating informed choice and demand, and incentives of a financial and a non-financial nature.

The NHS is commonly viewed as being in a state of chronic flux – a feature that does not distinguish it from health systems around the world. Now, it appears that the institution is undergoing a significant metamorphosis, manifested by a debate about the assumptions underpinning public service organisation and delivery for the present and the future. In February 2003, Chancellor of the Exchequer Gordon Brown remarked (Brown 2003):

*Take the health service. The essential question in a world of advancing technology, expensive drugs and treatments and rising expectations is whether efficiency, equity and responsiveness to the patient are best delivered through a public health care system or whether, as with commodities generally, market arrangements, such as the hospital selling and the patient buying, are the best route to advancing the public interest.*

As recently as 2002, an astute NHS observer wrote, “the government has moved away from using markets, competition and contracting to manage performance in the NHS” (Walshe 2002, p. 967). Yet what we witness in 2003 is a Government attempting to catalyse market dynamics of patient choice, address the asymmetry of information and implement “pay for performance” contracts.

A clearly right or wrong choice does not exist. However, it is imperative to define the model, make explicit the working assumptions and provide evidence as to the most reasonable instruments and tools to operationalise the model. Wild swings between vilification of the markets in 1997 and implementation of policies to stimulate market forces five years later are too dizzying for an already overburdened and confused health sector to be able to absorb without the assistance of public explanation.

### **Managing quality from the top down and bottom up**

As the Quality Agenda moves into mid-term status, it is time to ask: what is the desired blend of “top-down” and “bottom-up” leadership? What is the true intention regarding centralisation or decentralisation?

In England, health care is a public good, and central government is responsible for its allocation. Thus, the design and implementation of health care is transparently driven by policy articulation, centralisation of effort and production of information for top-down

management. In a contrasting model, the US views health services as a consumer product provided in a competitive market, influenced by a patchwork of regulation and faith in informed consumerism. The differences in strategy and operationalisation of quality largely reflect the fundamental structural and ideological orientations of the two countries.

The UK would seem to have an inherent advantage for systemically improving quality. This may, in fact, become evident in the coming years. It is possible in a centralised system to set policy, define priorities and accordingly allocate resources and align incentives. Centralisation has been a comfortable mode of operation in the UK, and is apparently not as controversial, at least until recently, as it would be in the US. Certainly, arguments can be made that some functions can be performed better by the centre, such as creating the legislative and regulatory frameworks, standard setting, performance monitoring and defining a locus of accountability.

Problems exist in centralised model, most particularly in terms of effectively managing an organisation on the scale and complexity of the NHS. Devolved power is needed if services are to be responsive to legitimate local priorities and to foster much-needed decentralised leadership. Moving away from central and regional control to a more devolved approach involving institutions and providers is challenging for many reasons. Perhaps the most strident challenge is reconciling local accountability with national level funding. As the collector of taxation monies that are the primary source of funding for the health service, the Government is almost inevitably seen by the electorate as ultimately responsible for the health care system. The buck stops with the Government; it is, therefore, uncomfortable and difficult for them to relinquish control.

There are obviously risks with centralisation and with devolution. However, the highest risks are in muddling through with an ambiguous or weakly articulated model. Whether it is intentional or serendipitous, England may very well be creating a fortuitously blended model, capitalising on the strengths of centralised design and devolved implementation. Moving forward, however, the model needs careful explication in order to allow managers and clinicians throughout the NHS to understand the organisational and strategic context in which they are going to operate in the future.

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# 11. Securing Change in Organisational Culture

## Introduction

The quality reforms undertaken by the New Labour Government since its election in 1997 are ambitious in scope and scale (see Box 11.1). Underpinning the Quality Agenda is an understanding that securing change in organisational culture, alongside concomitant structural reforms, is critically important in delivering significant health care improvement.

*Achieving meaningful and sustainable quality improvements in the NHS requires a fundamental shift in culture, to focus effort where it is needed and to enable and empower those who work in the NHS to improve quality locally.*

(DOH 1998, p. 71)

### BOX 11.1

#### Examples of the transformational changes sought in the new NHS

The Quality Agenda aspires to transform the NHS into an organisation that:

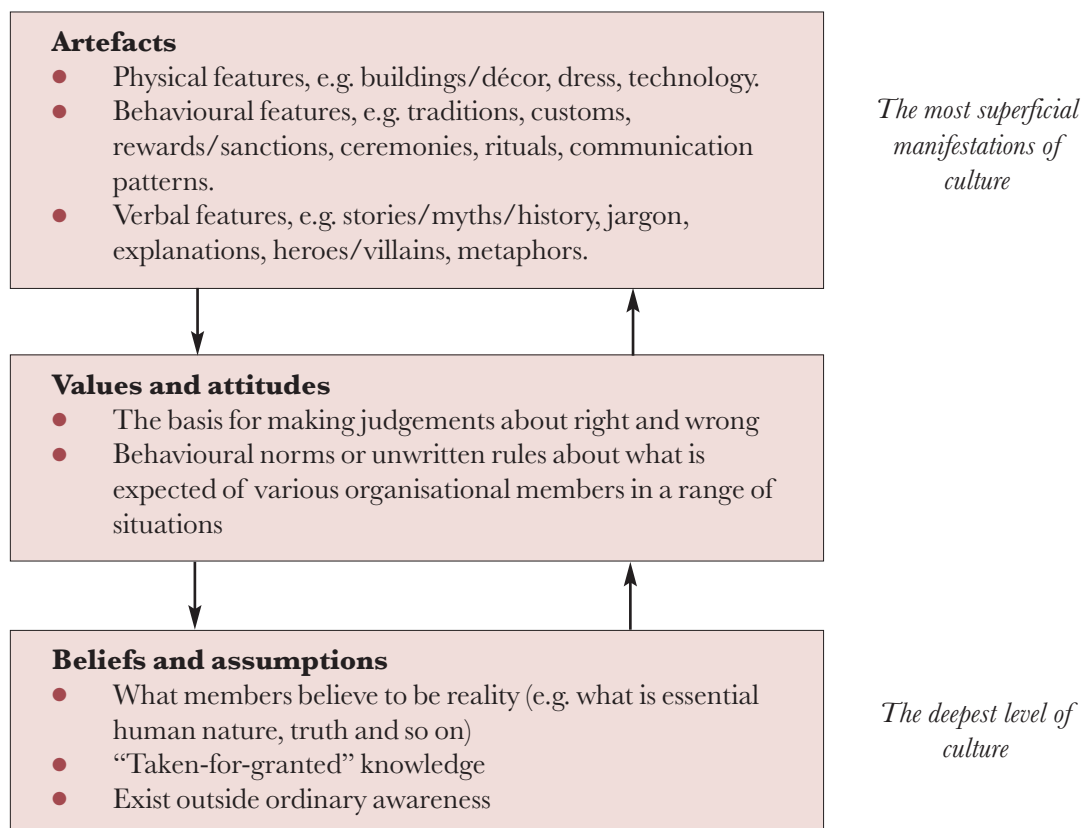
- is patient-centred (DOH 2000a, p. 17)
- is open and accountable (DOH 1997)
- celebrates and encourages success and innovation (DOH 1998, p. 72)
- learns from failure (DOH 2000b)
- is a model employer (DOH 2000a, p. 14)
- empowers those who work in the NHS to improve quality locally (DOH 1998, p. 71)
- fosters effective teamworking (DOH 1997, p. 46; 1998, p. 35)
- supports and develops local leaders (DOH 1997, p. 61)

SOURCES: DOH 1997; 1998; 2000a; 2000b

Organisational culture is an ambiguous concept with many and varied definitions (see, for example, Alvesson 1993; Brown 1998). It encompasses a network of values, beliefs, attitudes and expectations that members of an organisation hold (Schwartz & Davis 1981; Denison 1990; Williams et al. 1993; *inter alia*). Many see culture as a social construct. Organisational culture guides the behaviour of individuals, and simultaneously is shaped by those behaviours (Scholz 1987; Martin 1992).<sup>†</sup>

Highly complex, culture comprises both multiple layers and facets. Theoretical models often conceptualise organisational culture as three interconnected levels, ranging from the superficial to the deeply embedded (Schein 1985). On the surface are the most accessible and tangible manifestations of culture – artefacts. Underneath artefacts are cultural values and attitudes; and at the deepest level lie beliefs and assumptions (see Figure 11.1, adapted from Schein 1985). Cultural change occurs when new values are embedded into the basic assumptions held by the group.

**Figure 11.1** Layers of organisational culture



<sup>†</sup> Furthermore, the extent to which organisational culture is open to manipulation is contestable. Some see culture as an alterable organisational attribute, although one that cannot necessarily be altered in a straightforward or predictable manner. Others view culture as a metaphor for an organisation – a means of understanding what an organisation is – largely immune from orchestrated change efforts.

### Why is culture important in the quality agenda?

Culture is important because it offers insight into how to secure significant quality and health care improvement. In a study about the relationship between organisational culture and performance in the NHS, Mannion et al. (2003) identified a range of cultural characteristics that appear to be linked to organisational performance (see Box 11.2).

#### BOX 11.2

#### Links between cultural traits and organisational performance in NHS Acute Trusts

##### High-performance Trusts

- Characterised by top-down command and control styles of leadership
- Long tradition of strong directional leadership from the centre; senior management team sets clear and explicit performance objectives, establishes robust internal performance management and monitors support of these aims
- Clear and largely unequivocal lines of upward accountability
- Proactive approach to managing the local health economy
- Place considerable emphasis on developing and harnessing staff potential to deliver the external performance improvement agenda
- Place high priority on recruiting and retaining staff who display a high commitment to the corporate rather than purely professional agenda

##### Low-performance Trusts

- Leaders regarded as charismatic, but lacking transactional skills required to develop and maintain robust systems of performance management
- Senior management teams remote and self-regarding, intolerant of criticism, shaped by self-interest
- Underdeveloped and emasculated tier of middle management
- Confused and fragmented systems of accountability
- Poor relationships with other key stakeholders and local health-influencing organisations
- Human resource policies ignored or under-developed

SOURCE: Mannion et al 2003

Whilst popular opinion holds that particular cultural traits produce performance improvement, Mannion et al. point out that the reverse may be true – high-performing organisations may facilitate the development of particular cultural traits or, more likely, there is a reciprocal and mutually reinforcing relationship between organisational culture and performance.

Organisational culture is instrumental in co-ordinating activity, galvanising action and managing and motivating staff. In an organisation as vast as the NHS, it is impossible to co-ordinate and monitor individual members through explicit and overt control mechanisms. Far too many single encounters, decisions and actions occur every day for it to be feasible to monitor each one. Processes that are central to the development and perpetuation of organisational culture – socialisation, building organisational commitment and promulgating desirable behavioural norms – provide much more efficient and effective ways of co-ordinating and managing behaviour (Pfeffer 1997). Within the NHS, various professions widely use social control mechanisms to inculcate, nurture and propagate values, beliefs and assumptions amongst their members.

### ***The status of organisational culture in 1997/8***

Any description of NHS culture is necessarily a gross simplification of a broad range of disparate and multi-faceted characteristics. Yet it is possible to identify a number of distinguishing features that invoke the essence of the NHS in 1997. These features included a strong commitment to the public service principles underpinning the NHS, which view health care as a public good that should be delivered equitably. However, potentially problematic cultural attributes of the NHS have also been identified, including:

- a paternalistic relationship between professional and patient (Brown 1998);
- strong subcultures, both within and between professional groups (Harrison & Pollitt 1994; Degeling et al. 1998);
- work patterns that are task-oriented, rather than patient-oriented (Joss & Kogan 1995);
- medical models of care rather than holistic patient-centred approaches (Joss & Kogan 1995);
- power concentrated at the top and dominated by government; and
- low levels of staff morale (Finlayson 2002).

The problems created by such cultural characteristics were underlined in a report by the public inquiry into children's heart surgery at the Bristol Royal Infirmary (BRI Inquiry 2001). The

report describes an organisational culture that was secretive, defensive and shirked accountability. Professional affiliations outweighed affiliations with employer organisations. Patients did not receive sufficient respect and honesty. The report advised that

*the culture of the future must be a culture of safety and of quality; a culture of openness and accountability; a culture of public service; a culture in which collaborative teamwork is prized; and a culture of flexibility in which innovation can flourish in response to patients' needs (p. 13).*

In response to such perceived cultural inadequacies, the Government articulated a number of desirable culture shifts (see Table 11.1).

**Table 11.1 Desirable cultural shifts for the NHS**

	<b>From</b>	<b>To</b>
A shift in organisation and ways of working	<ul style="list-style-type: none"> <li>● hierarchical &amp; nationalised</li> <li>● detailed guidance with many milestones &amp; targets</li> <li>● focus on institutions</li> </ul>	<ul style="list-style-type: none"> <li>● devolved local networks</li> <li>● clear, long-term outcomes with latitude about method</li> <li>● working through networks</li> </ul>
A shift in the scale and quality of staff, patient and community involvement	<ul style="list-style-type: none"> <li>● small pockets of excellence</li> <li>● many enthusiasts but not fully embedded</li> <li>● supported by time limited 'soft' funding</li> <li>● many Boards still viewing this as peripheral to core business</li> </ul>	<ul style="list-style-type: none"> <li>● mainstream way of achieving change</li> <li>● professional &amp; systematic everywhere</li> <li>● properly resourced through recurring funds</li> <li>● central to Boards' way of working</li> </ul>
A shift in management focus	<ul style="list-style-type: none"> <li>● all management effort driven by delivery of centrally imposed key targets as ends in themselves</li> <li>● meetings, plans and strategy dominating management time</li> <li>● risk avoidance because of fear of penalties</li> </ul>	<ul style="list-style-type: none"> <li>● delivery of targets achieved as the by-product of wider sustained improvements in service quality</li> <li>● walking the job with a strong focus on clinical quality</li> <li>● incentives as a key part of improvement</li> <li>● penalties seen by all as fair</li> </ul>

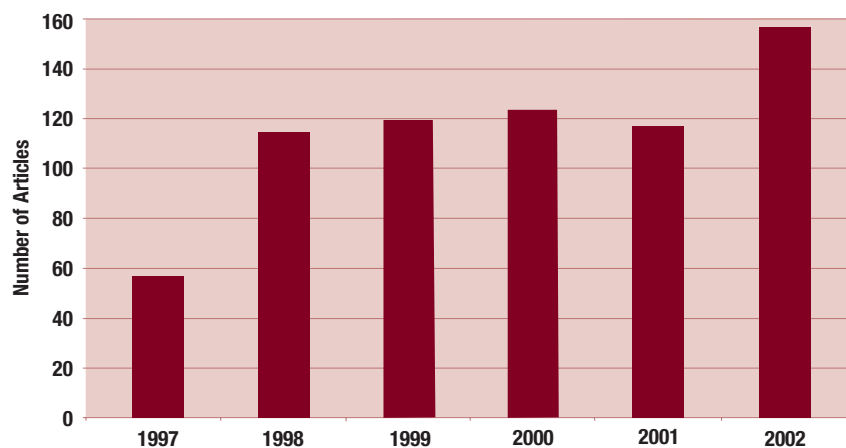
SOURCE: DOH 2002

### Progress in developing an organisational culture conducive to quality of care

Policy reforms, stretching back almost 20 years to the introduction of general management into the NHS (Griffiths 1984), have sought to bring about cultural change as a means of securing health care improvement. Changes in health policy have been successful in bringing about changes in cultural artefacts. Language, for example, shifted from an administrative focus to one much more steeped in business and managerial concepts (Pettigrew et al. 1992).

The policies flowing from *The New NHS – Modern, Dependable* have raised awareness about issues of health care quality. This is illustrated by an increase in the number of publications in the *British Medical Journal* that address quality issues (see Figure 11.2). Quality has moved to a more prominent and visible position. However, the question remains whether the change is at a superficial and artefactual level only, whereby beliefs and actions do not match the rhetoric.

**Figure 11.2** Increased attention to quality: trend in publications



SOURCE: British Medical Journal

By far the most high-profile vehicle for securing culture change in the new NHS is clinical governance, defined in *The New NHS – Modern, Dependable* (DOH 1997) as

*a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.*

(DOH 1998, p. 33)

Establishing clinical governance in the NHS was intended to create a no-blame, learning environment characterised by excellent leadership, highly valued staff and active partnership between staff and patients (Halligan & Donaldson 2001). We describe clinical governance in more detail in Chapter 6.



Early in its implementation, Walshe et al. (2000) reported that, despite general support for the concept of clinical governance, implementation appeared challenging, given the levels of available resources, skills and time. Further, they found that Trusts tended to focus their efforts on strategies and structures rather than on more critical success factors such as leadership, information systems and critical analysis of clinical practice.

Wallace et al. (2001a, 2001b) conducted a series of interviews with senior managers in Trusts and found that many Trust leaders used clinical governance as a new label for existing staff-development activities, despite equivocal judgements about their effectiveness in securing behaviour change. Most Trust leaders described clinicians as ambivalent to clinical governance (Wallace et al. 2001a).

The Commission for Health Improvement (CHI 2002), in its initial 175 clinical governance reviews, found that more than 80% of NHS organisations:

- tend to be reactive rather than proactive, responding to problems when they occur rather than anticipating and working to avoid them;
- lack organisation-wide policies and often have differing policies in multiple departments;
- fail to share learning between and across organisations;
- communicate ineffectively; and
- lack communication from strategic to operational levels (i.e. between managers and those providing services) and between doctors and nurses.

The CHI report found that, in general, NHS organisations satisfactorily implemented three components of clinical governance: clinical audit, effectiveness research and education/training and professional development. However, the remaining four areas of clinical governance – risk management, staffing and staff management, patient involvement and information use – were problematic (see Table 11.2).

<b>Table 11.2 Areas of weakness in clinical governance implementation</b>	
<b>Clinical governance principles</b>	<b>Problems in implementation</b>
Risk management	<ul style="list-style-type: none"> <li>● Many Trusts are poor at managing potential risks to patients</li> <li>● Many staff fear reprisals if they report adverse events</li> </ul>
Staffing and staff management	<ul style="list-style-type: none"> <li>● Trusts have poor workforce planning</li> <li>● Trusts are poor at providing career opportunities</li> <li>● Poor management of locum and bank agency staff</li> <li>● Widespread failure to check professional registration</li> </ul>
Patient involvement	<ul style="list-style-type: none"> <li>● Few Trusts routinely involve patients and relatives in the development of services and policies</li> <li>● There is a general shortage of information for patients about their care</li> <li>● There are many barriers to patients and staff making complaints</li> </ul>
Use of information	<ul style="list-style-type: none"> <li>● Doctors and nurses often do not have ready access to the information they need to treat patients</li> <li>● Poor use of information and complaints data</li> <li>● Too many breaches of confidentiality guidelines</li> </ul>

SOURCE: CHI 2002

CHI concluded that there was real progress in quality improvement across the NHS, and identified many examples of good practice. Nevertheless, their findings suggest that meaningful change in organisational culture is at best patchy. Further evidence of uneven progress is available in *Functioning as a Team*, the 2002 National Confidential Enquiry into Perioperative Deaths (NCEPOD) report. The report reviewed a sample of deaths occurring within 3 days of intervention between 1 April 2000 and 31 March 2001. There were 21,991 deaths reported to NCEPOD within 30 days of an operation, with just over a third (7,184) occurring within the first 3 days. Poor teamwork and communication were identified as contributing factors in cases where patients died within 3 days of a medical intervention. The report states:

*Individual clinicians are becoming transient acquaintances during the surgical patient's passage through an illness rather than having responsibility for continuity of care.... There needs to be more team working. This involves not only consultants working together but also trainees, nurses, managers, professions allied to medicine and sometimes patients themselves (p. 2).*

Often unresponsive and unpredictable, culture is usually resistant and sometimes impossible to change in a purposeful way. It is, therefore, unreasonable to expect to find transformation in NHS culture in five years. There are, however, accounts of success such as that described in Box 11.3.

### **BOX 11.3**

#### **An example of cultural shift**

*Innovation in the National Health Service – the acquisition of the Heart Hospital* describes how University College London NHS Hospitals Trust acquired an entire private sector hospital, the Heart Hospital, in August 2001 to serve as a specialised cardiac centre. The Trust did not follow the standard lengthy NHS process on capital investment, but instead moved quickly based on “sufficiently robust risk assessments”. The acquisition had a number of effects on quality of care: it ensured that target throughputs for cardiac procedures would be met locally; it provided extra capacity to help meet national targets; and it improved the environment for patients.

In terms of organisational culture, this episode illustrates two significant examples of how stated goals or culture change have been operationalised, at least at a local level. Firstly, the acquisition demonstrated the adoption of an entrepreneurial approach and encouragement of innovation in delivering public services. Secondly, the case provides clear evidence of the empowerment of local management and the devolution of power: “The DOH and Trust board had confidence that the Trust team, led by the Trust Chief Executive, could undertake a successful acquisition, and therefore delegated responsibility” (p. 7).

SOURCE: National Audit Office 2002

In summary, the evidence base about the nature of organisational culture in the NHS, its role in performance and quality and the extent to which policies have succeeded in securing change is sparse. This highlights the need for robust evaluative methodologies in the quest for quality. There are accounts of success in securing discrete changes within supportive cultural environments, but there is insufficient evidence to map the big picture, differentiating contextual effects and informing future policy.

### **What is important going forward?**

Culture is widely seen as an important component in delivering high-quality health care, and is currently a central policy theme. In a review of generic culture-management literature, Hassard & Sharifi (1989) found that:

- the deeper the level of change required, the more difficult and time-consuming the culture change programme is likely to be;
- if there are multiple cultures and subcultures, this will make the change programme still more difficult and time-consuming;
- managing the deepest layers of an organisation's culture requires a participative approach;
- top-down approaches yield changes that may be difficult to sustain in the long term, because they produce overt compliance, but not acceptance; and
- participative approaches are the most likely to be successful, and are the only real option if assumptions are to be altered. However, they are difficult to implement and extremely time-consuming to enact.

These findings suggest that securing significant culture change in the NHS will be a long and difficult process. So, what is important in moving forward?

### ***Consistency of messages for cultural change***

Securing and embedding culture change requires the alignment of rhetoric with action, and national with local policies. Inconsistencies in initiatives, attitudes and action often result in unintended consequences and cynicism. To date, perceived inconsistencies in the Quality Agenda have included:

- the espoused objective of a blame-free culture, at odds with the policy of “naming and shaming” poorly performing Trusts;
- the goal of greater openness, compared with the Government's slowness to publish unfavourable data and reticence to articulate explicitly intentions for the mixed economy that appears to be evolving in the health sector;
- the policy articulations of patient engagement, not reflected commensurately in committed and sustained action. For example, Mannion et al. (2003) found that Primary Care Trusts (PCTs) have made little progress in giving the public a louder voice in the organisation and delivery of services (discussed in Chapter 13); and

- the policy statements to decentralise decision-making and increase local autonomy, in stark contrast with the central control exerted in directives and target setting

Culture change is a slow and difficult process that can be assisted, but not controlled. Unintended consequences are to be expected and may highlight inconsistencies in approach. Unintended consequences may include the distortion of clinical priorities because of external performance targets, negative effects on staff retention and recruitment in Trusts with poor star ratings, and gaming practices in response to performance targets.

Without consistency across organisational contexts and over prolonged timeframes, the espoused vision of a patient-centred, open and accountable, innovative, quality-driven, blame-free culture risks being seen as the latest ‘fad’ in a series of policy initiatives. Change fatigue and cynicism are the result of a long line of initiatives (e.g. resource management, clinical audit, business process re-engineering, total quality management) that were embraced enthusiastically, attracting significant levels of investment, but did not sustain consistent example and support, and were largely unquantified in terms of impact and value for money.

### ***Attitudes toward data and accountability***

The NHS has yet to harness the power of data. As well as a management tool, robust data can be a trigger for cultural change. By providing evidence of organisational and personal deficiencies, data can result in a felt need for change and motivation for action (Lewin 1952).

Many in the NHS often view data with indifference or as a necessary evil offered up within a hierarchical and centrally commanded structure to be held to account, not as a useful tool to improve quality of care for patients within the local context. This may be rooted in concerns to protect professional autonomy, in perceptions about time and resource constraints, or in attitudes that data cannot capture complex situations. Alternatively, it may be the result of a negative spiral, whereby there is little regard for the value of data (other than as a means for satisfying central requirements), so little effort is expended in collecting timely and accurate data or meaningfully collating it. The resulting poor datasets are seen to provide an inaccurate picture of performance, thereby reinforcing the view that collecting data is not important.

Although there is evidence of significant change in the NHS in terms of data management (for example, the introduction of the Performance Assessment Framework and star ratings), this appears to be confined to a change at an artefactual level of analysis. Embedded change will be evidenced when each clinical team or unit, Trust and Agency perceive data as an inherently valuable tool to answer routine questions about effectiveness and to guide change.

### ***Unrealistic expectations***

Organisational culture is undoubtedly complex; it is multi-layered, intangible and largely invisible. Although we know it plays a role in determining performance, it is difficult to establish specific causality and understand contingent relationships. Perhaps because of these difficulties, approaches to understanding and changing organisational culture are often based on unrealistic expectations. On one hand, the pervasiveness and complexity of organisational culture can be so daunting that it becomes too difficult an issue to tackle, and represents a barrier to action. On the other hand, organisational culture is at times over-simplified, seen either as a unitary, homogenous entity common to all the members of an organisation, or as a route for reliably delivering wholesale organisational change.

### ***Evaluation***

Rigorous evaluation of new initiatives, agencies and approaches is critically important in securing culture change. Crises are often identified as a trigger for embedded culture change. In the NHS, we could view the events at Bristol Royal Infirmary as a precipitating crisis. At a lower level of analysis, a Trust may view a visit by the CHAI inspectors as a crisis. There is a widespread consensus that if cultural change is to be secured, it must be identified as the factor responsible for solving the initial crisis (Schein, 1985; Gagliardi, 1986; Brown, 1998). This underlines the importance of undertaking rigorous and transparent evaluation of any attempt to change culture purposefully.

### ***Conclusion***

Empirical studies of culture change in the NHS are limited in number and quality. Although there has been some valuable research undertaken recently on the link between culture and performance (e.g. Mannion et al. 2003), the field remains under-researched. Yet, vast political, managerial and financial capital has been invested in the idea that culture change is crucial to delivering quality improvement.

In recent years, culture has become a central concern for policymakers, managers and health services researchers (Davies et al. 2000). In England, it is commonly invoked as a powerful influence on the design and delivery of health care. Culture change is often viewed as a lever that can be relied upon to deliver quality and performance improvement, even though research evidence suggests that culture is too ethereal, elusive and contested a concept for it to be a reliable means of securing change. The value of culture lies instead in the way it reflects an organisation's capacity for change and improvement. An understanding of the beliefs, values and attitudes that underpin organisational life must inform action and shape change programmes if they are to impact on performance and quality.

Concepts such as responsibility for performance improvement and accountability are enacted through cultural artefacts and social norms. These determine how individuals delivering

health care will respond to and operationalise policies such as those concerned with evidence-based medicine, patient-centredness and safety, for example. The new NHS has many laudable aims. Realisation of these aims depends upon developing a clear understanding of the cultural contexts that populate the health sector, and identifying attitudinal, assumptive and artefactual barriers to progress.

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## 12. Engaging Patients and Citizens

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### **Why is patient and public involvement important?**

Improving responsiveness to patients has been a goal of health policy in the UK for several decades. The most obvious manifestation of this is the emphasis on reducing waiting times, a cause of great public concern that until recently has proved relatively intractable despite numerous policy initiatives. The previous Conservative Government promoted consumerism as part of its internal market reforms to the NHS in the belief that consumer pressure and competition would drive up quality standards and increase value for money. The rhetoric of patient power is still a feature of government statements, but the emphasis has shifted subtly. Now patients are less likely to be described as consumers – the preferred term is partner. The stated aim is to encourage active participation of patients in their care and in the planning and management of health services. Responsibilities are stressed as well as consumer rights, and patient empowerment has become a key element in the strategy for managing demand.

A growing body of evidence demonstrates that patient engagement in treatment decisions and in managing their own health care can improve the appropriateness and outcomes of care (Coulter 2002b). Information and involvement is at the heart of the patient-centred approach, but communication failures are the most frequent source of patient dissatisfaction. If clinicians are ignorant of patients' values and preferences, patients may receive treatment that is inappropriate to their needs. Patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanations about their condition and the likely outcomes with and without treatment. There is good evidence that sharing treatment decisions with patients can lead to better decisions, and better, more cost-effective outcomes (Kennedy et al. 2002; O'Connor et al. 2002). There is also good reason to believe that active involvement of patients could improve safety and reduce complaints and litigation (Vincent & Coulter 2002). More fundamentally, collective provision of health care relies on public consensus and support. British politicians now recognise that the survival of the NHS will depend on the extent to which the service can improve responsiveness to patients' needs and wishes. Active engagement of citizens in setting priorities and reshaping services should help to ensure closer alignment to the wishes and expectations of lay people, and may help increase public understanding of the economics of the system and the resource choices that have to be made (Coulter 2002a).

The inquiry into failures in children's heart surgery in Bristol revealed that the manner in which care was delivered in this and in many other hard-pressed corners of the NHS showed that these goals were a long way from being attained (Bristol Royal Infirmary Inquiry 2001). In

particular, Professor Ian Kennedy's inquiry team identified the need for substantial change in the way in which health professionals interact with patients and their carers. They made 198 recommendations, pre-eminent amongst which were exhortations to involve patients (or their parents) in decisions, to keep them informed, to improve communication with them, to provide them with counselling and support, to gain their informed consent for all procedures and processes, to elicit feedback and listen to their views, to be open and candid when adverse events occur, and to offer them opportunities to get involved in the planning, organisation and delivery of health care.

In reaction to quality failures such as those in Bristol, the British Government made patient-centredness the central theme in *The NHS Plan* (DOH 2000). This document set out the problems thus:

*The relationship between service and patient is too hierarchical and paternalistic. It reflects the values of 1940s public services. Patients do not have their own health records or see correspondence about their own healthcare. The complaints system in the NHS is discredited. Patients have few rights of redress when things go wrong. The patient's voice does not sufficiently influence the provision of services. Local communities are poorly represented within NHS decision-making structures. Despite many local and national initiatives to alter the relationship between the NHS and the patient, the whole culture is more of the last century than of this. Giving patients new powers in the NHS is one of the keys to unlocking patient-centred services.*

### **Commitments to patients**

The process of putting together the NHS Plan involved a large number of people, including representatives of professional and patient organisations, clinicians and academics. The team responsible for overseeing the work consulted widely and commissioned public opinion surveys to establish key priorities. These suggested that the public wanted shorter waiting times, better facilities, more and better paid staff, and improvements in information for and communication with patients (DOH 2000). The review was carried out at speed and the plan was ambitious, but the process generated a considerable measure of consensus about what needed to be done, and wide support among those working in the service.

The NHS Plan and subsequent documents † announced a number of initiatives to tackle the problems identified. Patients and the public were promised more and better quality information, more opportunities to feed back their views so that quality improvement is centred on the patient's experience, more choice, and much greater influence over the shaping and delivery of health services. The main commitments specifically relevant to the agenda for patient and public involvement are listed below. To facilitate analysis these have been grouped under four headings: information, feedback, choice and influence (Table 12.1).

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† For example, *The Expert Patient, Involving Patients and the Public in Healthcare, Reference Guide to Consent for Examination and Treatment, Delivering the NHS Plan, Learning from Bristol: the Department of Health's Response, NHS Complaints Reform.*

**Table 12.1 Policy commitments to the public and patients**

<b>Information</b>	Patients will be given much more information about diseases, treatments and services. <sup>1</sup> (para 10.2)
	NHS Direct, the 24-hour telephone helpline, will be available nationwide to answer queries and to act as a gateway for out-of-hours care. <sup>1</sup> (paras 12.2, 12.4)
	A National Knowledge Service will be established to support the delivery of high- quality information for patients and staff. <sup>2</sup> (para 2.11)
	Referral letters will be copied to patients, who will be issued with smart cards allowing easier access to their health records. <sup>1</sup> (para 10.3)
	National Service Frameworks will specify service standards so that patients know what to expect. <sup>6</sup> (para 2.3)
	Patients with chronic diseases will be offered information and training to support self-care. <sup>3</sup> (para 5.8)
	The Patients Charter, which has been in force since 1992, will be replaced by a new NHS charter specifying how patients can access NHS services, what the NHS commitment is to patients, and patients' rights and responsibilities. <sup>1</sup> (para 10.22)
<b>Feedback</b>	A Patient Advice and Liaison Service (PALS) will be established in each Trust to tackle patients' and carers' concerns. <sup>4</sup> (para 3.9)
	Financial rewards for Trusts will be linked to the results of an annual National Patients Survey, a methodologically robust measure of patients' views about local NHS services. <sup>1</sup> (para 10.24). Patient surveys will form a major plank when measuring the performance of the NHS as a whole. <sup>6</sup> (para 10.15)
	Local prospectuses will be published from Autumn 2002, to include an analysis of patients' complaints, star ratings and the results for each local provider of the annual patient surveys. <sup>6</sup> (para 10.15)
	Published information about patients' views of hospital services will influence the actions of primary care commissioners, who will be empowered to move service agreements from one hospital to another. <sup>1</sup> (para 10.7)
	The complaints procedure will be overhauled to make it more flexible, providing speedier resolution and independent review. <sup>7</sup>
<b>Choice</b>	The consent process will aim to engage patients fully in decisions about their care. It will be strengthened by giving patients written information and by providing guidelines and training to clinicians. <sup>5</sup> (paras 2.7, 2.8)
	Patients waiting for elective admission will be offered a choice of timing through the booked-admissions scheme. <sup>6</sup> (para 5.6)

	From 2002, regularly updated information on waiting times for all major treatments at all providers will be published on the Internet. <sup>6</sup> (para 5.3)
	Patients who have been on the waiting list for 6 months will be offered a choice of an alternative provider. <sup>6</sup> (para 5.3)
	By 2005, all patients will be offered a choice of time and location of hospital treatment by their GP at referral. <sup>6</sup> (para 5.6)
	More information will be provided to patients on how local health services compare with others. <sup>2</sup> (para 4.26)
	Data on the clinical performance of consultants and their units/teams will be published for use by both clinicians and patients. <sup>2</sup> (para 8.17)
<b>Influence</b>	A new duty will be placed on all NHS organisations to involve and consult the public. <sup>4</sup> (para 3.60)
	A Commission for Patient and Public Involvement in Health (CCPIH) will be established. <sup>4</sup> (para 2.10)
	Local Patient Forums will be established to provide direct input into how NHS services are run. <sup>1</sup> (para 10.24)
	The scrutiny powers of local authorities will be extended to include local health services, and local people will be consulted about plans for hospital reconfiguration and service redesign. <sup>1</sup> (para 10.26) <sup>8</sup>
	Lay representation will be increased on a host of bodies, including the General Medical Council, the NHS Modernisation Board, the Independent Reconfiguration Panel, the Commission for Health Improvement, and the National Institute for Clinical Excellence. <sup>4</sup> (para 3.66)

SOURCES: 1 (DOH 2000); 2 (DOH 2002b); 3 (DOH 2001c); 4 (DOH 2001a); 5 (DOH 2001b); 6 (DOH 2002a); 7 (DOH 2003d); 8 (DOH 2003c)

## Progress to date

### Information

Information is of critical importance to patients. Insufficient information about their illness and its treatment is the most common problem identified in patient surveys, and the quality of much of the printed information available to NHS patients has been shown to be poor (Coulter et al. 1999). Furthermore, there is some evidence that educating the public about how and when to use health services and supporting self-care can help to ensure that demand is channelled more appropriately (Coulter 2002b). The establishment of the telephone helpline, NHS Direct, and the associated website, NHS Direct Online, was therefore a significant step. Other planned initiatives include giving patients copies of referral letters, and providing patients with information about their rights and responsibilities.

### *NHS Direct*

NHS Direct was launched in 1998 to provide healthcare information and advice to the public in England and Wales through a telephone helpline and website. National coverage for the telephone service was achieved in November 2000. Staffed by nurses, it is the world's largest provider of telephone healthcare advice, handling more than half a million telephone calls and half a million Internet visits every month. By 2006, it is expected to handle 16 million calls a year and to be the main gateway to out-of-hours care (DOH 2003b). The online service provides information on health conditions and treatments, healthy living, and details of local services. This is to be supplemented by a digital TV service to be launched in 2004. It is hoped that this will reach groups such as men and low-income families that are hard to reach by other means. Basic information is also available via touch-screen information points in public libraries and other places.

Investment in these services is a key part of the strategy for managing demand in the NHS. By providing information to ensure that patients make appropriate use of services and by encouraging self-care, it is hoped that demand for GP services and outpatient visits will decline. The Treasury's review team, led by Sir Derek Wanless, were bold enough to put an estimate on the potential impact of this strategy: "...visits to GPs could decline by over 40 per cent and outpatient visits by 17 per cent as a result of increased self care ... for every £100 spent on encouraging self-care, around £150 worth of benefits can be delivered in return" (Wanless 2002). It remains to be seen if these ambitious targets will be achieved. An evaluation of the pilot sites, published in 2001, cautiously concluded that the telephone service "*is appreciated by callers and, to date, has not been unhelpful to other services*" (Munro et al. 2001). In a review published in January 2002, the National Audit Office was more bullish, estimating that the NHS Direct telephone service was offsetting around half of its running costs by encouraging more appropriate use of NHS services (Comptroller and Auditor General 2002).

### *NHS Direct Online*

NHS Direct Online provides four types of information: a health encyclopaedia giving basic information about a range of conditions and treatments; a self-help guide, which includes algorithms to guide patients on interpreting symptoms and deciding whether they need to consult a health professional; a local information database giving basic information about hospitals, general practices and other NHS organisations, including some performance information; and links to other quality-assured websites.

The website contains much information and its gateway function is helpful, but the didactic content and paternalistic tone of the material does not support the partnership notion that is supposed to be the keystone of the policy on patient and public involvement. The self-help guide is designed to assist decision-making in the home, but there is little help available for patients who want to play an active role in decisions about their care, or for those seeking a

second opinion to check medical advice they have been given. The lessons from the now extensive body of research and experience in shared decision-making have been ignored (Edwards & Elwyn 2001). There are no accessible summaries of the National Service Frameworks to be found here, and no link to the patient versions of NICE clinical guidelines. Despite the emphasis on self-help, there is little information on over-the-counter preparations, and nothing to help patients concerned about the risks or side-effects of medicines or looking for advice on how and when to take them. There is not much help here, either, for those patients with chronic conditions who want to be 'expert patients', actively involved in managing their condition (DOH 2001c). Further, the information provided on performance and quality indicators from NHS organisations is too thin to be much use to the patient who wants to choose a safe and effective provider.

The persistent patient could find some of this information by linking through to the National Electronic Library for Health, which was not designed specifically for patients, or by logging onto *Dr Foster*, a commercial website that contains detailed information on performance among healthcare providers and offers an e-mail and telephone enquiry service. Indeed, the Department of Health has been remarkably helpful to *Dr Foster*, allowing access to official datasets and facilitating their analysis of hospital rankings. But given the considerable investment in NHS Direct, it is a pity that so little attention has been given to ensuring that the content supports other elements in the strategy for involving patients and the public.

#### *Access to medical records*

For years, medical records have been seen as the property of the clinician rather than the patient. Few patients have seen their notes, and most are unaware of their right to do so. In both primary and secondary care, the notes are kept out of patients' reach wherever possible, and the way in which they are designed and used has reinforced the notion that they are for health professionals only. Referral letters and test results are often given to patients in sealed envelopes. The patient is told to hand them to the relevant specialist or to their GP, with no expectation that they might want to read or understand them. Curious patients are sometimes actively discouraged or reprimanded if they try to learn more, and those brave enough to demand a copy of their general-practice notes are often charged a fee for the privilege. So the commitment in the NHS Plan to give patients copies of referral letters is a small but very welcome step forward. Progress has been slow, however. A working group has drawn up guidelines on copying letters to patients and a small pilot project has been carried out, but little thought appears to have been given to how this new policy will be rolled out nationally (DOH 2003a). The key issue is how to engage clinicians' support for the process and ensure they comply.

As the working party recognised, giving patients access to their records has the potential to change the dynamics of the relationship between patients and health professionals in fairly fundamental ways. Increased openness could improve trust between patients and professionals. Patients would become better informed and better able to participate in decisions about their care. Compliance would improve if patients understood the reasons for taking medication or

treatment. Errors could be spotted and corrected by the patient, and the quality of communication in consultations would be enhanced. Advice on self-care and behaviour change could be reinforced, and the clarity of communications between professionals would also benefit if records were written in more accessible language. Given the importance of this move, it is disappointing that so little has been done to clear away the barriers to giving patients full access to their records.

The proposal in the NHS Plan to issue patients with smart cards was greeted with enthusiasm by patients (Coulter & Magee 2003) but has not been mentioned in subsequent documents, suggesting that the idea has now been quietly dropped. The NHS Information Authority's Electronic Record Development and Implementation Programme (ERDIP) has been piloting different aspects of the development and use of electronic health records, but only one small-scale project has looked at enabling patient access to their records (Pyper et al. 2002). This yielded very positive results, but funding for the project ceased in 2002, and as yet there does not appear to be a plan to implement it more widely.

### *Patients' rights*

The NHS Plan promised to replace the original *Patient's Charter*, introduced by the Conservative Government in 1992, with a new charter. This would emphasise patients' responsibilities as well as their rights, and would include a guide for the public on how to access health services. When it finally appeared, *Your Guide to the NHS* looked very different from the *Patient's Charter*. More like a contract between the NHS and its users than a charter, all mention of "rights" had been expunged, to be replaced by "commitments" and "responsibilities". Designed more to reassure staff than to empower patients, the *Guide* exhorts patients to look after themselves and not to bother professionals unnecessarily. It seems unlikely that it will have much impact unless there are clear incentives for patients and staff to use it and a mechanism for monitoring any deviations.

Recently, proposals have been floated for the introduction of individual "health contracts" between patients and their GPs, in which the patient would agree to adopt healthy behaviour – for example, stopping smoking, eating a healthy diet, or taking more exercise – in return for a particular course of treatment. This is intended to reinforce further the notion of personal responsibility for health; but, judging from initial reactions to the idea, it seems highly unlikely to achieve the desired effect.

### **Feedback**

The NHS Plan recognised that listening to patients and encouraging feedback is just as important as providing them with information. The main mechanisms for doing this were the establishment of a new patient liaison service, overhaul of the complaints procedure, and a series of patient surveys to obtain systematic feedback for use in setting priorities for quality improvement.

### *Complaints*

The complaints service has been comprehensively reviewed, and proposals have been drawn up for a radical overhaul of the system (DOH 2003d). However, these plans have not yet been fully implemented. The new Independent Complaints Advisory Service (ICAS) is intended to be more flexible, responsive and independent than the current system. In the meantime, the Patient Advice and Liaison Services (PALS) are expected to deal with problems before they become complaints and to help patients channel their complaints appropriately.

PALS have now been established in virtually all NHS Trusts and PCTs. They are responsible for liaising with patients and their carers, answering queries and maintaining links with local support groups. They aim to provide quick, on-the-spot resolution of problems and, where necessary, to provide advice on making formal complaints via the ICAS. PALS are also charged with responsibility for collecting continuous feedback from patients by means of comment cards. They are supposed to collate and record comments and concerns and ensure that action is taken to address the issues raised (DOH 2003d).

The total number of formal patient complaints about NHS care in England in 2002 was 140,000. It is hoped that the introduction of the PALS and related initiatives (Modern Matrons; training in communication skills and customer care) will achieve a reduction in the number of formal complaints. Pilot studies, for example in East Kent Acute Healthcare Trust, have suggested that a significant reduction is possible, but it is too early to know if these successes are being replicated across the service.

The role of the PALS in Acute Trusts is clear, and it should be relatively simple to ensure that inpatients and outpatients are aware of the service; but this is more difficult in primary care. Most users of primary care services have little awareness of the PCT or of the organisational links between individual general practices and other community services, such as dentistry, pharmacy, opticians and community nursing. Primary care PALS face a challenging task if they are to gain a sufficient profile to be the patient's first port of call, and they will need excellent networking skills and support to resolve any difficulties identified. There is a risk that development of the PALS will become lost among the long list of priorities that have to be tackled by PCTs (Anderson et al. 2002).

The PALS will need to be particularly effective operators, with strong Board-level support, if they are to make any headway as patients' advocates working within, and presumably employed by, the Trusts. It will be important for them to work closely with the Patients' Forum in each Trust, but they will also need the support of a national body, and they should have some direct connection with the local community served by their hospital or PCT.



### *Surveys*

The NHS Plan promised that every Trust would carry out a systematic postal survey of patients' experience of its services on an annual basis. They were to use a standardised postal questionnaire developed and co-ordinated by the Advice Centre for the NHS Patient Survey Programme. The first wave of surveys was implemented in 2002, covering Acute Trusts (inpatients) and PCTs (general practice only). Surveys carried out in 2003 included Acute Trusts (outpatients and emergency services) and PCTs (all services). Planned additions to the programme include mental health, ambulance services, children's services, and a programme of patient surveys linked to each of the National Service Frameworks.

Results from the inpatient survey were incorporated in the star ratings published by the Department of Health in July 2002, but publication of the national survey results was delayed until July 2003, when they were quietly placed on the Department's website. The delay appears to have been caused by fear of critical headlines in the press and the possibility of adverse political consequences. At one point it appeared that the Government wanted to bury the survey results altogether. In a response to Parliamentary questions asked in March 2003 by Dr Evan Harris MP, Liberal Democrat health spokesman, the junior Health Minister David Lammy stated that there were no plans to publish national reports of these surveys (Hansard 2003).

This timidity on the part of Ministers suggests a lack of top-level commitment to the patient and public involvement strategy. Trust boards and staff require timely, detailed feedback to help them to monitor their services and set priorities for quality improvement. To do this, each Trust needs national benchmarks to enable it to assess how well it is doing in comparison with other Trusts. Many other groups, including PCT commissioners, Patient Forums, Overview and Scrutiny Committees (OSCs), the NHS Modernisation Board, the Commission for Patient and Public Involvement in Health (CPPIH), CHI, the Audit Commission, lay members on various committees, patients' organisations and the public could make good use of the survey results. There is good evidence from the USA that publication is the best way to stimulate staff to take patient feedback seriously (Marshall et al. 2000). Without this there is a risk that the findings will be ignored and subsequent surveys will show no improvement.

*Delivering the NHS Plan* (DOH 2002a) stated that summaries of the survey results and other local performance indicators would be published in patients' prospectuses. The first of these were published by PCTs under the title *Your Guide to Local Health Services* and distributed to every household in England. Little more than a public relations exercise, they contained virtually no information from the patient surveys apart from bland statements such as "89% who had used a local health service in the past year were satisfied with the service that they had received" (Oxford City PCT 2002). These local guides included almost no information to enable evaluation of the quality of local services, and nothing that would inform patients wanting to choose between alternative providers.

Selected national results from the surveys carried out to date are included in Table 12.2. These reveal a significant amount of dissatisfaction with information, communication and involvement. For example, more than one in four patients in each of the different settings stated that they were not given sufficient information about their condition or treatment, they did not get clear answers to their questions, and they had insufficient opportunity to influence decisions about their care. The majority of primary care patients could not recall receiving a copy of *Your Guide to Local Health Services*, and very few indicated that they knew how to get involved in local policy committees or how to influence NHS policy decisions. These indicators of patient and public engagement, which are due to be gathered and reported each year, will provide an important measure of the extent to which the strategy for patient and public involvement is making an impact.

<b>Table 12.2 Selected results from NHS patient surveys, England 2002 and 2003</b>	
<b>Patients reporting a problem with specific aspects of care (%)</b>	
<b>Inpatients 2002 (n = 93,149; response rate = 64%)</b>	
Did not always get clear answers from doctors	30.9
Did not always get clear answers from nurses	30.9
Doctors talked in front of me as if I wasn't there	28.7
Nurses talked in front of me as if I wasn't there	18.8
Staff gave conflicting information	30.4
Couldn't find someone to talk to about my concerns	11.3
Not given enough privacy when discussing treatment	10.4
Not told about medication side-effects	31.0
Would have liked more involvement in treatment decisions	46.2
Insufficient opportunity for family to talk to doctor	13.5
Family/carers not given sufficient information to help with recovery	22.9
Not told about danger signals to watch for after discharge	38.5
Not always treated with respect and dignity	21.3
<b>Outpatients 2003 (n = 90,763; response rate = 65%)</b>	
Insufficient time with the doctor	25.6
Doctor didn't always listen to patient	20.5
Did not always get clear answers from doctor	24.3
Doctor didn't always give clear reason for treatment or action	22.8
Not given sufficient information about condition or treatment	11.6
Not given clear explanation of test results	27.4

Insufficient information about medication side-effects	31.5
Staff gave conflicting information	10.5
Would have liked more involvement in treatment decisions	29.9
Staff talked in front of me as if I wasn't there	11.6
Not always treated with respect and dignity	12.9
<b>Emergency patients 2003 (n = 59,443; response rate = 49%)</b>	
Insufficient time to discuss problem with doctor or nurse	37.1
Staff didn't always listen to patient	26.9
Not given clear explanation of condition or treatment	32.8
Not given sufficient information about condition or treatment	24.1
Staff gave conflicting information	16.0
Not given clear explanation of test results	31.6
Insufficient information about medication side-effects	38.8
Not given enough privacy when discussing treatment	21.8
Would have liked more involvement in treatment decisions	34.4
Staff talked in front of me as if I wasn't there	15.8
Not always treated with respect and dignity	22.6
<b>Primary care patients 2003 (n = 123,150; response rate = 48%)</b>	
Staff didn't always listen to patient	15.8
Not given sufficient time to discuss problem	21.8
Not given completely clear reasons for treatment or action	21.8
Did not always get clear answers from staff	18.4
Not given clear explanation of test results	26.8
Not sufficiently involved in choice of medication	15.2
Insufficient information about purpose of medication	18.1
Insufficient information about medication side-effects	34.1
Insufficient information about how to take medication	13.0
Would have liked more involvement in treatment decisions	25.5
Not always treated with respect and dignity	6.5
Not given choice in referral to hospital or specialist	71.5
Do not recall receiving a copy of <i>Your Guide to Local Health Services</i>	81.9
Do not know how to influence local NHS policy decisions	90.5

## **Choice**

Choice is important to patients in a number of ways, including choice of treatment and choice of provider. The Bristol Inquiry recommended that patients must be involved wherever possible in decisions about their treatment and care, and that health professionals should receive training in the principles of partnership, good communication and shared decision-making (Bristol Royal Infirmary Inquiry 2001, recommendations 1–20). The Government's response indicated virtually unqualified agreement with these recommendations, although details of how they would be implemented remained vague (DOH 2002b). While considerable progress has been made with the two pilot studies, *CHD Choice* and *London Patient Choice*, which are offering patients who have been on the waiting list for 6 months a choice of treatment location, progress on offering treatment choices is less clear.

### *Involvement in treatment decisions*

Many patients say they are not given full information about their treatments or a real opportunity to have a say in decisions about their care (Coulter & Magee 2003). The Department of Health has tackled this issue by issuing a document to clarify the law on informed consent (DOH 2001b). This makes it clear that valid consent must be obtained before starting treatment or physical investigation or providing personal care, and that the patient must be given information about the nature and purpose of the procedure. However, this document has little to say about the information that patients would need if their consent to treatment is to be truly informed. The Department appears to have adopted the traditional view of informed consent, which is that it is an essentially passive activity, at least as far as patients are concerned. This unduly timid approach contrasts starkly with the guidance produced by the General Medical Council, which stated that doctors should provide patients with sufficient information about treatment options to make a fully informed choice (General Medical Council 1999).

Although training in communication skills has been promised via the NHS University and a new core curriculum has been developed which is said to promote partnership (DOH 2002b), the details of how this will be achieved are unclear. Training in the principles and practice of shared decision-making will be essential, together with allocation of more time for consultations and the elimination of paternalistic attitudes towards patients. There is evidence that training can lead to significant improvements in consultation processes with demonstrable benefit to patients (Lewin et al. 2002), but this will require very careful attention to curriculum design and practical support for radical changes in care delivery to support a more patient-centred approach. This needs to be accorded a much higher priority, since involvement in managing their own care is likely to make a more significant impact on patients' experience of the NHS than choice of treatment location, which is currently attracting much more attention.

*Choosing time and location of treatment*

Patient choice in coronary heart disease was introduced on 1 July 2002 as a national pilot scheme designed to strengthen patient choice and reduce waiting times for elective surgery. The scheme is operating in 23 Acute Trusts in England. Patients who have been waiting some time for heart surgery are entitled to treatment in an alternative hospital, either within the NHS or in the private sector, or they can opt to remain on the waiting list at their 'home' hospital. In future, patients may be able to travel to hospitals in other European countries for their treatment. Each Trust has appointed at least one nurse as a Patient Care Advisor (PCA), whose role is to act as the first point of contact for patients eligible for choice. When patients have been on a waiting list for heart surgery for 6 months, they are contacted by a PCA who explains their options and helps them make a decision. A similar pilot scheme is operating in London, where eligible patients include all those waiting for elective surgical procedures; an extension of the scheme to include patients at the point of referral by their GP is being piloted in Manchester and West Yorkshire. No results from these pilots have yet been published, but uptake among patients has been high and the schemes have been credited with contributing to the overall reduction in waiting times for elective surgery (NHS Modernisation Board 2003). However, many 'choice' patients are offered alternative treatment in private hospitals, often carried out by the same surgeon who would have operated on them in their 'home' NHS hospital. Concerns have been expressed about the potential for surgeons and private hospitals to exploit the system to their own advantage.

Choice of treatment location is likely to prove popular with patients, especially if it avoids long waits. However, if choice is to be embedded across the system, it must be supported by reliable information systems so that patients can make choices based on quality indicators. Patients will need much more detailed and accessible information than is currently available from the Department of Health's published performance indicators (Magee et al. 2003). Waiting time information will be relevant, but it should be presented in a more user-friendly format than that currently available on the Department of Health website ([www.doh.gov.uk/waitingtimes](http://www.doh.gov.uk/waitingtimes)). Although it is currently possible to find a large amount of information on official websites, little of this has been produced for patients, and the choice schemes are handicapped as a result. It has been left to a commercial organisation, *Dr Foster*, to provide information of the type that patients find useful, including information about the experience and specialisms of hospital consultants and other health professionals (Magee et al. 2003).

The aim of offering choice of treatment location and a booked appointment at time of referral from general practice is a laudable one, but it will fail unless it is adequately resourced and supported. Patients will expect their GP to be able to answer their questions about the performance of local providers (Coulter et al. 2002). General practices will need to employ staff who can access the information and provide appropriate advice to patients. The role of the PCAs in the pilot schemes will need to be replicated in every general practice. It is not clear where the resources will come from to fund this new service. Success of the schemes will depend on the willingness of clinicians in primary care and in hospitals to make the system work as intended. In the current climate of reported low morale among doctors and disillusion with the

modernisation process, rolling these schemes out at the current fast pace looks like a high-risk strategy.

### ***Influence***

Great efforts have been made to engage patients and citizens in determining and implementing policy priorities. The duty to consult is being taken seriously, and lay representation on committees has increased dramatically since the publication of the NHS Plan. The intention is to “*move away from a system of patients being on the outside to one where the voices of patients, their carers and the public generally are heard and listened to through every level of the service, acting as a lever for change and improvement*” (DOH 2001a).

The decision to abolish Community Health Councils (CHCs) was the most controversial of all the proposals outlined in the NHS Plan. Their functions have been delegated to a raft of new bodies, including the PALS, the Patient Forums to be established in every NHS Trust and PCT, and the local authority Overview and Scrutiny Committees (OSCs). Other new bodies include the Independent Reconfiguration Panel charged with reviewing major service reconfigurations, and the Citizen’s Council, which is to advise NICE on its clinical assessments. Lay membership on a host of professional bodies has also been increased.

These new additions to the NHS’s alphabet soup of advisory bodies and quangos are all individually welcome, but with so many new groups finding their feet at the same time there is a real risk of fragmentation, overlap and muddle. While it is undoubtedly true that the effectiveness of local CHCs was variable and that there was real need for reform of their remit, funding and governance arrangements, abolishing them and replacing them with non-independent bodies looks like a retrograde step.

### ***Commission for Patient and Public Involvement in Health***

The new Commission for Patient and Public Involvement in Health (CPPIH) was launched on New Year’s Eve, 2002. Its remit is to ensure that patients and the public are involved in decision-making throughout the NHS. Disturbingly though, the organisation’s first annual budget was reckoned to be too small to accomplish the task satisfactorily; since CPPIH reports directly to the Secretary of State for Health, there was considerable scepticism about its ability to act independently. Its establishment was marred by continuing rows about the abolition of local CHCs and their umbrella body, the Association of Community Health Councils of England and Wales (ACHCEW).

The CPPIH will have its work cut out if it is to increase people’s sense of involvement in the NHS and their ability to influence policy decisions. The PCT survey results show that levels of awareness about how people can get involved are extremely low: less than 10% of respondents claimed any knowledge of local health groups.

*Patient Forums*

The CPPIH has responsibility for setting up Patient and Public Involvement Forums in every Trust, which are intended to be “truly representative of a broad sweep of the community”. The long-term future of these groups was thrown into doubt when it was announced that Foundation Trusts would not have to have a Patient Forum. Foundation Trusts are supposed to adopt governance arrangements that give local people a measure of control and ensure community involvement in the running of the organisation. The argument is that this will mean that the more limited functions to be exerted by Patient Forums will not be necessary when there is true local stakeholder involvement on Trust Boards (DOH 2003c). Since Ministers have indicated that their long-term aim is to enable every NHS organisation to become a Foundation Trust, the Patient Forums may have a relatively short life span.

Increasing the amount of community involvement is a laudable aim, but achieving it is not going to be easy. Up to now, most lay representatives have been recruited from organised groups. There is a plethora of organised patient groups, but many are small and poorly funded and the majority represent patients with specific diseases. Some patient groups were established with funding from pharmaceutical companies as part of their “disease awareness” strategies and others were set up by clinicians to support their efforts to raise funds for research. The representativeness of many of these groups is open to doubt. The relatively few umbrella or general groups cannot be expected to supply members for all the new committees; and anyway, since most patients are not members of organised groups, these cannot be said to represent the views of the majority. There are fears that the new Patient Forums will not be sufficiently independent from Trust management, that they may attract people with a particular axe to grind, and that they will not represent the views of disadvantaged members of local communities, who are unlikely to put themselves forward for membership.

While welcoming the new commitment to user involvement, it is important to recognise the limitations of direct participation. While most patients want providers to take account of their views and experiences, only a small unrepresentative minority will want to be actively involved in committees to achieve this. It will be crucial to ensure that the Forums have access to regular feedback from representative samples of patients and citizens to balance the views of special-interest groups – yet another use for the patient survey results that the Government has been so keen to bury. The data on patients’ experience should be supplemented with robust techniques for identifying citizens’ views on health care priorities to ensure that the public involvement programme has a sound evidence base on which to build. The establishment of a Citizen’s Council to advise the National Institute for Clinical Excellence (NICE) on the values that should underpin its assessments could perhaps be replicated at a local level (NICE Citizens Council 2002).

## Conclusions and recommendations

The strategy for patient and public involvement is an important part of the overall plan to modernise the NHS. The commitment to put patients at the centre of the NHS is commendable and some good progress has been made, but a critical stocktaking of achievements to date reveals a collection of disconnected initiatives rather than a coherent joined-up strategy.

For example, on information for patients, most of the effort has gone into developing innovative delivery mechanisms such as NHS Direct and NHS Direct Online, which patients can access outside the medical setting. Traditional methods of delivering information, for example leaflets or audiotapes for use in consultations with health professionals, have received much less attention. This is a serious oversight, because the evidence suggests that this type of “just-in-time” information is what patients find most helpful, and they look to clinicians to provide it (Coulter et al. 1998). Insufficient attention has been paid to information content and how it could support other elements of the strategy for patient and public involvement – for example, the Expert Patient programme. To be fair, this deficit has been acknowledged recently and a small sum, £7.5 million over three years, has been allocated to improving the quality of information. Perhaps the recently launched National Knowledge Service (currently a web portal that brings together the various NHS information initiatives) will provide the glue needed to produce a more co-ordinated approach.

The delay in publishing the results of the patient surveys and the reluctance to make them available in a useable form for the variety of groups who would find them helpful represents a triumph of political caution over commitment to the patient-involvement strategy. The national patient survey data constitutes one of the most useful sources of information with which to monitor the success of the strategy. Not to capitalise on this major investment in patient feedback would be a serious mistake. The suspicion that political considerations have intervened reinforces the need for a truly independent regulator. We hope that the new CHAI will be sufficiently independent to ignore such concerns and to adopt a more transparent and open approach.

Allowing patients a choice of treatment location is an interesting departure for the NHS, but it is high risk. It is too early to see who will be the gainers and who the losers in this system, but the potential for hospital consultants either to block progress or to turn it to their own advantage is great. As far as patients are concerned, if it succeeds in increasing capacity and reducing waiting times it will be viewed favourably, but the opportunities for choice of hospital are likely to remain quite limited. Having more say in the choice of treatment and more choice at the time of referral would be a more fundamental change affecting far more patients than just those undergoing surgical procedures; but it will require investment in counselling and information support at primary care level. Without the basic underpinning of support for shared decision-making and informed choice of treatment or management options, these hospital-choice schemes will have limited impact.



Most of the activity under the patient and public involvement banner has focused on increasing lay representation on NHS committees and regulatory bodies. This is welcome, but not enough attention has been paid to giving them the tools for the job, for example by ensuring they receive direct feedback from ordinary patients. There are also concerns that these new committee members are just “the usual suspects”, i.e., white, middle-class people with an axe to grind. This was one of the criticisms levelled at the CHCs, which have now been abolished. The CPPIH will have its work cut out to ensure that the new patient forums become effective and representative bodies. The CPPIH, the Patient Forums and the other bodies should be given independent status to ensure that they can act as critical friends of the NHS without fear of political pressure or redress.

Progress in the three years since the publication of the NHS Plan has been considerable, but there is still a long way to go. The strategy for patient and public involvement requires a more co-ordinated approach to ensure that different aspects of the programme reinforce each other. More attention should be paid to the evidence base that should underpin the strategy. For example, there is now an extensive knowledge base on patients’ information needs, effective methods of improving communication skills, ways to engage patients in their own care and in quality improvement and service redesign, and so on. It will be crucial to engage clinicians more actively in this agenda and to support them with training and organisational resources so that real change in their relationships with patients becomes possible. Above all, it is essential that the rhetoric about patient and public involvement is manifested in a genuine commitment to be honest and open with the public about the state of the NHS and the quality of care provided by its institutions.

- If real progress is to be made over the next five years in patient and public involvement, the current deficits in the programme must be rectified.
- A comprehensive patient and public involvement strategy document should be developed, spelling out the overall vision for NHS staff, patients and the public, showing how each of the individual initiatives is intended to contribute to the whole. This should include a set of performance indicators so that progress can be monitored.
- A strategy for patient and public information should be developed to sit alongside the general strategy document and to ensure information support for each of the elements. The content of NHS Direct Online should be reviewed and improved, and printed material for patients should be made widely available. Information brokers should be employed at primary care level to help patients access reliable information as and when they need it.
- All clinicians should receive training in communication skills and the competencies of sharing clinical decisions with their patients. There should be more support for patients who want to play a greater part in managing and monitoring their own treatment and for those wanting to make informed choices.

- Greater effort should be made to ensure that elements of the strategy for patient and public involvement are underpinned by research evidence; where this does not currently exist, new research must be commissioned. Robust mechanisms for engaging local communities in NHS governance and policy-making should be a priority for development and evaluation.

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## 13. The Role and Contribution of Primary Care Trusts in Quality Improvement

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### **Introduction**

The NHS underwent major structural reform in April 1999 with the formation of 481 Primary Care Groups (PCGs). These transient organisational forms had three core functions: to improve the health of local people and address health inequalities; to develop primary and community care services; and to commission community and hospital services (DOH 1998). Primary Care Groups brought together local providers, representing local GPs and nurses, social services and the local community. They evolved into Primary Care Trusts (PCTs), which had stronger accountability mechanisms, a less prominent management role for local providers, and a major role in both purchasing and providing services. A significant number of mergers took place, and by April 2003, 302 PCTs had been formed. Key features of PCTs were that they had control of the great majority of the NHS budget (with a target of 75% by 2004), and had responsibility for arranging the provision of all primary and community care services, for commissioning the majority of specialist care and for leading partnership-working with local authorities. In addition, the Chief Executives of PCTs acquired a legal duty to assure the quality of care being provided in their locality.

These changes happened at the same time as the development of the three-part national strategy for quality improvement, namely the development of national guidelines (e.g. National Service Frameworks [NSFs] and NICE), the development of mechanisms for quality improvement (clinical governance) and a national system of inspection of standards (under CHI, later CHAI). Primary Care Trusts were directly affected by all these developments. They were expected to use national guidance, such as NSFs, as a basis for developing services; they were required to have in place clinical governance structures; and they became subject to periodic inspection by CHI.

The period from 1999 to 2003 was therefore one of major organisational change. The formation of PCGs followed the abolition by the incoming Labour Government of GP fundholding. In this scheme, a significant proportion of secondary care services in the NHS had been purchased by primary care providers. Although this scheme was widely seen as inequitable, it was regarded as having demonstrated the benefits of a primary care orientation to secondary care

commissioning (Goodwin 1998), and may have led to some reduction in referrals to specialists (Gosden & Torgerson 1997). The formation of PCGs therefore reflected a desire to maintain the role of primary care in commissioning, while allowing the strategic needs of the whole health economy to be better reflected. When PCGs were formed, their board was constituted to have a majority of GPs, and the chairman was almost always a GP. The GP voice was therefore dominant. This was done partly to try to engage GPs with the process of abolishing fundholding and establishing PCGs. As PCGs developed into PCTs, the focus changed to one of stronger managerial presence and greater accountability. The number of GPs on the PCT board was reduced, with the post of chairman of the PCT board becoming an independent lay appointment. The professional voice was still influential through PCT Professional Executive Committees, though their overall influence was reduced.

While GPs appeared to accept and to engage with the formation of PCGs, they were, not surprisingly, more suspicious of PCTs, which continue in some areas to have some difficulty engaging GPs in their reform agenda, including their quality improvement strategies (see “Conclusion: Areas of concern”).

Many localities therefore experienced a series of major organisational changes in the four years from 1999 to 2003, often with a change of Chief Executive as the new organisations moved from PCGs to PCTs. There were many changes in staff with the abolition of health authorities, and significant effort was expended in finding premises for the new organisations and building up their most basic infrastructure. As an illustration of this change, the number of staff available to support core management functions increased from an average of 6.8 in a sample of PCGs in 2000/1 to an average of 31.5 in a sample of PCTs in 2001/2. Despite the increase, only 12% of PCT Chief Executives in 2002 believed that their organisations had sufficient staff. These figures come from the 2002 National Tracker Survey of Primary Care Groups and Trusts (Wilkin et al. 2002), a survey on which we draw in a number of places to identify activities taking place within PCTs.

In addition to organisational changes in primary care management, there were also major changes to the contractual relationship between PCTs and GPs, the major provider group in primary care. A new form of contracting was introduced (PMS, or Personal Medical Services), which 38% of practices had joined by 2003 – another major development on which PCT staff had to lead.

From the preceding paragraphs, it can be seen that PCTs are still immature and rapidly developing organisations, which have often had changes in their senior leadership. Nevertheless, they have been charged with some of the most challenging objectives in the NHS, such as ensuring that high-quality care is delivered and producing cultural change in the attitude of doctors to quality improvement. Their success or otherwise at achieving these aims in their first few years needs to be assessed in the context of changes in the organisations themselves, which often seemed overwhelming.

### **Quality improvement activities in Primary Care Trusts**

Primary Care Trusts now have responsibility for quality of care in all sectors of the NHS, though their responsibility is more direct for primary care and community services. In this section, we consider separately how PCTs have addressed clinical governance, as the main vehicle for quality improvement activities in primary care and in secondary care. Later, we consider how PCTs have used commissioning as a means of improving the quality of care.

#### ***Clinical governance in primary care***

All PCTs have appointed clinical-governance leads, most often a GP, but with a nurse as co-lead in about 18%. These are generally local practitioners, who have a small amount of protected time for their quality-improvement role. The potential scale of their task has been considerable, and inadequate time and resources were blamed by those clinical governance leads who left their posts up to Autumn 2000. They also found it difficult to deal with the impact that their new post had on their relationships with colleagues, and with the emotional impact of the job. They needed high-level support from their senior managers, and did not always feel this was forthcoming (Sweeney et al. 2002). At the same time, there was initially little support from the National Clinical Governance Support Team, which concentrated on helping Acute Hospital Trusts.

These problems underline the extent of cultural change that is implied by the policy of clinical governance. For the first time, doctors have been explicitly expected to account for the quality of their care, and to be prepared for such information to be shared with third parties. In part, the development of these new roles within PCTs has led to the development of a new breed of “doctor-managers” (Sheaff et al. 2002), and the distress reported by Sweeney and her colleagues in some of their interviews reflects the difficulties that some doctors have had in taking on these roles.

Nevertheless, very significant changes have occurred. Prior to the NHS Plan, there was little or no culture of reporting on quality of care within general practice. GPs were independent professionals, and the concept of managerial accountability was hardly discussed at all. GPs’ accountability was seen as limited to their patients, and to the General Medical Council (as the licensing body). Yet by 2002, 98% of PCTs were reporting that they received information on quality of care from ‘all or most’ of their practices (Wilkin et al. 2002). Most frequently, this was on care for coronary heart disease. Perhaps more remarkable was the use to which this information was put. In addition to sharing information within the PCT board, by 2002 a third of PCTs were feeding back information on quality of care to practices in identifiable form, and 7% were making identified information available to the public.

Other significant changes have taken place in the way in which practices work. Prior to 1999, education and quality improvement activities normally took place within individual practices.

Primary Care Trusts started to promote shared educational activities between practices, often providing funding so that all practices in a locality could close to routine work on one half-day a month for a joint educational session. By 2002, 69% of PCTs had developed such schemes, and many reported that all, or almost all, practices in their locality were represented at the meetings. Clearly, the gap between attending a quality improvement meeting and improving care may be significant. Nevertheless, the extent of the cultural change implied by such activities should not be underestimated.

Other prominent quality improvement activities led by PCTs have been the development of local protocols and guidelines, promoting the use of personal learning plans and of practice-development plans within practices, and the promotion of significant-event audits. In encouraging these activities, PCTs have often provided expertise or resource – for instance, an identified GP or group of GPs to help local practitioners develop personal learning plans. Again, these are all largely new activities in primary care since 1998.

There has also been a focus on underperformance and reduction in error. In 2002, 82% of PCTs reported that they were involved in some form of risk management activity. Through the legal responsibility vested with the Chief Executive to provide high-quality care, they also became responsible for issues around poor performance and were given delegated power to suspend GPs from the local medical list. However, work with under-performing doctors has generally focused on establishing structures to identify and support poorly performing doctors rather than taking a more proactive disciplinary approach. We discuss these in more detail later in this chapter. Many clinical governance leads have found substantial difficulties in resolving the conflict between their role in supporting and encouraging quality improvement in all practices, and their role in identifying and dealing with poor performance (Campbell et al. 2002).

Clinical governance priorities have in general been the major clinical areas identified as priorities by central government and included in the early NSFs, with coronary heart disease, mental health, diabetes and care of the elderly most commonly identified as priorities. This reflected the requirement for PCTs to report to central government on their progress in implementing NSFs. Resistance to the choice of priorities has been low among the professions, mainly because these are widely recognised as areas requiring improvement.

This account is therefore one of considerable activity. A key question is whether care has improved as a result, and it is probably too early to tell. It is clear that there is more information about care being provided. However, some of this change is simply due to practices developing more sophisticated information systems that allow them to determine the quality of care they are providing. It does not follow that care has actually improved. Many PCTs (75% in 2002) provided financial incentives to practices to provide information on the quality of their care, and one undoubted consequence has been an improvement in the information infrastructure of general practice. There has been one independent longitudinal study of quality of care in a



relatively unselected group of practices, which suggests that quality of care improved in a range of areas between 1998 and 2001 (see Table 13.1) (Campbell et al. 2003). Furthermore, evaluation of practices with PMS contracts suggested that targeted investment can produce improvements in care in the chosen areas, a development that we discuss further in “Commissioning by Primary Care Trusts” below (PMS National Evaluation Team 2002).

**Table 13.1 Examples of improvement in quality scores in 23 English practices from 1998 to 2001**

	1998	2001	Significance of difference
Access questionnaire (changes due mainly to availability of information by phone, and availability of interpreters)	73.5	86.8	0.016
Access (patients' assessment from GP Assessment Survey)	62.0	61.4	> 0.1
Chronic disease management (changes due mainly to increased use of registers, protocols and clinics)	58.7	92.4	0.039
Quality of care for angina (from review of patient records)	67.4	77.6	0.003
Quality of care for asthma (from review of patient records)	62.3	69.4	0.06
Quality of care for diabetes (from review of patient records)	78.9	81.4	0.06

SOURCE: Quality score data from Campbell et al. 2003

Since a wide range of activities have taken place under the umbrella of clinical governance since 1999, it is difficult to ascribe change to any one type or group of activities. Furthermore, the proposed new GP contract, which is the most ambitious scheme to measure and reward high-quality care undertaken by a large health care system anywhere in the world, is likely to have a major impact on quality of care (Shekelle 2003), making it even more difficult to unpick the success or otherwise of these new policies. However, if the contract is introduced, there is certain to be a major drive within practices to improve quality, which will be entirely consistent with PCT clinical governance objectives, if not entirely within their control. PCTs will need to develop an effective monitoring and inspection procedure for the large quality payments that will be claimed under the new contract. This will require skills and experience that many believe to have been lost to the NHS when Family Health Service Authorities were incorporated into Health Authorities, and are only now being redeveloped within PCTs.

### **Audit and clinical governance activity across the primary/secondary interface and relationship to hospital CG structures**

If considerable clinical governance and service development activity has taken place within primary and community services, it is much less apparent that PCTs have been able to reach out and extend this clinical governance work in partnership with colleagues within secondary care. In a national study of Primary Care Groups and Trusts that focused on twelve in-depth, case-study primary care organisations, it was noted that almost all clinical governance initiatives were based within primary care (Regen et al. 2001).

From the early experience of clinical governance activity in PCTs therefore, it would appear that the main emphasis has been on “getting their own house in order”, with a relatively low focus on cross-sectoral activity. PCTs have sought to set minimum standards for primary care provision, develop protocols for certain clinical conditions and procedures, implement new forms of peer review for professionals, and put in place structured training programmes for primary care professionals. In the area of the management of prescribing, there is more evidence of quality improvement activity that draws together primary and secondary care. For example, some PCTs have worked with local Acute Trusts to develop drug formularies and prescribing protocols across the whole of the local health economy, often within the context of Area Prescribing Committees. Another example of the type of cross-sectoral work being carried out was a project on referral guidelines in North East Lincolnshire PCT, where local GPs had worked closely with an Acute NHS Trust to develop guidelines for referrals to surgical specialties. This project had a clear focus on the quality standards expected of clinicians in both primary and secondary care, facilitated good partnership working between the hospital and primary care sectors and highlighted areas where communications needed to be improved (Regen et al. 2001). Nevertheless, it would seem that these more holistic approaches to quality development and improvement remain the exception rather than the rule.

What remains to be seen is how quickly PCTs will start to lift their heads above the immediate preoccupation of primary care, and, in their capacity as commissioners of local health services, seek to develop more integrated clinical governance activities that transcend the traditional primary/secondary care interface. PCTs are still new organisations, busy developing the engagement of their own constituents (especially GPs) and establishing structures and procedures within which to manage service and quality development. As they mature as the main commissioning organisations for local health, it would be reasonable to expect them to take a lead in developing approaches to clinical strategy and governance across the entire health economy.

## **Commissioning by Primary Care Trusts as a means of improving care**

### ***Commissioning of primary care services by Primary Care Trusts***

Where PCTs have been able to free up local monies, there is a range of examples of commissioning new services from primary care to improve quality. Often this has related to the needs of specific groups with identified health needs (such as asylum seekers). However, many PCTs inherited a budget deficit, and their ability to create new services has been severely limited. They have certainly not been able (even if they were willing) to move significant amounts of resource from secondary to primary sectors. Their ability to invest in primary care has therefore been substantially dependent on areas where resources could be earmarked for a specific purpose. For capital developments in primary care, the Private Finance Initiative (PFI) has been used for the development of new premises – a scheme known as LIFT (Local Improvement Finance Trusts).

One example where PCTs have been able to increase primary care resources has been in the development of PMS pilots. These change the contractual arrangement between general practices and the PCT, and have provided an opportunity for additional investment in practices, often with new money provided by central government. The process of selecting practices for PMS status has been a joint one between practices and PCTs. While PCTs have to put practices forward to central government for approval, it is the practices themselves who have to propose the area of care they would like to develop in order to bid for increased resource.

A national evaluation of PMS practices has been conducted (NPCRDC 1998). In contrast to the case with fundholding, where practice development was concentrated in those practices already well resourced, there is evidence that PMS has been able to be used to improve care in practices and areas with greater need. Further, there were clearly identifiable improvements in PMS sites that had a specific objective to improve certain aspects of care, such as in elderly and mental health care. The evaluation found that it was not appropriate to look on PMS as a unitary phenomenon but rather as a diverse set of approaches to the organisation and delivery of care. The success was substantially dependent on local factors such as the project having clear aims, effective teamwork in practices, and effective leadership at both practice and PCT level.

In future, there will be further opportunities for investment in primary care through a range of “enhanced services”, which will form part of a further move to locate services in primary rather than in secondary care.

### ***Commissioning of intermediate care and secondary care by Primary Care Trusts***

Early evidence on the commissioning activity of PCTs again suggests that the most significant progress has been made in the area of community services, primary care and intermediate care (Regen et al. 2001; Wilkin et al. 2002). In terms of developing specialist services, PCTs have often focused on new developments in community settings, for example new

intermediate diabetes services, locality-based rehabilitation teams, community mental health services, and demand-management initiatives. The development of such services has typically been seen as a means of facilitating the proactive and structured management of chronic disease, promoting patient independence and relieving pressure on secondary care services (Regen et al. 2001). There have been significant moves towards the employment of GPs with a special interest, and the development of Tier 2 services.<sup>†</sup>

A further benefit of the development of these new community-based services is the role such initiatives can play in facilitating service provision and professional collaboration across practices. In other instances, commissioning has focused more specifically upon seeking to manage demand more effectively at the primary/secondary care interface – for example, via the examination of referral data and patterns and the development of new protocols across the two care sectors (Regen et al. 2001).

In the area of acute services, evidence suggests that commissioning progress has been much more limited (Smith & Goodwin 2002). In this, PCTs are mirroring the experience of their predecessor primary care organisations with processes such as total purchasing schemes, GP commissioning and multifunds (Goodwin 1998). The possible reasons for this slow progress have been cited as follows (Smith & Goodwin 2002; NHS Alliance 2002):

- lack of stability in the wider policy context;
- absence of an appropriate range of approaches to commissioning within primary care organisations (e.g. not having clinical budgetary control located at a level where GPs and others can influence service design);
- lack of adequate clinical involvement in commissioning;
- inadequate management capacity for commissioning within primary care organisations; and
- under-developed relationships between PCTs and local Trusts.

The fact that previous primary care organisations, and indeed health authority purchasers, found it difficult to bring about changes in the provision of acute services is an important point to bear in mind when assessing PCTs progress in this area. Primary Care Trusts are still very new organisations, and in common with all new bodies, have been seen to focus very much on infrastructure issues and organisational development in their first year of operation (Regen et al. 2001; Wilkin et al. 2003). What is clear, however, is that PCTs have definite aspirations in relation to using their commissioning role as a means of bringing about improvements in the quality of patient care. In one study of primary care groups and Trusts (Regen et al. 2001, p. 54), the objectives for commissioning commonly set by PCG/Ts were suggested as being:

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<sup>†</sup> Tier 2 services are services provided between primary care and secondary care – for example, using a GP with Special Interest or a physiotherapist to direct orthopaedic referrals to the most appropriate professional, or for an initial investigation, rather than the outcome of the referral always being contact with a specialist. Some examples of Tier 2 services are covered in (GMSHA 2003).

- reducing waiting lists and times;
- managing demand, usually via the development of scoring systems;
- bringing about improvements in direct access to hospital services;
- securing improvements in the quality of hospital services;
- improving equity of access to services; and
- developing clinically led long-term service agreements.

The key question in relation to the commissioning of acute services by PCTs in the future is the extent to which these organisations can achieve objectives such as those cited above. This raises issues once again about the available organisational capacity for commissioning, the need to engage clinicians in the commissioning process, the potential of budget-holding by groups of primary care clinicians, and the importance of effective primary/secondary care relationships.

The commissioning task facing PCTs is also one that is growing in its scope and importance. From April 2003, a new “financial flows” regime is being introduced into the NHS, a new form of contracting for acute care episodes. Money will theoretically follow the patient, and NHS Trusts will be reimbursed on a cost-per-case basis for any activity above agreed contract levels, or likewise penalised at such a rate if they underperform against targets (DOH 2002). The introduction of a standard tariff for some procedures may also act to restrain increases in costs.

In addition to the introduction of financial flows, the new “patient choice” policy, whereby patients who have been waiting for elective treatment for more than 6 months can opt to move to another NHS or private provider, adds a further dimension to the complexity of the PCT commissioning challenge. PCTs, in their pivotal role within local health care systems, face at once the task of seeking to develop and improve primary care and community services, whilst also using their commissioning role to tackle some of the most long-standing problems within the health care system, namely improving access to and redesigning acute services. Whether PCTs will prove equal to this challenge remains to be seen.

### **New inspection and monitoring procedures**

In addition to charging PCTs with responsibility for improving quality of care, a number of inspection and monitoring procedures have been established. Linked to these is the development of annual appraisal of all general practitioners, which is a PCT responsibility. Satisfactory annual appraisal will lead to more or less automatic revalidation of doctors every

five years. Another new requirement is for PCTs to report on measures taken to improve patient safety. In the following sections, we describe in more detail two particularly important new initiatives. The first is the inspection of PCTs themselves by the Commission for Health Audit and Inspection, and the second are the procedures that PCTs themselves have established to identify and deal with deficiencies in the care provided by their own GPs. These both represent major developments since the publication of the NHS Plan in 2000.

### ***Inspection of Primary Care Trusts: the Commission for Health Audit and Inspection***

The Commission for Health Improvement (CHI) was established in 1999 to address unacceptable variations in NHS patient care in England and Wales by identifying both good practice and areas where care could be improved. It will become the Commission for Health Audit and Inspection (CHAI) in 2004. CHI had four main statutory functions: clinical governance reviews of NHS organisations, specific studies of the implementation of the NSFs and NICE recommendations, investigations of serious service failures, and dissemination of good practice.

CHI focused most of its attention on acute sector organisations. However, building on the lessons of the Health Authority reviews conducted in 2000, it conducted pilot reviews in eight PCTs in 2001/2002. The reviews assessed seven areas: patient involvement, risk management, clinical audit, staff management, education and training, clinical effectiveness and use of information. Each area was evaluated in terms of its impact on the patient experience and the organisation's strategic capacity for improvement.

The pilots demonstrated the significant challenges of reviewing the function of PCTs, not least because PCTs are new, diffuse organisations that are still working out their form and function. Indeed, the extent to which the reviews should focus on the PCTs or on their constituent practices is still unclear. In the pilots, a small number of practices in each PCT were visited by CHI assessors to evaluate the extent to which practices were engaging with their PCTs. Several practices thought that they were being reviewed independently of the PCT and were disappointed not to receive individual feedback from the assessors. CHI's emphasis on PCTs rather than on individual practices is probably the correct one at this stage, despite the fact that CHI's influence on quality at a practitioner and practice level will therefore be indirect and dependent on the management capability and capacity of the PCTs. However, practice-level assessments across the board would be prohibitively expensive. PCT-level assessment also confirms the PCT's strategic and operational responsibility to actively manage the quality of care provided by their constituent practices. The problem at present, however, is that some practices are completely disengaged from their PCTs, and are therefore unlikely to be influenced by CHI's activities. This is likely to change over the next few years as practices accept a reduction in their own autonomy and the statutory responsibilities of their PCTs.

As CHI merges with the Audit Commission and the National Care Standards Authority to become the Commission for Healthcare Audit and Inspection (CHAI), the primary care review procedure will continue to be adapted and refined. CHAI, through a new Office for Healthcare Information, will assume new responsibilities for collecting, collating and publicly reporting data relating to the performance of primary care organisations.

CHI reports have been used in combination with other NHS performance indicators to produce star ratings for Acute Hospital Trusts (see Chapter 5). It is too early to determine the long-term effect of the star rating system on the NHS. The only experience so far is with Acute Trusts. While they may represent an important step towards greater transparency about NHS performance, the blunt tools and methodology have been questioned by the service and by other observers. They will potentially have a dramatic impact – from extra money/involvement in policy making for the three-star Trusts, to radical changes in management and potentially poor impact on staff morale for zero-star Trusts.

From 2003, there will be a radical new departure in CHAI's assessment of primary care organisations with the development of star ratings. This means that each PCT will be assessed on the basis of a national set of indicators, making public the results within categories from three stars (high-level performance) through to zero stars (poor-level performance). Fifty performance indicators for PCTs have been developed by the Department of Health and CHI, grouped into three thematic areas: access to quality services, improving health, and service provision. Examples of indicators to be applied include: the percentage of patients offered an appointment to see a GP within two working days; the number of outpatients waiting longer than the standard; the number of drug misusers accessing treatment; the percentage of women aged 50–64 screened for breast cancer; conceptions below the age of 18; and access to NHS dentistry. As can be seen from the range of indicators, they seek to cover the PCT's core roles of service provider, care commissioner and improver of health. However, the choice of indicators is dependent on information already routinely available, and is extremely partial in terms of the range of services provided or commissioned by PCTs. The focus is on political priorities such as access and waiting time.

The implications of the use of the star ratings within PCTs are yet to be determined, but early experience suggests there may be potential problems with disaggregating data to PCT level, an absence of information systems in place for some indicators, a lack of indicators relating to key community services such as district nursing and health visiting, and the overly strong focus on access targets that relate mainly to the secondary care sector. Furthermore, there is concern that poor indicators may reflect the environment (e.g. social deprivation) in which PCTs find themselves, and not just their ability to manage health care in that environment. What is clear, however, is that the new system will have teeth. This aspect has already been seen in the secondary care sector, where managers of zero-star organisations have lost their jobs, and financial performance awards for Trusts are linked to the particular star rating of the institution.

In the medium term, CHAI has the potential to ensure that reviews are carried out in a systematic way, that good practice is widely disseminated, and that a valid and reliable set of indicators is developed for the star rating system. If this potential is realised, then this will represent a significant advance in the monitoring and improvement of quality in care in both primary and secondary sectors. The challenge is to do so in a way that encompasses the right quality markers, and does not completely alienate those involved in delivering the care.

### ***Procedures for dealing with poor performance of general practitioners***

From April 2002, the Chief Executive of each PCT acquired responsibility for ensuring high-quality care from all the PCT's providers. This focused the attention of PCTs on poor performance, and they have started to develop performance procedures based on those that had previously operated at health authority level. Although PCTs have formal responsibility for the quality of care in both primary and secondary sectors, we focus here on procedures being adopted in primary care, since these procedures are entirely new, and since the responsibilities of PCTs are more direct in this sector.

Health authority procedures for detecting and managing poor performance among general practitioners had been developed in the late 1990s. Initially, pilot procedures were tested in six sites in the north-west of England. These were subsequently rolled out so that each of the pre-2001 health authorities set up a performance panel. These continue under the aegis of PCTs, with panels sometimes covering more than one PCT.

Some of these panels have reacted responsively to complaints or concerns raised by patients, professionals or NHS managers, while others have sought to identify underperforming doctors from available health service statistics. The work carried out by the health authorities suggested that the problems that are really likely to arise in practice (see Box 13.1) are unlikely to be discovered through routine statistics, and that the responsive mode of working is going to be a vital part of the procedures.



**BOX 13.1****Types of concern considered by the Manchester performance panel**

- Poor communication in the practice
- Poor teamwork
- Inability to work with others
- Poor communication with patients
- Negative or uncaring attitude towards patients
- Minimal clinical service
- Poor clinical decision-making or clinical knowledge
- Absence of a complaints procedure
- Low cytology or vaccination coverage
- Poor prescribing, including repeat prescribing of benzodiazepines, unnecessary vaccinations, poor repeat-prescribing system, low generic prescribing
- Health and safety requirements not met
- Poor practice management or administration, disorganised practice

SOURCE: Roland et al. 2001

Based in part on the experience of the early performance panels, the National Clinical Assessment Authority (NCAA) was established in 2001. It set up a series of procedures for primary care (NCAA 2003) that are intended to be used to identify poorly performing doctors, and will be supporting PC Ts in operating these procedures. The NCAA procedures follow earlier locally developed protocols, but introduce greater rigour, including, for example, an occupational health assessment and a formal test of knowledge as part of the assessment of each referred doctor. It is anticipated that the NCAA themselves will carry out assessments in only a very small number of cases where it has not been possible to operate more local procedures effectively.

Over the past few years, considerable experience has been gained in the assessment of underperformance, and it is likely (though untested) that these procedures are reasonably robust in terms of assessing doctors who are referred to a panel or to the NCAA. What is not known is how effective the procedures are in detecting cases of serious underperformance, or in ensuring fairness in their detection (e.g. whether there is racial or other bias in the reporting of complaints).

A significant problem lies in addressing the problems of doctors whose performance has been identified as substandard, but is not so poor that they need to be suspended from practice (which falls outside the NCAA's remit). Experience in the Manchester panel (one of the original six pilots) has been that the pace of change that can be expected from these doctors and their practices is very slow. Many have got into a failing situation precisely because they lack the skills that would help them to improve (e.g. basic practice-management skills, self-awareness, ability to audit care in their practice, and change management). Some of the skills that might help these doctors are located within the postgraduate deaneries, whose main role in primary care is related to vocational training for general practice. Until recently, some of the deaneries have not seen the management of underperformance as part of their job, nor have they had the resources to commit to this task.

Since 2002, performance procedures for general practitioners have tended to be devolved from the old (abolished) health authority level, to PCT level, though in some areas panels represent a number of PCTs. There are significant concerns about this local "devolution", though some positive aspects as well. The concerns are that PCT-level panels will probably only see one or two cases a year, and may not gain sufficient experience to make sound judgements, or have sufficient experience to be able to identify effective remedies. There is also a problem that the relatively small size of many PCTs means that practitioners being assessed will usually know the members of the panel, and their assessors. It is not clear that the closeness of the inspectors to the inspected will help the process. We have already commented on the difficulties articulated by PCT clinical governance leads about combining their quality improvement ("carrot") and quality assurance ("stick") roles. PCT performance systems might operate more effectively if panels covered larger areas than one PCT, or if there was cross-coverage and inspection between local PCTs. It will be hard to know how effective the current procedures will be, as they are not being closely monitored. Compared with the National Patient Safety Agency, the NCAA has a very small budget for research and evaluation.

## **Conclusion: areas of success and areas of concern**

### ***Areas of success***

There are a number of important differences between approaches to quality improvement since 1998 and earlier initiatives. First, previous approaches that had been used to measure and improve quality of care, such as audit, were mostly voluntary. Clinical governance makes improving quality a duty of NHS organisations and their chief executives, one that is equal to their other statutory responsibilities such as financial probity. Second, clinical governance represents the first coherent, systems-based strategy aimed at the NHS as a whole.

There have been no previous systems-based quality improvement initiatives in the NHS of the type articulated by clinical governance, backed up with significant resources and national

policy commitment. Considerable progress has been made in establishing the infrastructure necessary to deliver quality services and to turn the rhetoric of clinical governance into reality. The government is championing national initiatives (e.g. NSFs) and PCTs are pursuing educational strategies (e.g. practice-development plans and cross-practice audits), and a more transparent quality improvement agenda is emerging as a result.

Resources have been used both to build up clinical governance infrastructure within PCTs and to provide practices with incentives linked to a variety of tasks, such as in audit and in meeting targets contained within NSFs. Offering financial incentives is a realistic mechanism for getting practices to participate in quality improvement, as there are genuine costs to independent practitioners in committing to such activities. Incentives are likely to become increasingly important to the provision of primary care in the UK with the new general-practice contract, and an increasing range of staff are likely to be employed in primary care practices with the aim of improving quality of care. This is a considerable advance on the approach in the 1990 GP contract, which to a significant extent rewarded activities that were unlikely to result in significant health gain.

Before the establishment of PCGs and PCTs, GPs worked largely independently of each other, and practised within a self-regulated environment. One of the challenges that faced PCG/Ts in implementing clinical governance was to develop a more corporate culture in which quality improvement is a shared enterprise. The evidence to date suggests that this shared-learning environment is beginning to take shape. There has been progress in terms of sharing data, cross-practice audits, and staff in a general practice learning together at PCT-sponsored educational events, which is a major cultural change for primary care. This is a sound approach to take, because education and learning at the organisational level, in this case of general practices, are effective methods of improving quality of care (Davies & Nutley 2000). PCTs seem aware of the need to address the underlying changes in behaviour and culture, both organisational and behavioural, that are required to create successful change (Marshall et al. 2002).

PCTs are increasingly active in commissioning a new range of services, such as intermediate care schemes, Tier 2 services and GPs with a special interest. These could have a significant impact on quality of care, though it will remain a challenge to ensure that new initiatives are well co-ordinated and do not fragment care, and that commissioning new types of service is more cost effective than strengthening existing ones.

### ***Areas of concern***

Areas for concern about the role of PCTs lie in two main groups. The first relates to the lack of evidence of effectiveness in terms of improved care, and the second relates to PCTs' difficulty so far in engaging primary care practitioners with the quality improvement agenda.

In terms of their overall effectiveness, it is probably too early to say what the impact of PCTs has been. What is most evident is change in activity. There has been plenty of that, with the establishment *de novo* of clinical governance structures across the country over the past five years. These have happened at the same time as the organisations themselves have been set up, and there has been real concern about their management's capacity to effect change. This is both at primary care level, where practitioners are not used to being managed at all, and at secondary care level. For the latter, Acute Trusts have been used to dealing with purchasers since 1990. Many are large and very powerful. The ability of PCTs, which are in most cases substantially smaller than the health authorities that used to negotiate with Trusts, to take on the powerful and vested interests within Acute Trusts is highly questionable.

Significant investment in new services is at the interface between primary and secondary care as mentioned earlier. It will be important to ensure that these enhance the efficiency of existing services, and do not produce waste through fragmentation and duplication.

Functions such as public health advice have become dispersed in the new NHS management arrangements, and this does not appear likely to be replaced effectively by support from the new Strategic Health Authorities. However, a new type of public health may also be emerging, in closer contact with service delivery in primary care, and potentially more prepared to engage in a wider public health agenda (e.g. developing partnerships with agencies outside the NHS) than was the case with traditional departments of public health medicine.

The second major area of concern is the mixed success of PCTs in engaging their local practitioners with the new quality improvement agenda. Primary Care Trust clinical governance leads in the National Tracker Survey of PCTs conducted by the National Primary Care Research and Development Centre (NPCRDC) report gradually increasing support for clinical governance. The proportion of general practitioners identified by clinical governance leads as "supportive" or "very supportive" rose from 28% in 1999 to 51% in 2002. Practice managers were reported as being more positive, with the proportion reported as being supportive rising from 39% to 67%.

These findings initially look encouraging. However, the figures represent the views of clinical governance leads in PCTs. When questioned directly, general practitioners themselves have been less positive. A national survey of 2,344 GPs conducted by the NPCRDC in 2002 (Sibbald, personal communication) showed that 33.5% felt "positive" or "very positive" about clinical governance, though this was a higher proportion than felt positive about the PCT as a whole (19.9%).<sup>†</sup> Furthermore, more GPs (24.1%) thought that the advent of PCTs had reduced quality of care than thought PCTs had improved quality of care (14.9%). Others have more positive findings: Regen (2002) asked a similar question of

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<sup>†</sup> This survey covered Great Britain, so some of the responses related to Local Health Groups in Wales and Local Health Care Co-operatives in Scotland.

306 GPs, and found that 26% thought PCTs had led to improvements in quality of services provided in practice, compared to 13% who thought quality had got worse. As with other surveys, Regen found enthusiasm for all aspects of PCT work to be greater among those involved with PCTs than among grass-roots GPs.

At local professional meetings and in the tabloid professional press, GPs are still actively cynical and suspicious of the role of PCTs. In part, this reflects the natural resistance of “independent” contractors to a changing environment where greater accountability is required and professional freedom is progressively being reduced. These changes are being seen in all professional groups and in most health care systems, so the reaction of British primary care practitioners is neither surprising nor unusual. However, there is also a paradox: general practitioners are critical of the inability of the PCT to manage, which is largely due to lack of management capacity and experience, but they would be equally unhappy if PCTs were suddenly to gain a high degree of management competence. From a secondary care perspective, PCTs do not appear at present to have the management capacity to challenge the major secondary care providers to whom most of their resource goes. There must also be some concern about the management capacity of PCTs to deal with all the new issues that will arise in relation to the new GP contract, such as taking responsibility for out-of-hours care or negotiating with potential third-party providers of primary care services.

These difficulties may be transitional ones, as the reorganisation of the NHS is relatively new. There is no doubt that there is a significant degree of reorganisation fatigue, relating, as Smith et al. (2001) have phrased it, to “re-disorganisation”. This is certainly seen among practitioners, who adapted to a sequence of new purchasing arrangements between 1990 and 1998, only to find them all abolished. The reorganisation fatigue is even more pronounced among managers, many of whom have had to apply for their own or new jobs several times in the past few years. As recently as spring 2003, one complete tier of the NHS (Directorates of Health and Social Care) was abolished only shortly after being set up. The work of Sweeney et al. (2002) emphasises the degree to which clinical governance leads feel beleaguered, being faced with a lack of funding, direction and guidance; long working hours; and lack of time to absorb and understand multiple initiatives. Stability in NHS organisations will enable them to develop more effective management capabilities, as well as improving staff morale. Reorganisation and mergers cause considerable disruptions to services, and appear to require greater management support than previously acknowledged (Fulop et al. 2002).

### **Summary of impact to date**

Under this topic, we have summarised the overall impact to date on primary care of PCTs' efforts to improve quality of care. We have contrasted the strengths and weaknesses in what has been achieved so far.

**Table 13.2. Summary of some strengths and weaknesses of developments in primary care: 1998–2003**

<b>Aim</b>	<b>Strengths/successes</b>	<b>Weaknesses/limitations</b>
Managing primary care	Development of more sophisticated and proactive management functions within primary care, a sector of the NHS previously run on an administrative and reactive basis.	Limited capacity for required tasks, both in volume and experience of staff. Frequent and disruptive changes to the structure of PCGs and PCTs and to their senior management.
Increasing accountability and public engagement	A greater degree of transparency, accountability and public engagement at both practice and PCT level, and some local examples of successful public engagement.	Little overall evidence of impact of user involvement on service development and in PCT boards or committees. Initial focus has been on establishing structures for user involvement – the challenge is to translate this into outcomes for patients.
Improving care through clinical governance	The introduction of clinical governance structures and arrangements into primary care and community services, and the relative enthusiasm of practitioners for this aspect of PCT activity.	Substantial activity (e.g. local guidelines, cross-PCT audits), but modest evidence of improvement in services to date. Some evidence of effective moves towards shared learning across practices and development, albeit slow, of greater corporate feeling across practices.
Commissioning primary care services	A clear national commitment to more systematic commissioning of primary care services from within primary care itself. Some evidence of successful targeted investment, e.g. through PMS contracts, the use of primary care collaboratives, commissioning of intermediate care services and GPs with a special interest.	Risk of duplication or fragmentation of existing services. Occasional uncritical introduction of new services.

Aim	Strengths/successes	Weaknesses/limitations
Commissioning secondary care services	Location of the responsibility for commissioning secondary care services within primary care organisations.	Limited change has been brought about within secondary care, and those developments that are reported are mainly in the area of intermediate care or at the margins. Concern that PCTs may not have the capacity for successful engagement and influence with large Acute Trusts.
Engaging with local practitioners (especially GPs)	Potential for PCTs to facilitate enhanced engagement with local practitioners in relation to local health planning, spending and service delivery. Emergence of a class of 'manager GPs' (re-stratification).	Engagement of GPs with early PCG structure was lost; limited evidence of engagement of most GPs with PCTs.
Monitoring performance of primary care	More robust and transparent performance procedures introduced into primary care. Successful establishment of processes to identify under-performing doctors.	Major problems of how to remedy underperformance when it has been detected.

### Future needs and recommendations

In this chapter, we have pointed to the wide range of activity that has resulted from the Government's quality improvement strategy at PCT level. Activity has been easier to describe than improved outcomes for patients, partly because much has been started only recently. While the role of PCTs has been very important, it is difficult to disentangle exactly what their impact has been, given the multi-faceted nature of the NHS Plan. This will continue to be the case. Indeed, from a primary care perspective, the large financial incentives to improve quality of care in the new GP contract may well have more impact than all the present initiatives started by PCTs. Since the contract is a national one, the role of PCTs in the contract may be limited to that of paymaster, with the ability to carry out intermittent verification visits.

PCTs have done some good work in developing local quality agendas for primary care. These approaches may be increasingly hard to sustain as PCTs expand their range of responsibilities and are directly accountable to central government for achievement of NHS Plan targets. Key challenges that lie ahead include:

- building on the early progress with clinical governance in primary care, including engaging a wider range of health professionals in the quality improvement agenda;
- making a difference to secondary/intermediate care through the commissioning process;
- making the star rating system work for practices and PCTs; and
- implementing the new GP contract in a way that engages practitioners and enables PCTs to improve patient care.

We would make the following recommendations in relation to the development of primary care and PCTs.

1. PCTs need stability in the policy context in order to be able to focus on their core tasks. Re-organisation of NHS structures, which is highly disruptive, should be avoided. Further mergers of PCTs should also be avoided unless there are particularly pressing factors that are agreed by local stakeholders to call for structural change; it should be accepted that the optimal PCT size differs for different functions (e.g. smaller for clinical governance, larger for commissioning). This should be dealt with within the context of current PCTs.
2. The commissioning function of PCTs needs to be strengthened in terms of management support, information and analytical expertise, clinical involvement, and the development of effective working relationships with local NHS Trusts. This may be accomplished by bringing PCTs together into commissioning networks or consortia, and by Strategic Health Authorities providing more active facilitation and support. The nature of commissioning will change as the full effect of financial flows starts to take effect and new policies on patient choice are implemented over the next two years. This will require development of yet another new set of skills within PCTs, many of whom are struggling to cope with old-style commissioning.
3. PCTs should continue to identify opportunities for targeted investment in primary care through either PMS or GMS contracts with GPs, through contracts with third-party providers, or by providing services directly. Additional investment needs to be clearly linked with the achievement of locally agreed service targets and quality indicators. In commissioning services from new providers, particular attention should be paid to the need for integration and co-ordination of services.
4. Attention needs to be given to careful co-ordination of care at the interface between primary and secondary care, building on the experience of PCGs and PCTs in developing new forms of intermediate care. Primary Care Trusts need to ensure that new services (e.g. Tier 2 services) take account of the risks of fragmentation and duplication. Service redesign initiatives within hospitals likewise need to look at the impact on the whole system of proposed changes.



5. Shortage of appropriately qualified personnel is a major problem in some areas. PCTs need support in developing effective strategies both to recruit and retain staff, and to use the skills available to address local problems.
6. Existing clinical governance arrangements should be strengthened and extended. Professional executive committees, sitting between those who manage and those who deliver the service, have a key role in engaging local clinicians. Although there is some evidence of progress, initial activity has not been matched with changes in services provided, or with a cultural change within general practice (e.g. in working more closely with other community and social services). Additional clinical governance activity needs to be focused on improving the integration of care at the primary/secondary interface and at the interface with other services, such as community health and social services.
7. The limitations of the PCT star rating system based on currently available data should be recognised. Until the new set of performance indicators for PCTs currently being developed by CHAI is available (2004/5), management decisions based on PCT star ratings should be made with extreme caution. Because of the relationship of some indicators to the socio-economic context (e.g. the teenage pregnancy rate), the rate of change will be a more appropriate indicator of PCT performance than the absolute level of performance will be.
8. Improved infrastructure support is needed to address the problems of health professionals who are underperforming or who are at risk of doing so. Significant additional investment may be needed to deal effectively with doctors who are underperforming (including deciding whether a problem is remediable). Consideration should be given to combining performance procedures for GPs across PCTs where there is inadequate caseload to build up experience within an individual PCT.
9. Users are currently marginalised in the development of primary care, despite rhetoric to the contrary. This is partly due to lack of clarity about the roles that users are expected to take, for example in clinical governance procedures. Greater clarity is needed about how users can be most effective in developing the service, and how examples of good practice can be disseminated.
10. PCTs will have continuing and increasing needs to develop management capacity. Imminent changes, such as the new GP contract, financial flows and patient choice, will severely stretch organisations that already struggle to cope with the agenda they face.

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# 14. Public Reporting of Information on Health Care Performance in the United Kingdom

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## **Introduction**

Robust information is a fundamental requirement for the efficient and effective operation of a health system (Donabedian 1980). The availability and quality of data in the NHS has been a source of persistent concern since the service was established in 1948. Over the years, a number of attempts, largely unsuccessful, have been made to address this problem, and it is now clear that improving data quality is an urgent priority for the NHS. One of the reasons for this is the high focus on data resulting from the policy of putting information into the public domain (McKee & Hunter 1995).

This chapter provides a critique of the policy and practice of public disclosure in the UK at this midpoint in the Labour Government's ten-year plan for modernisation of the NHS. It first explains why the public reporting of performance is an important part of the modernisation process, then outlines key reporting initiatives before and after 1997. There follows a review of the successes and deficiencies of the initiatives introduced since the election of the Labour Government in 1997. The chapter finishes by suggesting what we need to know in order to take the agenda forward; describes the risks of not taking action; and makes specific recommendations to maximise the benefits of public reporting in the future.

## **Why report on health system performance?**

A critique of the policy and practice of public disclosure requires us to be explicit about the objectives of public reporting and about how the various stakeholders are expected to respond (Marshall et al. 2000a). In principle, there are three broad reasons for putting performance data into the public domain. The first is to increase the accountability of health care organisations and individual health professionals and managers. Although the issue of accountability has become a mantra for advocates of reform, the detail of who is accountable to whom and for what is not always made clear. Nevertheless, in principle greater accountability offers patients, regulators, politicians and purchasers a more informed basis on which to express judgements or make decisions about the quality of care that is being

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provided. The information can then influence professional practice, performance management processes, purchasing activities or the decisions of service users.

The second reason for public reporting is to maintain standards and to stimulate improvements in the quality of care provided. An increasing body of evidence, derived mostly from studies conducted in the US, suggests that public reporting can be associated with improvements in both the processes and outcomes of care (Marshall et al. 2000b; Dranove et al. 2002). These improvements appear to result primarily from actions taken by provider organisations. A range of different mechanisms can be used to maximise the impact of the provider response – economic competition, performance management with or without incentives, or appeals to the professional interest of those working in health care to do a good job (Marshall et al. 2003). At present it does not seem that the public, purchasers or individual health professionals have to be, or are, engaged with the process (Schneider & Lieberman 2001).

The third justification for public reporting, giving service users the opportunity to express choice, is conceptually and practically more challenging for the UK than for most other developed countries. Consumerism is still the primary driving force behind public disclosure in the US, despite the evidence cited above that the majority of people do not use report cards in this way. The language of consumerism is starting to creep into the debate about modernisation of the NHS, apparently driven more by politicians than by any significant public demand (Hawkes 2001). At this stage, it is unclear whether the political rhetoric represents a modest desire to give the public a louder voice in the health service, or whether it represents a more ambitious desire to introduce consumer-driven market forces into the health system. The latter is dependent upon more than just the provision of information – it also requires a dramatic increase in supply (which is starting to happen as a result of initiatives such as Diagnostic and Treatment Centres) and true competition between providers (which might be stimulated by Foundation Trusts and by encouraging alternative providers of primary care services in the new General Practitioner contract). It is therefore possible that the foundations are being put in place for greater consumerism in the modernised NHS.

Policy documents published by the Department of Health (DOH 1998; 2000; 2002) since the launch of their strategy on public disclosure adhere more to the first two objectives than to the last one. Public reporting of performance has been promoted as a way of addressing the need for greater accountability of provider organisations and health professionals, and also as one of a wide range of approaches to improving quality. Although the opportunity to encourage greater consumer choice has been mentioned, the ways in which performance data are currently presented, and the incentives linked to the data, both suggest that provider organisations are seen as the primary audience.

### **Reporting activities in the NHS before 1997**

Before 1997, there were only a few examples in the UK of purposeful release of information specifically about quality of care. Some basic information about hospital performance in England and Wales had been in the public domain since the early 1980s, and by 1992 this data included hospital mortality rates. However, although the information was placed in the public domain, it was intended principally for managerial rather than public use, and had little discernible impact (Street 2002). In addition, there were isolated examples of publishing comparative data about issues such as renal transplants or the success rates of *in vitro* fertilisation. These examples were of short-term interest to the media and to a limited specialist audience, but again did not command much attention (Marshall et al. 2000a).

The first reporting initiatives deliberately aimed at the public, known as the *Patient's Charter*, were published by the Conservative Government in 1991 and revised in 1995. The Charter focused primarily on waiting times rather than clinical quality. Perhaps because this information did not form part of a larger policy on public disclosure, initial interest was not sustained. The most ambitious initiative before 1997 was undertaken in Scottish hospitals by the Clinical Resource Audit Group. A range of outcomes data comparing the performance of hospitals and health districts have been published since the early 1990s, including information about teenage conception, cancer survival and post-operative emergency admission rates. However, the release of the information has been purposefully low-key in order to discourage hostile responses from clinicians and the media (Mannion & Goddard 2000).

### **Reporting activities in the NHS after 1997**

So, before 1997 there were a few reporting initiatives but none of them attracted any significant or sustained public interest, and there was no co-ordinated policy to drive the agenda forward. This changed dramatically when the new Labour Government came into power in 1997 and made public disclosure a central tenet of their plans for modernisation (DOH 2000). The following section describes the key reporting initiatives introduced in the last five years.

#### ***The National Performance Assessment Framework***

The concept of a framework to assess performance was introduced in *A First Class Service* in 1998 (DOH 1998). The structure of the Performance Assessment Framework (PAF) was published the following year (DOH 1999b). Its aim was to create a more systematic and structured approach to performance reporting. Six broad areas were identified: health improvement, fair access, the effective delivery of appropriate health care, efficiency, patient/carer experience and health outcomes of NHS care. Some health/social care interface indicators were included under "health improvement". Established performance indicators were aligned to this framework, and new topic areas were evaluated to ensure that indicators addressing all relevant PAF dimensions were included. Standards for the indicators were agreed between the key stakeholders.

After a period of consultation, the first high-level indicators for Health Authorities and effectiveness indicators for Acute Trusts were published in June 1999 (DOH 1999a). The results of the first patient experience survey (see below) were published later that year (DOH 1999c). A modified version of the indicators was published in July 2000. (Following these initiatives, a period of consultation into the nature of the framework and the specific indicators took place in the summer of 2001.) At the same time, *The NHS Plan* was published, the first government document to refer specifically to provider level “report cards” (DOH 2000). In September of that year a selection of the PAF indicators contributed to a new star rating system for Acute Trusts (see below). Further publications took place in February and July 2002, the latter for the first time included data on PCTs, Ambulance and Mental Health Trusts.

Although the broad set of PAF indicators are still published alongside the star rating scheme, public and media attention now focuses on the latter. Over time, the PAF has been adapted to ensure its suitability for reporting at different levels – Health Authorities prior to their abolition, Acute Trusts and most recently PCTs. This adaptation and the introduction of the star rating system seems to have led to some reduction in the profile (or even, according to some commentators, the abolition) of the PAF as a discrete policy initiative.

### ***The Compendium of Clinical and Health Indicators***

Alongside the PAF, the Department of Health publishes an annual Compendium of Clinical and Health Indicators (CCHI), containing about 200 indicators at locality level. Previously known as the Public Health Common Data Set, this information was developed to inform the annual reports written by the Directors of Public Health on their local populations. There is some overlap between the PAF and CCHI indicators, but the public profile of the latter is low.

### ***The star rating system***

The PAF did not have as big an impact as the DOH would have liked. In order to raise their profile, a selection of the indicators at Acute Trust level were combined with the outcome of their clinical governance review by the Commission for Health Improvement (CHI) to produce a new star rating system for all NHS non-specialist hospitals in England. Twenty-nine indicators were included in the first rating system (relating to clinical care, patient and staff experiences), alongside specific performance indicators based on key Government targets (particularly waiting times and financial performance). The method of aggregation of the indicators to form the composite rating has been a subject of considerable debate (Klein 2002).

Each organisation is classified into one of four categories, from zero to three stars. Three stars were awarded to hospitals with the highest performance rating and a favourable CHI review, two stars to “those considered to be performing well”, one star to those with “cause for concern” and zero stars to hospitals with the poorest performance and an unfavourable review.

Three-star organisations are being rewarded with increased financial and strategic autonomy. Zero-star hospitals are being investigated by CHI, their senior management is being changed where necessary, and the Modernisation Agency is providing support to turn the organisations around.

The results for Acute Trusts were first published in September 2001. The most recent ratings were published in July 2003, when 52 Trusts were awarded three stars, 60 two stars, 30 one star and 14 zero stars. Although the latest round of published data appears to show some improvement from the baseline, no independent evaluation of the positive or negative consequences of the published ratings has been conducted to date. However, CHI plans to commission work on the impact of star ratings on Acute Trusts in the near future. A similar star rating system for PCTs was published for the first time in July 2003, when 45 PCTs were awarded three stars, 139 two stars, 98 one star and 22 zero stars.

### ***Dr Foster***

Most reporting schemes in the UK have been led by the Department of Health, but in late 2000 an independent group entered the arena. *Dr Foster*, established by two Sunday Times journalists, makes hospital performance data available on the Web ([www.drfooster.co.uk](http://www.drfooster.co.uk)) and sells its information to the media and other interested parties. The group published its first *Good Hospital Guide* as a supplement to the Sunday Times in January 2001, subsequently produced a *Good Birth Guide*, and in March 2002 produced a second *Good Hospital Guide*. The *Dr Foster* guides report on the performance of all public acute hospitals and the majority of hospitals belonging to the main independent providers. The early guides contained information about hospital-specific mortality rates, number of staff, waiting times, number of complaints, and services. They did not use a ranked or league-table format, but the most recent guide explicitly ranks the hospitals in terms of their relative performance.

*Dr Foster* has invited a number of high-profile figures from the medical establishment to endorse their publications, and has worked closely with the Department of Health to secure compliance and to co-ordinate reporting activities. The main contribution of the *Dr Foster* group has been to bring a level of communication skills to performance reporting that government agencies have failed to achieve. More recently, it has focused its attention on local rather than national reports, and in the near future intends to publish data on individual specialists and primary care practices. It also appears that *Dr Foster* may be failing to engage the public to the extent required for a commercial venture, and is now targeting provider organisations as the main market for its information.

### ***Patient surveys***

The Department of Health has also initiated a series of surveys designed to monitor the performance of the NHS as seen from the patient's perspective (DOH 2003). These offer

systematic comparisons of patient experiences over time and between different parts of the country. Most of the surveys have been contracted to an independent company, Picker Europe. The first survey was conducted in 1998 and covered users of general practices. This was followed in 1999 by a survey of coronary heart disease patients involving 194 NHS hospitals and over 84,000 patients. A third survey focused on patients' experiences of cancer services, and in 2002 the general-practice survey was repeated, the results of which have only recently been published. Responsibility for planning and publishing patient surveys has now been passed to the Office for Information on Health Care Performance (see below), along with the other performance-reporting activities. The Office plans to introduce new surveys relating to National Service Framework areas and to manage a rolling programme of established surveys approximately every three or four years.

### ***Patient prospectuses***

Alongside these national reporting schemes, *The NHS Plan* (DOH 2000) promoted the development of local report cards. All PCTs were required to produce these reports, termed *Patient Prospectuses or Guides to Local Health Services*, in October 2002. Guidance on the content and format was produced by the Department of Health. The first reports contain mostly structural data, but future reports are likely to contain more detailed information about the processes and outcomes of local health care providers. The NPCRDC is currently conducting a survey of these prospectuses.

### ***The Office for Information on Health Care Performance***

The enquiry into paediatric cardiac surgery deaths at the Bristol Royal Infirmary revealed that a great deal of unpublished information on the high mortality rates at Bristol was available, but was not acted upon (DOH 2002). The enquiry report recommended the creation of an independent Office for Information on Health Care Performance, a recommendation that has now been acted upon by the Government. The Office has been established as part of CHI and will become one component of the Commission for Health Care Audit and Inspection (CHAI), which formally comes into existence in April 2004. This organisation brings together CHI, part of the Audit Commission and the National Care Standards Authority, and becomes the independent regulator of UK health care in both the public and the independent sectors.

The new Office is responsible for the collection of data, its analysis to identify good and poor performance, its publication in the form of both national and local report cards, and the conduct of patient and staff surveys. In addition, the Office will be responsible for assessing data quality and making recommendations to improve data systems. It has plans to publish 30-day mortality rates for individual cardiac surgeons by April 2004, building on the work of the Society for Cardiothoracic Surgeons, which has started to publish unit-level post-operative mortality rates.



### Significant achievements to date

The previous section described the large number of public reporting initiatives that have been introduced as part of the ten-year plan to modernise the NHS. Overall, remarkable progress has been made in a short period. The following achievements stand out as particularly significant.

- *The level of commitment to public reporting*

Public reporting represents a significant challenge to the traditional culture of NHS organisations and health professionals. It was therefore inevitable that the policy would be a difficult one to implement. However, the combination of an explicit vision, integration with other policy initiatives, a clear implementation plan, the commitment of policy makers and the leadership demonstrated by some individuals working in the service has achieved much in the last five years. Many other countries are now watching what we are doing with great interest.

- *Willingness to learn from other countries*

The report-card movement has been prominent in the US for over 15 years and the US is acknowledged as the world leader in the field. There is much that other countries can learn from their experiences, and the Department of Health has demonstrated a willingness to do so (Marshall et al. 2000c; Marshall et al. 2000). The process has been helped by the work of the Nuffield Trust (Marshall et al. 2000a) and by a series of high-level international policy seminars that have focused on the role of public reporting in health system reform. For the most part, the Department of Health has been sensitive not only to the transferable lessons from the United States but also to the contextual differences that influence the transferability of new initiatives across the Atlantic (Davies & Marshall 2000).

- *Willingness to create an independent agency responsible for public reporting*

We know from work conducted in the UK and elsewhere that one of the barriers to public reporting is the perception amongst key stakeholders that the published data cannot be “trusted”. In the UK, members of the public have dismissed report cards as “a political stick to beat hard-working professionals” (Marshall et al. 2002). Both the public and health professionals state that they are more likely to engage with published data if they perceive it to come from an “independent body”. The Department of Health has responded by accepting the Bristol Enquiry’s recommendation to create a new Office for Information on Health Care Performance, constituted as part of CHI. The extent to which the Office is truly independent of the Department of Health is addressed later in this chapter.

- *Willingness to work with other interested parties*

A number of different groups have expertise that might usefully contribute to the implementation of public reporting. The Department of Health and, more recently, CHI have demonstrated a willingness to work in partnership with academic groups to examine the scientific basis of quality measures. They have also worked with the *Dr Foster* group and have benefited from their communication skills as well as from co-ordinating activities.

- *Understanding that NHS organisations are the key target audience*

The temptation to regard the public as the key audience for published data has, for the most part, been resisted. We know that for published data to have an impact, provider organisations are the key audience. The content, reporting format and incentives attached to information published within the NHS all suggest that Acute Trusts and PCTs are being targeted. At the same time, the importance of keeping the public on board with the process, and of helping them to become more engaged with the data, have also been recognised.

- *Getting the balance right*

When implementing any new initiative it can be difficult to judge the capacity of the service to cope with the demands being made on it. Putting too much emphasis on public reporting could have unintended consequences for other important activities, or induce dysfunctional responses from NHS organisations. At the same time, too little pressure can lead to stagnation. In general, this balance has been managed reasonably sensitively, though professional bodies and some NHS organisations may not perceive it that way.

- *Clarity about future intentions*

Significant compromises have to be made at the start of a new initiative such as public reporting. Whilst some will criticise these compromises, most will accept them as long as there is a clear commitment and an explicit plan to address them. The need for better-quality data is the first and most important commitment required; this is being addressed, though not as quickly as the service requires. Plans to extend reporting in terms of its organisational focus, level of reporting and usefulness at a local level all demonstrate a clear strategic direction.

## **Deficiencies to date**

Alongside these achievements, and in some cases closely aligned to them, there are some things that could have been done better. The most important deficiencies are listed below.

- *Too little attention to improving data quality*

It would be unrealistic to expect the Government to quickly turn around 50 years of under-investment in information systems. Nevertheless, there has been no appreciable improvement in data quality in the first half of the modernisation process, and the grand plan for information management and technology in the NHS seems to have difficulty getting off the drawing board. Improvements in access to high-quality data do not have to precede other initiatives but do have to be given a higher priority than currently appears to be the case.

- *Too much attention on producing data and too little on how it might be used*

Publishing data is the first and easiest part of increasing accountability and improving quality. How the key stakeholders use the data is what will really make a difference. So far, too little attention has been paid to this issue, and there seems to be a naïve assumption that simply putting information in the public domain will inevitably produce a desirable effect.

- *Failure to engage health professionals*

The publication of comparative data is generally perceived by health professionals to be a punitive action, and there is little professional support for the policy. This is starting to change in some specialities – for example, the Society for Cardiothoracic Surgeons is leading the development of report cards on post-operative mortality rates – but progress is slow. Overcoming professional resistance will speed up the process of implementation

- *Inadequate attention paid to the unintended consequences of publishing data*

Experience of publishing data in other sectors and in other countries suggests that unintended, and sometimes dysfunctional, consequences are almost inevitable and certainly predictable. In particular, gaming and misrepresentation of the data, the tendency to focus on what is being reported to the detriment of other activities, and the inclination to think in short reporting cycles rather than in longer-term strategic ways are all well recognised. Evidence of these activities has already been highlighted by CHI (with respect to ambulance response times [[www.chi.nhs.uk](http://www.chi.nhs.uk)]) and the Audit Commission (with respect to waiting times) (Audit Commission 2003). Despite this, the incentives for provider organisations to respond inappropriately are sometimes significant. No mechanisms have been put in place to audit these responses, and the actions that will result from dysfunctional responses have not been made clear.

- *Failure to present ‘the big picture’ to the service*

Although the implementation plan and future intentions with respect to public reporting might be clear to policy makers, they appear less clear to those working in the front line of

the service. Here there is considerable confusion about the ways in which published data will be used in managing the performance of the NHS and about the relationship between different datasets (for example, the PAF and the star rating system).

- *Unwillingness to hand over full responsibility for public reporting to CHI*

Published data will only be regarded as truly independent by the service and by the public if operational responsibility is really handed over to the Office for Health Care Information. This can be achieved at the same time as acknowledging the Department of Health's legitimate responsibility for setting the strategic direction. At present, there is a perception within the service that the Department of Health has a heavy hand on the tiller and that the Office is not being allowed to follow its own course. The Department has not yet demonstrated a willingness to let go.

- *Unwillingness to be explicit about the nature of the star rating system*

The star rating system is not simply a technical issue – its use is very much value-laden. This means that there is a significant political dimension to the system. It is not possible for such a small set of quality indicators, weighted heavily by political targets, combined in a way that lacks scientific rigour and linked to what are essentially qualitative judgements (the CHI reviews) to deliver a valid judgement about the 'quality' of a complex organisation. And yet absolute judgements are being made on the basis of the ratings. This does not mean that the ratings serve no purpose. On the contrary, they have been very useful in raising the public profile of organisational performance and in focusing the attention of managers and clinicians. It would, however, be more ingenuous to be honest about the inadequacies of the ratings and to respond in a more measured fashion to the results.

- *The intention to report performance at the level of individual doctors*

The delivery of health care is fundamentally a team activity, and policy initiatives should be designed to promote a team-based ethos. The performance of an individual surgeon is dependent on the performance of the anaesthetist, the theatre nursing team, the operating-department assistants, the porters, the ward staff and the hospital managers. In the modern environment, the surgeon has little authority over this extended team. Reporting at the level of the individual doctor is therefore neither fair nor appropriate, and risks perpetuating the traditional individualistic approach of some doctors.

- *The expectation that patients will use comparative data to exercise choice*

Although the focus has been on organisational responses to published data, some proponents nevertheless expect individual patients to use the information to exercise choice. Past experience and empirical evidence suggest that this expectation is naïve (Marshall et al. 2000b). Even in the consumer-orientated US, members of the public

have consistently failed to make use of even the most state-of-the-art report cards. Although greater use by the public might be an aspiration, expressing it as a current option is unrealistic and threatens to undermine the process.

### **What we need to know to take the agenda forward**

Some of the deficiencies described in the previous section result from a lack of information to guide policy and practice. This section briefly outlines the additional knowledge that we need in order to address these issues.

- *Information about the scientific properties of individual and composite indicators*

Many of the indicators that are published are not as robust as we pretend. The scientific credibility of objective measures – whether they measure what they are supposed to measure, whether they are reliable and whether they are stable (if quality remains constant) or sensitive (if quality changes) – are all important issues if public reporting is to achieve its potential. In addition, we need to experiment with different approaches to weighting indicators if they are to be aggregated into composite scores. All of this requires a commitment to continuous development and evaluation, and can be conducted on large-scale datasets alongside service developments.

- *How to help organisations to respond appropriately to published information*

We know that organisations often fail to maximise the potential of published comparative data and sometimes respond in a dysfunctional way. However, we know little about how to help them respond in a way that has the greatest chance of improving quality and minimises the risk of gaming. This requires support for research using methods such as in-depth, longitudinal, qualitative case studies.

- *How to engage the public with comparative information about performance*

The public may not play a significant role in responding to performance data at the moment. Even in the future, it is likely that only a small percentage will respond in a consumer-orientated way. Nevertheless, public engagement with the process is probably an important catalyst for stimulating provider responsiveness (Marshall & Davies 2001), and promoting better-informed service users should be a long-term strategic goal for the NHS. The publication of comparative data is one possible approach, and we need to know how this might be achieved in the context of the UK. This is likely to require a range of approaches, including orienting the content and presentation of the data around the needs of the public and providing ongoing support to help them understand the meaning of apparent differences in performance between providers.

- *How to engage the media*

The media play an important role as conduits for comparative information and in influencing public opinion. We know that it is possible to work with the media to ensure that their response is balanced, but we also know that coverage can be alarmist, engender a culture of blame and be overly simplistic. We need to focus more on the role of the media and to understand how to meet the needs of editors at the same time as ensuring that they make a positive contribution to the overall aims of public reporting.

### **The price of inaction**

There is increasing evidence that the benefits of public reporting in an open and democratic society can outweigh any possible risks. At the same time, we know that the implementation of the policy presents significant challenges and requires a high level of leadership. The UK is starting to build up a momentum with its ambitious plans, and we can be sure that greater public disclosure would continue to take place even if it became less of a priority for policy makers. However, lack of clear leadership would slow the process down, result in poorly co-ordinated and methodologically weak reporting ventures, and potentially damage the public perception that the NHS is, at last, becoming more accountable for its performance. It would also mean that the service would not be in a position to respond to what will almost certainly be more concerted calls for greater openness in the future.

### **The way forward**

In an ideal world, reliable and valid comparative information about performance would be routinely available in a timely fashion to the public, clinicians, managers, regulators and policy makers. The public would use the information to make judgements about the quality of health services and sometimes to make choices. Clinicians would work with managers to benchmark their performance over time and against other providers, and would have a sense of ownership for the information that would negate the risk of gaming. Regulators would use the information to ensure probity and accountability, and policy makers use it to make informed decisions about the future structure and function of the health service. We are a long way from this idyll, but what should we be doing now to ensure that we are closer to this picture in five years' time? This final section briefly highlights the key issues raised in this chapter under three headings: improving the support systems for public reporting, improving reporting initiatives; and supporting people to make the best use of information.

### ***Improving the support systems for public reporting***

- *Improve the quality of data in the health service*

This is fundamental; accessible, high-quality information must be the foundation on which future initiatives are built.

- *Give CHI/CHAI greater independence*

The Office for Information on Health Care Performance, working in partnership with external experts, has the expertise to produce a public reporting system that could be the envy of the world. Once the strategic direction has been set and the boundaries within which the Office operates have been agreed with the Department of Health, it should be given the freedom to get on with the job. This partial de-politicisation of the process would significantly increase the acceptability of public reporting to the service.

- *Consider greater use of incentives aligned to public reporting*

Incentives can have a strong influence on performance and can be a useful help to public reporting. This applies both to explicit incentives such as financial rewards and freedom from regulation or sanctions, and to implicit incentives such as professional satisfaction and peer recognition. Such incentives can be used to discourage unwanted actions and align desirable actions to organisational priorities and personal values. Greater thought should be given to the most appropriate balance to these incentives.

- *Predict and manage the unintended consequences of public reporting*

Strategic Health Authorities and CHI/CHAI should have systems in place to audit and monitor potential unintended responses to public reports. At the same time, more thought should be given to the balance of incentives driving functional and dysfunctional responses. In addition, where it is necessary for sanctions to be applied, they should be commensurate with the level of misdeed and should be made explicit to Trust chief executives beforehand.

### ***Improving reporting initiatives***

- *Improve the star rating system*

Despite its conceptual and methodological problems, the star rating system serves an important purpose, at least at this early stage in the implementation of the policy. However, it has to be dramatically improved if it is to gain public and professional confidence. In particular, if it is more truly to reflect the “quality” of an organisation, then the indicators need to be more comprehensive and the method of aggregation of the indicators more sophisticated. Alternatively, policymakers should be explicit that the system represents only a partial view, and should improve other performance management systems to give a more accurate picture of the quality of care provided.

- *Abandon plans to publish performance data at the level of individual doctors*

Individual provider-level data is useful for internal quality-improvement purposes, but the risks outweigh the benefits when the information is made publicly available. This is

partly for methodological reasons (the stability of data at the level of the individual is unclear), partly for practical reasons (even the best risk-adjustment systems can adversely influence patient selection) and partly for philosophical reasons (it promotes individualism over teamwork).

- *Consider different approaches to reporting*

At present, the focus of performance reporting is on organisations. This has some advantages in terms of simplicity, but is not necessarily the most appropriate approach from the perspectives of patients, professionals and society as a whole. The Office for Information on Healthcare Performance should experiment with other methods, including reporting at the levels of patient pathways of care, specific diseases or whole health economies. Each of these approaches serves a different purpose and they should be seen as complementary ways of providing a balanced view of performance.

### ***Supporting people to make the best use of information***

- *Provide support for providers to respond appropriately to the data*

The Modernisation Agency could play an important role in helping provider organisations to understand the data and respond appropriately to it. This support should be a central component of the overall policy on public release.

- *Work with and support professional societies*

Professional societies such as the Royal Colleges have an important role to play in persuading professionals about the significance of greater openness. The Society for Cardiothoracic Surgeons has demonstrated the importance of leadership. Other professional societies should be similarly encouraged.

- *Work with patient groups and advocates*

Unfocused efforts to get the public engaged are likely to waste resources. Targeting the key groups is more likely to be effective. In the first instance, general practitioners have great potential to act as advocates for the patient and to interpret comparative information about Acute Trust performance on the patient's behalf. They require help to fulfil this role. At the same time, special interest groups, such as Diabetes UK or the Sainsbury Centre for Mental Health, are starting to show interest in relevant data and should be supported to help drive the agenda forward.



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## 15. Building the Data and Informatics Capabilities: The Role of Information and Communications Technology in Improving Quality

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This chapter is an overview of the current approach to data and informatics capabilities and its ability to deliver threshold improvements in health and health care to meet stated national health policy objectives. To this end it will:

- review current health policy objectives, including those for communications, quality performance and information technology as stated in the recent NHS National Programme for Information Technology (NPfIT) (DOH 2001);
- review recent concepts and policy recommendations regarding change in complex adaptive systems and decision support in health systems;
- review the current status of policy and implementation before and since the release of the NHS NPfIT in light of the above;
- review some key components and perspectives needed for success, including issues relating to the workforce and necessary educational initiatives; and
- discuss the climate for essential quality research and improvement today in light of cultural and policy issues.

### **Status of policy and implementation prior to delivering 21st-century IT support for the NHS**

It is generally agreed that a safe, high-performance health care system in a developed economy requires an information and communications infrastructure (ICT) that allows for the free flow of accurate, secure data amongst the array of professionals, patients and other key parties (DOH 1998; NEHRT 2000; DOH 2001; OHIH 2001; IOM 2001; NCVHS 2001). To succeed, this requires an appropriate mixture of programmes, informed personnel, and a hardware and software infrastructure to support all dimensions of health care (Detmer, 2003). The NHS has clearly announced the intention to “go for a gold medal” in terms of robust goals and expectations (DOH 2000).

Today in England and Wales the current Government strategy to achieve this state of affairs goes by the title *Delivering 21st-Century IT Support for the NHS*, otherwise known as the National Programme for IT (NPfIT) (DOH 2001). Its explicit aims are to connect delivery of the NHS Plan with the capabilities of modern information technologies in order to:

- support the patient and the delivery of services designed around the patient, quickly, conveniently and seamlessly;
- support staff through effective electronic communications, better learning and knowledge management, so as to cut the time needed to find essential information, notes and test results and to make specialised expertise more accessible;
- improve management and delivery of services by providing good-quality data to support NSFs, clinical audit, governance and management information.

The NHS Plan states that it:

*aims to deliver a NHS that improves equity of access, and ensures that a consistently high quality of service is provided to patients and to the public. The achievement ... will rely on the provision of efficient and effective information systems to enable the benefits for patients and the public to be achieved. In particular, it seeks to develop a health service centred round the patient, enable closer team working across the health care sectors, and enable closer working with Social Services*

SOURCE: DOH (2000)

The core of these strategies is to take greater central control of the specification, procurement, resource management, performance management and delivery of the information management and technology agenda, based around four key elements of work:

- the further development of the national IT infrastructure;
- Integrated Care Records Services (ICRS), covering the generation of, access to and movement of health records, and subsuming both the Electronic Patient Record (EPR) and the Electronic Health Record (EHR) concepts on which *Information for Health* was based;
- eBooking – a national standard service for booking hospital appointments electronically from primary care; and
- Electronic Transfer of Prescriptions (ETP) from primary care to pharmacies.

This chapter will take these documents and robust objectives at face value, examine present evidence and offer what are intended to be constructive comments.

### **Creating change in complex adaptive systems**

Since the release of the Information for Health strategy in 1998 (DOH 1998) there has been a great deal of research policy work focused upon creating desired changes in large complex organisations such as health care systems so that step-threshold improvements in performance can be accomplished. A brief review of this work and related policy statements is presented now, after which we return to the NPfIT strategy and discuss current efforts in light of these insights.

We know that the future of health care posits a blend of carbon- and silicon-based intelligence; human memory cannot possibly meet the demands facing health care. Further, success in managing chronic illnesses requires a variety of skills and kinds of health professionals to gain the best outcomes. Modern health care is complex even when we actually agree upon what we are wishing to accomplish for a given patient. For example, liver transplantation may involve up to 300 or more health care workers from the time the decision is made to proceed until the patient is back with his or her family. Further, there are many, many circumstances in which we do not yet know the best thing to do. Moreover, our current data systems may not be giving us the right kind of information when we need it, so that we can work with a less complicated set of circumstances. At its worst, health care policy and practice can be chaotic, and sorting out where to go is really beyond human cognitive limits. At its best, health care practice can be precise and make a major difference to people's health status and longevity. In between these extremes, we face circumstances of complexity where we know parts of the solutions but the parts may not come together as we wish.

Complex Adaptive Systems theory relates to how change occurs in large complex environments. It concerns itself with ways in which one can improve the chances that appropriate change will occur in a timely and constructive manner (Plsek 2001; Chapman 2002). Some of this work ties in nicely with research over the past decade or so with respect to learning and learning organisations (Senge 1990). Learning of various kinds needs to occur. Single-loop learning is simple "learning from experience", but incorrect assumptions about the world may be reinforced (e.g. paranoia). Double-loop learning involves the examination of the learning process itself. It can succeed where single-loop learning may fail, so that effective learning takes place and the learning process itself is improved and speeded up. Triple-loop learning involves developing new processes or methodologies for arriving at such re-framings. In triple-loop learning, not only are norms questioned, but so too are embedded assumptions of how we think and learn (Argyris & Schon 1978; Romme & Witteloostuijn 1999).

There has also been a great deal of development in the recent past in the use of computer-based decision-support systems to improve dramatically the quality and safety of medical practice, particularly with respect to medications. More will be said about this later.

Just as the 1998 *Information for Health* report was being released, a committee of the US Institute of Medicine was embarking on a set of studies which aimed to make use of insights from complex adaptive systems theory and the knowledge-management and decision-support literatures so that step-threshold improvements in health system performance could be achieved.

The first report focused on safety, and has produced a salutary impact (IOM 2000). The second, *Crossing the Quality Chasm* (IOM 2001), may prove to be the more useful of the two. It asserts that health care today needs to cross a large chasm, from its previous approaches to creating and managing care to one consistent with the complexity that health care will possess for the foreseeable future, especially with the growth of pharmacogenetics and the knowledge base of medicine.

Perhaps the most useful dimension of the report was to identify the six most important aims for health care systems. A proper health system should be *safe, efficient, effective, patient-centred, timely and equitable*. A review of the NHS Plan reveals that this list of aims fits the NHS vision very well (DOH 2000). If everyone working in the system knows these aims and seeks throughout their week to make decisions that are likely to move toward these aims, then, over time, assuming sufficient flexibility and a small set of simple but important priorities, the system will self-organise. More explicit evidence-based care protocols will develop, be used and be refined over time, based upon the march of science as well as on local experience. Obviously, in order to make significant progress, a robust communications infrastructure is essential.

To provide care that is safe, cost-effective, timely, efficient, equitable and patient-centred, there is a need to capture fine-grained data, including patients' opinions and their own narratives, as well as the process and outcome data that confirms their health status. Only such a structure will allow one to perform ongoing loops of analysis of this data back to system managers and clinicians so that better care protocols and better regional systems of care can emerge. Only with such working "collaboratories" can all relevant sources of data be analysed, care models improved and triple-loop learning be assured. Simply having "observatories" off to the side will not get the job accomplished.

### **The recent and current situation in the NHS**

With these concepts in mind, we can now return to looking at the recent past and the current situation, and reflect upon the various policies and practices relating to health care system modernisation and IT implementation. Do they reflect a sufficient concordance with how complex systems self-learn, or not? Further, what steps might the DOH and NHS take to assure much higher levels of performance?

The effort of government to implement IT in the NHS began formally with the publication of the *Information for Health* policy in 1998, accompanied by a public statement that a billion-pound investment would assure its implementation. Four years later there has been some modest improvement with scant capital investment, but the new initiative (NPfIT) promises an investment of over 2.3 billion pounds sterling. Past efforts by the Government to deal constructively with IT to improve quality of services in other sectors have also been only marginally successful, so health has been no exception to the rule.

A number of problems with the health-oriented initiative have occurred.

- Past funding available for IT was given to localities, but use of these monies was not ring-fenced to assure that the financial support would be used for IT.
- Purchasing of equipment was done locally without attention to national standards, so interoperability was not achieved. The attenuated procurement processes resulted in older-model computers with slower processors being delivered to work sites. Money was wasted through a failure to exploit the enormous power of the NHS for bulk purchasing of standard IT components.
- The NHS Net was developed to connect GPs' offices with each other, while what the system mostly lacked and still lacks today is local connectivity amongst GPs, local consultants, pharmacists and health visitors to help integrate the provision of care and support dramatic improvements in working practices.
- Even relatively simple initiatives such as changing X-400 e-mail addresses within the NHS to be much shorter and conform with Internet norms have been extraordinarily slow to be implemented, so that effective e-mail connectivity across the NHS has been a lingering problem. The speed of improvements to a few basic functionalities has been painfully slow.

In summary, accomplishments are realised but are typically not exploited. Local teams were compelled to develop their own sense of priorities and initiatives into a local/regional plan. This generated, for the first time, a substantial enthusiasm and commitment in some regions, leading to some solid and creative IT plans. However, in Scotland excepted, these UK efforts were seldom met with equal enthusiasm from the centre. Efforts to integrate funding and planning between the periphery and the centre to improve performance have been essentially ineffective. Indeed, only a few of the primary care clinician/informaticists have been linked effectively into a consulting arrangement to help move the entire system forward. Furthermore, too few IT managers are strategically oriented in their thinking.

Co-ordination of a host of agencies and units will be essential if the NHS Plan and the NPfIT are to achieve their admirable goals. Despite a broad national commitment to e-government, today there is scant evidence of interagency collaboration with respect to the NPfIT. This must change if all of the relevant communications are to occur. Today, there is still a great tendency to think of IT as a way of handling current communications and ways of doing things, and not to give components up and down the system sufficient flexibility for IT to be used as a strategic tool to redesign work. By the latter means, old processes can fall to the wayside and more efficient, effective, timely, patient-centred, safe and equitable approaches can take their place.

This section makes a few comments about each of the key entities and their current relationships to the joint aims of the NHS Plan and the NPfIT, as evident by a review of documents and their respective websites. Included, in no particular order, are:

- those units that create real pressures for local health care organisations to change (Commission for Healthcare Improvement, the forthcoming CHAI and the Commission for Social Care Inspection);
- those relating to knowledge evaluation and decision support (National Institute for Clinical Excellence, National Service Frameworks, National Electronic Library for Health);
- those relating specifically to patients (NHS Direct);
- those relating to system improvement (Modernisation Agency, National Patient Safety Agency Board (NPSA), National Clinical Assessment Authority (NCAA), National Patient Record Analysis Service, NHS Net, Electronic Record Demonstration and Implementation Programme, public health observatories);
- those relating to education (NHS University); and finally
- those relating to research (DOH Health Research Units and the Medical Research Council).

### *CHI and CSCI*

The Commission for Healthcare Improvement (CHI) has done an exceptional job in its three years of audits for system quality. However, there is no evidence on its website to suggest that it has developed a plan to use IT either in its auditing activities of organisations or, more importantly, in developing criteria for assessing the use of IT and its system performance in patient care on a day-to-day basis. Whether the new Commission for Social Care Inspection will consider IT as a priority in its inspections remains to be seen.



*National Institute for Clinical Excellence*

Commendably, as e-health on the Internet allows patients new opportunities for managing their own health care, the National Institute for Clinical Excellence (NICE) has both a web-based stakeholder-registration form for Clinical Guidelines and Service Guidance as well as a Citizens' Council. NICE would be wise to make the Council's activities web-accessible and interactive.

*National Service Frameworks*

The National Service Frameworks (NSFs) are ostensibly created to improve the quality of care for major chronic illnesses or conditions. We have known for some time that guidelines alone do little to improve the quality of medical practice (Lomas et al. 1989; Ayanian et al. 1998). At present the NSFs are not constructed to be computer-based, nor are they constructed to integrate co-morbidities, a limitation that simply defies real-world practice conditions. Amazingly, the NSF website nowhere mentions the use of or any intention it may have to use IT as a way to improve the quality of clinical decision-making. The NSFs have rolled forward on a pre-NPIT mentality set out as static guidelines built by clinical experts. They are not being set up to incorporate knowledge generated by observing outcomes that result when protocols are followed and when they are not. Further, they are scarcely relevant for patient-centred care, such as for use by patients who want and need information about treating their disease and who can benefit from interacting with the NSFs (see the later discussion headed "Patient-centredness in IT").

*NHS National Electronic Library for Health*

The NHS National Electronic Library for Health (NELH) shows real progress, but will need more investment if it is to provide adequate support for the knowledge needs in a patient-centred care system.

*NHS Direct*

Although NHS Direct has been quite effective and remains popular with the public, it has conducted its work essentially by telephone, with little web-based support. The web support that is available is not interactive. While there is an attractive feature allowing patients to identify their local services, the pages relating to complaints from patients do not let an individual forward a complaint to a local service directly from NHS Direct. Once the patient has identified the correct local service through a set of screens, it would be firmly patient-centred if the website would allow the complaint to be submitted immediately. Software at NHS Direct could then route the complaint to the responsible NHS unit, as well as collect such complaints for review to improve service further.

### *Modernisation Agency*

For those working at the front lines of care, there is little evidence that an IT perspective has informed such major initiatives as the redesign of patient care undertaken by the Modernisation Agency. A look at its website confirms this impression, since its language of transformation fails to mention information technology either on its home page or within sections relating to redesign, new ways of working, or leadership. IT represents new ways of working, deeply involves redesign, and requires leadership.

### *National Patient Safety Agency*

A review of the website for the NPSA failed to reveal any evidence that information technology can and must play an important role in improving the performance of clinical care systems.

### *National Clinical Assessment Authority*

A review of the corporate and business plans as well as the website for the NCAA only revealed a single mention of the importance of IT with regard to managing its own responsibilities. Indeed, it did not mention IT as a method by which it would seek to communicate with others, nor did it suggest that competence as a clinician in the future will involve the clinician's capable use of information technology.

### *National Patient Record Analysis Service*

When viewed from outside the NHS, explicit linkages that exist between the centrally defined IT strategy and the Quality Agenda appear to be meagre. One recent policy document, relating to IT and quality, describes the initiative to create a National Patient Record Analysis Service (DOH 2003). Its stated objective is "to improve the management and quality of health services by providing access to good quality information to support performance and resource management, clinical governance, planning, research, and surveillance." While the document is eloquent in its language about goals and plans, it is mute on how it will accomplish these grand ends; nor does it speak about how IT will be used to accomplish them.

### *NHS Net*

Despite the NHS Net that links GPs together, it is hard to find evidence that IT today is playing a significant role in the care of patients or meaningfully improving the quality of care. One exception mentioned above is the General Practice Administration System for Scotland ([www.gpass.demon.co.uk](http://www.gpass.demon.co.uk)) where hundreds of GPs are connected to one another, and where consultants and pharmacists are increasingly capable of communicating electronically. Indeed, the development of the NHS Net offers lessons that should not need to be repeated again. NHS Net is a key example where its planners thought about hardware first (easy-to-hit

targets), then thought about applications/software (which is not so easy to install), and only then thought about training and culture change (rather more difficult). Once the process started, the overall objective – to support change – was lost, with no focus on what changes should come first and how they should be achieved. Without real effort, the current NPfIT may head in the same direction as a result of its focus on making rapid progress and its pattern of seeking little interchange with the ultimate users.

#### *Electronic Record Demonstration and Implementation Programme*

While regional experiences with the Electronic Record Development and Implementation Programme (ERDIP) of the NHS Information Authority are nicely summarised on its website ([www.nhsia.nhs.uk/erdip](http://www.nhsia.nhs.uk/erdip)), lessons from those ERDIP sites that were quite successful do not appear to have been integrated into systems elsewhere.

#### *NHS University*

The educational challenge to refit the workforce to meet the objectives of the NPfIT initiative will require a great deal of work. Some of it is currently underway through collaboration between the Information Authority, the NHS University and the informatics community in the UK. Whether or not the NHS University can meet this challenge effectively is not yet clear.

#### *DOH Health Research Units and the Medical Research Council*

There is not a sufficiently developed research strategy to support the future evolution of the Electronic Patient Record, the Electronic Health Record, the NHS Plan, the NPfIT and the NPRAS. How the public health collaboratives should be integrated into the mix is not clear either. Indeed, the community of UK health informaticists is just now developing its own coherent research strategy. A conference sponsored by the Medical Research Council (MRC) in July 2002 (see [www.mrc.ac.uk](http://www.mrc.ac.uk)) made it abundantly clear that the nation's informatics experts are not yet sufficiently organised to offer coherent policy advice.

#### **Status today**

What is the real status today with respect to IT in the NHS and the National Programme for IT (NPfIT) in particular? One is hard pressed to get a clear view unless one is privileged to be in a small group of insiders. However, by the time this report is published, more should be known publicly. A review of some “inside” documents suggests that a number of approaches to the IT issues are sound and should carry the NHS forward. Since the NPfIT speaks to a great deal of change in practices, it would be wise to start seeking greater buy-in from the various users across the land, since their creative contributions will be essential if the systems are to work well in all the various levels and components of the NHS.

In short, based upon what is available for assessment today, it is likely that only the first and fourth of the following explicit goals for NPfIT (NHS 2001) will be accomplished system-wide to any degree.

1. Improve patient experiences and the quality of care, and support service reconfiguration with modern IT.
2. Improve the capacity of the NHS to deliver change and reform.
3. Facilitate change in working and clinical practices.
4. Support front - line clinicians in delivering improved patient-centred care.

Upon analysis of the plans described in available policy documents, and after four years of direct observations of the NHS, it appears that the use of IT to facilitate significant change in working and clinical practices (including service reconfigurations) is likely to be only marginally applied for the foreseeable future. However, it is hoped that in a few geographic areas sufficient resolve and resources will cross the chasm and achieve truly new levels of performance.

To accomplish the stated goals for IT in the NHS will require strong yet flexible direction from the centre, as well as a strong commitment to change through substantial educational initiatives, job redesign, loosening of central controls (except for the setting of system standards) and sufficient resources at the periphery to make the changes occur. The NHS does not have a history of such approaches in a paper-based world; achieving them in a world consisting of both paper-based and computer-based systems will be dramatically new territory. Obviously, this challenge is not unique to the UK.

First, the ICT infrastructure must possess an architecture that allows for intercommunication, and this requires the requisite hardware and software plus value-added dimensions such as decision support and knowledge management. The latter two are just emerging as sub-disciplines in their own right, as is consumer health or e-health (Detmer et al. 2003). Despite the language of the aims, plans to date give little attention to integrating the patient into the centre of a computer-based care system. Further, it appears there is a mechanistic centre-driven approach to implementation, rather than an organic view of how self-organisation and learning occur in complex systems. Reading the materials currently available on the web about the National Patient Record Analysis Service does not instil confidence when looking forward. In such a system, public health talents must both be distributed close to the front - line and also be capable of aggregating local data into larger databases for evaluation at the regional, national and international levels.

### ***Key components for progress***

The UK is amongst the world leaders for getting computers into GP offices and for generating a vision for the future. However, progress in moving the Information for Health vision, and now the NPfIT, toward reality has been painfully slow and is likely to remain so, given the pace of technological innovation, social change and the scale of the NHS bureaucracy.

We know that a set of basic requirements will be needed for future success, much as certain amino acids are essential for the synthesis of key proteins (IOM 2003). Genuine political will and leadership is needed to move them forward (Ash et al. 2003). This set of basic requirements includes the following:

- *Unique identifiers* for patients, practitioners, Trusts and managers. For example, at present there seems to be no strategy to move the NHS towards the use of consistent, system-wide, unique patient identifiers for authentication purposes, despite the existence of a unique National Health Service Number for patients for many years.

Real attention should be given to the EU Commission's suggestion of a common European health insurance card. The Commission has proposed 1 June 2004 as the launch date. The single, personalised card is designed to replace all current paper forms needed for health treatment necessary during a temporary stay in another member state. The new card should make life easier for EU citizens, care providers (such as doctors and hospitals) and social security institutions. It will first replace the existing E111 form for short stays such as holidays and then, in a second phase, all the other forms used for temporary stays – employees posted to another country (E128), international road transport (E110), study (E128) and job seekers (E119).

In a third phase, it will take the form of an electronic “smart” card, readable by computer. The card will simplify procedures but not change EU citizens' rights and obligations. It will, for example, allow patients who have to pay for their health care abroad to be reimbursed more quickly by their own social security system. However, the card will offer more advantages as EU rules gradually open up more possibilities for EU citizens to be treated while on a temporary stay in another member state. One such possibility, already agreed at political level between the states, is the right to all necessary care in the host state, not only emergency care. The Commission has adopted these proposals at the request of the Barcelona Spring Summit of March 2002, which asked the Commission to table, before the Brussels Spring Summit of 21 March 2003, the necessary details for the phasing in of a European health insurance card. If the UK has taken a position on this matter, the author is unaware of it.

Adopting the EU strategy would move the personal identifier forward a great deal. Meanwhile, little discussion is heard about the relevance of the other key identifiers – and all are needed if the objectives set out in the policy documents are to be met.

- *An e-health strategy* that includes rapid-advance sites to integrate NHS Direct with interactive web-based components, linking national sites with local practitioners and consultants.
- *National Service Frameworks in a computer-based, just-in-time, point-of-care system tied to EPRs and EHRs*, discussed in Chapter 6 as a central element for improving quality of care. They must be developed into interactive computer-based decision-support systems for diabetes, heart disease, ageing, etc.
- *NHS National Electronic Library for Health linked to NICE, NSFs and NHS Direct*. The NHS needs to support patients who wish to be more actively involved in managing their chronic illnesses. To this end, answers to questions that patients are often likely to ask (Frequently Asked Questions or FAQs) need to be developed on the NSF topics and for other common diseases and conditions.

These need to be written in everyday language that the public can understand, so that NHS Direct and local surgeries and hospital Trusts can offer e-mail consultation to their patients. The NELH, NICE, NSFs and NHS Direct should all see their missions focusing on ways to discern the best answers and to get that information not only to GPs, consultants, nurses, visitors, etc. but also directly to the public when a citizen has a specific health question. While not all questions can be answered with an FAQ strategy, nearly two-thirds can be.

- *Standards* of a variety of kinds (in addition to the unique identifiers mentioned above), including those for the rising number of digital medical devices that will change the whole picture of monitoring patient progress via telemedicine.
- *Continuation of successful work with the HL7 international collaboration*. This work is excellent; data standards for quality are now beginning to appear, and will be put into a computer-based context. For example, an IOM report on this subject should be released in the autumn.<sup>†</sup> This same kind of collaboration is needed for quality templates that could offer the quality and safety components for computer-based patient records.

Today in the UK, the kind of national ICT infrastructure needed to serve the needs for the future health care delivery system scarcely exists (Duncan 1994; Detmer 2003). It is not present in England and Wales. Perhaps the push offered by the new NPfIT initiative will trigger development of a truly comprehensive strategy. There are now active efforts to organise the informatics talents within the nation in a better way, particularly to create a structure and a range of curricula to meet the educational challenges. However, these developments will take some time to organise and funding will be needed, particularly if they are to address the serious lack of IT skills amongst consultant clinicians.

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<sup>†</sup> Corrigan, J.: personal communication.

The recent plan to computer-link the Greater London area into one interoperable system is excellent in concept. Although it is well led and will benefit from units such as CHIME at the University College of London (see [www.chime.ucl.ac.uk](http://www.chime.ucl.ac.uk)), it is unclear at present whether or not this initiative will succeed. Further, whether similar robust working integrated subsystems in other localities will develop is also unknown. Basically, the London approach is the correct strategy in terms of core infrastructure. A few truly robust model sites are needed to serve as living examples for clinicians, patients and managers to experience the future world of practice. Those visiting these sites will see what the future looks like and how it will allow a continuing reinvention of health care for real people living and practising at the coal face, and not simply in the rarefied air of political rhetoric or the “vapourware” of IT enthusiasts. What is *not* needed are a few isolated beacon sites to model one aspect of care or one chronic illness. At least half a dozen comprehensive, robust NHS IT rapid-advance sites (IOM 2002) are needed along the lines of the Genetic Knowledge Parks initiative (see [www.doh.gov.uk/research/documents/gpkdocument.pdf](http://www.doh.gov.uk/research/documents/gpkdocument.pdf)).

As mentioned earlier, too often IT is seen as a set of tactical tools to support current care models rather than being envisioned as both a tactical and a strategic resource to reinvent clinical care in order to improve safety, timeliness, effectiveness, patient-centredness and equity. For example, telemedicine in the UK is still focused largely on the traditional needs of professionals, rather than on bringing patients and professionals together in new, creative, successful combinations. The NHS Net’s focus on hardware rather than applications and software, training and culture change, meant that the overall goal of supporting change was compromised. NHS Net is still focused in its evaluation efforts on determining whether telemedicine is cost-effective within the context of historically inefficient models of care and practice.

In the United Kingdom today, Tayside University Hospitals Trust in Dundee, Scotland, has the most progressive vision combined with a working version of both the ICT and clinical care models, including an architecture that allows one to look at population data as well (see [www.show.scot.nhs.uk/tuht](http://www.show.scot.nhs.uk/tuht)). It has a network of hardware, software and ICT experts engaged with the clinical workforce to allow prompt, ongoing communications amongst general practitioners, consultants, pharmacists and other care givers. The right mixture of professionals, IT personnel, creative thinking and triple-loop learning has been created. To my knowledge, Tayside has yet to link patients directly into their network, but they are exploring this crucial step. Long-term financial support for this region would allow it to collaborate closely with the excellent initiative being shown at St Andrews, thus assuring the UK of a robust research and development centre equivalent to the bioinformatics research resource around Cambridge (see [www.cgkp.org.uk](http://www.cgkp.org.uk)). Funding R&D informatics sites requires long-term investment (at least a decade) to allow for genuine progress; if the pool of monies is not sufficient to fund half a dozen sites adequately, it is best to fund two or three adequately.

### **Key perspectives for realising the IT vision for the NHS**

A set of perspectives is critical to making rapid progress in the NHS IT environment, and this section discusses the priorities. Within the commentary are recommendations for ensuring that these particular perspectives receive action. The list reflects an understanding of the current UK informatics environment and focuses on those dimensions typically overlooked or dismissed as already receiving sufficient attention. These perspectives and recommendations deserve genuine appraisal and reappraisal over the next three to five years. Without greater in-depth focus on these dimensions, it is likely that little movement will occur despite the investment of substantial sums of money and human resources.

### ***Patient-centredness in IT***

In early IT implementation, real attention needs to be focused on engaging the patient as an integral part of the care process. Patient-centredness is regularly mentioned, but all too often plays out as doing things to people rather than helping people to do the right things for themselves.

The very essence of care is changing because chronic illness is increasing, with complicated medical regimens needed to achieve desired outcomes. For example, cancer is now essentially a chronic disease that requires far more direct patient involvement for proper management than in the past. The NHS, with its National Service Frameworks, anticipated the importance of dealing with the rise of chronic diseases; but as already mentioned in this chapter, they are not constructed to be IT-friendly and dynamic templates for local implementation and incorporation into the EHR/EPR systems of patient care. Further, there does not appear to be any conceptual integration of patient roles and responsibilities into the NSFs. Looking a decade forward, there will be developments such as pharmacogenetics with personalised care, mobile populations demanding greater choice of providers (including the EU-wide level), and a dramatic increase in the use of alternative and complementary therapies. All will demand skilful organisation and management of health care information for both individuals and populations. Each development increases the need for better communication for advice and/or monitoring. It requires the capacity to store and remember important records of communications, with the patient as a central active player within the IT framework. Together, they imply a “new medicine” that cannot possibly work well without a robust ICT infrastructure. But making these transitions will be more a triumph of change management than of IT systems *per se*. Certainly, the changes will not necessarily happen simply because one puts computers and networks beneath current care and organisational structures.

Two examples from the Oxford area illustrate the type of functionality that must be built into the rapid-advance regional sites for excellent care to result. Communications at the most local level amongst all key players must occur, including having outcome data collected from patients. Much of the patient-related data can be fed electronically from homes or worksites, as



part of a range of programmes and initiatives that assess fitness, use the workplace environment as a location for health promotion and management of simple depression, and/or monitor a patient's tests directly into databases for both personal care and (secondarily) for system improvement. The Oxford Maternal Infant Care Research and Telemonitoring Centre (see [www.medicine.ox.ac.uk/ndog/tmr](http://www.medicine.ox.ac.uk/ndog/tmr)) is a demonstration project for neonates that uses home monitoring of infants. We know that such systems in the US can enhance quality and also be cost-effective (see [www.babycarelink.com](http://www.babycarelink.com)).

Well before these systems for home monitoring are in place across the UK, patients will want to access their medical records via the web and become full participants in the management of their care. The ERDIP Online Patient Access Project at the Bury Knowle Health Centre and Department of Public Health, University of Oxford (Pyper 2003) has proved that patients like this kind of interaction. They have shown quite clearly that UK residents can and wish to relate interactively with their health data and their GP. If this is not given a priority, the NHS will soon start feeling pressure from citizens aggressively seeking such capabilities. If the NHS fails to respond, another niche for private care will develop to meet the needs of the growing web-savvy population.

If the NHS is serious about meeting its objectives of a patient-centred system with work redesign, quicker access to consultants, etc., it will achieve this state of affairs much faster by giving patients the ability to interact with their own GPs through the Internet. If the e-health capability is pursued solely from the side of the providers, it is certain to take much longer to make a reality. Early e-health experiences in the US in which there are such "clicks and mortar" connections between patients and care-givers are showing that this kind of connectivity is very highly valued by many patients and practitioners alike. Websites that allow interactivity but do not relate directly to the patient's needs are far less helpful.

Such e-mail communication between the GP surgery and the patient gives a surprisingly direct human touch to care, something that is sorely needed in a system too often seen as bureaucratic and/or inaccessible. In addition to enabling more efficient interactions with patients than are possible with telephone calls, experience has shown that the answer to many of the e-mailed questions from patients are quite routine and can be supplied in a much more timely fashion from constructed FAQ lists. Patients consider such messages to be directly created for their needs, a reaction that increases both satisfaction and compliance.

Internet connectivity with the general population will be ubiquitous within a decade in the UK, but the forward thinking on how to tie all patients and citizens together into the system appears to have been overlooked. The NHS Net was initially designed to offer secure communications amongst GPs, and more recently consultants and eventually pharmacists. To my knowledge, it cannot accommodate electronic communications between NHS Direct, patients, and the admixture of the patients' health professionals.

A number of new and innovative systems will need to be mainstreamed into the rapid-advance sites once they are shown to be cost-effective and of high quality. One-off demonstrations, however successful, do not tend to become mainstream innovations in healthcare. We must actively create environments that integrate successes built elsewhere.

### **Creating an NHS-wide knowledge management capability**

If these costly and time-consuming investments in health IT are to offer their transformational value in quality of care, including better outcomes and greater patient and provider satisfaction, then the NHS and its NPfIT strategy must accommodate to the realities of *self-organisation in complex adaptive systems*. It must actually view itself as one system of many parts that must collaborate and communicate as a complex entity needing to adapt in some sense of synchrony.

Health care in developed economies takes place within complex systems with a diverse set of players, and the care itself often involves complex regimens if good outcomes are to be obtained (Detmer 2003). Unless these systems are capable of making flexible adjustments to the important aims of *safety, efficiency, effectiveness, patient-centredness, timeliness and equity*, all the best efforts of planning and investment will achieve far less than would be achievable otherwise. Self-organisation and self-learning can occur within systems, but the degree to which this happens depends upon the joint wisdom of leaders and followers. A substantial amount of time and effort is needed to set up the knowledge management structure, develop skills, and support an environment in which small but valuable changes can be made within the organisation at all levels.

It is imperative that all health care workers keep a handful of aims in mind as they proceed with their work. Often one can make a decision to effect work in one of several ways, but unless one tests the options against a set of simple yet important aims, the system overall is not moved closer to its goals. The aims for modern health care systems to be safe, effective, efficient, timely, patient-centred and equitable make up one such short list of desiderata worth keeping in mind, especially when one is dealing with a complex situation where the choices and likely outcomes are not so clear.

Where there is common agreement on what care should be given and what one should do under the circumstances, a different strategy is needed, one that goes beyond the current NSF approach. Here, one would wish to have computer-based health records that would offer evidence-based decision support for the specific circumstances. What is needed are evidence-based, adaptive decision-support systems as described by Sim et al. (2001). Just-in-time knowledge is served up to the clinicians at the point of care as part of a computer-based record based upon evidence of what affects patient outcomes, drawn from the scientific literature as well as from local experience. These systems will be continually adapted, since clinicians have the power to override the recommendations made. All overrides are tracked along with

outcomes, so that a clinical research capability is built in, allowing comparisons of process and outcomes. Computational intelligence, emerging from the application of statistical packages to the data, can both help clinicians critique the results and also seek out new powerful correlations not apparent to unaided human cognition.

The system architecture must support communications based upon evidence and be capable of tracking what was done, so that in the process of giving care we can study the decisions and their outcomes and learn from them. The Navigation Care Maps developed at the Kameda Clinic in Japan are one model for emulation and development elsewhere (see <http://kameda.or.jp>). Protocols are integrated into the computer-based patient record based upon the patient's circumstances and degree of illness, so that one can either follow or override the protocol. Later, clinicians can meet to find out if they and their colleagues should have followed the protocol closely or not, based upon treatment of similar patients where the protocol was followed. Such adaptive, evidence-based decision support systems need to become a very high priority for research funding from both the MRC and the NHS.

There are many places in which such decision support systems can improve care. The IHC Institute for Health Care Delivery Research in the US has led much of these developments. The controlling variables for system design in hospitals are patient volumes, costs per case, perceptions of likelihood of risk, and damage to health if things are not done right. Initially, they identified 600 distinct processes, of which 62 (10%) accounted for 92% of all inpatient care delivery. Fifteen acute and 15 chronic disease processes accounted for almost 80% of all outpatient disease-specific care delivery processes. Examples include adverse drug events (medication errors); hospital-acquired (iatrogenic) infections; deep venous thrombosis with risk of pulmonary embolism; decubitus ulcer prevention and treatment; patient strength, agility and cognition; and blood product transfusions. Sentinel events were also highlighted, such as wrong-side surgery or assaults. Drug orders tracked the type of dose, timing, dose ceilings, checks for allergies, patient characteristics, drug–drug interactions, laboratory values and genetic sensitivity. For example, older patients with cognitive or visual limitations are supplied with default computer-based nursing orders to put up bed side-rails in the evening to help prevent the patient breaking a hip while getting up at night to go to the toilet. Such protocols have greatly reduced these events.<sup>†</sup>

Miller and Geissbuhler (1998) identify areas where such decision-supports with greater or lesser degrees of computational intelligence can be particularly helpful. Points where IT can improve care quality include:

- alerts – high or low results in laboratory tests;
- assistance – tailoring antibiotic choices;
- calculations and suggestions – adjusting a mechanical ventilator;

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<sup>†</sup> Brent James, MD: personal communication.

- critiques of judgement – rejecting an order;
- diagnosis – diagnosis in clinical practice;
- interpretation – ECG;
- prediction – risk of mortality, with a severity score;
- reminders – take a pill; and
- to structure thinking.

### ***Capturing learning through system-wide communications***

We know that health care is characterised by local practice patterns of physicians. Therefore effecting large-scale changes in quality and safety throughout the NHS depends upon the ability to aggregate data for evaluation at regional and national levels (depending on the question under consideration). The National Patient Record Analysis Service plan within the *Delivering 21st Century IT for the NHS* document does not appear to include such an approach. Two excellent working models for this strategy are the Northern New England Cardiovascular Disease Study Group (see [www.nneedsg.org](http://www.nneedsg.org)) and the IHC system that draws upon Utah's Institute for Health Care Delivery Research, mentioned earlier (see [www.ihc.com/xp.ihc/physician/research/institute](http://www.ihc.com/xp.ihc/physician/research/institute)). It is likely that the set of requirements for treatment of a given patient's diabetes may be different in New England from that in Utah, or in Luton from that in Cardiff. Further, the requirements for tracking a bio-terrorism threat or dealing with any other public health issue are only likely to be collected coherently if the ICT architecture is set up to let this happen. Otherwise, very important questions may not be pursued.

### ***Adequate education and training for work redesign***

Making the advances described in this chapter depends upon placing a premium on the education and flexible behaviour of the workforce. Securing high performance at the systems level and improved clinical outcomes will demand the existence of industrial-strength decision-support systems, and a variety of new skills and knowledge.

A range of educational offerings, time and resources will be needed to allow all health care workers to receive an adequate mix of Internet and direct educational experiences. We know that dramatic implementations of IT require strong leadership as well (Ash et al. 2003). Dual-skilled health professionals, not widely existent in England, will be needed: for example, someone who is both an expert clinician and an informaticist, or an expert clinician who has skills in management and leadership. Jobs must be redesigned to allow people who have these potentialities and aptitudes to spend half their time in each skill domain. This will greatly increase the uptake of innovation and change at the local level.

### ***A robust research and development agenda in clinical informatics***

The informatics community and the clinician leadership community must get together to help the NHS innovate to create both the momentum and the research agenda that is needed to meet the excellent vision being set forward. This will require funding from both the NHS and Medical Research Council to develop working models for e-science that assure robust clinical science and care based upon the genomic revolution, as well as e-health-services research to assure higher performance from practice analysis, as outlined above.

A significant threat to the necessary research exists today in the bureaucratic barriers against gaining access to data. The Information Authority has clear evidence to show that nearly all people want their health care team to have access to the data they need to offer excellent care. Instead of empowering citizens to make their own decisions regarding the use of their own information, the nation has shifted from a medical paternalism to a government-mandated paternalism legislated and controlled by the state. The net result is that communications between patients and their care givers and between Trusts and legitimate quality researchers is being hampered and slowed significantly. The intense concerns of a small fraction of patients are leading to very costly regulations. The fear of risk-taking that has engaged many ethics committees is quite real; as a result, access to data for even the most legitimate of researchers and research questions is becoming a challenge.

The negative impact of this well-intentioned but ultimately misguided policy on quality and safety will most likely never be known. Unless and until ethics committees are given much clearer directions from the Government, there will be insufficient progress in the UK on phenotypic genomic research and on practical, working e-science or e-health-services research that could greatly benefit the UK population.

### **Conclusion**

Since the Information for Health strategy was announced in September 1998, progress has been quite slow but steady. The recent substantial funding combined with the administrative commitment from the top makes it certain that progress will occur. What is most lacking to supplement the sensible vision of the NPfIT is the articulation of what it will take to get the work accomplished across the NHS. Implementation strategies must be pursued by an educated set of strategic thinkers at all levels of the system – especially clinicians, who after all are at the core of health care. Today they are largely off to the side, out in the cold, under-informed and overworked

Information and communications technology is not an end in itself, but simply a means to an end. IT strategies can and must be related continually to the goals of *safety, patient-centredness, effectiveness, timeliness, equity and efficiency*. Until this happens and self-organisation is celebrated, a great deal of money can be spent on an expensive IT infrastructure that will not achieve the stellar objectives set out for it. Neither Britain nor the world can afford for this to happen.

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## SECTION V

# Advancing Quality: The Way Forward

Section V summarises our conclusions and makes recommendations for the near term, as the NHS embarks upon the second half of the Ten-year Quality Agenda



## 16. Recommendations for the Near Term (12–18 Months)

*The NHS of the 21st century is still evolving. The resources going into the NHS are paying dividends for patients, but there is still a long way to go. Capacity problems remain. The building blocks are there and the culture of the NHS is changing. With extra resources about to come on stream we feel confident that fast and effective progress can be made. The patient centred NHS, once a distant ambition, is now drawing visibly closer.*

INTRODUCTION AND EXECUTIVE SUMMARY, THE NHS MODERNISATION BOARD'S ANNUAL REPORT [DOH 2003]

Qualitative and quantitative data indicate that mid-term overall performance is trending in the right direction, most particularly in those areas on which attention and effort has been focused by policy mandates, performance-reporting requirements and extrinsic incentives. Legislation, increased NHS funding, new organisational capacity, regulatory structures and targeted quality-improvement interventions appear to be demonstrating some generalised salutary effect. However, although quality data indicates improvement, there is no assurance of forward momentum. The Government's ambitious aims will not be met easily.

Our evaluation of progress to date and the need to be succinct and cogent has shaped the development of our recommendations for the next 12–18 months. Box 16.1 provides an overview of the state of the Quality Agenda in terms of its accomplishments and priorities for the future.

Accomplishments thus far have created a receptive context for significant and sustainable quality improvement. The upbeat assessment in the May 2003 Modernisation Board Report, as quoted at the beginning of this chapter, may be warranted. However, it most certainly is open to challenge, in part because of continuing deficiencies and weaknesses in areas inarguably important to the Quality Agenda. Addressing these weaknesses in the next 12–18 months will strengthen the platform for the second half of the Ten-year Quality Agenda.

We have identified four main areas of weakness. Firstly, there are significant data and analytic weaknesses in the NHS, which mean that carrying out a comprehensive, robust, definitive, transparent and defensible assessment is impossible. The unrelenting and distracting problem of inconsistent and highly contested data throws the whole of the Quality Agenda into a confusing fray, and begs for corrective action to increase the analytic capacity needed to produce accurate and authoritative quality measurement and reporting. Secondly, the need to engage the professions and the public in the pursuit of a predictably high-performing NHS is pressing. There are many methods to achieve this objective, but they may be challenging to

implement effectively, particularly given the long histories of self-regulatory autonomous practice that characterise many professional groups. Thirdly, reliance on Primary Care Trusts (PCTs) requires provision of the requisite skills and the level of resourcing implied by that. Fourthly, clarifying and refining the regulatory approaches, such as the inspection process and public reporting of performance, will help secure significant behaviour change in quality improvement across the health service.

### **BOX 16.1**

#### **Overview of the Quality Agenda**

##### **Strengths in the first half of the Quality Agenda**

- Will and courage to admit problems with the quality of care
- Policy context to address quality deficiencies
- Reasonable resources committed
- Organisational capacity developed
- Multi-prong strategy of improvement interventions

##### **Priorities needed for the second half of the Quality Agenda**

- Common understanding of the “state of quality” in health care
- Data and analytic capabilities sufficient in volume and distribution
- Public and patient involvement
- Clinical professions engaged and “on board”
- Sustained effort in key building blocks, such as PCT support and performance reporting

Our recommendations will focus only on areas that will either facilitate or hinder progress toward quality improvement. Some cases require new resourcing, whereas others simply need clear thinking and explicit articulation of intent and direction. All will require significant advances to be made in IT infrastructure and informatics.

We have culled our recommendations from many legitimate and defensible candidates according to one principal criterion: what is essential to make likely and predictable improvements in patient care and NHS performance? We will discuss the seven recommendations in Box 16.2 by first identifying the critical need or gap requiring intervention, and then proposing corrective action(s).

**BOX 16.2****Recommendations for the Quality Agenda**

1. Establish a National Quality Information Centre
2. Publish an annual National Quality of Care Report
3. Engage citizens and patients
4. Engage the professions
5. Optimise the role and contributions of PCTs
6. Refine the inspection and accreditation strategy
7. Advance methods of public reporting and accountability

**Recommendation 1: Establish a National Quality Information Centre*****Critical need***

A shared understanding of the magnitude and scope of problems facing the health service is necessary to provide a basis for communication and co-operation among the many stakeholders interested in improving performance. In fact, one reason for uneven and unpredictable quality of care in many countries is the lack of systematic reporting that describes the nature of quality deficiencies and monitors progress in the public domain (Leatherman & McCarthy 2002). England's Quality Agenda simply cannot thrive in an environment that is deficient in access to valid, reliable data; and in the necessary analytic and interpretive skills for expert performance evaluation and credible reporting.

The data and information deficit occurs in two areas. The first is in the production, collection and analysis of the requisite strategic and operational data, both clinical and managerial, at all levels of the NHS. This type of data collection and analysis must exist as a core competency in an enterprise of the scope and scale of the NHS and be customised at national, regional and local levels for a variety of uses. The Department of Health must have the ability to understand, generally and specifically, the entire range of performance issues. Off-loading this to private concerns such as *Dr Foster* is a short-term option, but should not be the long-term solution. Rectification of these problems calls for a comprehensive strategy that encompasses an information systems infrastructure, electronic patient records and expert informatics.

The second information deficit is the focus of this recommendation. The NHS is deficient in well-organised data that produces coherent, defensible, credible and actionable analyses of system performance and clinical quality. The lack of a shared robust information base that provides a common understanding of the NHS's strengths and weaknesses jeopardises the Quality Agenda and prevents the various organisations and initiatives from living up to their potential.

### ***Proposed action***

Create a National Quality Information Centre (QuIC). The goal is independent reporting of NHS performance in the domains of effectiveness, safety, responsiveness, equity, efficiency and access. The collected and collated information should be at a high level of aggregation – not at the level of performance data depicting institutional and individual effectiveness. The information should be available for multiple users such as the NHS, the Department of Health, Parliament, Royal Colleges, the public, patient advocacy bodies, researchers and academics.

Selecting a locus for the QuIC should draw on the criteria of credibility, independence, expertise, stability, ability to operate in the public's interest and a critical mass to produce information in a timely and authoritative way. Some locations that could accommodate the QuIC, all with varying strengths and limitations, include the NHS/Department of Health, the Commission for Healthcare Audit and Inspection (CHAI) and an outsourced agency. The relative merits of these different options are discussed below.

#### *NHS/Department of Health*

The NHS/Department of Health houses the bulk of data that the analytic centre is likely to use. It is not, however, likely to be perceived as plausibly impartial or dispassionate in reporting on its own performance. As the funder, provider and manager of health services, it simply cannot be viewed as a disinterested body, and thereby may lack credibility in the public's eyes.

#### *Commission for Healthcare Audit and Inspection*

If it is a fully independent body at its 2004 inception, CHAI would be a reasonable venue for QuIC. The Office of Health Information, established under the Commission for Health Improvement, is the logical locus, as it is consistent with its remit to report to the public and congruent with its task to synthesise performance information for a multitude of purposes. Therefore, presumably the synergy of these tasks represents an efficient use of expertise and analytic capacity. Whether CHAI can accomplish this task in the near term, given its already expansive portfolio, is a critically important question. If it is unable to produce complete analyses, CHAI might outsource all or part of this function until it can absorb the work internally.

#### *Outsourcing to academia or consultancy*

Another reasonable option is to outsource the functions of the analytic centre to an organisation with the appropriate skills and experience. This would preserve independence and, if chosen correctly, meet the needs for credibility and expertise. Potential advantages include a faster start-up and avoiding the distractions inherent in placing the QuIC in organisations with other currently onerous pressures. Disadvantages are the inability to a) leverage the strengths of recently established organisations; b) capitalise fully on existing knowledge in the health service; and c) integrate functions and share expertise across the organisation.

## **Recommendation 2: Publish an annual National Quality of Care Report**

### ***Critical need***

Given the policy priority and the public interest in health care quality, it is critically important to have a credible, authoritative and regularly released report on the state of quality within the NHS, including care purchased by, but delivered outside of, the NHS. The report should be carefully conceptualised using well-validated data to present a clear and unequivocal picture of quality. So far, in 2003, at least three published reports could be precursors to a National Quality of Care Report. The first is the Modernisation Board report that contained some data, but appeared biased toward policy and political imperatives rather than being neutral in performance reporting. Second, the May 2003 CHI report *Getting Better*, in which the intent was correct, but performance quantification was minimal. Third, the Chief Executive's report to the NHS 2002–03 ([www.doh.gov.uk](http://www.doh.gov.uk)) presented a significant amount of aggregated performance data. However, because of the inherent conflict of interest in NHS self-reporting, it is unlikely to appear objective. Further, its primary audience was the health service, rather than the general public and other stakeholders.

### ***Proposed action***

Issue an annual National Quality Report through QuIC. This could be part of, or a complement to, CHAI's annual report to Parliament. The primary audience is the public. Key secondary audiences would include Government, the professions, the health sector at large and patient advocacy bodies. The primary purpose is to establish a common understanding of the “state of quality”, the progress being made in selected areas and the priorities for the future.

## **Recommendation 3: Engage citizens and patients**

### ***Critical need***

The NHS has promised to make significant changes in order to increase “patient-centredness”, moving away from what has been acknowledged as an archaically paternalistic health system that was not predictably responsive to the needs and preferences of patients. Furthermore, evidence now demonstrates that engaging patients and the public is associated with salutary effects, such as more cost-effective outcomes, improvements in safety, reduction in complaints and litigation and better congruence with public expectations. In brief, judicious engagement of citizens and patients is not only the philosophically right direction for 21st-century health care, but may very well improve health care system performance, with attendant benefits to patients. The second half of the Quality Agenda should prioritise these actions in order to make significant progress in engaging the public (details are in Chapter 12).

***Proposed action***

1. Develop a comprehensive strategy document for patient and public involvement, including explicit goals and objectives, the role and intended contributions of individual initiatives, and performance indicators to monitor progress. Research evidence should underpin the strategy; where this does not exist, new research should be commissioned.
2. Develop a patient and public information strategy to include printed material widely available to patients, primary care information brokers to help patients access reliable information when they need it, and a review of NHS Direct Online
3. Train all clinicians in the communication skills and competencies needed to share clinical decision-making with their patients. Provide more support for patients who want to play a greater part in managing and monitoring their own treatment, and for those wanting to make informed choices.
4. Develop and evaluate robust mechanisms to engage local communities in NHS governance and policy-making.

**Recommendation 4: Engage the professions*****Critical need***

Getting the professions “on board” is an essential factor that is currently deficient. A multi-faceted Quality Agenda is likely to improve quality through numerous interventions; however, individual professional conduct, along with the collective professions’ values and normative tools, will always provide a patient with the best quality assurance. Quality legislation and regulation from the outside in is inherently limited. A robust and professions-led initiative for standard setting, specification of quality measures and comparative peer review is essential.

Resources may be an issue. Whilst the Royal Colleges clearly have an important role to play, the requisite skills and capacity are not available in each Royal College. There are exemplary capabilities in several sites, such as in the Royal College of Physicians (demonstrated in the MINAP and Sentinel Stroke Audit Programmes), the Royal College of GPs (demonstrated in quality-measure development) and in the Intensive Care National Audit and Research Centre.

***Proposed action***

Develop a published strategy detailing how the major clinical professions, presumably through the Royal Colleges, will a) set quality standards; b) develop quality measures; c) collect data and perform analyses; d) conduct peer review; and e) publish results and aims for improvement.



The strategy must include resource requirements and provisions, as well as plans to leverage current capabilities (such as are present in several Colleges). Possible funders to seed this activity include charitable foundations and the Department of Health through the Modernisation Agency, as part of its intention to evolve and embed capabilities and functions in the health service and professions. Independent health foundations, in collaboration with interested Royal Colleges, could accept responsibility for convening the necessary meeting(s) to develop the strategy.

### **Recommendation 5: Optimise the role and contributions of Primary Care Trusts**

#### ***Critical need***

Primary Care Trusts have an instrumental role in improving quality of care. Policy actions to support this role include the reallocation of the majority of the NHS budget to PCTs for management and distribution, and the “pay for performance” aspects of GP contracts. The future responsibilities and accountabilities of PCTs may very well exceed their current competency and capacity. As PCTs are central to the Quality Agenda, it is important to maximise their capabilities in several key areas.

#### ***Proposed actions***

1. Give PCTs organisational stability, critical mass and infrastructure support.
  - Avoid further re-organisational initiatives and mergers so that PCTs can deliver on essential tasks.
  - Support PCTs in developing effective strategies to recruit and retain staff, and use available skills to address local problems.
  - Strengthen and extend clinical governance arrangements to include integration of primary/secondary care and care via other services, e.g. community health and social services.
  - Invest in measures to deal effectively with underperforming doctors.
2. Clearly define how users can be most effective in developing the service. Disseminate examples of good practice.
3. Strengthen the commissioning function of PCTs in terms of management support, information and analytic expertise, clinical involvement and the development of effective working relationships with local NHS Trusts. Methods to accomplish this include bringing PCTs together into commissioning networks or consortia and, through Strategic Health Authorities, providing more active facilitation and support.

4. Refine the use of performance data for evaluation and payment. Recognise the limitations of the PCT star rating system based on current data. Exercise extreme caution when making management decisions based on PCT star ratings, because, for example, at present it does not sufficiently integrate the heterogeneity of case-mixes.

### **Recommendation 6: Refine the inspection and accreditation strategy**

#### ***Critical need***

Introducing inspection capability to anchor the new regulatory framework of the NHS was a major accomplishment. It was implemented expediently, and is generally acknowledged to have galvanised attention to quality. To build on early history, and to instil greater rigour in methods for transparency and defensibility, a number of issues must be addressed.

The approach and philosophy underpinning the inspection regime should be explicit, in order fairly and accurately to inform stakeholders of the underlying values and processes for inspection. The development of standards and inspection processes must be efficient and judicious. Effective and efficient use of information must become the hallmark of the new CHAI, as one-off inspection processes cannot proficiently or predictably improve quality in an ongoing manner.

#### ***Proposed action***

1. Clarify the CHAI model, explicitly opting for an inspection or accreditation approach. Usually, *inspection* connotes a process using standards developed for minimally acceptable performance. On-site visits (normally supplemented by written information) ascertain compliance to a “floor”, the intent being to assure the public that there is an adequate performance level. In contrast, *accreditation*, which may be either voluntary or mandatory, implies a process that seeks to identify organisations (or parts thereof) where performance is not only compliant with minimal standards, but also reflects a “good” standard of care. In many situations where accreditation exists, it is a supplement to a basic inspection process. We recommend that CHAI consider a staged evolution, starting with a process to assure the public that all organisations meet minimally acceptable standards, and evolving to a set of standards and review processes that would seek to shift the performance curve to exceed minimally satisfactory performance.
2. We recommend two types of standards: core standards and improvement standards.
  - Core standards, which all organisations must fully meet, would require explicit and uniform review and assessment. These would constitute the universal floor for health service organisation and delivery. Nationally defined standards set through mechanisms such as the National Service Frameworks and the National Institute for Clinical Excellence should be included in core standards.

- Improvement standards, which would supplement core standards, would serve two purposes. First, they would recognise and integrate local priorities into the inspection regime, and second, they would encourage and recognise health care improvement. In this category of standards, organisations would identify the areas in greatest need of clinical and managerial performance improvement, and CHAI would monitor progress against the locally established priorities and goals.
3. CHAI should establish an ongoing formal evaluation programme with two objectives: to inform the design of standards and the inspection procedures, and to examine the impact and cost-benefit of CHAI processes.

### **Recommendation 7: Advance methods of public reporting and accountability**

#### ***Critical need***

The compelling rationale for using performance targets lies in their ability to galvanise and direct system behaviour, as well as to focus attention and resources on priorities. Unfortunately, early stages of the Quality Agenda saw publication of excessive numbers of targets and indicators, in some cases accompanied by overly ambitious, and possibly unrealistic, target levels. Overuse blunted the potential power of performance targets to achieve meaningful and sustainable improvement. Such a surfeit can result in cynicism and disregard for what is an important role and rationale for performance indicators. The desired effect was one of getting the health service to “tune in”, but instead some “tuned out”. The Government appears to acknowledge these problems, and has begun to refine the use of public reporting.

#### ***Proposed action***

The challenge is to strike the right balance between attending to a sufficient number of the priority areas legitimately needing attention, and maintaining sufficient focus of resources. Performance indicators are a necessary and beneficial instrument for improving quality if properly defined and implemented. It would be a mistake to do as the Conservative Party is proposing, that is “to dismantle the target culture” (Conservative Party 2001, p. 8).

A mid-course correction started to occur in early 2003, with a reduction of performance targets for the various Trusts. At this juncture, it is important to conduct and publish an evaluation of the past five years and a strategy document for the next five years. This should include an inventory of all performance targets in use, or intended for use, against explicit criteria, including the following:

- validity of the data necessary for each performance indicator;
- clinical meaningfulness and utility of improvement indicators visible to patients; and
- comparability of indicators for fair and reliable benchmarking of performance.

The results of the evaluation should be published, and should include a ratified set of performance indicators that will be implemented for a stable period of at least three years. Without this fix and stabilisation, it will render useless a longitudinal tracking of performance over time by a series of standardised data points. This process is fundamental to clarify the true priorities that should drive resources, and to evaluate progress in a transparent and defensible manner.

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## 17. Conclusion

The NHS is a venerable institution, an icon of health care as a “public good”, based on the values of universality and equity. Most people in the UK support the NHS: 80% think that it is important to British society, and 75% wish to retain a universal health care system rather than move to a two-tier health service (Wanless 2002).

The Ten-year Quality Agenda, first articulated in 1997–98, is, without doubt, impressive and ambitious. We agree with the assessment that, in terms of constructing a health service focused on providing quality health care, “the building blocks are there” (DOH 2003, p. vii). This is a heroic accomplishment given the complexity, scale, resource constraints and other pressures on government in the last several years, including threats to the global economy and security.

It has been acknowledged that the improvements in the NHS are not yet of large enough scale to be felt by a majority of the public at the front lines of service delivery (CHI 2003). This assessment is likely to be true; but given the complexity of the task, transformation is not a realistic expectation at the barely five-year milestone. The central questions in evaluating the Quality Agenda are whether quality improvements are visible and whether the NHS demonstrates the predictable capacity to improve. Though credible and validated data remains elusive, a sampling of available data shows quality improvement trends in salient areas, including appropriateness of care, use of effective interventions and patient outcomes.

At the outset (Section I), we identified four questions guiding the design and conduct of our research.

- Is the development of new organisational, regulatory, monitoring, change management and evaluation capacity reasonable for accomplishing a multi-year improvement agenda?
- What is the evidence of impact to date?
- Is the Quality Agenda sustainable?
- What are reasonable mid-course corrections to increase likelihood of success?

It is premature to answer these questions fully. At the halfway mark of the Ten-year Quality Agenda, the efforts and investments in capacity building have been prudently responsive to a fragile and underperforming NHS, and are reasonable in design.

Though current data has notable deficiencies, it does demonstrate improved performance in a number of areas. This is not to say that there are not deep and abiding problems in access, clinical effectiveness, responsiveness and safety – of course that is true, as it is in the US, where quality-of-care studies during the past two decades continue to show deficiencies. Though causality cannot be established, performance has improved in many, but not all, areas where priority has been stated, such as access to inpatient and outpatient care as well as appropriateness of process and patient outcomes in cardiovascular and cancer care.

As would be expected, we recommend mid-course corrections. Importantly, the mid-course corrections are not an overhaul, but are incremental in nature. Much of the hard work has been done. Still ahead lie challenging but necessary tasks, such as engaging the professions and the public.

Is the Quality Agenda sustainable? To date the investment in capacity building appears to have yielded a number of important and viable parts of an institutional, procedural and programmatic nature, as well as positive changes in patient care and outcomes. Investment, of course, can always be a point of vulnerability. But the budget programme for 2003–04 to 2005–06 for Centrally Funded Initiatives and Services and Special Allocations (CFISSA) shows that initiatives for significant levels of investment are to be maintained. For example, improving access will receive £1.2 billion; improving services and outcomes in cancer, coronary heart disease, mental health, older people and children will together receive £1.4 billion; improving patient experience will receive £0.2 billion; reducing health inequalities will receive £0.7 billion; building workforce capacity will receive £13.4 billion; and The Modernisation Agency will receive £0.26 billion (DOH 2003). However, even if investment is maintained at satisfactory levels, the greatest threat to the sustainability and progress of the Quality Agenda is likely to be the unrelenting and often damaging politicisation of the NHS.

Although managing and improving the performance of a massive enterprise such as the NHS is daunting, it seems reasonable to conclude that, to date, the policy formulation carried out through a multitude of initiatives and supported by increased funding have provided the fundamentals to maintain momentum in the Ten-year Quality Agenda. Buffering the NHS from political turbulence, continuing with planned funding increases, reducing the frequency and magnitude of unnecessary reorganisation, advancing the information infrastructure and continuing to put quality of care as central to modernisation efforts will make performance improvement more predictable, and the achievements sustainable.

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## Appendix A. List of Interviewees

Gwyn Bevan, Commission for Health Improvement  
Helen Bevan, Modernisation Agency  
Carol Black, President, Royal College of Physicians  
Nick Black, London School of Health and Tropical Hygiene  
Julian Brooke, Department of Health  
Jocelyn Cornwall, Commission for Health Improvement  
Paul Corrigan, Advisor to the Secretary of State for Health  
Angela Coulter, Picker Europe  
Nigel Crisp, Department of Health  
Ron Cullen, Department of Health  
Jennifer Dixon, The King's Fund  
Nigel Edwards, The NHS Confederation  
David Fillingham, Modernisation Agency  
Anne Fletcher, Department of Health  
Marcia Fry, Department of Health and Commission for Healthcare Audit Inspection  
Pam Garside, consultant  
Peter Gillespie, Audit Commission  
Maggie Haines, Modernisation Agency  
Aidan Halligan, Department of Health  
Chris Ham, Department of Health  
Felicity Harvey, Department of Health  
Penny Humphris, Modernisation Agency  
Donald Irvine, previously General Medical Council  
Tim Kelsey, *Dr Foster*  
Ian Kennedy, Commission for Healthcare Audit Inspection

Rudolph Klein, Professor  
Martin Marshall, University of Manchester  
Fiona Moss, Quality and Safety in Health Care  
John Oldham, National Primary Care Development  
Susan Osborne, National Patient Safety Agency  
Michael Pearson, Royal College of Physicians  
Jean Penny, Modernisation Agency  
Martin Roland, University of Manchester  
Michael Scott, Modernisation Agency  
Clive Smee, previously Chief Economist, Department of Health  
Richard Smith, *British Medical Journal*  
Tom Smith, University of Cambridge  
Simon Stevens, No. 10 Downing Street  
Karen Taylor, National Audit Office  
Stephen Thornton, The Health Foundation  
Nick Timmins, *The Financial Times*  
Andrew Vowles, Audit Commission  
Peter Wilkinson, Audit Commission  
Susan Williams, National Patient Safety Agency  
Richard Willmer, Department of Health  
Tim Wilson, Department of Health  
John Wyn Owen, The Nuffield Trust

## Appendix B. Biographical Information

### *Sheila Leatherman*

Sheila Leatherman is a Research Professor at the School of Public Health, University of North Carolina, and a Senior Associate of The Judge Institute of Management (1996) and Distinguished Associate of Darwin College at the University of Cambridge, England. She was elected a Member of the Institute of Medicine of the US National Academy of Sciences in 2002 and a Member of the National Academy of Social Insurance in 1997.

Actively working in the US and UK, her primary areas of research, policy analysis and publication are quality of care, health systems reform, performance measurement and improvement, and the economic implications of implementing quality-enhancing interventions in health care delivery. She conducted pioneering methodological research in quality measurement for managed-care populations (awarded a US Patent in 1996). She was appointed by President Clinton in 1997 to the President's Commission on Patients' Rights and Quality, chairing the sub-committee to develop a national strategy for quality measurement and reporting. She is the lead author of a series of Chart books on Quality of Care in the US. She was commissioned by The Nuffield Trust (UK) to assess the Labour Government's proposed quality reforms for the NHS in 1997–98 and to conduct an evaluation of the mid-term impact of the Ten-year Quality Agenda in the NHS (2002–03).

She has a broad background in health care management in State and Federal health agencies, as CEO of a health maintenance organisation and senior executive of a large national managed-care company in the US. She is a Senior Advisor to The Nuffield Trust and to The Health Foundation in the UK, a member of the Healthcare Advisory Board at the Institute of Medicine and a member of the RAND Health Advisory Board. She has published widely in the fields of health policy and quality of care, including in *JAMA*, *Health Affairs*, *Medical Care*, *BMJ*, *the International Journal of Quality, Quality and Safety in Health Care* and the *British Journal of General Practice*. International experience includes teaching an intensive executive course at the University of Cambridge for senior health leaders from countries worldwide, as well as lecturing and providing technical assistance in Asia, Australia, Europe and Latin America.

*Kim Sutherland*

Kim Sutherland, BSc, MSc, MBA, PhD, is a Senior Research Associate at the Judge Institute of Management, University of Cambridge. Her current research interests include health policy with a special focus on quality, the management of change and the role of sense-making in medicine. She has worked extensively in health systems in the UK, Australia, Russia and the Middle East in a range of health-related roles, including hospital scientist, microbiologist, health services researcher and organisational-change consultant. She was presented with the British Association of Medical Managers' Book of the Year Award 2002 for *Organisational Change: a review for health care managers, professionals and researchers*.

*Angela Coulter*

Angela Coulter is Chief Executive of Picker Institute Europe. A UK-registered charity, the Picker Institute works with European health care providers to obtain feedback from patients and promote patient-centred care. Angela has a doctorate in health services research from the University of London and has published widely on a variety of topics. Her two most recent books are *The Autonomous Patient*, published by The Nuffield Trust, and *The European Patient of the Future*, published by McGraw Hill.

*Don Detmer*

Don E. Detmer, MD, MA, has been the Dennis Gillings Professor of Health Management and Director of Cambridge University Health at the Business School in Cambridge since 1999 and is Professor Emeritus/Professor of Medical Education at the University of Virginia. He is a lifetime Associate of the National Academies, and a Fellow of the American Colleges of Medical Informatics, Surgeons and Sports Medicine. He is a Board member of Quality and Safety in Health Care, The Nuffield Trust of London and the China Medical Board of New York, Inc. Before coming to England, he was Vice-President for Health Sciences at the Universities of Virginia and Utah and on the faculty at the University of Wisconsin–Madison. He is immediate past chairman of the Board on Health Care Services of the IOM and the National Committee of Vital and Health Statistics, and has also chaired the Board of Regents of the National Library of Medicine.

*Martin Marshall*

Martin Marshall, BSc, MB, BS, MSc, MD, FRCGP, is Professor of General Practice at the National Primary Care Research and Development Centre, University of Manchester, and a part-time general practitioner in an inner-city practice. Before this, he was a principal in general practice in Exeter for 10 years. His research interests are in the field of policy-related quality of care – quality indicators in primary care, the public disclosure of performance information, patient safety and organisational culture. He was a member of the GMC/RCGP working group that produced *Good Medical Practice for General Practitioners*, the basis for revalidation of general practitioners.

*Martin Roland*

Martin Roland is Director of the National Primary Care Research and Development Centre, based at the University of Manchester. He was trained at Oxford University, and entered general practice in 1979, initially in London, then in Cambridge, and now in a deprived inner-city practice in central Manchester. Following academic general-practice posts at St Thomas's and in Cambridge, he became Professor of General Practice at Manchester University in 1991, and Director of the NPCRDC in 1999. His research interests include quality of care, back pain in general practice, hospital referrals, use of time in general practice and out-of-hours care. His main research interests at the NPCRDC relate to quality of care, with a particular focus on developing ways of measuring and improving the quality of primary care.

*Judith Smith*

Judith Smith, BA, DipHSM, MBA, MHM, has been involved in health services research since 1995, before which she worked as a senior manager in the NHS. Her main research interests are concerned with primary care, the development of health care organisations, and the evaluation of different approaches to the commissioning and provision of health services. In addition to her research interests, Judith is joint academic lead for research and development activities at the Health Services Management Centre, University of Birmingham. She is also director of the postgraduate education programme followed by all NHS Management Training Scheme (MTS) graduate trainees. In 2002, she was appointed to serve as a non-executive director of the South Birmingham Primary Care Trust.



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