

	<b>Research SUMMARY</b> 	<b>Authors</b>  JOHN APPLEBY NANCY DEVLIN	<b>Key topics</b>  NHS PERFORMANCE MEASURES PATIENT CHOICE HEALTH-RELATED QUALITY OF LIFE	<b>Date</b>  JANUARY 2005
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# MEASURING NHS SUCCESS

Can patients' views on health outcomes help to manage performance?

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## WHAT ARE PATIENT-ASSESSED HRQOL MEASURES?

Patient-assessed HRQoLs involve a patient answering straightforward questions about their health. Typically, questionnaires generate an overall numerical score (or scores on a number of health dimensions). Such measures are commonly used in clinical trials, before and after treatment, as one of a number of ways of measuring health outcomes. Brief generic questionnaires, such as the EQ-5D and the SF-36 (see p 5), cover key aspects of health such as emotional state and physical functioning, and take a few minutes to complete. Other HRQoL measures have been developed for specific interventions (such as hip replacements), diseases (such as cataracts) and patient groups (such as children). All aim to capture the patient's view of their own health status, and all implicitly recognise that the patient's subjective viewpoint is important.

The primary task of the health service is to improve people's health. A fundamental goal within this is to improve patients' health-related quality of life (HRQoL).

But, while measuring and monitoring many aspects of its performance, the NHS does not routinely measure the impact of its care on patients' HRQoL. This research was commissioned by the Dr Foster Ethics Committee, and reviews the potential benefits, costs and practical issues associated with the routine measurement and use of patient-assessed HRQoL to manage the performance of health care providers.

The research found that the potential benefits of using routine measurement of patients' health outcomes include: establishing where the real improvements in health are to be made; gaining more accurate measures of productivity; and obtaining more relevant information to help patients make choices. This form of assessment could also help monitor service providers on the basis of their main objective – to improve patients' health. However, the question is not just whether the routine use of health outcomes data could make a positive difference to NHS performance and the well-being of patients, but also what the scale of this difference might be. Would the benefits outweigh the costs involved? The answer is likely to be yes but there are issues still to be researched that a nationally-organised pilot could investigate.

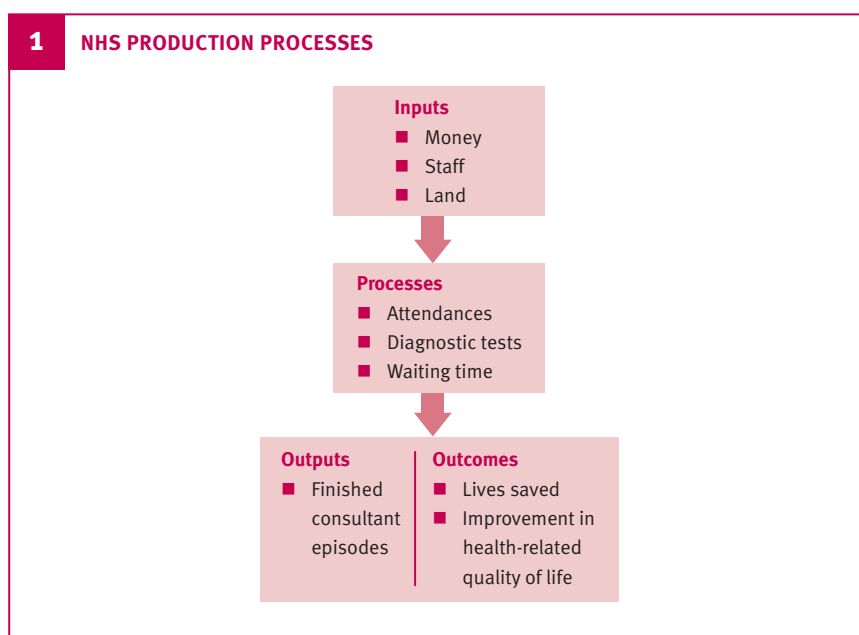
In recent decades, a more patient-centred approach in medical care has led to an increase in the use of patient-assessed HRQoLs, but the NHS has been slow to adopt HRQoLs across the board.

A fundamental question for the NHS, therefore, is how can it ensure the delivery of one of its key goals – improving patients’ quality of life<sup>2</sup> – when it has no formal, routine system for measuring the very thing it is trying to improve?

In recent decades, a more patient-centred approach in medical care has led to an increase in the use of patient-assessed HRQoLs, but the NHS has been slow to adopt HRQoLs across the board. This is due partly to the costs involved, and partly to the lack of a gold-standard method for measuring health outcomes.

## NHS performance measures

One way of looking at the performance of the NHS is to break down the system into a production process where inputs are combined in a process to produce outputs and outcomes.



Traditionally, performance measures in the NHS have focused on aspects of inputs, processes and outputs, with much less attention paid to the ultimate outcomes of care as measured by quality-adjusted life years or health-related quality of life.

If the NHS is to position itself at the leading edge of health systems around the world in promoting a patient-centred approach to performance management, it will need to make a real commitment to improving performance, backed up by appropriate actions.

## Potential benefits

The potential benefits of routinely measuring patient-assessed HRQoL are wide-ranging and include providing basic evidence to inform:

- the professional regulation of clinicians based on health gains in patients
- the performance of hospitals, clinical teams and individual health care professionals providing care at all stages of a patient's journey through the health system
- the provision of relevant, appropriate information to patients to inform their choices
- decisions about where extra money earmarked for the NHS would produce the best results.<sup>3</sup>

Such data could also have an impact on the wider health system. It could:

- help in the ongoing assessment and evaluation of old and new treatments
- provide a source of information about patients' views on health and health care
- track changes in clinical opinion and action regarding when to admit and treat patients
- allow, for the first time, a proper evaluation of broader government health policies in terms of who benefits as well as the degree of benefit.

The research concludes that there is much to be gained by routine before-and-after measurements of health, both as a means of monitoring and managing the performance of providers, and as a way of facilitating a system-wide refocusing of the NHS on improving health.

However, more information is required before the routine use of HRQoL measurements can be advocated. While the costs of implementing routine measurement are unknown, the potential benefits to patients and NHS performance in general are likely to be great. What is certain is that if the NHS is to position itself at the leading edge of health systems around the world in promoting a patient-centred approach to performance management, it will need to make a real commitment to improving performance, backed up by appropriate actions. Unless measurement is accompanied by rewards for good performers, and an action plan for poor performance, there is little to be gained from introducing yet more systems of measurement.

## Background

### A focus on outputs

More than 100 years ago, Florence Nightingale devised a simple, three-point health-related outcome measure for her patients – relieved, unrelieved and dead.<sup>4</sup> But the NHS has failed to develop a consistent system for measuring the impact of its services on patients, or the performance of the health system as a whole. For many years the NHS reported its hospital activity statistics as a composite of two measures – discharges and deaths – making no overt distinction between the two. Today, along with process measures, such as waiting times and length of stay, the main output measure for the NHS is the number of patients treated.

### HRQoL measures

Thousands of disease-specific, patient group-specific and generic tools have been developed to measure health status (as essential measures of health outcomes) in clinical evaluations. The last 30 years in particular have seen a rapid growth in the development and use of patient-assessed health-related quality of life (HRQoL) measures. This reflects a greater recognition that purely biomedical measures of health status (eg blood pressure or tumour size) fail to capture fully what individual patients feel is important, while there is also a growing interest in a more patient-centred approach in medical care.

The NHS has made some use of evidence from patient-assessed HRQoLs to help inform the work of the National Institute of Clinical Excellence and – in general, through the generation of evidence – best clinical practice. However, the health service has been slow to explore the potential benefits of such measures in relation to wider policy and practice on performance management, resource allocation and budget-setting, despite recognising that routine measurement of quality of life could provide useful information.

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## Key findings

There is no gold standard method for measuring health outcomes or health improvement.

### How should health outcomes be measured?

#### *No gold standard*

There is no gold standard method for measuring health outcomes or health improvement. Garratt *et al*<sup>5</sup> note the proliferation of measures of quality of life: in 2000, there were 1,275 separate measures, and many new ones were being developed; for example, in 1999, 650 papers were published reporting the development or evaluation of such instruments. The ‘validity’ of HRQoL measures is often determined by comparing the relative performance of one against another. This complicates both the comparison (there is unlikely to be one approach that is unequivocally ‘the best’) and the selection of appropriate measures that are fit for purpose.

#### *Use of generic measures*

Two main types of measures exist: those that are specific to a particular condition, patient group or disease; and those that are designed to capture patients’ experience of their health in a generic way. Generic measures (see Table 1 for examples) offer considerable advantages in assessing and comparing HRQoL change across the diverse range of activities and procedures undertaken in the NHS. But there are concerns about their lack of sensitivity in detecting changes in health resulting from specific conditions and interventions. The choice of which measure to use should be informed both by existing use and evidence (from experience and data, which are

**TABLE 1: CHARACTERISTICS OF TWO GENERIC MEASURES OF HEALTH: SF-36® AND EQ-5D**

Characteristics	SF-36®	EQ-5D
<b>How is health described?</b>	A 36-item questionnaire. (Sample page from the SF-36® is available at: <a href="http://www.SF-36.org/tools/pdf/SF-36®v2_Standard_Sample.pdf">www.SF-36.org/tools/pdf/SF-36®v2_Standard_Sample.pdf</a> )	Five dimensions (mobility; self-care; usual activities; pain/discomfort; anxiety/depression; three levels within each (no, some or extreme problems).
<b>Does it generate an overall summary score?</b>	Scores can be presented as Physical Component Summary Scores and Mental Component Summary Scores, each ranging from 0–100. SF-36® does not generate a single ‘summary’ index.	The descriptive system is accompanied by a self-rated 0–100 score, summarising the patient’s assessment of their own health.
<b>Ease of completion?</b>	The SF-36® takes five to ten minutes to complete. Shorter versions are available.	Two pages long. Takes one to two minutes to complete.
<b>What is the evidence base?</b>	Extensively researched and widely used. Subject to ongoing research and development.	Developed and disseminated by the EuroQol Group. Subject to ongoing research and development.
<b>Use in the United Kingdom?</b>	Widely used in clinical and population health research in the United Kingdom and internationally. Adopted by BUPA for measuring the performance of health care providers.	Wide use in clinical studies, patient groups and general population studies. Data available for samples of the population. No previous use in measuring the performance of clinicians that we are aware of.

Source: Appleby and Devlin (2004)

already available), and by relevant developments in the NHS and the private sector. A number of current or planned initiatives involve the use of HRQoL measures. These include: investigations into their use in the NHS in managing referrals and managing the performance of treatment centres; and to highlight performance variations of BUPA hospitals and clinicians.<sup>6</sup>

## How could the use of health-outcome measures be improved?

What might health care services and, more importantly, patients, have to gain from the NHS refocusing its thinking about quality and performance firmly onto improving health? Information from patient-assessed HRQoL measures could be used to manage the performance of providers in direct and indirect ways (see Table 2).

TABLE 2: MANAGING PERFORMANCE USING MEASURES OF HRQoL		
	Direct use	Indirect use
<b>Good performance</b>	<ul style="list-style-type: none"> <li>Financial rewards (eg bonuses) for exceptional performance</li> <li>Evidence to inform consultants' Clinical Excellence Awards</li> <li>Evidence to inform compliance with clinical contracts (eg through negotiated 'job plan')</li> </ul>	<ul style="list-style-type: none"> <li>Purchasers use the information to choose good-quality providers: good performers gain market share and revenue</li> <li>Patients, given a choice of provider at the point of referral, access and use the information to choose good-quality providers: good performers gain market share and revenue</li> <li>Enhanced professional reputation/satisfaction</li> </ul>
<b>Poor performance</b>	<ul style="list-style-type: none"> <li>Evidence considered as part of clinicians' annual appraisal and five-yearly revalidation. Remedial actions may be required, resulting in improved performance – or the licence to practise withdrawn</li> <li>Disciplinary actions outside the revalidation process</li> </ul>	<ul style="list-style-type: none"> <li>Loss of professional reputation/satisfaction</li> <li>Purchasers and patients use HRQoL information to avoid low quality: poor performers lose market share and revenue</li> </ul>
Source: Appleby and Devlin (2004)		

HRQoL information could make a significant impact in improving quality in four areas: revalidation and professional regulation; targets for trusts; patient choice and purchaser choice.

### *Revalidation and professional regulation*

New systems for professional registration in medicine are currently being introduced by the General Medical Council (GMC). From 2005, doctors who want to practise medicine in the United Kingdom must hold a licence to practise, which is retained by 'revalidating' every five years that the doctor is 'up-to-date and fit to practise'.<sup>7</sup> To meet these requirements, and to demonstrate good medical practice, all doctors are required routinely to

Increasing effective choices for patients means that information about the available options needs to be accurate and accessible, especially on those aspects of their care that patients value most.

#### **COST-WEIGHTED EFFICIENCY INDEX (CWEI)**

The CWEI is a ratio of changes in NHS activity (such as numbers of inpatients treated and ambulance journeys) from one year to another, to annual changes in NHS spending. Different types of NHS activity are weighted by the proportion of the total NHS budget spent on each activity and then added together.

This measure has been criticised for not capturing the full range of activities carried out by the NHS, and for failing to reflect changes in the quality of care over time.

collect and report data and information on their clinical performance. Evidence must also be submitted to show that there are no concerns about the doctor's practice or performance. This might include, for example, information on adverse outcomes from treatment.

The principles of good medical practice and standards of 'competence, care and conduct' are outlined by the GMC.<sup>7</sup> Many of these principles and standards – and therefore presumably the evidence to be submitted via annual appraisal – focus on quality in the process or delivery of care rather than health outcomes from treatment. Submitting evidence on the changes to patients' HRQoL following treatment could considerably strengthen these processes by shifting the focus to the clinical and rehabilitation team's achievement of positive health gain in patients – not simply the avoidance of adverse events.

#### **Value for money targets**

The Department of Health and the Treasury have recently changed the nature of the NHS value-for-money target. Traditionally, the Treasury has set this target – as part of its public service agreement (PSA) measures<sup>8</sup> – in terms of a percentage improvement in the cost-weighted efficiency index (see sidebar).

However, as set out in the 2002 PSA targets, the current requirement is for the NHS to achieve a 1 per cent increase in a redefined measure of cost-efficiency and a 1 per cent increase in the value of quality.<sup>9</sup> But exactly how the NHS should measure (and value in financial terms) increases in quality remains unclear. The availability of HRQoL evidence could provide a way forward by providing data that directly bears on quality health outcomes.

#### **Patient choice**

Since the publication of the *NHS Plan* in 2000,<sup>2</sup> policy on patient choice has expanded rapidly. But increasing effective choices for patients means that information about the available options needs to be accurate and accessible, especially on those aspects of their care that patients value most.<sup>10</sup> For example, in the London Patient Choice Project, the reputation of health care providers was a crucial factor in patients' choices.<sup>11</sup> Some information currently available to patients is useful, such as individual performance indicators published by the Healthcare Commission,<sup>12</sup> composite measures such as star ratings,<sup>13</sup> hospital reviews by the Healthcare Commission<sup>14</sup> or Dr Foster *Good Hospital Guides*.<sup>15</sup> However, much of the information available is inappropriate for the decision at hand (eg mortality rates, when most care is about quality, not length of life changes) or is presented at the wrong level (eg hospital, not clinical team). The use of routine HRQoL data could provide appropriate, relevant evidence for patients to make informed choices.

Information on patient-assessed HRQoL has an important part to play in differentiating the performance of providers based on quality of care.

### ***Purchaser choice***

Effective commissioning of services by primary care trusts (PCTs) relies upon them being able to differentiate between the performance of providers, and to select and contract with the highest quality providers at the prevailing fixed prices. The new provider reimbursement system being rolled out under Payment by Results<sup>16</sup> requires a greater focus on results (that is, outcomes-based purchasing) if the intended gains in quality throughout the NHS are to be generated.

As with patient choice, purchaser choice will increasingly need to be informed by data relevant to purchasers' objectives to improve the quality of care. Therefore information on patient-assessed HRQoL has an important part to play in differentiating the performance of providers based on quality of care.

### **System-wide benefits**

The routine use of HRQoL measures would offer numerous system-wide opportunities for quality improvement. Below are five key examples.

#### ***Health technology (re)evaluation in the real world***

The method generally recognised as the gold standard for evaluating the clinical effectiveness of health care technologies (eg drugs, devices, surgical techniques) is the randomised control trial (RCT), which is the best way of isolating the impact of a health care technology from other factors that may affect clinical outcomes. However, due to prohibitive limits on sample size, and ethical considerations concerning patient inclusion in (or exclusion from) trials, RCTs rarely provide definitive or unambiguous results. Once a technology receives approval from the National Institute for Clinical Excellence (NICE), largely, but not exclusively, on the basis of trial results, its use in the real world almost always differs from the controlled world of the RCT.

Linked to specific treatments, patient and provider characteristics and patient-assessed HRQoL information could add an important dimension to the data NICE could consider in reviews of its guidance on technologies as they are used in the real world.

#### ***Patients' values***

Patients' views about their health care provide a vital input to a range of health care decisions. However, the use of patients' views in performance management is largely restricted to surveys of their satisfaction with the delivery of care – not its outcomes.

Patient-assessed HRQoL data on health improvement would allow patients' opinions and values to be directly incorporated into, for example, NICE



HRQoL information could provide a more sophisticated way of identifying and assessing health needs in population subgroups.

health technology appraisals. Patients' assessments of their pre- and post-operative health states could also help to inform assessments of the effectiveness and cost-effectiveness of services.<sup>17</sup>

### ***Clinical thresholds***

There is ample evidence that decisions made by health care professionals as to when to start treatment, when to stop – and what form intervention should take – varies, with the variation only partly explained by clinical factors. Clinical opinion about, for example, what constitutes a reasonable waiting time, appears to be influenced partly by current waiting times.<sup>18</sup> Understanding how clinical thresholds (the propensity, for example, to refer patients on to waiting lists, or add them to operating lists) vary in relation to the health status of patients would start to illuminate a relatively unclear area of clinical decision-making. However, this could have potentially significant policy implications such as the way demand for care (generated by clinicians) changes in response to other factors, for example, reductions in waiting times.

### ***Fairness and health care needs based on population subgroups***

Differences in health between population subgroups (defined, for example, by age, gender or socio-economic group) need to be measured and monitored to help inform health policy and allocate resources. Linked to other routine NHS data sets (for example, databases such as hospital episode statistics, which draw upon the patient record), HRQoL information could provide a more sophisticated way of identifying and assessing health needs in these groups.

### ***Measuring productivity***

The traditional NHS productivity measure is a ratio of outputs (activity) to inputs (money): the relatively large increases in NHS spending since 1997/8 have not been accompanied by similar increases in outputs. With spending rising even faster since 2000/01, this downward trend is likely to continue in subsequent years. Extra spending has been partly absorbed by higher costs (rather than higher outputs); invested in services and activities that may take some years to be reflected in increased outputs; increasingly channelled into activities not captured by the productivity measure; and used to increase the (unmeasured) quality rather than the (measured) volume of outputs.

There are significant problems involved in measuring productivity in the NHS. However, patient-assessed HRQoL could have a role to play in assessing changes in the quality of services provided, and could also help to shift the focus by which productivity is measured towards health outcomes rather than health service outputs.

Unless measurement is accompanied by rewards for good performers, and an action plan for poor performance, there is little to be gained from introducing still more measurement.

### **What are the risks and costs of collecting and using HRQoL measures?**

While the direct unit cost of administering HRQoL measures will be relatively small – around the price of a basic blood test – the total cost of implementing a collection and reporting system is likely to be relatively large given the millions of patients in contact with the NHS, and will depend on decisions about the method of administration, sample size and coverage.

There is some uncertainty among researchers about how best to detect and report unacceptable variations in health care performance and ensure the buy-in by clinical staff. More information is therefore required before large-scale implementation for gathering and using HRQoL data can be confidently recommended for the NHS. However, a crucial question is whether the NHS is prepared to make a real commitment to improving performance, backed up by appropriate actions. Unless measurement is accompanied by rewards for good performers, and an action plan for poor performance, there is little to be gained from introducing still more measurement.

## Key recommendations

Given the uncertainties associated with the routine collection and use of patient-assessed HRQoL data in the NHS, there is a clear need for a Department of Health/NHS-backed pilot study. This should be designed to investigate the feasibility, benefits and costs of using HRQoL data to manage providers' performance. Specifically, the pilot study should be designed to provide evidence on:

- the feasibility of data collection (such as response rates) and the acceptability to patients of data collection (for example, in terms of ease of completion, the availability of appropriate language versions of questionnaires, the availability of help if patients are unsure how to complete the forms)
- the best timing and frequency of seeking health-outcome measurements from patients. Options include: pre-operative measurement at the point of referral, or outpatient consultation; measurement during treatment; post-operative measurement taken at intervals following treatment (and variations in the appropriate interval between therapeutic areas)
- the ways in which patients can, and do, make use of the results to inform their choices about providers
- the acceptability and usefulness of using HRQoL measurements to the whole clinical team
- precise cost projections for the collection and analysis of data if rolled out across the NHS or expanded across services or interventions
- the feasibility of taking a sampling approach (eg measuring 1 in 20 patients) versus a census
- the relative performance of condition-specific and generic measures in detecting variations in performance between doctors, surgical teams and hospitals
- how information can be used to identify poor performers – and what is the most effective way of communicating this to doctors, hospitals and managers
- how the information is used (eg in annual appraisal processes) and resultant actions taken
- what the relationship is between poor performance on health outcomes and other measures of provider performance.

HRQoL data has the potential to strengthen the management of performance of clinicians, surgical teams and hospitals. The data generated also has a wide range of applications throughout the NHS, by shifting the emphasis from processes and outputs to the outcome – patients' health. Such a shift in focus is long overdue.

Given the uncertainties associated with the routine collection and use of patient-assessed HRQoL data in the NHS, there is a clear need for a Department of Health/NHS-backed pilot study.



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