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# Getting the most out of PROMs

Putting health outcomes
at the heart of NHS
decision-making

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Nancy is co-author of a leading UK textbook on health economics, *Economic Analysis in Health Care* (Morris *et al* 2007), and has published widely on health economics topics in economics, health services research and health policy journals. Her publications include papers on the National Institute for Health and Clinical Excellence's cost-effectiveness threshold, methods of analysing and reporting patient-reported outcome measures (PROMs) data, National Health Service (NHS) patient choice policies, and the effects of government targets on waiting times. She is engaged in theoretical and empirical research on measuring and valuing patient benefit, is currently leading European research studies to develop new 'time trade-off' methods for valuing quality of life, and is leading a programme of research funded by the Department of Health to provide English values for the new EQ-5D-5L.

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The focus of his research and commentary work at The King's Fund is on current health policy matters, in particular the economic issues associated with the government's reform agenda for health care. such as the introduction of competitive forces into the NHS, the use of targets to reduce waiting times, patient choice, Payment by Results and PROMs. He has published widely on a range of health care finance and economic issues in books, academic journals, reports, magazines and newspapers. Recent work includes co-authoring a major study of NHS performance since 2002 with Sir Derek Wanless and colleagues, published by The King's Fund (Wanless *et al* 2007), an analysis of the public's attitudes to the NHS (Park *et al* 2009), and an analysis of future prospects for NHS funding written in partnership with the Institute for Fiscal Studies (Appleby *et al* 2009a).

John has also acted as an adviser to the UK government and parliament in various capacities, including carrying out a review for ministers of the future funding needs of Northern Ireland's health service, and, currently, serving as a task force member for the Marmot Commission on Health Inequalities. He is also a special adviser to the House of Commons Health Select Committee, a member of the National Quality Board's priorities sub-committee and a health economics expert for the Prime Minister's Commission on the Future of Nursing and Midwifery.

# Acknowledgements

# Foreword

For too long, the principal clinical outcome data routinely and effectively collected in health care has centred on death. Other routinely collected clinical indicators have included infection rates, readmissions, re-operations and adverse incidents, but none of these give any sense of the ultimate outcome for the patients unless, in the case of an adverse incident, it leads to death.

In fact, however, only a tiny proportion of the people being treated in our health care system in any specific period die. Most experience at least some degree of improvement in their health as a result of their treatment, but, until quite recently, little attempt was made to measure this routinely, although such measures have been frequently used in clinical research studies on selected populations, and are now increasingly employed in specific clinical audits.

The need for better measurement of health improvement on a day-to-day basis, and for this information to come from the patients themselves, has led to increased interest in patient-reported outcome measures (PROMs). Clearly, patient-reported outcome data are important to clinicians as feedback on the care they have provided. In this excellent review, however, as well as describing the nature and types of PROMs and their potential widespread application (eg, to surgery, long-term conditions and mental health), the economic value of PROMs to the various stakeholder groups is considered.

Devlin and Appleby have considered the value of PROMs collection to patients themselves, to commissioners, to hospitals and to clinicians. They have highlighted the significant change to the measurement of clinical quality that routine measurement of patient-reported outcomes will bring, and have drawn out the opportunity for driving both cost-effectiveness and clinical quality improvement through incentives – opportunities that the Department of Health is keen to pursue.

These are all going to be important at a time of increasing financial constraint and, in the penultimate section, the authors also give brief consideration to the potential effect of the widespread development of PROMs on the vexed question of National Health Service output and productivity. If routine PROMs collection can indeed lead to genuine Payment by Results, and begin to move thinking on health care productivity from output and activity to outcome, then we will surely have taken a huge step forward.

**Andrew Vallance-Owen**
Chair, Department of Health PROMs Stakeholder Group

# Introduction

The ultimate measure by which to judge the quality of a medical effort is whether it helps patients (and their families) as they see it. Anything done in health care that does not help a patient or family is, by definition, waste, whether or not the professions and their associations traditionally hallow it.

(Berwick 1997)

The routine use of patient-reported outcome measures (PROMs) was introduced into the National Health Service (NHS) in 2009 and is a landmark development.

The goal of most health care is to improve patients' health – and, arguably, it is the patients themselves who are best placed to judge how they feel. The introduction of PROMs reflects a growing recognition throughout the world that the patient's perspective is highly relevant to efforts to improve the quality and effectiveness of health care. PROMs are likely to become a key part of how all health care is funded, provided and managed.

In this report, we explain what PROMs are and why they are highly relevant to patients, commissioners, clinicians, providers and regulators. We discuss the benefits of using PROMs, as well as the challenges in realising them. Many of the issues we address cut across a number of NHS stakeholders. For example, patients, commissioners, providers, and clinicians will all have a keen interest in PROMs, but the most useful way of analysing and reporting PROMs data might differ for each of these groups. We consider these issues within each chapter.

## The economic context

Health accounts for a substantial proportion of UK government spending – amounting to slightly more than 18 per cent of the total in 2007/8 (Hawe 2009). In common with all economies in developed countries, the health sector in the United Kingdom accounts for a substantial and growing proportion of overall economic activity.

What is *produced* from this spending? What *value* does expenditure on health services generate for patients and for the United Kingdom? While most other sectors of the economy generate outputs that can readily be measured and valued – quantities of goods and services, and the prices at which they are bought and sold – in contrast, health services have traditionally posed considerable challenges for the measurement of output and productivity (Office of Health Economics 2008). Following the historically unprecedented increases in real spending on the NHS from 2000 onwards, commentators have reasonably asked: where did the money go? What was achieved by the massive increase in spending?

In stark contrast, the current economic environment in which the NHS operates has changed dramatically as a result of the financial crisis and recession of 2008/9. The NHS has had to adjust to a medium-term prospect of zero growth or, indeed, budgets that are

decreasing in real terms (Appleby *et al* 2009a). Notwithstanding the changed economic context, the questions remain essentially the same:

- Can we be sure that spending on the NHS is justified by the outputs that it produces?

- Are scarce NHS resources being used in a way that maximises their value to patients and society?

## Special issues with measuring and valuing health

Health care services pose particular problems in assessing output and productivity. Health care services or products themselves are easy to record and count: the number of hospital admissions, doctors' visits, surgical procedures undertaken, tooth cavities filled, prescriptions issued, and so on. But these should not simply be 'added up' to give an indication of what, overall, is produced. More importantly, they are *intermediate* outputs: most health services are not valued in their own right, but rather because of the effects they have on something much more fundamental: health.

Yet efforts to measure the 'health' produced by the NHS have been fairly rudimentary. Traditional measures have tended to focus on the prevalence of adverse outcomes, such as post-surgical mortality, hospital-acquired infections and readmission rates. It is, of course, important to know about these 'bad' things, and they do need to be minimised, but such incidents are also relatively rare and shed little light on the great majority of health service interventions for most patients.

As a basis for assessing the value of the more than £100 billion of taxpayers' funds currently spent on the English NHS, however, these measures are hopelessly inadequate. The purpose of the NHS is not just to minimise the harm caused by its activity, but also to produce health and social benefits for patients and society. Despite a century of developments in medical technology, and vast improvements in the ability of medical science to prevent, diagnose and treat disease and ill health, attempts to measure the outputs of health care in terms of their impact on patients' health have barely progressed beyond Florence Nightingale's time. More than 100 years ago, she suggested a simple three-point health-related outcome measure for her patients: relieved; unrelieved; and dead (Appleby and Devlin 2004).

Clinicians have, of course developed measures to guide and inform their clinical practice. These provide important and relevant information about the impact of health care interventions on clinically defined variables, but, while useful, they typically fail to inform wider questions crucial to measuring the *overall* output and quality of the NHS.

Moreover, the many different clinical indicators used in medical practice do not always distinguish the aspects of health that patients consider important, or their relative value to patients. The apocryphal surgeon's observation that the operation was a success but the patient died might be an example of the dark humour of the medical profession, but it is nonetheless indicative of the gap that can exist between the views of clinicians and patients on what matters in health care.

Furthermore, the many different clinical measures used make it hard to compare health impacts across specialties. It is therefore difficult to draw any conclusions about the overall effects of spending and service delivery across different disease areas, or their ultimate effects on health outcomes. And nor is it possible to identify how those outcomes could be improved by different allocations of resources between services and patients.

In addition, although patient-reported experience measures (PREMs) can provide useful indications of patients' perspective on their care, by their nature these reflect experience of the *process* rather than the *outcome* of care. As the final report of the NHS Next Stage

Review observes, '…just as important is the effectiveness of care from the patient's own perspective, which will be measured through patient-reported outcomes measures…' (Darzi 2008).

It is clear that a fundamental rethink about what 'outputs' and 'outcomes' mean in the NHS is long overdue.

## A fundamental shift in focus

Against this backdrop, there has been a marked shift internationally in thinking about what health is and how it is measured. Traditional clinical ways of measuring health and the effects of treatment are increasingly accompanied by, or indeed replaced by, PROMs.

In broad terms, PROMs comprise a series of structured questions that ask patients about their health from their point of view. (For those who are unfamiliar with PROMs, the next section, 'A primer on PROMs', provides a beginner's guide to the various questionnaires used and how they are employed to measure patient health.)

This shift in focus is most evident in the appraisal of new health care technologies, where products and practices are subject to rigorous evaluation. The United States' Food and Drug Administration (FDA), which has recently recommended the inclusion of patient-reported outcomes (PRO) in US clinical trials (Food and Drug Administration 2006), notes: 'the use of PRO instruments is part of a general movement toward the idea that the patient, properly queried, is the best source of information about how he or she feels' (Bren 2006).

In parts of the NHS, most notably in the appraisal of new health technologies by the National Institute for Health and Clinical Excellence (NICE) (National Institute for Health and Clinical Excellence 2008a), the use of PRO data is already commonplace, and, indeed, is a required part of the evidence used in the appraisal of, and decision-making about, health technologies.

Over the course of several decades, clinical, health services and social sciences researchers have produced literally thousands of validated instruments that facilitate the consistent, reliable measurement of patient-reported health. Patients' perspectives on their health outcomes can now be measured in most clinical areas.

## Routine measurement of PROMs: a step forward in the NHS

An important development in this area took place in the NHS in England in April 2009. Since then, the Department of Health has required the routine measurement of patient-reported health outcomes for all NHS patients in England before and after receiving surgery, via its PROMs programme (Department of Health 2007, 2008a).

Initially the requirement to collect PROMs data applies to just four surgical procedures – hernia repair, hip and knee replacement, and varicose veins – but work is now under way to explore the plausibility of and case for extending routine measurement to a range of chronic conditions, including diabetes, asthma, stroke, chronic obstructive pulmonary disease (COPD) and others. Contingent on there being positive evidence to support their use, it is possible that the routine collection of PROMs data could be introduced across a wide range of NHS services.

In the Insight box on pages 5 and 6, Katy Peters gives some key facts about the implementation of PROMs. Appendix 1 (see p 76) shows the PROM questionnaire that is currently completed by patients after undergoing varicose vein surgery.

The Department of Health is considering if and how to use the PROMs data across a range of applications, including measuring and managing hospitals in their efforts to improve patient health. Indicators of hospital performance, based on PROMs, could be included in the information provided to patients being referred for elective surgery, to assist them in choosing the hospital at which they will receive treatment.

This reflects a key theme in the NHS reforms, namely to improve the responsiveness of the NHS to patients' views, preferences and choices. Research has indicated that patients regard the relative performance of providers in improving their health as highly important in choosing where to receive surgery (Burge *et al* 2006), yet to date it has been the aspect of performance about which least information existed.

The PROMs initiative is a truly remarkable development for the NHS – and a first internationally: the NHS will be the first health care system in the world to measure what it produces in terms of *health*, rather than in terms of the production of *health care*. The intention is that, in addition to clinical measures of outcome, PROMs will enable patient perspectives to be taken into account in key aspects of the NHS, including:

- informing the choices patients make with regard to their treatment and its providers

- measuring and benchmarking the performance of health care providers

- linking the payment received by providers to their performance in improving patient health

- understanding and managing referral from primary to secondary care

- facilitating co-operation between clinicians and managers in the delivery of care

- enabling health care professionals to monitor and improve health care practices

- regulating for safety and quality in health care services.

As the potential scope of the PROMs programme in the NHS could extend beyond elective surgery, these data will offer a powerful new means of managing the performance of the NHS.

## Getting the most out of PROMs

The aim of this report is to provoke and encourage thinking about the wide range of ways in which PROMs data can be used to inform decisions in the NHS.

- What opportunities do these data present?

- What are the limitations of PROMs, and what are the possible pitfalls in the use and overinterpretation of data produced from them?

- What work needs to be done now in order to get the most out of PROMs?

In the next section, we give an overview and explanation of the PROMs instruments. Then we look first at how PROMs data might be used by patients in choosing both *where* to receive treatment, and also *what* treatment is best for them; and then we consider other ways in which the data now being collected can be used to transform decision-making in the NHS (and, by extension, in any health care system anywhere in the world).

Following on from this, the next section discusses how providers can use the data to benchmark and improve clinical performance within their own organisations, drawing on the example of Bupa. The largest private medical insurer in the United Kingdom, until

## INSIGHT

### Key facts about the implementation of PROMs in the NHS in England

Katy Peters, Head of Choice and System Management, Department of Health

- From 2009, PROMs are being collected for four elective procedures:
  - hip surgery
  - knee surgery
  - hernia repair
  - varicose veins.

- Those four procedures cost the NHS in England a total of £800 million per year.

- Cataract surgery was also to have been included in the PROMs programme, but there were concerns about methodology.

- Each year, 250,000 patients will be invited to complete questionnaires both before and after surgery.

- All NHS providers (100 per cent) are currently collecting these data.

- It is hoped that an 80 per cent patient response rate will be achieved.

- The annual cost of the current PROMs programme is estimated to represent less than 0.5 per cent of expenditure on the relevant interventions.

The Department of Health is currently working to extend the PROMs programme over a wider range of conditions and treatments in the NHS, including:

- mental health, eg, anxiety and depression

- cancer care

- six long-term conditions:
  - asthma
  - COPD
  - diabetes
  - epilepsy
  - heart failure
  - stroke.

In each case, the Department of Health's approach to the PROMs programme comprises the following careful process:

- identifying the appropriate PROM instruments

- piloting their use and reviewing their potential to be rolled out across the NHS

- implementing data collection and related procedures

- evaluating the programme.

Progression depends on there being sufficient evidence at each stage to support the use of PROMs.

**INSIGHT**

## Key facts about the implementation of PROMs in the NHS in England
*continued*

The key questions asked at each stage in this process are summarised in the figure below, and an example of the post-surgical questionnaire currently being used in the PROM programme for varicose vein surgery patients is shown in Appendix 1.

The patient-reported outcome measures (PROMs) programme: the approach

**1. Identify**
Which areas?
Which measures?
Assess the evidence base

↓

**2. Pilot**
How to administer?
Questionnaire design?
Sample sizes?
Statistical power?

↓

**3. Review**
Feasible?
Cost-effective?
Acceptable?

↓

**4. Implement**
How to implement?
How to support implementation?
Guidance?

↓

**5. Evaluate**
What works well?
What hasn't worked?
Where should changes be made?

recently Bupa also owned and operated many private hospitals providing non-emergency services. Bupa collected and successfully used PROMs data for many years as a means of managing and enhancing quality.

Next, we show how commissioners (the NHS term for the purchasers of health care on behalf of patients) can use PROMs data in assessing value-for-money and deciding how to purchase health care services that maximise improvement in the health of the communities they serve. We also consider the possibility of commissioners directly linking provider reimbursement to PROMs performance.

After this, we consider how clinicians might use these data. Drawing on the experience of the Canadian and New Zealand health care systems, we consider whether there is scope for using PROMs data to guide referral practices, to ensure that the people who receive health care are those that will benefit from it the most.

We conclude by showing how measuring improvements in patient health can address high-level questions about productivity and performance in the NHS.

Routine use of PROMs has the potential to put the views and values of patients squarely at the heart of NHS management and clinical thinking about the provision of health care services. Our aim is to help ensure that these benefits are realised, and that the NHS maximises the benefit to patients that collecting these data makes possible.

# A primer on PROMs

## What are PROMs?

A patient-reported outcome measure (PROM) is a series of questions that patients are asked in order to gauge their views on their own health. The name is fairly self-explanatory: PROMs are completed by *patients* themselves. The purpose of PROMs is to get patients' own assessment of their *health* and *health-related quality of life* – PROMs questionnaires do not ask about patients' satisfaction with or experience of health care services, or seek their opinions about how successful their treatment was.

In the various uses of PROMs that are the focus of this report, it is *patients* who answer the questions, but these same questions are often included in surveys designed to measure health among the general population, such as the annual Health Survey for England commissioned by the Department of Health. In those contexts, the 'P' in PROMs could just as easily stand for 'people' rather than 'patients'. The main thing about a PROM is that health is assessed by the person experiencing it, not by a doctor or anyone else.

The questions can be asked by paper and pencil questionnaires, interviews, or, increasingly commonly, by electronic means (eg, via a computer, or a handheld electronic device).

There are literally thousands of different PROM questionnaires or instruments, differing in terms of the wording and nature of the questions asked, the number of questions asked, and how the answers are scored or summed up. The quality of these instruments, in terms of their reliability and validity, varies considerably. The particular instruments being used in the NHS PROMs programme (*see* box below), were chosen by the Department of Health after careful consideration and testing in pilot studies (see Browne *et al* 2007).

### Patient-reported outcome measures used in the NHS PROMs programme

The questionnaires that patients are asked to complete shortly before and some months after surgery comprise a disease-specific instrument, a generic instrument, and a series of additional questions about the patient's health and symptoms. Those currently in use are shown below.

| Treatment | Condition-specific PROM | Generic PROM |
|---|---|---|
| Knee surgery | Oxford Knees Score | EQ-5D |
| Hip surgery | Oxford Hips Score | EQ-5D |
| Varicose vein surgery | Aberdeen Varicose Vein Questionnaire | EQ-5D |
| Hernia repair | n/a | SF-36 and EQ-5D |

There is no condition-specific PROM for hernia repair, so these patients complete two generic instruments: the EQ-5D and the SF-36.

Appendix 1 reproduces the PROM questionnaire currently used for varicose vein patients by way of an example.

The various PROM instruments (sets of questions) available fall into a number of distinct types. The most important differences/types are summarised in Table 1 and are explained below.

## How do PROMs measure health?

Some PROMS instruments set out to describe or measure health in a way that is general (or generic), so that the same questions can be used for patients with completely different conditions, and so that health and changes in health can be compared across different patient and population groups. These generic instruments measure health in terms of the effect of any given state of health on the ability to function and enjoy life, which is why they are sometimes referred to as measures of health-related quality of life (HR-QoL) or Quality of Life (QoL). The focus is on the *impact* that a person's state of health has on his or her overall life.

Other sorts of instruments measure patient-reported health in a way that is specific to a particular disease, set of conditions, or part of the body. In Table 1, these have been called condition-specific measures (they are sometimes also referred to as disease-specific measures). The questions in these instruments measure the severity of a particular condition or some specific aspect of health, as viewed by the patient. The questions focus on the particular sorts of limitations or problems that people can experience as a result of a very specific *condition* (for example, the International Restless Leg Syndrome Study Group rating scale (IRLS; Walters *et al* 2003), or ask questions relevant to a wider set of conditions that affect a *body part* (for example, the Oxford Knees Score; Dawson *et al* 1998), or might focus on a particular type of functioning (for example, the VF-14 measures visual functioning; Steinberg *et al* 1994). Condition-specific instruments are relevant to patients, that is, people who suffer, or are suspected of suffering, from health problems. They are not usually used in population health surveys.

**Table 1** A taxonomy of different types of PROMs, with examples

| How is health summarised? | How is health described? | |
| --- | --- | --- |
| | **Generic** | **Condition-specific** |
| **Scores** | The most widely used instrument of this sort is the SF-36 (Ware and Sherbourne 1992). It comprises 36 questions. The patient's health is then summarised by a mental health component score and a physical health component score. There is no overall score. | There are literally thousands of these sorts of instruments. In addition to the ones mentioned in the text, a further example is the St George's Respiratory Scale (Jones *et al* 1992). |
| **Values** | The most widely used instrument of this sort in the United Kingdom and Europe is the EQ-5D (Brooks 1996). Patients answer five questions, each on a different dimension of their health. In addition, they are asked to provide an overall assessment of their health, on a scale ranging from 0 (worst possible health) to 100 (best possible health).<br><br>The patient's health, as he or she describes it on the five dimensions, can also be given a value that represents society's views about that state. These values are available in EQ-5D value sets, which are based on the views and preferences of the general public, asked to imagine living in EQ-5D health states.<br><br>This is how the National Institute for Health and Clinical Excellence, for example, uses these data in estimating quality adjusted life years. | None of the condition-specific measures claims to capture patients' *overall* quality of life, nor the value patients or society place on that. |

## How is a patient's self-reported health on the various dimensions summed up?

The answers patients give to the PROMs questions provide detailed information on a variety of aspects of their health and quality of life. However, in order to provide an *overall* assessment of a patient's health, and to make comparisons (for example, between before and after treatment, or between sub-groups of patients), it is necessary to sum up the answers the patient has provided on each question. PROMs instruments achieve this in a number of different ways.

One method is to assign a score to each answer, and then add them up. For example, the International Prostate Symptom Score (IPSS) is a condition-specific PROM used in urology to measure men's prostate problems (Barry *et al* 1992). It contains questions such as: 'Over the past month, how many times did you most typically get up to urinate from the time you went to bed until the time you got up in the morning?' There are six possible answers: (a) none; (b) once; (c) twice; (d) three times; (e) four times; (f) five times or more. Each of those answers will be given a score (a) = 0; (b) = 1; (c) = 2; (d) = 3; (e) = 4; (f) = 5. The score on that question is then aggregated (condition-specific PROMs usually do that in a simple linear way, that is, scores on each item are simply added up) with the scores on the other questions asked, and summed to give an overall score.

For a discussion of how clinicians use instruments such as the IPSS in their clinical practice, *see* the Insight box on p 51 by Professor Mark Emberton, consultant urologist at University College Hospital, London.

The problem with scoring is that the scores can be assigned in an arbitrary way, and the weight placed on increasing levels of problems, and on each type of problem, might not reflect their relative importance to the individual patient answering the questions. An alternative is to ask patients to summarise their overall state of health. For example, the second part of the EQ-5D (*see* box opposite), the EQ-VAS, asks patients to indicate how they feel overall on a scale of 0–100. This might be thought to show how patients value their own health, in that their overall score will reflect the relative importance they place on the different aspects of their health that have been described.

However, relying on these overall scores loses some of the descriptive richness of the answers to the individual questions in the PROMs, and for some purposes patients' values might not be the most pertinent. For example, in the economic evaluation of health care using PROMs (*see* box on p 40), it is believed that society's values for each health state should be used, rather than those of patients (National Institute for Health and Clinical Excellence 2008b).

Where patients' values are not considered relevant, an alternative is to use values (sometimes also called utilities) provided by members of the general public for the health states described by the PROMs instruments. These values are listed in a social value set, obtained via a complex process in which members of the general public are asked to imagine living in the different health states, and then to state their preferences using one of a range of methods designed by economists for that purpose (Morris, Devlin and Parkin 2007).

### The EQ-5D and the EQ-5D-5L

The EQ-5D (so named because it was developed by the EuroQol Group and has five dimensions) is the generic instrument being used in the NHS PROMs programme in England. It comprises two parts.

In the first part, the patient is asked to describe his or her health in terms of the levels within each of five dimensions:

- mobility

- self-care

- usual activities

- pain/discomfort

- anxiety/depression.

In the second part of the instrument, patients are asked to provide an overall assessment of their health on a visual analogue scale of 0–100.

The best-known version of the instrument, which has been in widespread use internationally for more than two decades, asks patients to report their health in each dimension by indicating whether they have 'no problems', 'some problems' or 'extreme problems'. This three-level version of the EQ-5D is the one now being used throughout the NHS as part of the PROMs programme (*see* p 8 of the questionnaire in Appendix 1).

A newer version of the instrument has recently been published offering five levels within each of the five dimensions, giving patients more options for describing their health (Herdman *et al* 2008). Called the 'EQ-5D-5L', this five-level version is reproduced in Appendix 2 (*see* p 81).

The five-level version is intended to be more sensitive to changes in health, and includes other improvements (for example, it no longer uses 'confined to bed' to describe the most severe problems with mobility).

## Condition-specific vs generic PROMs

Given that the condition-specific and generic PROMs instruments are clearly very different, is one type better than the other? More generally, on what basis might any given PROMs instrument be judged superior to any other?

There is a considerable volume of health services, psychometric, clinical and economics research literature on these issues, but, in brief, generic instruments such as the EQ-5D and SF-36 have been shown to work well in a wide range of health problems. They measure health in ways that:

- are broadly consistent with other, different, ways of measuring health (validity)

- mean individual health experiences tend to be reported in the same way (reliability)

- capture salient changes to health (sensitivity).

However, for some patient groups, and some sorts of health problems, generic instruments do not perform well on these criteria, and seem to miss important aspects of health status and changes in health.

The condition-specific instruments in common use generally do tend to be valid, reliable and sensitive. Usually (although not always) they outperform the generic instruments in capturing the detail of specific conditions. They are more focused on a tightly defined aspect of health, and tend to be good measures of that. However, the measures of health they produce do not allow comparisons of health across patients with different sorts of conditions. This is a fundamental limitation in many of the applications we will discuss.

For these reasons, the usual recommendation, no matter what the application, is that *both* a condition-specific and a generic PROM be used, as is the case in the current collection of PROMs in the NHS. The condition-specific PROM provides a detailed picture of a patient's assessment of his or her own health, and is the kind of PROM most likely to be relevant in clinical practice (*see* 'Clinicians: clinical decision-making'). It also helps to check that the generic measure does not miss anything that is important from the patient's perspective. The generic PROM provides the vital common currency that allows for aggregation and comparison across completely different patient groups and health services. It is the generic PROMs that are most relevant in applications such as assessments of value-for-money (*see* 'Commissioners: provider performance and value-for-money') and analysis of NHS productivity and performance (*see* 'National organisations: regulation and NHS productivity').

## Subjective vs objective measures of health

One concern about the use of PROMs information that is occasionally noted is that the data are subjective. That is, they rely on patients' views and feelings, with the implication that these are neither an adequate nor appropriate basis for making important decisions.

PROMs data *are* subjective – but purposefully so! Their intention is to capture patients' views about their own health on the grounds that making patients feel better and making them better able to do what they want to do – everyday functions – is the goal of most health services, and that patients are usually likely to be the best judge of how they feel.

However, PROMs are not the only relevant information for decision-making. For example, raised blood pressure and high cholesterol are extremely important indicators of serious health problems, but because these will not be felt by patients, their presence or alleviation will not be detected by PROMs. Occasionally, PROMs may pose considerable challenges – relying on patients to self-report their health is difficult with patients suffering from severe cognitive deficits, paralysis or dementia, or those who are unconscious or not literate (eg, babies). There are also clearly problems where an intervention pre-empts the emergence of a condition that would harm a patient's health. While proxy versions of PROMs (eg, that can be completed by caregivers) and PROMs designed for completion by specific groups (eg, children) are available, the reliance on self-reporting health presents an issue for the use of PROMs in some contexts.

PROMs data should therefore be seen as complementing – rather than replacing – clinical and other information about patients.

## Measuring *change* in health

So far, PROMs have been described as measuring patient-reported health at one point in time – a sort of snapshot of patient-reported health. But most of the uses of PROMs data we will go on to consider involve, in one way or another, measuring and comparing *changes* in health. If the purpose of health care is to improve how patients feel, or to prevent them from feeling worse, then PROMs must be used across time, such as before and after treatment, so that it is possible to gauge what improvement (or other change) has occurred that might be attributable to treatment.

In the current PROMs programme in the English NHS, data are collected before and after each of four elective surgical procedures. In each case, the health care intervention – surgery – is a one-off, well-defined procedure. A simple before and after measurement of PROMs is most likely to yield helpful information in this situation. Yet even then, what would have happened in the absence of surgery – the counterfactual – remains unknown (for a detailed discussion of this issue, *see* 'Commissioners: provider performance and value-for-money').

In other situations, the treatment or intervention might be less well defined or more prolonged, and therefore more variable in the quantity and quality of delivery (eg, support services, home-help, counselling). The condition might be chronic and the treatment an ongoing process rather than a point-in-time intervention (eg, asthma, chronic obstructive pulmonary disease, care and support services for schizophrenia). Also, treatment might be more likely to comprise a complex package of health and social care rather than a single intervention.

These characteristics pose substantial, although not insurmountable, challenges for data collection and analysis, which we address in later sections.

The following box gives sources of additional information about PROMs.

### Further resources on PROMs

For more information, the following websites provide a handy source of free information, including references to key publications reporting on PROMs instruments.

- Oxford University provides an extensive, searchable database of PROMs instruments: http://phi.uhce.ox.ac.uk/

- The EuroQol Group website www.euroqol.org provides information on the EQ-5D instruments, and a searchable references list. Users of the EQ-5D must register their studies with the EuroQol Group and respect the copyright on the instrument. However, the EQ-5D is generally free-of-charge for academic research use, and NHS users can now also use the EQ-5D under an arrangement with the Department of Health.

- The International Society for Pharmacoeconomics and Outcomes Research provides useful material on patient-reported outcome methods, concepts and studies on its website: www.ispor.org/

- ProQolid ( www.proqolid.org/ ) is the France-based MAPI Institute's database of instruments. This is publicly accessible, with payment options for additional access.

- The Department of Health's PROMs webpages are located at: www.dh.gov.uk/ en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/ Department of Health_092647

# Patients: information and choice

Patients are not only the source of patient-reported outcome measures (PROMs) data, but also a key potential user of the information they generate. Patients suffering from health problems and being considered for treatment will be able to refer to the PROMs data provided by similar sorts of patients to help them:

- decide where and from whom to receive treatment

- judge the likely benefits of treatment in their own case.

This section considers the various ways in which PROMs data could be used by patients, and how such information could be presented.

Enhancing patient choice has been a key theme in English health policy reform, and is part of a wider goal of increasing the responsiveness of the National Health Service (NHS) to patients' preferences. This has been particularly reflected in a shift towards offering patients who need a hospital referral a choice about which hospital they attend.

Starting with the London Patient Choice Project in 2002, and followed by the national choice initiatives for coronary heart disease, in 2005 patient choice was extended to all NHS patients in England who were being referred to hospital, giving them a choice of five providers. Since 2008, NHS patients in England have been offered an 'open choice' of any NHS (and some independent sector) providers in England.

As patient choice of provider has been rolled out across the NHS, a growing body of research and experience has accumulated about how patients make choices about their hospital, and the sort of information patients say is important to them in making those choices.

To date, information for patients on hospital performance has been limited to indicators of negative outcomes, such as rates of post-operative mortality, readmission, and meticillin-resistant *Staphylococcus aureus* (MRSA) infection, which are relevant in only a minority of cases. The introduction of PROMs is, in part, a response to the need to provide better information to patients about provider performance in improving health. But how will patients use this information? How is it most effectively presented to patients? Will the availability of PROMs data change their choices? And how will providers respond?

## Which hospital?

Since May 2006, the Department of Health has collected quarterly survey data on patients' awareness and experience of choice, including questions on factors that patients say influence their choice of hospital. Early survey results suggested that location and ease of access were the most important factors for patients, with factors such as quality of care being mentioned by only a minority of those surveyed. However, by December 2008, cleanliness and quality of care were being cited by many more patients as influential in their choice of hospital (*see* Figure 1, opposite). It should be noted that the early survey

**Figure 1** Factors influencing patients' choice of hospital
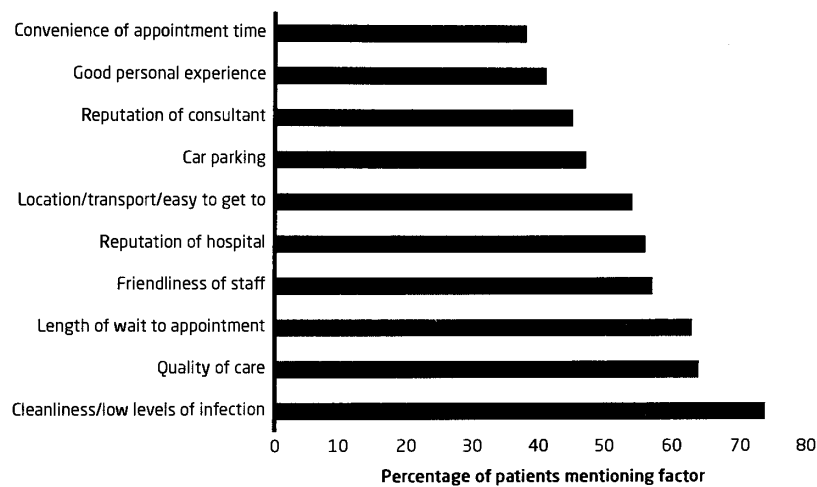


Source: Dixon (2009).

did not prompt patients with specific factors, merely asking for their top three, whereas later surveys asked patients to identify important factors from a list.

Other surveys confirm the importance of quality of care in shaping patients' choices. Research carried out in 2005, for example, asked a sample of the public how important factors such as waiting times and hospital facilities were in informing their choice of hospital (Burge *et al* 2006). The results, shown in Figure 2, below, suggest, as might be expected, that advice from GPs and waiting times were important to many people in

**Figure 2** Importance of various factors to patients in choosing a hospital for treatment
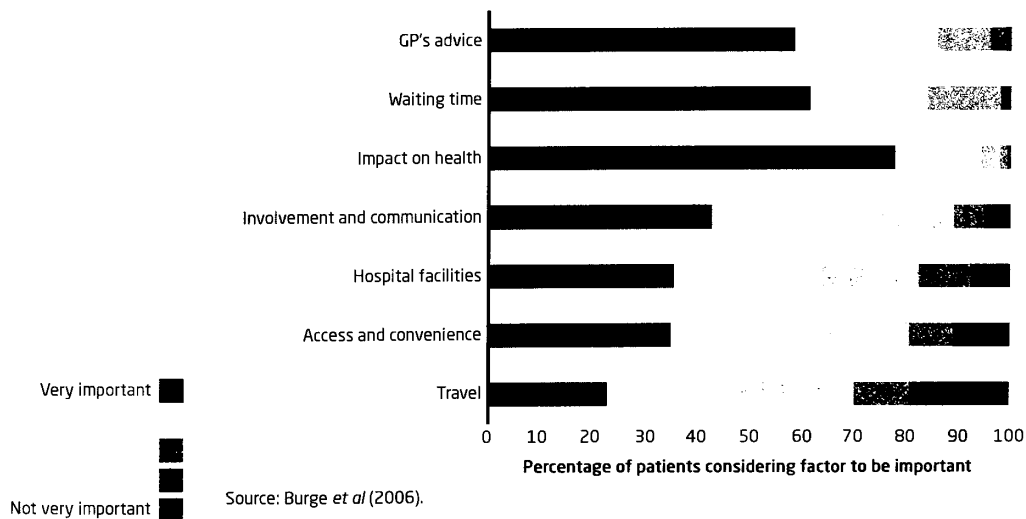


Source: Burge *et al* (2006).

making a choice of hospital. However, the most important factor, with nearly 80 per cent of respondents rating it as very important, was 'the impact on their health as a result of treatment'.

The importance of the quality of care, particularly the health outcome of treatment, has also been confirmed by other studies. For example, research using a discrete choice experiment (DCE) asked members of the public to choose a hospital for treatment from a list of hospitals with varying performance on, for example, waiting times, travel distances and factors such as impact on their health, GP advice and so on (Burge *et al* 2006). As might be expected, this work revealed that people weigh up many factors in making a choice: GP recommendations, waiting times and other factors can all play a part in arriving at a decision to go to a particular hospital.

The research also showed that trade-offs were made. In an ideal world, patients would want a high-quality hospital on their doorstep with minimal waiting times. However, faced with a less than ideal world, in which waiting times at a local hospital may be longer than those at one that is more distant, for example, people make decisions that reveal the importance of one factor over another. On this basis, 'impact on health' was the most important influence guiding the choices made.

Patients will, of course, attach varying levels of importance to any particular measure of hospital/clinical performance or to the so-called 'attributes' of hospitals (such as proximity), depending on personal tastes and the current state of their health. Nevertheless, a key result from the surveys and research noted here suggests that, if available, quality of care and treatment outcomes in terms of health-related quality of life are among the most important pieces of information that would influence patients' actual decision-making processes. PROMs data can provide vital information on this aspect of hospital performance.

## Which clinician?

Research evidence also suggests that patients would overwhelmingly like such information not just for hospitals as whole organisations, but also at lower levels, such as the clinical team that would be involved in their care or even individual clinicians (Burge *et al* 2006). For the moment, the collation and presentation of PROMs data collected by the NHS in England is planned to focus on aggregations of data at the level of hospitals. However, with PROMs data linked to Hospital Episode Statistics (HES) data, the connections potentially exist to produce clinician- or clinical team-level information.

Nevertheless, although the data connections exist, there are of course statistical issues to address in order to produce valid and comparable PROMs information, given the low number of observations at such a disaggregated level for many hospital units, and the larger number for a few. However, the existence of clinician-level PROMs data will undoubtedly prompt interest from clinicians themselves about what such patient-derived outcome data have to say about their practice (*see* 'Clinicians: clinical decision-making' section).

Clinician-level PROMs data could also have policy consequences for the current policy on patient choice such that it might be hard to resist the potential pressure to deepen the scope of choice for patients from hospitals down to individual consultants.

# Which treatment?

While national policy on patient choice focuses on the choice of hospital, there are, of course, more fundamental choices that patients have to confront, not the least of which is choosing whether to have a particular treatment at all, and, if so, the various treatment options that might be available.

The guidelines on informed consent issued by the General Medical Council (GMC; *see* box below) make it clear that doctors are required to provide a range of information about treatment options for patients including: 'The potential benefits, risks and burdens, and the likelihood of success, for each option; *this should include information, if available, about whether the benefits or risks are affected by which organisation or doctor is chosen to provide care*' (our emphasis) (General Medical Council 2008, paragraph 9, sub-section e, p 10).

### GMC guidelines on informed consent

9. [Doctors] must give patients the information they want or need about:

   a. the diagnosis and prognosis

   b. any uncertainties about the diagnosis or prognosis, including options for further investigations

   c. options for treating or managing the condition, including the option not to treat

   d. the purpose of any proposed investigation or treatment and what it will involve

   e. the potential benefits, risks and burdens, and the likelihood of success, for each option; this should include information, if available, about whether the benefits or risks are affected by which organisation or doctor is chosen to provide care

   f. whether a proposed investigation or treatment is part of a research programme or is an innovative treatment designed specifically for their benefit

   g. the people who will be mainly responsible for and involved in their care, what their roles are, and to what extent students may be involved

   h. their right to refuse to take part in teaching or research

   i. their right to seek a second opinion

   j. any bills they will have to pay

   k. any conflicts of interest that you, or your organisation, may have

   l. any treatments that you believe have greater potential benefit for the patient than those you or your organisation can offer.

Source: General Medical Council (2008, p 10).

There are two important issues regarding this aspect of the GMC guidance. First, it notes that patients should be given information about the benefits and risks of any treatment option. Second, it also instructs doctors to tell patients if such benefits/risks vary by hospital or clinician.

PROMs information could play a supporting role in helping doctors and patients with making informed treatment choices. At present, PROMs data do not alone have the power to predict the benefits (or lack of them) of a particular treatment option for a particular patient. However, as the NHS in England accumulates data on PROMs, there is the potential to establish, via risk adjustment, the extent to which certain patient characteristics – such as age, sex, pre-existing conditions, severity of condition, and so on – are associated with changes in PROMs (*see* box below).

Similarly, as noted above, comparative PROMs data at hospital (and clinician) level can (could) provide patients with an insight into any outcome variations that might exist. In this regard, the NHS Institute carried out some research on informed decision-making for patients considering knee replacement surgery (NHS Institute 2009).

### Initial investigation of data collected by the NHS as part of the PROMS pilot study

A study of 410 patients who underwent a hip replacement operation examined whether a range of factors relating to patient and clinical characteristics were associated with the outcomes of surgery (Devlin *et al* 2010). The factors examined included the pre-operative disease-specific health measure (the Oxford Hip and Knee Score), sex, symptom duration, co-morbidities, a composite score of socio-economic deprivation, and a general measure of health and hospital.

The study examined whether these factors could be used to predict the probability of patients showing, following surgery, as measured by the EQ-5D:

- improvement (on at least one dimension, with no worsening on any other)

- worsening (on at least one dimension, with no improvement on any other)

- mixed change (improvement on one or more dimensions, worsening on one or more dimensions).

Overall, the patient's pre-operative health and other factors were poor at explaining changes in the EQ-5D, due in part to the small numbers involved. However, the pre-operative measure was significant, and suggested that patients with a worse score on this measure (ie, worse health) had a higher probability of improvement post-operatively as measured by the PROM EQ-5D. Age and sex, on the other hand, appeared to be unrelated to the change in the EQ-5D measure.

This study was small-scale and no robust conclusions can be drawn. However, it shows how, as more PROMs data are collected, the relationships between PROMs information and other factors can be investigated.

One example of how PROMs data can be used to inform patients about the possible benefits of treatment is shown in Figure 3, opposite, taken from patient information provided by Bupa on its website.

Bupa used PROMs before and after surgery carried out in its hospitals (now renamed Spire Healthcare) for more than a decade. In this instance, the SF-36 (a generic PROM, *see* 'A primer on PROMs') was used before and after hip surgery. The average physical component score before and after surgery is shown, and compared with that of other people of a similar age in the general population. This information can be used to help

**Figure 3** Bupa's use of the SF-36 to report the benefits of hip surgery



Physical summary score (higher score equals better health)
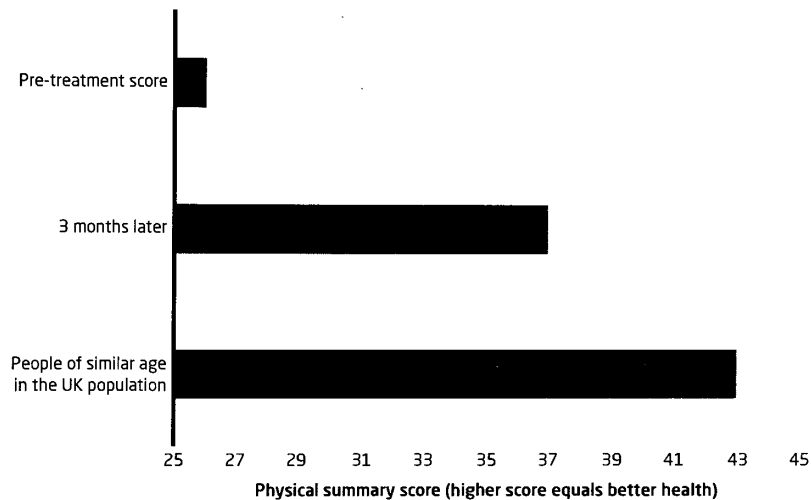
Source: Bupa website, reproduced with permission from Bupa.

patients form reasonable expectations about the likely benefit of surgery: clearly, hip surgery results in patients feeling much better, but still not enjoying the same levels of physical health as those enjoyed by people of a similar age in the United Kingdom.

## Ways of summarising and presenting PROMs

Presenting PROMs data to the public and patients in an unambiguous and comprehensible manner presents a real challenge. However, a prior issue is *what* data or measures to present. For all the PROMs in routine use in the NHS (*see* box on p 8), there are many different ways of presenting and summarising the data each measure captures.

For example, patients EQ-5D 'profile' (their answers to the five sets of questions) can be assigned a 'social value' (*see* 'A primer on PROMs'). Alternatively, patients' own overall assessment of their health on the 0–100 scale can be used. But which approach best conveys what patients want to know when choosing a hospital?

Below, we describe some of the ways PROMs data can be analysed and presented, drawing on recent research and current recommendations.

### EQ-5D 'adjusted score'

The recommendation from the PROMs pilot study commissioned by the Department of Health is that both the generic measure of health – the EQ-5D – and the disease-specific measures should be made available, at the level of hospitals. For the EQ-5D, the recommendation from the pilot PROMs research is that the 'mean post-operative [PROMs] scores adjusted for the value attached to different EQ-5D health states and then further adjusted for patients' pre-operative characteristics' (Browne *et al* 2007) is the preferred measure of health gain.

The use of these values is common practice in economic evaluations, where they are applied to EQ-5D data used as a means of estimating quality adjusted life years (QALYs) gained, but it could be argued that there are problems with their use in PROMs.

First, these social values come from having asked members of the general public their opinions about EQ-5D states that they may or may not have experienced. The values do not come from patients completing the PROMs instruments. This means that the data can no longer be regarded as being purely *patient-reported*, since each patient's score incorporates values that reflect the preferences of the general public about the patient's health state. This can bias conclusions about whether a given change in health is statistically significant (Parkin *et al* 2010).

Second, collapsing the EQ-5D profile data into one score, while potentially useful in many respects, also means losing information about where (ie, in which dimensions of health-related quality of life) differences in patient health arise. For example, differences may be due to changes in one particular dimension, which may be worth knowing about.

Third, the recommendation to focus on post-operative EQ-5D data as the measure of interest appears to miss the opportunity to compare the before and after EQ-5D data. In other words, there is no comparison of the *change* in EQ-5D measure.

Given these problems, an alternative approach would be to measure in health terms the value added by treatment, that is, use patients' before and after EQ-5D data to see what difference the provider/treatment made to patient health. However, there is then a question of what constitutes a significant or 'minimally important difference' (MID) in score value.

A statistical answer to the 'meaningful change' problem is to calculate confidence intervals around the average score to indicate the probability of the score being different simply due to random variations in the data. The average difference between before and after scores for a procedure in one hospital compared with another, for example, would be interpreted as being statistically different if the confidence intervals did not overlap. However, while scores may differ significantly in a statistical sense, such differences may not necessarily be 'clinically important'.

Although there are other ways to identify MIDs, the PROMs evaluation carried out for the Department of Health found that across all the PROMs measures tested, including the generic and disease-specific measures, it was difficult to pinpoint what might constitute an MID (Browne *et al* 2007). The current recommendation is therefore to use statistical significance testing as a guide to important or meaningful differences.

The evaluative research for the Department of Health suggested that the indicator (the mean post-operative score, both unadjusted and adjusted for pre-operative patient characteristics) recommended to the Department should be illustrated in the form of funnel plots (*see* box opposite). These show the summary scores for each hospital plotted against the volume of work carried out in each hospital. However, focus group work with managers, clinicians and patients indicated that 'patients were less enamoured' than commissioners and managers with the use of funnel plots as a way of communicating a PROM summary indicator (Browne *et al* 2007).

What patients did find helpful were star ratings and bar charts, the latter ranked by hospital together with confidence intervals around each hospital's PROMs indicator. Examples of this form of reporting (although not showing the confidence intervals) using real PROMs data, are shown in Figure 4 (for hip replacement; *see* p 22).

## What is a funnel plot?

In the context of the reporting of PROMs, a funnel plot is a scatter diagram of the PROMs summary outcome measure for each hospital, plotted against the total number of operations it performed. The tendency is for average PROMs values to vary more widely for those hospitals undertaking fewer operations than those carrying out more. The resulting plots funnel down from left to right.

The funnel plot shows provider performance measured in terms of the post-operative EQ-5D score. The hollow circles show each provider's unadjusted post-operative EQ-5D score. The solid circles show the EQ-5D score, adjusted for various risk factors. The horizontal line shows the average post-operative score for these patients (which, here, is 0.74). In this instance, there is no statistically significant difference between each provider's risk-adjusted performance and the average.

### Example of a funnel plot
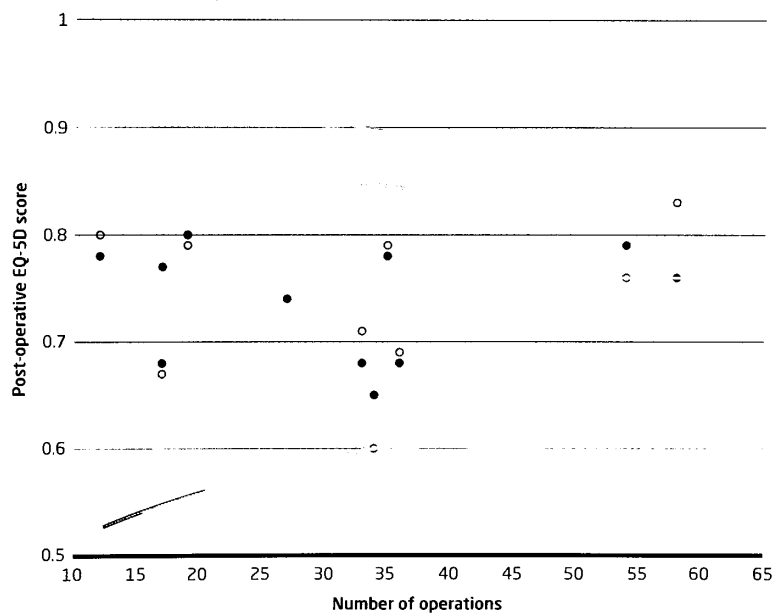


Source: Browne et al (2007)

In addition to the scatter plots, funnel diagrams can also show the average or mean PROMs score across all hospitals. Control limits at various degrees of stringency can also be shown. For example, a control limit of +/– three standard deviations from the average would mean that around 99.7 per cent of all the hospitals would be within the control limit, and would imply that virtually no hospital was of unacceptable performance. It is important to note that while control limits are calculated statistically and become tighter around the average as the number of operations increases, they are essentially based on a judgement about what should and should not be considered acceptable variation in performance.

**Figure 4** Sample report from PROMs data, benchmarking NHS trust performance on hip replacement: patients' utility weighted EQ-5D health profiles, before and after hip replacement
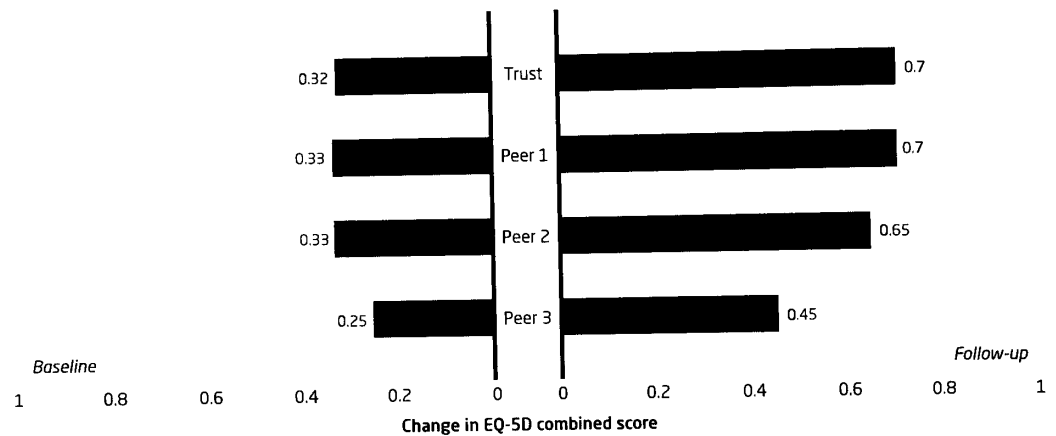


Source: CHKS (2009). Reproduced with permission from CHKS.

## Overall health measure

Given that the current NHS PROMs data collection includes the collection of an overall measure of health (based on a thermometer-type scale, the EQ-VAS, where zero is 'worst imaginable health' and 100 is 'best imaginable health'), comparison of the before and after values on this broad measure could provide an alternative indicator of value-added health-related quality of life. An example, for the EQ-VAS reported by patients before and after varicose vein surgery, is shown in Figure 5 below.

**Figure 5** Sample report from PROMs data, benchmarking NHS trust performance on varicose vein surgery: patients' EQ-VAS before and after varicose vein surgery, by age
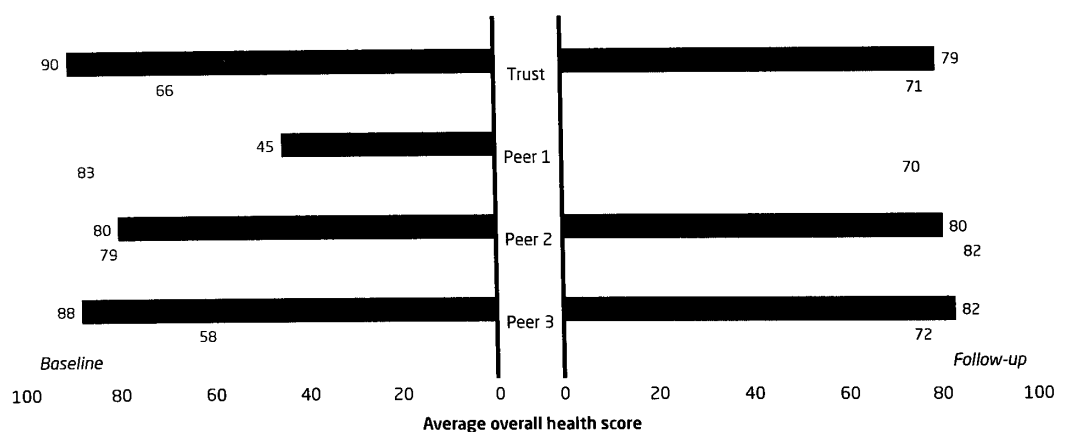


Source: CHKS (2009). Reproduced with permission from CHKS.

■ Age <60
  Age >59

Again, however, there remains the problem of what might justifiably constitute an MID on this measure. Furthermore, the PROMs pilot study reported that patients were not particularly enthusiastic about this measure. Presentation of this sort of measure could be similar to that for the EQ-5D overall score, using vertical histograms together with confidence intervals.

## Categorising changes in the EQ-5D profile

Rather than summarising EQ-5D profiles by their social values or by the patients' own overall 0–100 score, an alternative approach is to examine the health profile data itself. One way of doing this is to use a Paretian classification of health change approach (Paretian principles are central to welfare economics; they concern the way individual preferences, expressed in ordinal terms, can be aggregated to make social judgements about whether welfare has improved). The Paretian classification of health change approach is based on the idea of identifying unambiguous improvements or deteriorations, and, specifically, where:

■ an improvement means improvement in problems on at least one dimension and no worsening on any other

■ a worsening means worsening in the level of problems on at least one dimension and no improvement on any other

■ a mixed result means improvement (or worsening) in the level of problems on one or more dimensions and worsening (or improvement) on one or more others.

This has the advantage of revealing a bit more information from the raw EQ-5D profile data, information that can be lost when summarised into a single number. Figure 6, below, gives an example of how such information can be presented, using data from two of the elective surgical procedures included in the NHS PROMs pilot study.

**Figure 6** Presentation of Paretian classification of health change using EQ-5D profile data before and after two elective procedures
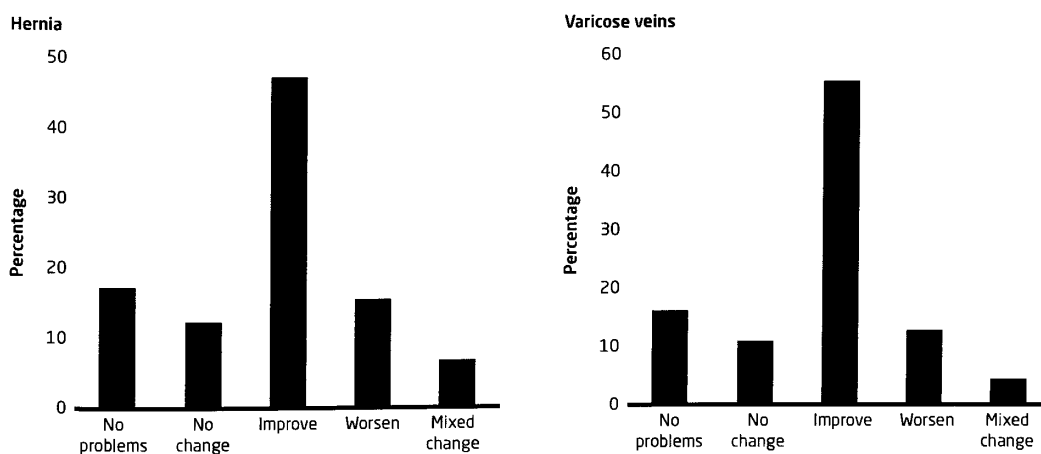


Source: Devlin et al (2009).

## Will PROMs make a difference to patients' choices?

As noted earlier, surveys show that patients value information on the quality of care provided by hospitals, and consider information on the quality of providers in terms of the impact of treatment on their health to be one of the most important factors when choosing between providers.

Facilitating choice by providing that information was an important reason for the introduction of the PROMs programme in the NHS in England. However, recent research on the impact of patient choice policies on how patients choose, and how providers respond, suggests that in reality patients make limited use of the data already available on hospital characteristics. A survey of nearly 6,000 NHS patients in 2009 found:

> *Patients drew on various information sources to help them choose, including their own past experience (41 per cent), and advice from their GP (36 per cent) and from friends and family members (18 per cent). Only 4 per cent had looked at the NHS Choices website and 1 per cent consulted other websites.*
>
> *Of patients who were offered a choice, 60 per cent were satisfied with the amount of information they were given, 22 per cent did not want any information and 14 per cent would have liked more.*
>
> (Robertson and Dixon 2009)

The survey also found that, similar to the studies referred to at the start of this section, cleanliness, quality of care, and the standard of facilities were the three most important factors that patients said had influenced their choice of hospital. However, it seems that few patients actively seek and compare the objective information on these factors that is already provided, relying instead on GP recommendations and anecdotal/reputational 'evidence' from friends and family. The relatively poor use by patients of current performance information might, though, reflect their view that this is not the information they really need to make an informed decision.

Furthermore, the publication of hospital performance data in terms of PROMs is likely to generate a provider response independent of any effect on patient choice, because of providers' own goals in terms of quality and reputation, clinicians' pursuit of clinical improvement, and changes in behaviour where PROMs are linked to various incentives offered by commissioners and regulators.

In the following sections, we examine the use of PROMs by hospitals, commissioners, clinicians and regulators.

# Hospitals: managing clinical quality

Clinical teams up and down the country are now measuring the quality of care that they provide to their patients, and all acute trusts are recording this information so that they can publish the first ever set of Quality Accounts alongside their Financial Accounts for the year 2009/10. This will make the NHS the first health system in the world to systematically measure, record and openly publish the quality of care that it achieves. Our new approach to payments means that quality improvement is financially recognised and rewarded, making quality the watchword.

(Professor The Lord Darzi in NSR Implementation Team 2009, p 4)

While Lord Darzi rightly acclaims the English NHS as a global leader in the collection – via patient-reported outcome measures (PROMs) – of information directly bearing on quality of care, a central issue for trusts is how such data can actually be used to improve performance, not just in terms of the quality of care provided to patients, but also in other dimensions such as the efficiency with which that care is delivered.

PROMs data offer tremendous opportunities for providers to benchmark themselves against others and to monitor a key aspect of the quality of care they deliver. This section examines how providers could use PROMs data to facilitate dialogue between managers and clinicians, and to identify actions that might be taken to improve quality and efficiency. It should be noted, however, that the Department of Health will report PROMs data not by hospital site, but by trust, as a result of the linkage arrangements with Hospital Episode Statistics (HES) and data quality/incompleteness problems with the reporting of site codes.

We begin by describing the PROMs data that will be available to providers. We then discuss the experience of Bupa, which led the world in pioneering the routine use of PROMs data in the quality management of its (then) network of hospitals. The resulting knowledge-base built up over more than a decade provides clear lessons for the NHS.

## What PROMs data will be available to NHS hospitals?

### Data collection/reporting process

The process for collecting and generating record-level and aggregated PROMs data is illustrated in Figure 7 overleaf.

Of most relevance to trusts will be the outputs from the PROMs analysis contractor. The intention is that all trusts will be able to receive anonymised trust-level data via standard data extraction platforms along the lines used for the HES data set. Although it was

**Figure 7** Collection and reporting of data in the NHS PROMs programme in England

| PROMs administration contractor | The NHS Information Centre | | PROMs data aggregation contractor |
|---|---|---|---|

Pre-operative PROM questionnaire data ↓ Identifiable, record level data ↑ Post-operative PROMs questionnaire data

Other databases ↓ NHS Information Centre ↑ Scoring outcomes

Linked non-identifiable data ↓ Extract service ↓ Record level data

Develop adjustment methodology ↓ Case-mix adjustment ↓ Aggregate and apply adjustment ↓ Aggregated data

PROMs analysis contractor

Source: Department of Health (2008a).

initially intended that data would also be made available for hospitals at clinician/clinical team level in respect of their own patients (Northgate Solutions 2009), this will not now happen until the full data and information governance implications have been examined. Importantly, PROMs data will not be isolated from other routine NHS data sets, and will be linked to, for example, Hospital Episode Statistics (HES) at patient level and, for hip and knee procedures, the National Joint Register (NJR) database.

The linkage of PROMs to HES hugely increases the value of the information and will allow much more in-depth exploration of, for example, possible reasons for variations in health-related quality of life outcomes between trusts. For example, PROMs data facilitates the examination of hospitals' production functions and analysis of the determinants of 'technical efficiency' in the production of improvements in patient health (*see* box opposite).

## Technical efficiency in the production of patient health by hospitals

The PROMs programme initiative facilitates a fundamental rethink about what hospital efficiency means and how it is measured. Traditional analyses of hospital production and cost functions, and estimates of hospital technical efficiency, have focused on identifying variations between hospitals, and the factors associated with those variations, in the production of *health care*. The availability of PROMs data provides a way of redefining the variable of interest as the production of *health*, and, instead, of measuring hospital efficiency in terms of the extent to which hospitals achieve improvements in patient health given their inputs, resource use and other relevant characteristics, both relating to service delivery and the patients themselves.

The standard risk-adjusted PROMs analyses of hospital performance that will be undertaken in the NHS will identify relevant variations between hospitals, but will not *explain* what factors are associated with either very good or very poor performance by hospitals. Furthermore, while PROMs data show variations in output, they do not on their own show the underlying variations in technical efficiency, that is, the way the production of health relates to the hospital's use of inputs.

Professor Andy Street at the Centre of Health Economics at the University of York is currently leading innovative research that uses PROMs data in hospital production and efficiency analyses, testing and comparing a range of methods including:

- multi-level multivariate modelling (MVM)

- stochastic frontier analysis (SFA)

- data envelopment analysis (DEA).

These approaches, deriving from production economics, have been widely used to analyse and explain the differences between hospitals' efficiency in the production of services. PROMs data will instead facilitate, for the first time, analysis of the relative efficiency of providers in the production of *health*.

Overall, in addition to the aggregated average PROMs scores by procedure for each trust, more detailed HES-linked data that will be available will include:

- summary change scores for all PROMs measures (ie, the difference between the pre- and post-operative scores) with appropriate case-mix adjustment applied

- raw pre- and post-operative PROMs scores

- raw pre- and post-operative EQ-5D profiles (ie, the responses to the five questions on the EQ-5D plus the visual analogue (EQ-VAS) overall health measure.

This information will include average aggregate change scores plus the distribution of scores at patient/record level, and will be linked to some patient characteristics (such as age and sex). NHS Information Centre rules on disclosure mean that no data will be available that is derived from five or fewer patients. Also, all data for trusts will be pseudonymised in accordance with the consent model for the collection of PROMs information from patients, which guarantees anonymity. This also minimises the 'halo effect' problem, where patients may adjust the information they provide if they know such data will be identifiable.

Although patients are free not to complete PROMs questionnaires, initial data for the first quarter of 2009/10 show a high rate of return for the pre-operative questionnaires. Overall, there are more than 300 NHS and independent sector providers involved in the national PROMs programme, and some 90,000 completed PROMs questionnaires were collected and processed in the period April to December 2009.

## Publishing PROMs

Immediate considerations for trusts will be:

- how and in what form to publish details of their PROMs information as it is released nationally

- preparing how to explain to local and national media and their local populations their performance in comparison with that of other providers.

All this will require a planned communications strategy underpinned – once data is available – by a clear analysis of the PROMs information, its key messages and implications for trusts' quality improvement strategies.

## Quality Accounts

An obvious outlet for PROMs data will be trusts' Quality Accounts. With effect from April 2010, and as part of the focus on quality as an organising principle of the NHS (as alluded to by Lord Darzi in his summary letter in *High Quality Care For All: NHS next stage review final report* [Darzi 2008]), all providers of care to NHS patients will need to produce and have signed off by boards, an annual Quality Account to be published on the NHS Choices website.

Although these accounts are intended to provide and reinforce a focus on quality and quality improvement by providers themselves, the aim is also to improve transparency by providing the public with information on the quality of care provided by their local health care services so as to improve local accountability and choice. In addition, the accounts can be used to benchmark performance and drive forward improvements in care.

Although the detail of what is included in these accounts (and how information is presented) is up to individual providers, the accounts must cover three aspects of health care quality:

- safety

- effectiveness

- patient experience.

Along with national and local patient experience surveys, the information generated by PROMs should provide a key perspective on patients' views of their health-related quality of care.

From the point of view of patients and the public, it would be helpful if trusts all adopted similar presentational arrangements for PROMs data. Figure 8, opposite, shows one way of presenting summary PROMs data, but there are other ways of doing this (as noted in an earlier section) and, importantly, of presenting other aspects of the data (such as the composite elements of the EQ-5D, for example), which can provide a more detailed picture of patients' views about their health-related quality of life.

**Figure 8** An illustrative example of summary PROMs data in Quality Accounts

### What patients say about the impact of their treatment on their quality of life

One way all hospitals now monitor the quality of their work is to ask patients themselves to record their state of health before and then after their operation. Patients complete two questionnaires; one relates to their specific condition, the other contains more general questions about their health and quality of life.

Below we show our results for the general health/quality of life measure known as the EQ-5D compared with other hospitals in the country. The data has been adjusted to take account of factors outside the control of the hospital – such as the age profile of patients – that can affect the before and after reports. By and large, therefore, the information is comparable between hospitals.

### Primary hip replacement

**Commentary**

Between April 2010 and April 2011 we carried out 123 hip replacements on 115 patients. 90 patients completed both before and after questionnaires and these form the data on the right.

Compared with local hospitals, on average our patients report the largest improvement in their quality of life following their hip operation, and slightly better than the national average.

This is an average across all patients; some of our patients report larger and some smaller improvements.

More detail of the patient-reported outcomes data is available in a special report on the trust's website.



Legend:
- Before operation
- After operation
- Change in health score
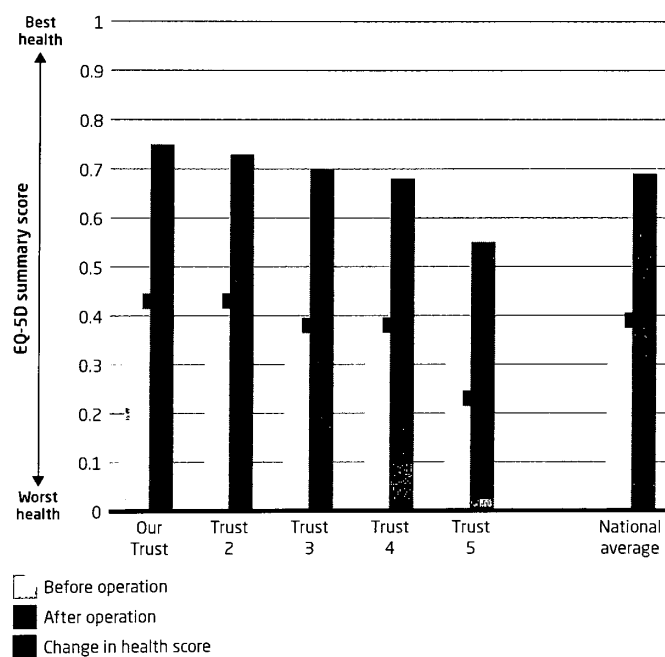
### Understanding outcome variations

PROMs data should act as a focus and a starting point for providers, first to identify the reasons for their performance, and then to identify what they need to do in order to improve. Inevitably, PROMs data will reveal variations in health-related quality of life, both between hospitals, and between clinicians in hospitals, which is likely to lead to questions about why some hospitals/clinicians appear to perform better/worse than others and why some patients report more/less benefit than others. Understanding the reasons associated with good and poor outcomes will be important.

## Patient characteristics

Explaining variations in average PROMs scores is an empirical issue. Average scores for hospitals will hide the variation within hospitals and between patients. Consequently, part of the variation in average PROMs scores may, in some cases, be due to outlier scores for some patients. Equally, similar average scores can conceal very different distributions of scores between hospitals.

However, there are two main factors that can influence a hospital's average score: the characteristics of patients, and the nature and characteristics of the hospital. Although PROMs data will be case-mix adjusted for patient characteristics such as age and sex (that is, factors beyond the control of the hospital), some care is needed in the selection of factors to adjust for. For example, one contributory factor explaining part of the variation in PROMs scores between hospitals could be the level of health-related quality of life patients reported to have before their operation. Figure 9, below, shows, for example, a distinct relationship between patients' pre-operative EQ-5D summary scores and the change in scores post-operatively. Linkage to HES provides access to a very rich set of patient characteristics, which will help in further work to adjust raw PROMs scores more accurately.

A hospital that tends to admit patients with higher (better) pre-operative scores (circled in grey) may have a lower average gain than one that tends to admit patients with lower (worse) pre-operative scores (circled in green). The figure also shows an obvious 'ceiling' effect: as pre-operative EQ-5D scores improve, the size of any possible gain post-operatively falls.

**Figure 9** The relationship between treatment effect and pre-treatment health



EQ-5D before score
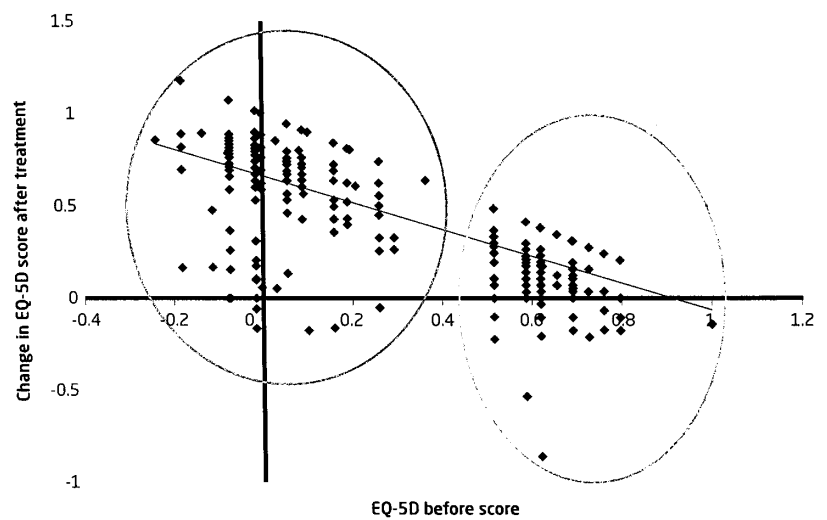
Source: Simulated dataset, based on the characteristics of the PROMs pilot study dataset.

Comparative analysis (between hospitals, and between clinicians within hospitals) of the 'before' PROMs data can also provide a starting point for further investigation of the 'threshold' decisions made by clinicians. Variations in pre-operative PROMs scores (both the generic PROMs and the operation-specific scores) may be indicative of variations in hospital patient management systems and clinical decision-making (for example, concerning referrals to outpatients and then subsequent decisions along the care pathway about how and when to treat patients). Such variations have consequences for equity of access for patients, capacity or opportunity to benefit from treatment, and also for the efficient use of resources. These issues are examined in more detail in the next section.

Comparative analysis of the individual questions that comprise the PROMs scores will also be relevant as responses to these questions are also likely to vary. In addition, patterns of responses or changes post-operatively, particularly health-related aspects of patients' lives (for example, pain, mobility, anxiety) might indicate where effort is needed to improve overall PROMs results.

## Provider characteristics

If there is one question providers need to ask themselves (and which in any case will be asked of them), it is this: what is it about the nature of the hospital and the care provided that gives rise to the outcomes reported by patients?

There is considerable research literature investigating the reasons for variations in hospital performance on a whole variety of measures – from lengths of stay to infection rates and mortality. As PROMs data emerges nationally, there will be similar research seeking to explain variations in PROMs results in terms of the characteristics of hospitals (their size and type for example), inputs to care (staff:patient ratios, etc), workload and capacity (the volume of activity) and other factors related to providers, including measures concerned with primary care.

What such research will reveal about the explanations for any observed variation in PROMs is an empirical matter. However, analogous research into the causes of variations in hospital mortality has suggested that a significant proportion of the variation can be explained by hospital and primary care factors. For example, a high proportion of all admissions being emergencies, and a low number of hospital and primary care doctors per bed and per head of population, respectively, are all associated with higher in-hospital mortality (Jarman *et al* 1999). It would be surprising if similar associations were not found in the case of PROMs – if not exactly the same factors or strength of association.

Providers should draw on the results of PROMs variation research as it emerges to inform their strategies for improving their PROMs performance. Evidence of poor performance relative to other hospitals should prompt internal action to explore the data in detail, so as to assess its statistical significance. The evidence can then be reviewed with the clinical teams in order to identify possible explanations for the PROMs results.

## Incentives

Providers face a number of system reform incentives designed to improve their performance, from patient choice to the fixed price tariff of Payment by Results. It is arguable, however, that the actual impact of such levers on the quality of care has been at best attenuated, as a result of the dearth of information on quality that is available for patients to use in making their choices, and the nature of the tariff which, again due to the relative lack of data on quality, acts, potentially at least, mainly on costs, regardless of the possible impact on quality.

Accepting PROMs as a key measure of quality has, as noted in the 'Patients: information and choice' section, the power to strengthen the influence that choice can have over providers' quality of care and, through mechanisms such as Commissioning for Quality and Innovation (CQUIN) (see following section), the ability to connect payments directly with outcomes.

Although PROMs have the potential to strengthen system reform incentives such as choice and Payment by Results, these operate at the level of providers as organisations. However, just as budgetary devolution through, for example, service line reporting (SLR), more closely aligns the responsibility within a provider between the individuals and teams directly involved in decisions to commit resources and actual budgets, so the reporting of PROMs as part of the SLR process can add the link between inputs and outcomes in a way that provides incentives that not only act on the professionalism of staff, but also possibly on their (or, more likely, team/specialty) financial interests.

Linking performance to pay, or, more commonly, to access to resources for a department or specialty, are not new, of course (and neither are they without some contention). However, PROMs may well offer an advantage over other attempts to 'internalise' external incentives, such as waiting time targets, as they are more directly concerned with clinical interests and motivation – the quality of care as it impacts on patient health.

## PROMs, costs and hospital efficiency

An important issue for providers – now made extremely pressing as the NHS enters a period of much restricted financial growth – is the measurement and monitoring of productivity and technical efficiency. Over the next few years, providers will come under increasing pressure to address their costs of production as the Payment by Results tariff is squeezed. Providers will need to ask themselves how productive they are. What is the relationship between costs, the clinical quality of the care provided, and patient-reported outcomes? And is there scope for improving efficiency?

Hospital managers probably have a very good understanding of how their 'input' use relates to the production of services: they know which 'levers' to pull to produce more activity, and how the production of those services relates to cost. However, given that the collection of PROMs data is still new, managers probably have a very poor understanding of which levers to pull to produce more patient health. The use of PROMs-based performance indicators – and the likelihood of revenue being linked to that performance, either indirectly (via patient choice and Payment by Results) or directly (via CQUIN payments) – will create strong pressure for managers to understand not just how their hospital's performance compares with others – but also the causes of those variations.

What the data will inevitably show is that performance and efficiency varies between hospitals. What will also be inevitable, as noted above, will be the need for providers to analyse the underlying reasons for such variation. Poor performance will be due to a number of reasons. For example, outcomes might be good, but produced at high cost, or costs might be low, but outcomes poor.

## What can the NHS learn from Bupa?

Bupa Hospitals first started routine collection of patient-reported outcome data in 1998, prompted by the case of the rogue gynaecologist Rodney Ledward.

Ledward practised in the NHS as well as for Bupa in the private sector. Following revelations of Ledward's gross malpractice, Bupa's Medical Director, Andrew Vallance-Owen, reviewed activity and other performance statistics for Ledward but found that there were no '…deaths, no readmissions, no complaints – there was nothing to tell us about him. There were patients who clearly had serious complications but we knew nothing about it. It made me determined to collect patient-reported outcomes' (Coombes 2008, p 1465).

Over the past decade, Bupa Hospitals (now Spire Healthcare) collected PROMs data on more than 100,000 patient episodes. Although initially data collection covered a wide range of procedures, now the focus is on one or two sentinel procedures for each specialty, using generic measures, such as the SF-36, and condition-specific questionnaires, such as the VF-14 and the Oxford Hip and Knee scores.

While the original stimulus for collecting PROMs lay in a desire to spot clinical 'bad apples', it was clear that PROMs offered the potential for continuous quality improvement and to provide feedback to GPs and patients. Moreover, with the PROMs results (at hospital level) posted on their websites, Bupa Hospitals were able to promote and market the health-related quality of life benefits of the interventions they provided.

Feedback to health professionals developed over time, with straightforward bar charts of before and after results being supplemented with statistical control Shewhart charts detailing results relative to the mean for individual consultants together with limits set at +/– 3 standard deviations to indicate exceptional outliers (see Vallance-Owen et al 2004).

For Dr Vallance-Owen, the argument in favour of collecting and using PROMs data is clear:

> How can we know if a process brings benefits and continues to improve it without measuring the outcome, and how can we rely on process alone when the evidence shows such widespread variation and inconsistency in process in clinical practice? For patients, there is much more to success than alive or dead. How often have we heard: 'They said my hip replacement went well, but I am now housebound' or 'He says I have a good flow rate in my bypass graft, but I still get pain at 10 metres?'
>
> (Vallance-Owen 2008, p 344)

The collection and analysis of PROMs enabled Bupa to change clinical practices in its hospitals. For example, in one case, low scores prompted a hospital to change its care pathway for hysterectomy; in another, it identified a need to communicate more realism to patients concerning their expectations about the outcome of treatment. Further details of how Bupa implemented its use of PROMs, and the benefits this yielded, are given in the Insight box on pages 34–35.

## INSIGHT

### Bupa's use of PROMs

Dr Andrew Vallance-Owen, Bupa Medical Director

One of Bupa's key objectives when it launched its programme in 1998 was to promote a learning culture in support of a broader clinical governance strategy. The programme was successful in providing a catalyst for enquiry and discussion among clinicians and hospital managers, working together to understand their results. In order to achieve this, a number of choices were made.

- To use a PROMS tool that was already thoroughly validated in a range of specialties, so that clinicians could have confidence that the results would be meaningful. Initially, this meant the selection of the SF-36 questionnaire, but once a consensus developed that another tool designed for a specific condition would be better, this was adopted (so we switched to the VF-14 for cataract surgery, and the Oxford Hip and Knee questionnaires for these joint replacement procedures).

- To build confidence among clinicians that they were not about to be 'named and shamed' by making the programme confidential and publishing only anonymised results. At a later stage in the programme, confidence had reached a level where consultant leaders were ready to relax the need for confidentiality when using the data for clinical governance.

- To avoid the temptation to measure everything, but to focus on the higher volume and higher risk procedures. This ensured that the results would be statistically relevant.

- To use the simplest possible design of form so that patients would not be intimidated by the number of questions being asked. The forms were therefore fitted on to two sides of a folded A3 sheet.

- To monitor and compare hospitals' relative success in recruiting patients to the survey, in order to ensure that the resulting data were representative.

- To provide managerial incentives to hospital managers, to ensure that the programme did not disappear among other competing interests.

- To focus only on results that were statistically important (significant) and thus avoid the wasteful 'witch-hunts' that tend to follow the use of league tables.

- To use the PROMS data as an indication of where other process and outcomes data might need deeper analysis, rather than expecting the PROMS data to be conclusive on their own. There were many occasions where one source of data would corroborate a tentative conclusion provided by another source of data, at which point management action could then be taken with confidence.

**INSIGHT**

### Bupa's use of PROMs
*continued*

The benefits of using PROMS included:

- **Identifying poorly performing clinical teams/clinicians** If a number of patients treated by a consultant surgeon have unusually poor results this prompts further enquiry. Care must be taken, of course, to avoid the assumption that this is the result of any one individual clinician involved in the overall care episode, as it may have involved more than one doctor, physiotherapists, occupational therapists and of course the nursing teams. The next step would be to access and review all clinical, process and outcomes data relating to that clinician as part of the overall review of clinical performance, and then to use this to inform any decision regarding restriction of practice (or even referral to the General Medical Council).

  An example would be where a concern was raised about a consultant surgeon working in the United Kingdom for Bupa Hospitals on a temporary contract. The PROMs results were unusually poor for the surgeon and, because they corroborated the impression given by other data sources, the hospital management was confident that it would be appropriate to cancel the surgeon's contract.

- **Identifying and sharing best practices** An example would be where Spire Hospitals (formerly Bupa Hospitals) identified consistently higher than average health gain following hip replacement at Gatwick Park Hospital. Upon investigation, it emerged that the physiotherapy department had started to run an intensive pre-operative work-up of patients planning to undergo hip replacement surgery, meaning they were better prepared both for their procedure and recovery periods.

  In another example, a Bupa hospital, alerted by the data to poor outcomes in one specialty, conducted further investigation and found the specific area of weakness to be post-operative pain relief for hysterectomy. Targeted improvements were made, and the outcomes of patients were seen to improve.

# Commissioners: provider performance and value-for-money

Patient-reported outcome measures (PROMs) are highly relevant to the work of the agencies that commission health care services for patients, including:

■ general practitioners (GPs), who act as the gatekeepers to the National Health Service (NHS) and obtain and manage health services for their patients

■ primary care trusts (PCTs), the organisations in England that hold the budgets for their local communities and use them to purchase health care services from NHS and other health and social care providers.

The performance of PCTs in purchasing services for the communities they serve is assessed against so-called 'world class commissioning' criteria. PCTs can use the PROMs data now being generated to inform many of their key functions and activities, including:

■ monitoring the performance of the providers they commission services from

■ specifying minimum performance on PROMs via their contracts with those providers

■ incentivising providers to improve patient health by linking payment to performance on PROMs

■ using evidence on PROMs *across* different service areas to inform decisions about how much the PCT should spend

■ benchmarking their own performance against that of other PCTs, ie, identifying which PCTs are most effective in commissioning improvements in patient health measured using PROMs

■ monitoring (and acting on) inequitable variations in patient health outcomes that are revealed when PROMs data are examined by age, gender, sociodemographic characteristics, and so on.

Broadly, PCTs must decide *what* to commission, *who* to commission it from, and *how best* to commission services. The potential for using PROMs in economic evaluation concerns the first of these questions. But how might PROMs be used to decide which providers to purchase services from; on what basis; and how to incentivise providers to lift their performance on PROMs?

In this section, we begin by considering the opportunities and issues for PCTs using PROMs data as a basis for assessing the value-for-money of the services they commission. We then discuss the role of PROMs in PCT contracts with service providers to address ways of incentivising provider performance, and the benchmarking of performance with other PCTs.

## Value-for-money from commissioner budgets

Within any given budgetary period, the total NHS budget – and the budgets of each PCT – available for spending on health care are fixed. The challenge for a PCT is to allocate that fixed budget among health care services so as to achieve, to the greatest possible extent, its goal of meeting the health care needs of its resident population.

The challenge for the budget-holder is to weigh up the costs and benefits of the services it could buy, and to allocate budgets among activities so as to maximise the overall improvement in health possible within the budget constraints. In practice, there is a wide range of complex national and local influences on commissioning, and cost-effectiveness may not be the principal (or even an important) consideration in how these choices are made at the local level (Williams *et al* 2008; Appleby *et al* 2009b).

At present, the systematic use of economic evaluation is exemplified by the approach taken by the National Institute for Health and Clinical Excellence (NICE) in its appraisal of (predominantly) new health care technologies. NICE's approach to weighing up benefits and costs relies on a particular form of cost-effectiveness analysis: benefits are measured as quality adjusted life years (QALYs) gained from treatment, and considered alongside the change in costs associated with that treatment. The focus is on the benefits and costs incremental to the existing treatment, and cost-effectiveness is captured by the incremental cost-effectiveness ratio (ICER), which shows the addition to cost (in pounds sterling) per QALY gained.

The judgement about whether any given 'cost per QALY' represents good value-for-money is made by comparison against a normative benchmark: the cost-effectiveness threshold. NICE intends its threshold to reflect the marginal cost of buying an additional QALY, given NHS budget constraints. At present, NICE's guidelines are as follows:

- a treatment with a cost per QALY of less than £20,000 is considered to be clearly cost-effective

- if a treatment costs £20,000–30,000 per QALY, other sorts of benefits or considerations must be evident

- if a treatment costs more than £30,000 per QALY, an increasingly strong case needs to be made for the technology to be recommended (National Institute for Health and Clinical Excellence 2008a, 2008b).

NICE's approach is far from perfect: QALYs capture only part of the benefits that result from health and health care; and the threshold that is crucial to its decisions lacks a basis in evidence. However, it is the best example both within the NHS and, arguably, internationally, of an attempt to make difficult resource allocation decisions in health care in a way that is explicit, transparent and based on sound economic principles.

Partly because of this, and partly because denying access to a new health care technology is often controversial, NICE's decisions can be contentious. But the products and technologies available to NHS patients in England and Wales as a result of NICE's decisions over the past decade so far account for less than 10 per cent of total NHS spending, which raises an interesting question: what is known about the value-for-money of the *other* 90 per cent?

While some evidence exists, the majority seems to focus on new treatments or technologies. In part, this is because new technologies tend to be expensive, and so are an obvious focus for decision-makers; and it is also because the availability of data from clinical trials more readily facilitates sophisticated and interesting (to economists) analyses than does the sort of administrative and observational data available on existing

services. The result is that the effectiveness and cost-effectiveness of much of what is done routinely in the NHS remains unknown. Some services, for some patients, may be very poor value-for-money. Finding out more about these and reallocating money toward services that *are* cost-effective could yield substantial improvements in patient health from existing budgets.

## PROMs and commissioning

These are, of course, matters of considerable interest to the people who hold the budgets in the NHS: the commissioners. The decisions made every day by PCTs in commissioning health care for their communities result in a particular allocation of resources and a corresponding aggregate improvement in, and distribution of, health. But, unless health is measured in some way, PCTs will not know what outcomes result from a given set of commissioned services – and whether commissioning a different set of services would be better overall.

PROMs have a potentially very important role to play in helping PCTs make sure they are getting good value-for-money. The current Department of Health PROMs programme in the NHS in England includes, as noted earlier, both condition-specific and generic measures. The generic instrument being used – the EQ-5D – has two features that make it particularly useful in the context of commissioning.

First, because it describes health in a general way, it facilitates comparisons of health improvements across dissimilar illnesses and treatments. This is critical to assessments of value-for-money, because weighing up benefits and costs necessarily involves assessing health improvements in one area of health care versus deterioration in health elsewhere.

Second, the EQ-5D is designed to facilitate economic evaluations, and is accompanied by social 'value sets' (Dolan 1997) that make straightforward the estimation of QALYs from EQ-5D data. The EQ-5D is already widely used in cost-effectiveness analysis in the United Kingdom – indeed, it is the instrument recommended for use in evidence submitted to NICE (National Institute for Health and Clinical Excellence 2008a).

A simple explanation of how EQ-5D health states are valued and used in the estimation of QALYs is given in the box opposite.

At present the PROMs data are available only to the NHS in England for a small set of elective surgical procedures. But if the collection of PROMs data is rolled out across more conditions (*see* Insight box on p 5) and are embedded in most health service delivery, it will be possible to analyse these data at a number of levels. For example:

■ PROMs data could be examined alongside programme budgeting data to look for high-level disparities in the value yielded from PCT allocations of resources between programme budgets

■ it would be possible to examine how levels of spending relate to health outcomes for patients in each programme budget area

■ the analysis can also drill down to look at the value-for-money of particular services

■ alternatively, drilling down still further, it would be possible to investigate differences in the effects of treatment on different patient sub-groups, and the comparative effectiveness of different ways of delivering services.

There are, however, some important limitations to using EQ-5D data from the PROMs programme in this way. In particular, there are challenges in applying the standard methods of economic evaluation to PROMs data because they are *observational* in nature.

## Valuing EQ-5D PROMs data

As explained earlier (*see* 'A Primer on PROMs'), the EQ-5D is a generic measure of health-related quality of life. For the purposes of economic evaluation, standard methods of analysis typically rely on data from the first part of the instrument, where patients tick boxes to describe their health in terms of the dimensions and levels on the EQ-5D. For example, a patient may describe their health as follows:

By placing a tick in one box in each group, please indicate which statement best describes your health today.

**Mobility**

| | |
|---|---|
| I have no problems in walking about | ☑ |
| I have some problems in walking about | ☐ |
| I am confined to bed | ☐ |

**Self-care**

| | |
|---|---|
| I have no problems with self-care | ☐ |
| I have some problems with self-care | ☑ |
| I am unable to wash or dress myself | ☐ |

**Usual activities**

| | |
|---|---|
| I have no problems with performing my usual activities | ☐ |
| I have some problems with performing my usual activities | ☐ |
| I am unable to perform my usual activities | ☑ |

**Pain/discomfort**

| | |
|---|---|
| I have no pain or discomfort | ☐ |
| I have moderate pain or discomfort | ☐ |
| I have extreme pain or discomfort | ☑ |

**Anxiety/depression**

| | |
|---|---|
| I am not anxious or depressed | ☑ |
| I am moderately anxious or depressed | ☐ |
| I am extremely anxious or depressed | ☐ |

*No* problem on a dimension is coded as '1', *some* problems as '2' and *extreme* problems as '3'. Recording these in the order the dimensions appear, this health state is '12331' – this is simply a shorthand way of describing this particular state. The standard 3-level version of the EQ-5D describes ($3^5 =$) 243 possible health states, from 11111 (full health) to 33333 (extreme problems on each dimension).

To use these data in the estimation of QALYs, a quality of life 'weight' for each of the 243 states is needed. These weights (also referred to as *utilities* or *values*) are meant to reflect the opinions of the general public about what it would be like living with these health problems. A UK social value set is available for all 243 states, obtained from responses to questions asked of a large, representative sample of the general public (Dolan 1997; Szende *et al* 2007). These are the values used by NICE in assessing cost-effectiveness.

*continued overleaf*

**Valuing EQ-5D PROMs data** *continued*

These values are on a scale from 1 (the value assigned to full health) through to 0 (dead), with values < 0 reflecting health states considered worse than being dead.

For example, the UK value for health state 12331 is 0.07 – this means that 10 years lived in that state is considered 'worth' just 0.7 of a year of full health (i.e. 0.7 of a QALY). In this case, the low value is particularly influenced by there being extreme problems on two dimensions, with one of these being pain/discomfort. A value of 1.0 means that 10 years living in that state is equal to 10 years full health, whereas a value of 0 would imply that 10 years lived in that state would equal 0 QALYs.

A value set for the ($5^5$ =) 3,125 states described by the EQ-5D-5L (*see* Appendix 2) is currently being developed.

## Limitations and problems with using PROMs data in economic evaluation

The key problem in using simple 'after minus before' PROMs data to estimate gains in QALYs is that it takes no account of the counterfactual: that is, what would have happened to the patient if he or she had not had the surgery? The box below shows how PROMs data can be used to calculate a cost per QALY. While arithmetically straightforward, there are limitations to such calculations, which are discussed below.

**Calculating cost per QALY using PROMs data**

The EQ-5D data used in the following example are simulated, but accurately reflect the variation in individual patient-reported health on the EQ-5D observed in real groups of patients receiving orthopaedic surgery (Derrett *et al* 2003, Browne *et al* 2007; Oppe and Devlin 2009).

Orthopaedic surgery does not generally improve patients' length of life except in very rare cases, so the gain in patients' QALYs arises from improvements in the *quality* of their remaining life years. Health-related quality of life is likely to be affected by joint problems in a number of ways. The most obvious would be limitations on mobility and the ability to engage in usual activities, plus the experience of pain or discomfort. Other, less obvious, aspects of health might also be affected by joint problems, and improved by surgery. For example, Devlin *et al* (2009) showed that problems with anxiety/depression are very commonly reported by those awaiting hip replacement, and that alleviating this is also an important source of improvement in quality of life following surgery.

Using individual patient-level EQ-5D data before and after surgery, each health state is assigned its corresponding social value, using the same value set used by NICE. To estimate QALYs, some timeframe over which to attribute these health-related quality of life weights needs to be defined. The benefits of joint replacement surgery will not last for ever, and revision surgery is usually required at some point. So we have taken the average 'life' of an artificial joint to be 15 years, and used this as the relevant period of time for the estimation of the benefit of surgery. The estimated QALYs before

*continued overleaf*

### Calculating cost per QALY using PROMs data *continued*

surgery is deducted from the estimated QALYs after surgery, to give an estimate of the change in QALYs each patient experiences following orthopaedic surgery.

The cost of orthopaedic surgery to the NHS can be proxied by the HRG tariffs that apply for each type of surgery: this is the price list, set at approximately NHS average cost levels, that shows the price primary care trusts pay to providers for each sort of NHS service. For illustrative purposes, we have used the 2009/10 Payment by Results tariff price for 'major hip procedures with trauma and complications' – one of the most expensive HRG categories for hip surgery – of £9,300.

The diagram below shows the results in the form of a cost-effectiveness 'plane'. Each point on the plane represents one patient, and the scattering of these points indicates the variation between patients in terms of the changes in health (shown on the horizontal axis). The vertical axis shows the cost of the treatment, which, in this case, has been taken to be £9,300 for everyone. Patients whose health has improved on the EQ-5D (which, for orthopaedic surgery, is the vast majority) are in the right-hand section of the diagram. The patients with the greatest gain in QALYs per pound sterling spent on their surgery are those furthest out to the right. For this sort of surgery, there will typically also be a small number of patients who will report worse health for various reasons. These appear in the left-hand section of the diagram.

Cost-effectiveness plane for orthopaedic surgery
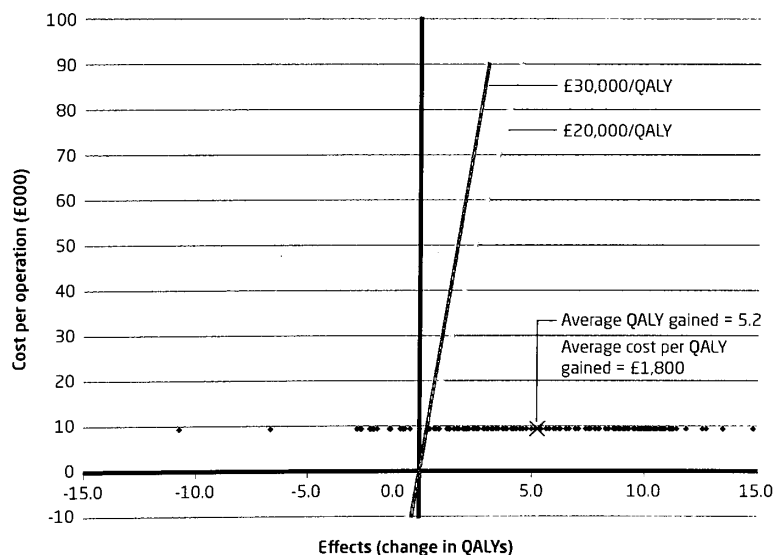


Taken at face value, the results suggest that – notwithstanding the variation between individual patients' baseline and post-surgery PROMs – overall, orthopaedic surgery is extremely good value-for-money. The average gain in QALYs for these patients was 5.2, ie, each patient gained an average of 5.2 years in full health as a result of the surgery. The cost-effectiveness ratio – the average cost and average gain in QALYs – is just £1,800 – much lower than the threshold range of £20,000–30,000 per QALY that NICE uses as its cut-off in assessing value-for-money.

In the example cost per QALY calculation shown in the box above, it was assumed that patients' pre-surgical health would have remained unchanged over the relevant period, but in many cases the quality of life reported by a patient before surgery would deteriorate over time if surgery were not performed. By not taking that into account, the results will underestimate the improvement in health gained for those patients. This will be especially important to take into account when evaluating treatments for conditions that are chronic and degenerative. In some cases, health care has as its principal goal not the improvement in health, but rather the slowing down of the rate of disease progression and degradation in quality of life, or the avoidance of a future health problem. As shown in the box opposite, the *change* in health measured by PROMs before and after surgery is not the same thing as the *benefit* from surgery.

There are other issues with the use of the PROMs data to estimate QALYs and cost-effectiveness ratios.

- It is not possible to be certain that the quality of life reported after surgery is *caused* by that surgery. Other things might have happened – to patients' general health, other conditions they suffer from, or their life circumstances – that could either improve or worsen self-reported health as captured by PROMs. These need to be controlled for.

- Inferring the benefit of treatment from just two observations of PROMs makes the timing of the second observation crucial. For example, collecting PROMs data six months after hip surgery might miss the time when patients first get back to their usual activities, as well as giving no real indication of the longer-term outcomes and their durability.

- In our simple example, we took account only of the cost of the surgery itself. Without surgery, patients might have required increasing levels of pain and symptom relief, mobility aids and supportive care services. After surgery, patients might also require help with pain control, physiotherapy assistance with regaining full mobility, and so on. The relevant costs are the *net incremental* costs, in relation to the relevant comparator. Again, the issue with PROMs data is that we do not know what the comparator is for these patients.

In effect, all of these issues link to the nature of the data:

- there is a limited number of 'snapshots' available from which to extrapolate quality of life changes over time

- there is uncertainty about the relevant 'counterfactual'

- other, unobserved, factors that are not controlled for also exert an influence.

These problems are important, but are they insurmountable? The issues involved in using observational data in economic evaluation are well known (Drummond 1998), and there are means of addressing them. For example, clinical evidence and clinical consensus panels can be used to construct appropriate counterfactuals. Factors that might bias results (such as co-morbidities or patients' general health) can be controlled for. Although PROMs data cannot reveal the future prospects for patients receiving treatment now, the same limitation applies to data obtained in the context of clinical trials of new medicines, and modelling techniques offer a means of addressing this source of uncertainty. And PROMs data do have the important advantage of reflecting actual patient experience of real health service delivery – in comparison with clinical trials, which are often undertaken under conditions that are not typical of normal practice.

## Possible effects of change in PROMs after surgery
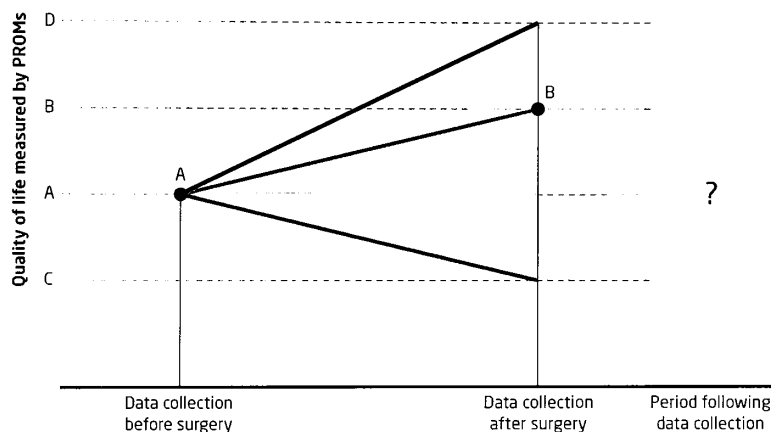


PROMs data are currently being collected at just two points in time: before and after surgery.

Imagine a patient we will call Mr X. Before surgery he reports his health to be 'A'. After surgery he reports his health to be 'B'. It is tempting to conclude that the benefit to Mr X equals the difference between B and A over that time period, but the change in health observed between these two points in time could be misleading with regard to the benefits Mr X has received from his surgery. For example, if Mr X had not undergone surgery:

■ his health might have deteriorated to something like 'C', in which case (B–A) underestimates the benefit

■ his health might have improved anyway – possibly even more than that achieved by surgery, such as 'D', in which case (B–A) overestimates the benefit.

Furthermore, there is no information about what happens to the patient's health after the second 'PROM' data is collected. Does the new level of quality of life persist? Or does the condition deteriorate again?

Unless Mr X's health 'before surgery' would remain exactly the same without surgery, estimates of benefit based on PROMs data taken at face value could be misleading.

## Looking ahead

Notwithstanding the limitations of PROMs data, they represent a hugely valuable source of evidence that will help to establish – in many cases, for the first time – whether NHS services are effective and good value-for-money. Even rudimentary analyses may be broadly informative and identify areas of service delivery and spending where there are large disparities in cost-effectiveness across programmes. The relevant question is not 'How does an economic evaluation based on PROMs data compare with a perfect economic evaluation study?', but rather, 'Is an economic evaluation based on PROMs data, even if imperfect, better than having no evidence at all?'

In the Insight box, opposite, Professor Martin Buxton outlines what needs to be done to ensure PROMs data can be used in assessments of effectiveness and cost-effectiveness of services.

Although there are problems with using PROMs data to undertake economic evaluation, there are still some ways in which these data can be used immediately to strengthen some technical aspects of health technology appraisal, such as the following.

■ They will provide a source of typical patient outcomes and 'utilities' for different diseases/conditions so as to allow better economic modelling of new interventions. The size of the data sets that will be generated in the NHS means it will be possible to examine the impact on disutility of diseases by patient characteristics (such as age) or when experienced alongside specific combinations and severities of co-morbidities, and so on. It is not generally possible to obtain these insights within the context of clinical trials, in which the numbers are relatively small.

■ They will permit detailed analysis of the relationship between the EQ-5D and the disease-specific measures.

■ They will begin to identify interventions or sub-groups of patients in which/whom apparent benefits of interventions are less than had been expected, and than might be justified by costs. PROMs data can serve to identify topics where further investigation is required; and which can then be the subject of a more formal assessment (where data are obtained both on the treatment and the counterfactual).

Key to the wider use of PROMs in assessing value-for-money will be the development of economic evaluation and statistical methods that take into account the observational nature of the data noted above, in a manner that is robust and facilitates legitimate comparisons of value-for-money across dissimilar conditions and treatments.

As the NHS confronts an era of financial restrictions, PROMs data can and should be used to make sure spending is directed at services that offer the greatest benefit to patients, and that decommissioning focuses on the services offering the least benefit (NHS Confederation 2009).

## INSIGHT

### Using PROMs in economic evaluation: the way forward

Professor Martin Buxton, Brunei University

The PROMs data will provide an important method of comparing sub-groups of patients within each area of surgery. For valid comparisons to be made between sub-groups (whether those groups be patients treated in a particular trust or whatever), some appropriate adjustment for any additional sources of variation in outcome will be necessary. This adjustment will be critical, and it is essential that the national data set is open for detailed analysis to ensure that we fully understand the factors that influence these patient responses.

Beyond that, however, PROMs data offer the tantalising prospect of assessing how much patient benefit is actually achieved from routine health care interventions in the NHS, as well as a means of exploring their cost-effectiveness. This will allow the NHS to identify whether some well-established practices are perhaps not justifiable, and also offer a better understanding of when to intervene surgically, and when to stick to less aggressive management and monitoring.

In each case, it is essential to know the counterfactual – what would have happened if patients had not had a particular intervention. The PROMs data currently being collected provide important information – but they do not tell us everything we need to know to facilitate evaluations of service effectiveness and cost-effectiveness. For this reason, it is crucial that we build information on the counterfactual. Rather than focusing data collection on a specific service alone – such as surgery, for example – we should:

- use PROMs with *all patients considered for surgery*

- use PROMs with *all patients with a particular diagnosis*

- extend the use of PROMs into *related supportive care and health services provided across the primary and secondary care sectors.*

PROMs data should then be used to build up a long-term time series to understand the change in health-related quality of life over time. Further, it will be important to be able to link PROMs data to robust, patient-level cost data.

## Using PROMs to manage provider performance

The presentation of comparative information of provider performance on PROMs – such as the simple benchmarking shown in Figures 4 and 5, or the more complex risk-adjusted comparison of provider performance shown in the box on p 21 – clearly has the scope to be used by PCTs in monitoring performance, setting minimum performance standards, and selecting high-performing providers.

Just as there is a need to establish what sort of comparative information on provider performance is relevant to patients, similarly there is a need to know which form of analyses and reporting are most useful to PCTs in discharging their role as commissioners. For example, while variance around the average performance may be of most relevance to patients, the identification of performance that falls below some acceptable minimum standard might be of greater interest to PCTs. Once more data become available as a result of the implementation of PROMs across the NHS, further work will be required to help PCTs identify the levels of performance that should trigger concern and remedial action. Providers will be equally concerned about their comparative performance on PROMs – and in the next section we consider how PROMs data can be used by providers to monitor and improve their own performance.

One way in which PCTs will be affected by PROMs is via patients 'voting with their feet' and choosing providers that perform well on PROMs-based indicators. Under Payment by Results, money follows the patients – and the corresponding revenue flows from PCTs to providers creates indirect incentives for providers to improve their performance on PROMs.

However, PCTs can also employ more direct means of linking payment to performance. This is possible through Commissioning for Quality and Innovation (CQUIN) payments scheme. In effect, CQUIN is a scheme under which PCTs can make bonus payments to providers to reward them for achieving specified performance targets (Department of Health 2008b).

As data and knowledge around normal or expected variance in provider performance on PROMs grows, PCTs will be able to sharpen up the use of CQUIN schemes to incentivise and reward directly good performance from providers. In the absence of those data, PCTs are cautiously using PROMs as part of their CQUIN payments (*see* Insight box opposite for an example and some preliminary data from Lincolnshire PCT).

Will the incentives implemented by PCTs via CQUIN be strong enough to motivate the desired changes in provider behaviour? Do providers, even if motivated to perform well on PROMs, know which 'levers to pull' within their own organisations to improve patient-reported health? We turn to these issues in the following section.

## INSIGHT

### Paying for performance on PROMs

Sharon Sinha, Clinical Governance Co-ordinator, United Lincolnshire Hospitals
Edie Butterworth, Director of Quality and Involvement, NHS Lincolnshire

NHS Lincolnshire is using PROMs data to reward providers that improve their performance on patient-reported outcomes. Relative to some other PCTs, NHS Lincolnshire is 'ahead of the game' here because it has been involved in the Patient Outcomes in Surgery (POIS) audit, which pilots the use of PROMs data in elective surgery. However, although this has meant our PCT is now familiar with the collection of data and the sort of data generated in baseline (pre-surgical) measurement of PROMs, we have yet to see our post-surgery data.

Payment to providers is being linked to PROMs via CQUIN. In practice, this means:

■ 5 per cent of the £1.5 million CQUIN funding available from NHS Lincolnshire is being directed to achievements on PROMs

■ the aim is to encourage progress toward improved performance, to focus service improvements, and ultimately to improve patient outcomes

■ the CQUIN 'thresholds' are as follows:
  – achieved significant progress toward targets: providers receive 100 per cent of the CQUIN payment for PROMs performance;
  – underachieved demonstrable progress toward targets: 50 per cent
  – failed, little or no progress: 0 per cent.

At present, we have seen only our pre-operative PROMs data, so how our main NHS provider trust will fare against these criteria remains to be seen.

Our clinicians are extremely interested in their PROMs data and await the results with interest. In the meantime, we have been examining the baseline data, and even these, compared against other providers, have generated considerable interest. As an example, the following table shows the pre-operative PROMs results relating to knee surgery at the United Lincolnshire Hospitals NHS Trust (ULHT) compared with other providers in the POIS audit. This shows, for example, that the average pre-operative EQ-5D score for ULHT patients before surgery is, at 0.3 (on a scale in which 0 = dead and 1 = in full health), somewhat lower than the 0.4 scored by all other providers included in the POIS audit.

Pre-operative Oxford Knees Score and EQ-5D scores* for knee replacement patients in the ULHT compared with all NHS providers

| | Pre-operative Oxford Knees Score: mean (sd) | Pre-operative EQ-5D: mean (sd)* |
| --- | --- | --- |
| ULHT | 17.6 (7.2) | 0.3 (0.3) |
| All | 18.7 (7.6) | 0.4 (0.3) |

*EQ-5D data shown here are summarised by their social value set 'values' and then averaged (see 'A primer on PROMs'). An alternative way of presenting these data would be to use patients' overall EQ-VAS scores, or to present the changes in the EQ-5D profiles.

# Clinicians: clinical decision-making

Although some clinicians are sceptical about patient-reported outcome measures (PROMs), many others have long been interested in, and strong advocates of, them because they believe they provide data that are highly relevant to their clinical practice and the pursuit of clinical quality.

In 2004, predating the Department of Health's PROMs programme, we surveyed the Royal colleges to gauge clinicians' views and practices in this area, and were struck by how many examples we found of clinicians collecting and actively using these data to monitor and inform their own clinical practice (Appleby and Devlin 2004). These included:

- examining patient PROMs data before treatment, and using them as a basis for discussing treatment options with patients

- ad hoc outcomes-based research on clinical interventions (What works? What does not work?)

- obtaining a detailed understanding of how clinical indicators relate to patients' self-reported health.

As reimbursement of providers becomes increasingly linked, either directly (via Commissioning for Quality and Innovation [CQUIN]) or indirectly (via patient choice) to performance on PROMs (see 'Patients: information and choice' and 'Hospitals: managing clinical quality'), it is likely that providers will, in turn, wish to use incentives to ensure that the health professionals they employ – who have the most detailed understanding of the factors that lead to improved patient-reported health – are rewarded for good performance. Financial rewards may be introduced (eg, bonuses) for exceptional performance, or PROMs could become part of the evidence used to inform consultants' clinical excellence awards.

Similarly, PROMs might be used to identify and address poor performance. Outliers – in terms of lower-than-expected improvements on PROMs – could help clinicians to identify poor clinical practices within their own clinical units. PROMs could form part of the evidence considered as part of clinicians' annual appraisals and five-yearly revalidation (Appleby and Devlin 2004). In extreme cases, PROMs data might conceivably be used as part of disciplinary proceedings.

The box opposite suggests which data might be available for clinicians.

In this section, we consider the use of PROMs in two aspects of clinical decision-making. First, we discuss how condition-specific PROMs can be used in clinical practice to benefit patients directly. Second, and rather more controversially, we consider whether there is any place for using PROMs data to inform referral practices – for example, as part of referral guidelines.

**Which data will be available to clinicians from the PROMs programme?**

In the national PROMs programme, the collection of baseline and post-operative data is co-ordinated nationally by organisations contracted by the Department of Health.

Once patients have completed a PROM, those data are entered and linked, using patient NHS numbers among other identifiers, to the main national database of Hospital Episode Statistics (HES).

Although it is technically possible to link the pseudonymised patient PROM data to individual clinicians through HES, a decision on the information governance and confidentiality issues arising from this are yet to be resolved. Currently, therefore, clinicians will not have access to their own patients' PROMs data, even in an anonymised form.

Even with such information, such data will *not* facilitate the sorts of patient-level uses of PROMs that are the focus of this section. The use of PROMs as a screening tool, as a guide to referral, or as a means of monitoring and managing patients, will require separate data-collection efforts at the level of the practice itself.

## Using PROMs in clinical practice

As noted earlier, PROMs information can be used to inform patients' decisions about the likely benefits of treatment, either as part of shared decision-making or, more formally, as part of patients' decision tools. For example, Brundage *et al* (2006) examined the effect on choice of treatment of providing patients with data on health-related quality of life from clinical trials.

PROMs can also be used by clinicians as part of routine patient assessment and management – especially in longer-term conditions. Patient-reported outcomes can provide baseline information about patients' health-related quality of life. Condition-specific PROMs are used as one-time screening questionnaires – for example, in depression – with follow-up on patients triggered by scores above some predetermined threshold (Snyder and Aaronson 2009). Measured again at subsequent visits, PROMs can help evaluate disease progression or regression as well as the effects of treatment (Fung and Hays 2008). It has also been argued that PROMs can allow the identification of vulnerable patients and enable clinicians to undertake continuous assessment of quality of care (Valderas *et al* 2008).

Feldman-Stewart and Brundage (2009) point to other, less obvious, benefits of PROMs. They assert that their use by clinicians in monitoring health over time improves patients' memory of and ability to describe their problems. Also, PROMs can highlight problems that patients experience, but might not have thought to raise with their clinician if they were unaware of their relevance, and which clinicians therefore assumed not to be of concern. Completion of a PROM instrument might in itself contribute to helping patients to feel cared for, and the information provides a structured basis for patients' discussions with their clinician.

The use of PROMs at the health system level, as in the Department of Health's PROMs programme, focuses on a limited number of observations, but in clinical use more frequent data collection might be more appropriate and informative. PROMs data can be collected during each patient contact – or can be completed at home. Creative examples

of the use of PROMs – albeit in research settings – include use of the EQ-5D in a daily patient diary, in order to monitor the impact on health-related quality of life of long-term changes and acute exacerbations experienced by patients with multiple sclerosis (Parkin *et al* 2004). A study that is currently under way is exploring giving patients a handheld electronic device to use at home to make a daily record of their quality of life. This data will be fed through to and be continuously monitored by clinical teams in order to determine whether it can be useful in the early detection of treatment needs of patients with a wide range of chronic conditions. The development of touch-screen computers and other electronic means of collecting PROMs data offer potential for improving how PROMs data are collected and used in clinical practice (Rose and Bezjak 2009).

However, a note of caution is required. The use of PROMs data in clinical practice is relatively new, and although it clearly has the potential to improve the process of care, its potential to improve patient health *outcomes* is as yet unproven.

In order for PROMs to be used in and be useful to clinical practice, such data must be acceptable to clinicians, and the instruments themselves must be seen as offering legitimate and relevant data. This makes the selection of the instruments to be used crucial – they must be supported by clear evidence of validity and reliability. PROMs data must also be affordable and practical to collect – and not adversely affect the clinical workflow (Snyder and Aaronson 2009).

A review of the impact of the use of PROMs in clinical practice (Marshall *et al* 2006) concluded that the feedback of patients' PROMs data to clinicians had a significant impact on some processes of care – particularly on the diagnosis of mental health conditions – but that evidence on the impact on patient health status was inconsistent. Robust evaluation of the value of PROMs in clinical practice is required – as indeed it is in all the uses of these data described here.

There is clearly potential for PROMs to confer benefit when used in the clinical context – but this depends on how the data are collected, how they are fed back to clinicians, and how they are actually used by clinicians in consultations and monitoring. Unless clinicians actively use the data their patients provide, additional data collection is of little benefit. An example of a good use of PROMs with seemingly clear benefits in one area of medicine – urology – is shown in the Insight box opposite.

Snyder and Aaronson (2009) argue that one important factor in the usefulness of PROMs in clinical practice is that there are clear links between PROMs data and guidelines for practice and clinical pathways.

This raises an interesting question: to what extent can and should PROMs data play a role in referral guidelines and clinical judgements about treatment?

## Are PROMs relevant to decisions about referral?

There are substantial variations in referral rates in the NHS (cf, Clarke *et al* 2009). These variations have been noted as a cause for concern for many years, but addressing them presents considerable challenges.

Reducing this sort of variation in referral rates in effect requires a change in the clinical decisions being made by individual referring GPs, and there is a tension between the pursuit of consistency in treatment of patients across the NHS and clinical autonomy. Furthermore, as the NHS continues to place greater importance on responsiveness to patients, and ensuring that patients' preferences are taken into account, this also presents

## INSIGHT

### An example of the use of PROMs in clinical practice - urology

Professor Mark Emberton, Clinical Director, Cancer Services, University College Hospital, and Consultant Urologist, University College Hospital

PROMs are a central part of our clinical practice in urology at University College London Hospitals NHS Trust (UCLH), and are used to inform a wide range of clinical decisions.

A good example of the benefits of using PROMs in clinical practice is provided by the case of benign prostatic hyperplasia (BPH). This is a common disorder, affecting more than 50 per cent of men over the age of 60 years. It is characterised by urinary symptoms, and thought to be due to prostate enlargement. However, historically there was no clear definition of the disease in terms of symptoms, urinary flow, prostate size or pathology. This, in turn, led to considerable 'small area variations' in interventions rates, and the possibility of overtreatment – which, combined with the complications from treatment being underestimated, were an important cause for concern.

In the 1980s, the US Agency for Health Care Policy and Research established a Patient Outcomes Research Team. This resulted in systematic reviews, the development and validation of symptom scores, and their use in inception cohort studies. These efforts resulted in: an agreed definition of BPH; the availability of an unambiguous measure of symptom severity; the development of agreed thresholds for patient referral and therapy; and a basis for monitoring the outcome of treatment. PROMs are now considered a crucial part of the clinical assessment of men with lower urinary tract symptoms, and their outputs inform the thresholds of: disease severity; threshold for referral; threshold for treatment; and defining treatment success.

PROMs are firmly embedded in clinical practices in urology. While there are some areas of clinical practice in which there is currently an absence of appropriate, well researched PROMs instruments (for example, female reconstruction, male reconstruction, gender dysphoria, infertility and stone disease), PROMs *are* available for more than 70 per cent of the activity commonly undertaken in urology units.

Among the PROMs we commonly use in urology today, by far the most common is the International Prostate Symptoms Score (IPSS; *see* 'A primer on PROMs'). The US Food and Drug Administration requires IPSS scores as a primary endpoint in clinical trials, so it is also used in all clinical trials in this area. The IPSS is used both in general practice and in clinics. It is used to monitor referral thresholds and intervention rates, and changes in IPSS scores before and after treatment are used to measure effectiveness – as well as to measure the cost per unit of health gain. The second most often used score is the International Index of Erectile Function.

Finally, PROMs have an important role in quality management and improvement. For example, the IPSS is currently used in audits by the British Association of Urological Surgeons.

In future, we also anticipate that PROMs evidence at the level of the individual clinician will be part of the evidence routinely used to assess clinical competence.

a tension with attempts to introduce systematic approaches to 'demand management', which are aimed at improving the appropriateness of referrals but which can also limit patients' choices.

The differences in referral rates are also mirrored in substantial differences in surgical intervention rates across the NHS. The explanation for these variations is unclear, suggesting that considerable idiosyncrasy in clinical decision-making might exist at both primary and secondary care levels. A review of this issue concluded:

> Variations between GP practices' referral patterns and rates remain largely unexplained. Patient, practice and GP characteristics account for less than half of observed variation, the impact of social class is not clear-cut and 'no one variable or group of variables appears to be a predictor of variation'. There has been 'no relationship found between referral rates and age of GP, years of experience or membership of the [Royal College of General Practitioners]...', and there is 'conflicting evidence about the relationship between practice size and variation in referral rates'.
>
> (British Medical Association 2009; phrases within quotes are taken from O'Donnell 2000)

However, wider influences might affect the variation. For example, O'Donnell (2000) suggests that high levels of referrals are related to high levels of supply.

Greater clinical consensus over what constitutes an appropriate referral, and when treatment will benefit the patient, could yield important benefits to overall patient health, improve how resources are used, and, potentially improve equity in access to care.

How do other health systems address these issues? What can be learnt from how referrals and access to surgery are handled elsewhere? And is there any role for using PROMs data to address this issue?

An example of how PROMs-type instruments can be used in referral and treatment decisions is provided by the Canadian and New Zealand health care systems. Of course, there are important differences between these countries and the NHS in terms of how health care is funded, provided and managed, which could limit the relevance of the experience there to the NHS. For example, an important context to the introduction of 'explicit patient prioritisation' in both countries is that it was stimulated in part to address long waiting times (eg, Noseworthy et al 2003). In contrast, the United Kingdom has addressed its waiting times by the use of waiting time targets, ie, using supply-side, rather than demand-side, initiatives.

## International use of PROMs in referral management

With that caveat in mind, we now provide a brief summary of the 'points systems' used in New Zealand and Canada, and the role of PROMs in those systems, and then we consider the relevance of them to clinical decisions to refer and treat in the NHS.

For more than a decade, New Zealand has used a points system to determine patients' access to publicly funded elective surgery. Introduced in the mid-1990s (Hadorn and Holmes 1997a, 1997b), the aim is to develop standardised sets of explicit criteria that assess the extent to which patients have the 'ability to benefit' from a range of elective surgical procedures. These criteria for assessing ability to benefit were applied consistently across the country, to ensure fairness in access to treatment for any given condition, and also to facilitate direct comparisons of ability to benefit across different conditions and treatments.

Clinical Priority Assessment Criteria (CPAC) were developed and used in decisions about patient access to cataract surgery, coronary artery bypass graft, hip and knee replacement, cholecystectomy and tympanostomy tubes for otitis media with effusion. Patients with sufficient 'points' under this system were guaranteed treatment within a short period through a surgical booking system. Those who do not have enough points to merit surgery (ie, fall below an agreed 'clinical threshold') are not offered surgery. This is, in effect, an explicit form of 'rationing' (Derrett 2001).

An example of one aspect of the 'points system' currently used to prioritise patients for cataract surgery in New Zealand's publicly funded health care system is provided in Appendix 3, p 82. This shows an 'impact on daily living' questionnaire developed for self-completion by patients. This PROMs information is used alongside the clinician's assessment about the improvement in health possible through treatment, as the basis for prioritising patients for cataract surgery. This approach is endorsed for use by the Royal Australian and New Zealand College of Ophthalmologists.

The principles underpinning this 'points system' are summarised in the Insight box below, written by Dr Ray Naden and Alison Barber, who lead the management of elective surgery in the New Zealand Ministry of Health.

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## INSIGHT

### Ethical principles underlying explicit prioritisation of patients for elective surgery

Dr Ray Naden and Alison Barber, New Zealand Ministry of Health

The aim of points systems is to ensure horizontal equity in access to publicly-funded health care services, that is, patients with *equal need and ability to benefit* from treatments should have equal access to treatment, regardless of, for example, where they happen to live, their ethnicity, their education or income. Points systems work by providing an explicit and consistent basis for answering the following key questions.

- **Question 1**: Is the treatment in the best interests of the patient? (ie, is the patient's net ability to benefit, weighing up the benefits and the risks of treatment, > 0?)

- **Question 2**: Is the treatment available to this patient? If everyone who needs it can have it, then no prioritisation is required. If not, who should have it and who should not?

Because taxpayer-funded health care budgets in New Zealand, as in the NHS, are limited, inevitably priorities for access to services must be made both overall (should more be spent on ophthalmology or on other areas of treatment and prevention?), and within any given clinical area (should more be spent on cataracts, or on other sorts of ophthalmological problems?).

Points systems are a means of making those judgements in a way that is fair, explicit and consistent. The use of points systems marks a departure from a reliance on paternalistic, potentially idiosyncratic, decisions by individual clinicians.

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**INSIGHT**

**Ethical principles underlying explicit prioritisation of patients for elective surgery**
*continued*

The points systems currently being used across elective surgical procedures in New Zealand entail a mix of PROMs and clinical judgements. The points assigned to a given patient are based on two questions.

■ **What impact does the patient's condition have on his or her quality of life?** This is clearly best judged by patients themselves. Existing PROMs, such as the EQ-5D, are not always adequate for this, so bespoke PROMs have been developed and validated for each area of elective surgery.

■ **To what extent is the patient's condition able to be ameliorated by treatment?** This is clearly best judged by clinicians – and the points system systematises these judgements.

The points system does use PROMs, but as a complement to, rather than a substitute for, clinical judgements. Achieving clinical consensus about the way in which patients are assigned points is crucial to the success of the system.

The introduction of these points systems in New Zealand has conferred significant benefits.

■ Important differences in access to surgery for people of equal need were revealed to exist by *region*, and were addressed.

■ Important differences in access to surgery for people of equal need were revealed to exist by *ethnicity*, and were addressed.

■ Important disparities between access to surgery *within* clinical areas (eg, cataract surgery versus treatment for other ophthalmological conditions) were revealed, and this has informed resource allocation decisions *within* that clinical area.

■ Disparities between different areas of elective surgery, in terms of patients' *relative* ability to benefit, informs decisions about resource allocation between different clinical areas, affecting different groups of patients.

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Similar schemes to these are also in use in Canada's social insurance system. For example, priority criteria are used to determine treatment for hip and knee replacement surgery (Arnett and Hadorn 2003) and cataract surgery (Romanchuk *et al* 2002).

Derrett (2005), noted the potential concern that the use of PROMs in points systems might prompt patients to exaggerate their problems to 'game' the system, but she found that, in practice, quantitative and qualitative analysis of the data suggested patient exaggeration was not an important influence on CPAC scores. Rather, she stated: 'The over-riding message from patients was of support for a "fair" system in which patients in greater "need" accessed surgery first – irrespective of whether or not they themselves were in the groups receiving surgery' (p 36).

Arguably, one of the most important impacts of the points system has been on equity of access. One of the key aims of New Zealand's elective surgical reforms was to make the

system fairer for patients and to ensure horizontal equity – that is, equal treatment for those with equal needs. Evidence on this has been reported from Counties Manukau, one of the poorest and most ethnically diverse regions of New Zealand. Historically, the Maori rate of *elective* surgery has been well below that in other ethnic groups of the population. As the points system was implemented, this gap has closed. The biggest changes were evident for hip and knee replacements, cardiac procedures and cataracts, and, notably, the largest improvements in access occurred in the areas of greatest deprivation (Lindsay *et al* 2007). The implication is that assessing priority for treatment using explicit criteria that provide a consistent basis for referral and access to treatment can promote equity in access to health care.

However, the implementation and use of these points systems is not without its problems (Gauld and Derrett 2000; Dew *et al* 2005). Of critical importance is the validity of the specific PROMs-type instruments that are used to award points: early versions of the CPAC scoring systems were *not* properly validated, and were of questionable scientific merit as a means of judging patients' ability to benefit.

Furthermore, there is a fundamental challenge in developing scoring systems that are both sufficiently sensitive to facilitate judgements about relative ability to benefit *within* a given clinical area – such as ophthalmology – but also broad enough to facilitate legitimate comparisons of relative ability to benefit across different clinical areas.

PROMs-based tools also give rise to the possibility of 'gaming' behaviours (by both patients and clinicians). In New Zealand, their introduction coincided with a period of reductions in real budgets, which posed particular challenges that are of direct relevance to the NHS in the current financial context.

## The potential role of points systems in the NHS

So what are the prospects for the use of these sorts of PROMs-based tools in the NHS? Might points-type systems be useful as a means of overcoming known variations in referral and treatment of patients? Does the PROMs programme present an opportunity to capitalise on the pre-surgical collection of PROMs, to facilitate explicit patient prioritisation?

The use of explicit patient prioritisation would mark a significant departure from current practice. Department of Health-sponsored research on referral guidelines has not promoted explicit scoring systems, but rather has focused on how to take 'patient preferences about treatment' into account in the decision to refer (Clarke *et al* 2009).

On the other hand, Edwards *et al* (2003) suggest that there *is* support among GPs, consultants, commissioners and patients in the NHS for a more explicit way of prioritising patients for treatment. Their results showed that all groups included in their survey agreed that the level of pain, rate of deterioration of the disease, level of distress, and level of disability are factors that should have an influence on which patients receive treatment.

The key questions are whether the PROMs now routinely collected in the NHS are sufficiently robust to be used in this way and whether they are adequate predictors of patients' ability to benefit from treatment.

The New Zealand points system does not use the EQ-5D, and a prospective study of the points system suggested that the EQ-5D is imperfect as a tool for predicting patient benefit (Derrett *et al* 2003). This suggests that 'purpose-built' instruments may be required. Current work in New Zealand is focused on developing and validating, in

partnership with both patients and clinicians, bespoke scoring tools. PROMs are an important aspect of these, but are complementary to clinician judgements.

It therefore seems likely that the PROMs data currently being collected in the NHS 'at baseline' will not *in themselves* provide a sufficiently robust basis for referral guidelines. However, those data, combined with condition-specific data also being collected and combined with consensus clinical judgements, *might* be relevant.

## PROMs and other health professions

To date, most of the focus on PROMs has been on doctors. This may reflect a belief that it is their performance that is most crucial in effecting improvement on patient-reported health from treatment. But what of the role of other health professionals? For example, the quantity and quality of nursing may exert an independent (of clinicians' quality) effect on improvements in patient-reported health.

Similarly, the services of allied health professionals may also be important to PROMs. For example, the quantity and quality of physiotherapy is likely to exert an influence on improvement of patient-reported health following orthopaedic surgery (Devlin *et al* 2010).

The focus on doctors so far is probably due to the initial focus on *surgical* procedures, where the role of the clinician dominates (and the need to get 'buy in' from powerful professional groups is most crucial). But, as PROMs is rolled out across a wider range of NHS services, such as mental health, primary care and services for longer-term conditions, the quantity and quality of care, advice, supportive services and a wider range of health and social care services, is likely to become as – if not more – important in determining self-reported improvement in patients' health.

# National organisations: regulation, quality and NHS productivity

## Regulation

Over the past decade, the scale and methods of regulating health care organisations to ensure safety and quality has undergone enormous change. The newly formed Care Quality Commission (CQC) now succeeds and subsumes previous organisations, namely the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission. The key aim of the CQC is 'to make sure better care is provided for everyone, whether that's in hospital, in care homes, in people's own homes, or elsewhere' (Care Quality Commission 2009b).

Apart from changes in the regulatory structures, the way health care organisations are regulated and the data employed to do this have also changed. The most recent measures to assess the quality of care provided by acute trusts applied to 2008/9 and cover seven 'domains', such as safety, patient focus, etc. Within each domain, more detailed measures and indicators were also assessed. The eventual composite assessment of a trust's level of quality (excellent, good, fair or weak) also included its performance on 23 'national priorities' and 'existing commitments', such as cancer treatment waiting times, stroke care, incidence of *Clostridium difficile*, experience of patients, and total time spent in accident and emergency departments. Within these aspects of performance are further aspects or indicators for each particular priority or commitment.

Of note was the focus on measures of *process* rather than *outcome* in this assessment of quality of care, and furthermore, the reliance on indirect measures of quality. In terms of patients' own views and assessments, while elements of the national patient survey data were included, there was little direct input from patients on the quality of the care they received, and no information on their health-related quality of life.

However, under the terms of the Health and Social Care Act 2008, from April 2010 this system of regulation and assessment will be replaced by a registration requirement for all health care providers coupled with inspections and special investigations by the CQC.

In its draft guidance on compliance with the act (Care Quality Commission 2009a), the CQC noted that its approach to registration will draw on the experience of people using services by, among other things, '...defining quality in terms of *outcomes* wherever possible' (p 6), and '...frequently and regularly using *information on the views and experiences of those using services* and their families and carers' (p 6) (our emphasis). Furthermore, the CQC will check that providers '...obtain the views from the people who use their services to understand the quality of people's experiences' (p 12). Finally, in terms of monitoring and reporting of the quality of services used by patients, health care organisations will be required to (among other things):

- *Have appropriate systems for gathering, recording and evaluating accurate information about the quality and safety of the service, in particular people's experiences of the care, treatment and support they receive and its outcomes.*

- *Gather information about the safety and quality of their service from all relevant sources, including feedback from people using services, audits, adverse events, complaints, claims and other comments received.*

- *Use the findings from clinical audits, including those undertaken at a national level, and national service reviews to ensure that action is taken to protect people from risks associated with unsafe care, treatment and support.*

- *Use the information gathered to set goals about how the service can improve the quality and safety of experience for people who use services in order to comply with the Health and Social Care Act 2008 (Registration Requirements) Regulations 2009.*

(Care Quality Commission 2009a, pp 77–78)

The emphasis on patients' own views, assessments and experience, and the focus on providers collecting and reporting on quality (ie, outcomes) in the new registration and inspection regime suggests that patient-reported outcome measures have an important potential role for the CQC.

## Measuring NHS output and productivity

Measuring the output of the National Health Service (NHS) (indeed, any industry, public or private) is a difficult task. Although conceptually straightforward – productivity is the amount of output for a given level of input – in practice, calculating such an apparently simple ratio is rather hard. Traditionally, the NHS has measured the output part of the productivity ratio in the form of a cost-weighted activity index, where cost is used as a substitute for price and all the various activities of the NHS – inpatients, outpatients, prescriptions, etc – are added together using their shares of the total spend on the NHS as weights. The implication is that costs reflect the values society places on the activities carried out by the NHS. Dividing changes in this index from year to year by changes in total spending provides a measure of the change in productivity. On this basis, the most recent estimates of NHS productivity by the Office for National Statistics (ONS) suggest that over the decade from 1997 to 2007, the productivity of the NHS fell by an average of 0.4 per cent per year.

Although there have been developments in the number and type of activities included in the cost-weighted activity index to make the measure more sensitive to changes over time in the mix of activities carried out by the NHS, there remains a key problem: no account is taken of changes in the quality of the outputs produced by the NHS. The implicit assumption has been that the NHS has made no progress over time in the quality of, say, hip replacements, and that the quality of such procedures is the same regardless of the surgeon or hospital. It is as if the output of the computer industry is calculated simply by counting the number of machines produced, ignoring the difference in quality between, for example, a Sinclair ZX Spectrum and an Apple Mac Pro.

A key recommendation of the Atkinson Review (Atkinson 2005) was that the output of the NHS (and indeed that of all public services) should be adjusted for quality. Failure to do so could mean that where quality improves and leads, for example, to a reduction in the amount of activity necessary to achieve a given outcome, it would appear that output, as measured by the cost-weighted activity index, had reduced, and also that productivity (also based on the relatively crude cost-weighted activity measure) would also appear to have fallen, providing a misleading picture of the actual change. Specifically, Atkinson suggested that NHS activities could be 'marked up or down' by a percentage reflecting indicators of success and the contribution of the service to that success.

Various attempts have been made to adjust NHS output for changes in the quality of the 'product'. For example, researchers at York University and the National Institute of Economic and Social Research (NIESR) constructed an alternative to the cost-weighted activity index using weights based on waiting times and change in health status of patients. Taking three illustrative procedures and using actual cost, waiting time and health outcome data, they found that weighting coronary bypass surgery activity in terms of the change in quality adjusted life years (QALYs) that such procedures generated, led to smaller increases in the activity index than weighting for cost. However, the reverse was the case for hip replacements and upper genital tract procedures (Dawson *et al* 2005). The basis for the 'Q' in QALY used in the York example was an EQ-5D index score.

The ONS has also attempted to adjust NHS outputs for quality using a range of measures suggested by the York/NIESR team (cf, Carless 2008). Overall, adjustments for quality factors such as reduced waiting times, changes in heart attack survival and improvements in patient experience, increased the level of NHS output and productivity by around 1.1 percentage points over the five-year period 1999–2004 (*see* Figure 10 below).

**Figure 10** Change in NHS productivity with/without quality-adjusted output



Productivity without quality adjustment ▬

Productivity with quality adjustment ▬

Source: Office for National Statistics (2008).
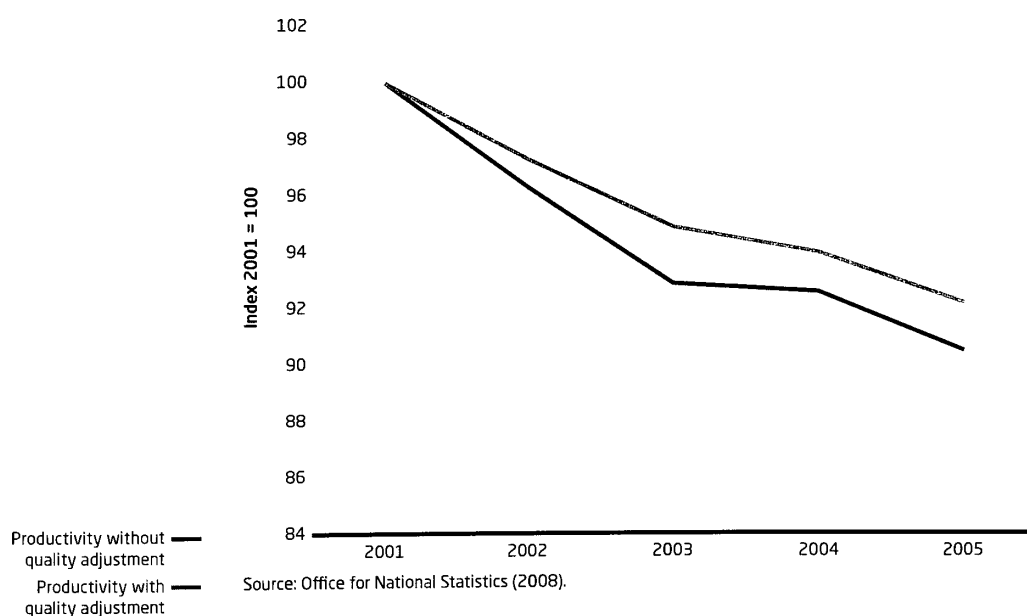
There has been broad agreement among those investigating ways to improve the measurement of the outputs and productivity of the NHS that changes in patients' health status would be a desirable quality adjustment. So far, the problem has been the lack of any data directly bearing on this. However, the EQ-5D data now being generated through patient-reported outcome measures (PROMs) can be used not only to monitor quality-adjusted output and productivity at the level of individual procedures and health care organisations, but also changes in these measures over time. An example of the difference adjusting for quality using EQ-5D data can make is illustrated in the box overleaf.

## A better way of measuring NHS output?

Pritchard (2004) provides an example of the way that relative costs are used in the construction of output measures, using knee replacement and varicose vein procedures.

### Approaches to measuring output

| Categories of treatment and activities | Year I unit cost £ | Year 1 expenditure £ million | Year 1 expenditure shares | Year 1 activities | Year 2 activities | Index 1999/2000 | Index 2000/1 | Percentage growth 2000/1 |
|---|---|---|---|---|---|---|---|---|
| Illustration of detailed calculation (method used from June 2004): | | | | | | | | |
| Knee replacement | 4,785 | 165.9 | 0.833 | 34,662 | 39,902 | 100 | 115.1 | 15.1 |
| Varicose vein procedures | 835 | 33.3 | 0.167 | 39,923 | 42,150 | 100 | 105.6 | 5.6 |
| Total | | 199.2 | 1.000 | 74,585 | 82,052 | 100 | 113.5 | 13.5 |
| Illustration of unweighted calculation (method used before June 2004): | | | | | | | | |
| Total | | | | 74,585 | 82,052 | 100 | 110 | 10.0 |

Source: Pritchard (2004).

The table shows that weighting by cost produces a measured increase in output of 13.5 per cent, whereas no weighting suggests an increase of 10.0 per cent.

However, the cost-weighted calculation relies on the strong assumption that the cost of each procedure is a reflection of the *value* these interventions provide to patients, with knee replacements being valued at five times more than varicose vein procedures.

PROMs provide an alternative means of assessing the relative value of these interventions. For example, we could base the 'weight' to be applied to the two sorts of operations on the relative *value of the health improvement* resulting from them.

| | Mean pre-operative EQ-5D index | Mean post-operative EQ-5D index | Change in utility |
|---|---|---|---|
| Knee replacement | 0.39 | 0.70 | 0.31 |
| Varicose veins | 0.76 | 0.87 | 0.11 |

Source: extracted from Browne et al (2007).

Note: the figures show the average values (utilities) for the EQ-5D profiles reported by patients in the PROMs pilot study before and after surgery.

This would suggest that, on average, the value of the improvement in health resulting from a knee replacement is 2.82 times greater than that from a varicose veins procedure. Factoring this into the activity figures above suggests a percentage increase in output of around 12.5 per cent. This is lower than the cost-weighted estimate, but higher than the unweighted estimate. Knee replacements cost more than varicose veins *and* produce much greater increases in health-related quality of life, but using the relative share of total expenditure as the basis for the weight applied to each exaggerates the relative value of the health improvement from knee replacement.

Clearly, the current scope of the PROMs data set only covers a small fraction of the total activities of the NHS and will have a marginal impact on the overall measure of outputs and productivity. Nevertheless, as the scope of the PROMs programme expands, there is the prospect of using this data in combination with the traditional cost-weighted activity measure, and expanding the use of PROMs as a quality adjustment.

A remaining challenge, noted by the Office of Health Economics Commission on NHS Outcomes, Performance and Productivity (Office of Health Economics 2008), is the importance of being able to link health outcomes to the delivery of 'complete treatments', packages or pathways of care, rather than its individual components.

Ultimately, the availability of routinely collected PROMs data, as well as programme budget data for each primary care trust creates an important opportunity to link costs, activity and outcomes that '…will offer the NHS a powerful tool to assess overall performance and to understand key areas for change' (Office of Health Economics 2008, p 59).

# Where next for PROMs?

The NHS is the first health care system in the world to introduce the routine collection of patient-reported outcome measures (PROMs) data at the system level. This is a landmark development, and represents a fundamental shift in focus from the production of health care to the production of health. The NHS PROMs programme is generating considerable interest from other countries, including Germany, Sweden, New Zealand and Canada, which recognise the potential for PROMs to improve choices and decisions about how health care resources are used.

PROMs do offer enormous potential to the NHS, but, it must be borne in mind that at present only four procedures are covered by the national PROMs programme, and these account for just a small fraction – around 3.3 per cent – of all elective activity in the NHS. The obvious challenge for the future is therefore to extend the coverage of PROMs, not just to other elective interventions, but into specialties and areas of NHS activity in which data on quality (and effectiveness) have traditionally been poor or non-existent, and yet which are areas that consume a substantial proportion of NHS resources.

Disease areas such as mental health, and long-term conditions such as diabetes, asthma and chronic obstructive pulmonary disease (COPD) will provide challenges in terms of the design and implementation of routine PROMs collection and analysis. The interventions are less clearly defined than surgical procedures: patient management may comprise complex packages and pathways of care, rather than a discrete, readily described treatment event. Nevertheless, PROMs in these areas offer the opportunity to scrutinise better the effectiveness and cost-effectiveness of a major area of NHS activity.

As well as widening the scope of PROMs coverage, there are other potential developments and uses for PROMs information. These include:

- providing an additional source of effectiveness information for assessments by and guidelines from the National Institute for Health and Clinical Excellence (NICE)

- a more co-ordinated process for demand management, value-for-money and performance

- a basis for international comparisons of health care quality.

Below, we examine the challenges involved in extending the scope of PROMs into long-term conditions, and then the potential for PROMs data to help inform NICE assessments and what PROMs could reveal about the internal cost-effectiveness threshold of the NHS. Finally, we consider how the NHS experience with PROMs in England could provide an example for other countries' health systems and inform comparisons of patient-generated information on the quality of health care.

## Long-term conditions

Long-term conditions such as asthma, diabetes, COPD, heart failure and stroke affect millions of people and account for substantial spending by the NHS. The direct cost of these conditions was £8 billion in 2008/9, accounting for around 8 per cent of the NHS budget (British Heart Foundation 2009; Saka *et al* 2009; NPBP 2009), with spending varying considerably among different primary care trusts (cf, NPBP 2009).

Although these and other chronic conditions can lead to death, most people should be able to control the symptoms of the disease with appropriately supported self-management and some direct NHS care. A key outcome is therefore not the avoidance of death but the maintenance of quality of life. It is partly for this reason that the Department of Health has initiated pilot studies into the appropriate condition-specific and general PROMs for a group of long-term conditions. Six have been identified:

- diabetes

- COPD

- epilepsy

- asthma

- heart failure

- stroke.

There are significant problems to overcome, however. Unlike the four elective procedures currently subject to PROMs, long-term conditions generally have no specific intervention point around which to carry out the 'before and after' type approach to the recording of PROMs. Measurement of PROMs therefore becomes, in a sense, a continuous process of recording trends in patients' assessments of their health-related quality of life and one where, even with the best management and intervention, 'no change' might be the best that can be expected.

Furthermore, care and intervention is not only ongoing, but is also delivered by a range of providers (including patients and their carers). This multiplies the difficulty in interpreting the resultant trends in PROMs and attributing any change (or deviation from an expected trend, which might be downward) to particular providers or interventions. This, together with the fact that many people with these conditions could have difficulty in completing PROMs questionnaires because of frailty and incapacity, demonstrate that the challenges in generating PROMs data for long-term conditions are considerable.

Nevertheless, there are many examples of successful testing and application of the collection of PROMs data for what some may consider 'difficult' conditions. One such is the Scottish Schizophrenia Outcomes Study, the results of which are summarised in the box overleaf.

## Measuring patient-reported outcomes in mental health: the Scottish Schizophrenia Outcomes Study

The Scottish Schizophrenia Outcomes Study (SSOS) (Hunter *et al* 2009) was funded by NHS Quality Improvement Scotland and aimed to assess 'the feasibility and utility of routinely collecting outcome data in everyday clinical settings', to compare clinician and patient reports on outcomes, and assess trends in outcomes over time.

From 2002 to 2005, data were collected from more than 1,000 Scottish NHS patients using the clinician-rated measure the Health of the Nation Outcome Scale (HoNOS), and the patient-reported assessment the Avon Mental Health Measure (Avon).

More than three-quarters of those recruited for the research completed the study, and over the three-year period 'significant decreases were seen in the number of hospitalisations, incidence of attempted suicide and self-harm, and civil detentions'.

Interestingly, the patient-reported Avon scores indicated significant improvement on all sub-scales, while the clinician assessment on behaviour and symptom sub-scales did not change; assessments on the impairment sub-scale increased significantly (indicating increased levels of impairment), while clinician-derived scores on the social sub-scale decreased significantly (indicating improved social functioning).

The researchers concluded that it was 'feasible within the Scottish NHS to routinely collect meaningful outcomes data in schizophrenia'. Moreover, they found that patient-reported assessments were also successfully collected and used in care plans. They also found, however, that the 'pattern of outcomes and interventions confirms that despite the introduction of guidelines, new treatments, and new services, people with schizophrenia continue to have high levels of chronic disability'.

Source: Scottish Schizophrenia Outcomes Study 2006.

However, there are issues to resolve in terms of the ability of PROMs to capture health-related quality of life information in a meaningful and accurate way. For example, analysis of EQ-5D data from cataract patients in the PROMs pilot appeared to suggest that nearly one-third of patients had 'no problems' before surgery, and that as many patients experienced a worsening of health as experienced health improvement following surgery. Does this suggest a cause for concern about the referral and treatment for some patients? Or is it possible that the EQ-5D has simply failed to detect important changes in visual functioning for these patients (Devlin *et al* 2010)?

Visual problems do seem to be difficult to measure using PROMs – similar problems have also been reported using the SF-36. One explanation is 'response shift': patients may have adapted to poor vision and, when questioned before surgery, do not report much impairment of their quality of life. Following surgery, they may adapt quickly to their improved vision. The change in self-reported health between baseline and follow-up might not reflect important changes in health-related quality of life.

The results on the EQ-5D are an interesting contrast with what the patients themselves say, when asked, about the outcome of their surgery: 93 per cent of patients rated the results as 'good', 'very good' or 'excellent' (Black *et al* 2009). On the other hand, responses to questions like this may be coloured by gratitude for having received treatment, and positive experiences of the treatment itself.

Interestingly, in the PROMs pilot study, the problem with measuring benefit from cataract surgery was not restricted to EQ-5D: although Black *et al* (2009) reported that VF-14 scores were unchanged or worse in 25 per cent of cataract surgery patients, they concluded that this was partly due to inadequacies in the validity of that instrument. Yet in other studies, and in Bupa's use of PROMs, as shown in Figure 11 below, the VF-14 *did* seem able to measure improvements resulting from surgery.

**Figure 11** Change in VF-14 score before and after surgery: comparison of Bupa Hospitals' patients and NHS patients in the North Thames Region
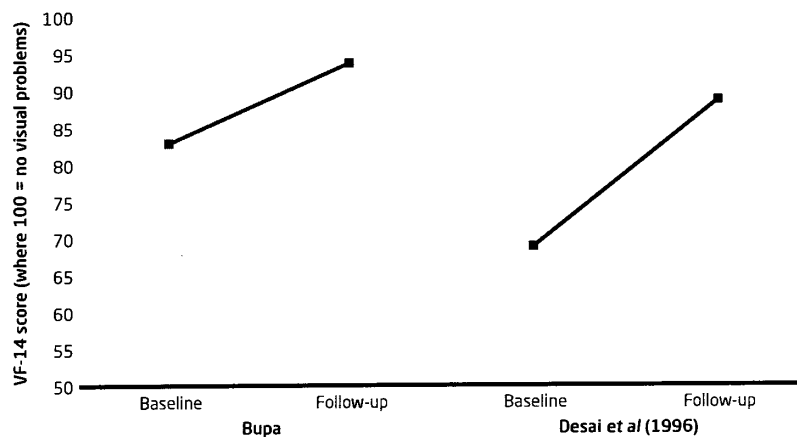


Source: Desai *et al* (1996). Reproduced with permission from Bupa.

This rather mixed picture makes it difficult to know how to interpret PROMs data with respect to cataract surgery. Is there a problem with the instruments? Is there a problem with service delivery? For example, perhaps intervention rates are too high, or some patients are being referred for surgery too early. It is partly because of uncertainty about these issues, and also because the view of the research team on the PROMs pilot was that the VF-14 needed modification to reflect the current clinical environment, that cataracts were not included in the roll-out of PROMs in the NHS in England in April 2009.

Given the high volumes of cataract work carried out by the NHS, it is especially important that efforts continue to be made to identify a valid, reliable and acceptable PROM for cataract surgery.

## NICE, the real-world evaluation of services, and the cost-effectiveness threshold

In nearly all the technologies that NICE has to consider, it is faced with the significant problem of a dearth of appropriate or robust evidence – either from trials or, often more importantly, about the use of technologies in practice. The introduction of routine PROMs collection has potentially important implications for enlarging the base of real-world evidence on effectiveness and cost-effectiveness that NICE can draw upon to inform its guidance to the NHS.

One example is the evidence problems faced by NICE in its consideration of total hip replacement. In its *Guidance on the Selection of Prostheses for Primary Total Hip Replacement* (THR; National Institute for Health and Clinical Excellence 2000), NICE made a number of recommendations concerning the criteria that the NHS should use in selecting the best prostheses based on, for example, the rate of revision and the impact on patients' quality of life. However, the report also noted that 'specific recommendations on the selection of hip prostheses for primary THR are difficult to construct because the evidence base is generally poor and difficult to interpret' (p 6). It also pointed out that there were few long-term studies of effectiveness, and that there had been no assessment of the impact on effectiveness (and cost-effectiveness) of the interaction between the surgeon, the hospital team and other factors specific to individual interventions.

The NICE guidance went on to recommend further research to collect evidence of the long-term performance of hip prostheses and the impact on patients' quality of life, noting, however, that long-term evaluation would be costly and might inhibit innovation.

A key recommendation was the need to establish a United Kingdom-wide hip replacement registry that would collect details of hip operations for individual patients and so add to long-term data on the performance of hip prostheses. In 2002, the National Joint Registry (NJR) was set up and collects a range of information on patients' operations for knee as well as hip replacements (*see* Appendix 4, p 83, for an example of the information collected by the NJR). Although the NJR provides invaluable information that can enable, for example, poorly performing prostheses to be identified and withdrawn if necessary, it does not include information on patients' health-related quality of life.

Linking PROMs data on hip and knee replacements to the NJR data set (as is the intention) will provide a rich source of information on patients' own experience and assessment of the performance of their prostheses.

The NJR provides one example of the need to collect routine patient-based data on effectiveness, but the general issue of a lack of effective evidence applies to virtually all NHS activities and interventions. Moreover, the variation in outcomes arising from the day-to-day practice of individual clinicians and clinical teams, and the impact of particular hospital systems, are not restricted to hip operations but are, of course, issues that affect all operations and procedures. These and other factors also affect the cost-effectiveness of interventions.

The setting up and running of registries such as the NJR is one way to boost the evidence base for NICE to draw on, and the collection of PROMs data is another. As well as providing patients' own assessments of change in health-related quality of life (which can then be linked to clinician/hospital characteristics), the 'in the field' data supplied by PROMs also offer the possibility of computing cost per quality adjusted life year (QALY) ratios. In the absence of a patient-based costing system in the NHS, such cost-per-QALY calculations can be based only at the level of trusts (using, for example, the Healthcare Resource Group [HRG]-based National Reference Cost data collected by trusts). Nevertheless, even at this level, such data can add a real-world (and ongoing) dimension to evidence of effectiveness and cost-effectiveness derived from trials (*see* box on p 40).

The use of PROMs data in this way are, of course, subject to the important limitations and concerns we emphasised in 'Commissioners: provider performance and value-for-money'. That is, the analysis relies on the strong assumption that any change in PROM recorded is a direct reflection of the effect of treatment. Finding ways of overcoming this particular limitation of these data, and identifying and taking into account the 'counterfactual', is an important challenge for the future use of PROMs data in this sort of application.

The potential to derive cost-effectiveness ratios from PROMs data also raises the possibility that these data might be used to investigate the critical issue of the congruence between the cost-effectiveness threshold range used by NICE to inform its assessments of health technologies and the 'threshold' evident from decisions being made in the NHS about the funding and delivery of services. Attempts to identify the cost-effectiveness threshold in the NHS have been frustrated by a lack of cost-effectiveness evidence on many of the investment and disinvestment decisions being made in the NHS, along with a failure to regard cost-effectiveness as *the* (or even an) important consideration in commissioning decisions (Appleby *et al* 2009b).

The increasing availability and use of PROMs data by commissioners in assessing the effectiveness and cost-effectiveness of services will result in much more information on the comparative value-for-money of existing and potential new services.

## Concluding remarks

Throughout this review, we have identified a multitude of potential applications for PROMs data, each of which has the potential to lead to important improvements in service delivery and patient health. However, it is important to emphasise that PROMs data should be thought of as adding new patient-based insights that supplement, rather than replace, existing measures of quality and performance.

The PROMs being used in the NHS were developed for use in measuring patient or population health – with the aim of monitoring how health is affected by treatment, or changes over time. The instruments were not developed specifically for the purpose of hospital performance indicators – and the use by the NHS of these instruments as a basis for provider performance indicators is novel. Although the Department of Health has been extremely prudent in its piloting, testing and implementation of PROMs, as the scope of the programme expands it will be important that the development and testing of PROMs themselves is maintained so as to ensure that the data continue to provide robust and useful information. It is also equally important that data collection efforts are accompanied by the continued development of robust methods to ensure that performance indicators based on PROMs are isolating factors under the providers' control.

The development of methods is also important for ensuring that the NHS benefits from the much wider set of applications of PROMs data described in this report. For example, in the current financial climate, the development of analytical methods and decision-making approaches that identify opportunities for improving efficiencies in the delivery of services – or that can inform disinvestment decisions – will be especially important. An example of this is methods that use PROMs to form the basis of economic evaluation of NHS services. This use of PROMs data can help ensure that when difficult decisions are unavoidable, they are made in a way that does the least harm to patient health.

We have shown that PROMs have the potential to inform decision-making at all levels within the NHS:

- patients' decisions about their treatment

- commissioners' decisions about allocation of resources

- hospital management decisions about resources and technical efficiency

- decisions about the management and monitoring of patients in clinical practice

- high-level issues around output and productivity in the health system.

In each case, there is a need to ensure that the way PROMs data are analysed and reported are appropriate and useful. Overall, however, there is a need to assess the costs of collecting, processing and reporting PROMs data, and to consider these alongside the benefits of this new information.

But what is equally important is that decision-makers are prepared to *act* on the basis of these data. Ultimately, whether the NHS gets the most out of PROMs – and whether the benefits of the PROMs programme justify its costs – will depend on the willingness of policy-makers, commissioners, managers and clinicians to make tough decisions about services that are low quality, ineffective or poor value-for-money, and to promote practices and services that benefit patients the most.

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# Appendix 1: Example of a Department of Health PROMs questionnaire

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**NHS**

# Varicose Veins Surgery Questionnaire

## After your operation

About three months ago you had a Varicose Veins Operation. You may remember that you agreed that we could send you an *After your operation* questionnaire. Please can you fill in this questionnaire and return it using the provided pre-paid envelope. Thank you for your help.

**Q1. Is anyone helping you fill in this questionnaire?**

Yes □₁   No □₂

**If the answer is yes, please give the relationship to you of the person assisting you**

[                        ]

**Q2. What is your date of birth?**

[D|D] [M|M] [1|9|Y|Y]

A question about your current home circumstances

**Q3. Which statement best describes your living arrangements?**

I live with partner/spouse/family/friends □₁
I live alone □₂
I live in a nursing home, hospital or other long-term care home □₃
Other □₄

**Q4. Please confirm when your varicose veins operation took place (day, month, year).**

[D|D] [M|M] [2|0|Y|Y]

1

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Varicose Veins Surgery Questionnaire – After your operation

**Some questions about your surgery and your health**
Please mark the boxes below with a tick or numbers where appropriate.
If you are unsure about how to answer a question, please give the best answer you can.

**Q5. Did you experience any of the following problems after your operation? Please tick *Yes* or *No* for each problem.**

|  | Yes | No |
|---|---|---|
| Allergy or reaction to drug | □₁ | □₂ |
| Urinary problems | □₁ | □₂ |
| Bleeding | □₁ | □₂ |
| Wound problems | □₁ | □₂ |

**Q6. Have you been readmitted to hospital since the operation on your varicose veins?**

Yes □₁   No □₂

**Q7. Have you had another operation on your varicose veins?**

Yes □₁   No □₂

**Q8. In general, would you say your health is:**

| Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|
| □₁ | □₂ | □₃ | □₄ | □₅ |

**Q9. How would you describe the results of your operation?**

| Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|
| □₁ | □₂ | □₃ | □₄ | □₅ |

2

Varicose Veins Surgery Questionnaire – After your operation

**Q10. Overall, how are the problems now with your varicose veins on which you had surgery, compared to before your operation?**

| Much better | A little better | About the same | A little worse | Much worse |
|---|---|---|---|---|
| ☐1 | ☐2 | ☐3 | ☐4 | ☐5 |

The following questions relate to problems commonly associated with varicose veins. We appreciate that you may no longer have any visible varicose veins after your surgery but please try and answer each question as best you can.

**Q11. Do you have any visible varicose veins on your legs at the moment?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| Yes | ☐1 | ☐2 |
| No | ☐1 | ☐2 |

**Q12. If Yes, please draw in your visible varicose veins in the diagram(s) below. If No, please proceed to Q13.**

Legs viewed from front    Legs viewed from back
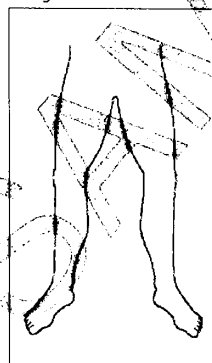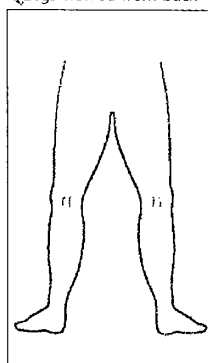
3

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Varicose Veins Surgery Questionnaire – After your operation

**Q13. In the last two weeks, for how many days did your varicose veins cause you pain or ache?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| None at all | ☐1 | ☐2 |
| Between 1 and 5 days | ☐1 | ☐2 |
| Between 6 and 10 days | ☐1 | ☐2 |
| For more than 10 days | ☐1 | ☐2 |

**Q14. During the last two weeks, on how many days did you take painkilling tablets for your varicose veins?**
*(Please tick one box)*

| | |
|---|---|
| None at all | ☐1 |
| Between 1 and 5 days | ☐2 |
| Between 6 and 10 days | ☐3 |
| For more than 10 days | ☐4 |

**Q15. In the last two weeks, how much ankle swelling have you had?**
*(Please tick one box)*

| | |
|---|---|
| None at all | ☐1 |
| Severe ankle swelling | ☐2 |
| Moderate ankle swelling (e.g. causing you to sit with your feet up wherever possible) | ☐3 |
| Severe ankle swelling (e.g. causing you difficulty putting on your shoes) | ☐4 |

4

Varicose Veins Surgery Questionnaire – After your operation

**Q16. In the last two weeks, have you worn support
tights or stockings?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| No | ☐₁ | ☐₂ |
| Yes, those I bought myself without a doctor's prescription | ☐₁ | ☐₂ |
| Yes, those my doctor prescribed for me which I wear occasionally | ☐₁ | ☐₂ |
| Yes, those my doctor prescribed for me which I wear every day | ☐₁ | ☐₂ |

**Q17. In the last two weeks, have you had any itching
in association with your varicose veins?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| No | ☐₁ | ☐₂ |
| Yes, but only above the knee | ☐₁ | ☐₂ |
| Yes, but only below the knee | ☐₁ | ☐₂ |
| Both above and below the knee | ☐₁ | ☐₂ |

**Q18. Do you have purple discolouration caused by tiny
blood vessels in the skin in association with your
varicose veins?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| Yes | ☐₁ | ☐₂ |
| No | ☐₁ | ☐₂ |

5

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Varicose Veins Surgery Questionnaire – After your operation

**Q19. Do you have any rash or eczema in the area
of your ankle?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| No | ☐₁ | ☐₂ |
| Yes, but it does not require any treatment from a doctor or district nurse | ☐₁ | ☐₂ |
| Yes, and it requires treatment from my doctor or district nurse | ☐₁ | ☐₂ |

**Q20. Do you have a skin ulcer associated with your
varicose veins?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| Yes | ☐₁ | ☐₂ |
| No | ☐₁ | ☐₂ |

**Q21. Does the appearance of your varicose veins
cause you concern?**
*(Please tick one box for each leg)*

|  | Right Leg | Left Leg |
|---|---|---|
| No | ☐₁ | ☐₂ |
| Their appearance causes me slight concern | ☐₁ | ☐₂ |
| Yes, their appearance causes me a great deal of concern | ☐₁ | ☐₂ |

**Q22. Does the appearance of your varicose veins influence
your choice of clothing including tights?**
*(Please tick one box)*

|  |  |
|---|---|
| No | ☐₁ |
| Occasionally | ☐₂ |
| Often | ☐₃ |
| Always | ☐₄ |

6

Varicose Veins Surgery Questionnaire – After your operation

**Q23. During the last two weeks, have your varicose veins interfered with your work/housework or other daily activities?**
(*Please tick one box*)

No ☐₁

I have been able to work but my work has suffered to some extent ☐₂

I have been able to work but my work has suffered to a moderate extent ☐₃

My veins have prevented me from working one week or more ☐₄

**Q24. During the last two weeks, have your varicose veins interfered with your leisure activities (including sport, hobbies and social life)?**
(*Please tick one box*)

No ☐₁

Yes, my enjoyment has suffered to a slight extent ☐₂

Yes, my enjoyment has suffered to a moderate extent ☐₃

My veins have prevented me from taking part in any leisure activities ☐₄

7

By placing a tick in one box in each group (Questions 25–29) below, please indicate which statements best describe your own health state today.

**Q25. Mobility**

I have no problems in walking about ☐₁

I have some problems in walking about ☐₂

I am confined to bed ☐₃

**Q26. Self-Care**

I have no problems with self-care ☐₁

I have some problems washing or dressing myself ☐₂

I am unable to wash or dress myself ☐₃

**Q27. Usual Activities**
(*e.g. work, study, housework, family or leisure activities*)

I have no problems with performing my usual activities ☐₁

I have some problems with performing my usual activities ☐₂

I am unable to perform my usual activities ☐₃

**Q28. Pain/Discomfort**

I have no pain or discomfort ☐₁

I have moderate pain or discomfort ☐₂

I have extreme pain or discomfort ☐₃

**Q29. Anxiety/Depression**

I am not anxious or depressed ☐₁

I am moderately anxious or depressed ☐₂

I am extremely anxious or depressed ☐₃

8

SAMPLE SAMPLE

Varicose Veins Surgery Questionnaire – After your operation

Q30. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Best imaginable
health state
100

Your own
health state
today

Worst imaginable
health state    9

Varicose Veins Surgery Questionnaire - After your operation

Q31. **Today's date (day, month, year)**

D D    M M    2 0 Y Y

Q32. **Do you consider yourself to have a disability?**

Yes          No

☐₁          ☐₂

Thank you for your assistance.

**Please return this questionnaire in the envelope provided.
You do not have to use a stamp – the postage is already paid.**

10

# Appendix 2: The EQ-5D-5L©

By placing a tick in one box in each group below, please indicate which statements best describe your own health state TODAY.

**MOBILITY**

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

**SELF-CARE**

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

**USUAL ACTIVITIES** *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

**PAIN / DISCOMFORT**

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

**ANXIETY / DEPRESSION**

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

**The best health you can imagine**
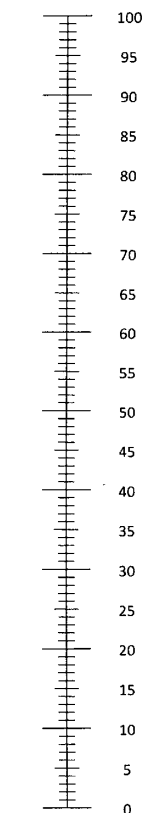
- We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.

- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.

- Mark an X on the scale that shows how good or bad your health is TODAY.

- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐

| 100 |
| 95 |
| 90 |
| 85 |
| 80 |
| 75 |
| 70 |
| 65 |
| 60 |
| 55 |
| 50 |
| 45 |
| 40 |
| 35 |
| 30 |
| 25 |
| 20 |
| 15 |
| 10 |
| 5 |
| 0 |

**The worst health you can imagine**

# Appendix 3: Example of an impact on daily living PROM used in the New Zealand points system for cataract surgery

The Royal Australian and New Zealand
College of Ophthalmologists
New Zealand Branch

N·Z·A·O

NEW ZEALAND ASSOCIATION
OF OPTOMETRISTS INC

## Visual difficulty with cataracts: impact on daily living
### Patient self-assessment

### Questions

> 1: How much does difficulty with your vision affect your personal safety?

> 2: How much does difficulty with your vision affect your personal care?

> 3. How much does difficulty with your vision affect your ability to fulfil your responsibilities to others, do meaningful things for yourself and others?

> 4. How much does difficulty with your vision affect your ability to interact with the world around you?

> 5. How much does difficulty with your vision affect your social interaction?

> 6. How much does difficulty with your vision affect your leisure activities?

### Considering the impact of your cataract on your life overall

7. How much trouble are you having with your vision?

8. How satisfied are you with your vision?

### Evaluation

9. Do the questions adequately reflect the impact of your cataract on your life?   Yes   No

10. How important is it to you that your Doctor considers the answers to these questions in assessing your priority for cataract operation relative to other people?

11. Was the questionnaire easy to use?

12. Comments: Do you have any suggestions about how this questionnaire might be improved?

# Appendix 4: Example of data collected by the National Joint Registry

## National Joint Registry
www.njrcentre.org.uk

| MDS VERSION 3.1 | Form. MDSv3.1 H1 v1.2 |
|---|---|
| Hip Operation | |

### H1 Hip Primary

Patient Addressograph

**Important:**
Please tick relevant boxes. All component stickers should be affixed to the accompanying 'Minimum Dataset Form Component Labels Sheet'. Please ensure that all sheets are stapled together

All fields are Mandatory unless otherwise indicated

| REMEMBER! MAKE A NOTE OF THE NJR REFERENCE NUMBER WHEN YOU ENTER THIS DATA | NJR REF. |
|---|---|

### PATIENT DETAILS

| | | | |
|---|---|---|---|
| Patient Consent Obtained | Yes ☐ | No ☐ | Not Recorded ☐ |
| Patient Hospital ID | | | |
| Body Mass Index (enter either H&W OR BMI OR tick Not Available box) | Height (IN CM) Weight (IN KG) | BMI | Not Available ☐ |

### PATIENT IDENTIFIERS

| | | | | |
|---|---|---|---|---|
| Forename | | | | |
| Surname | | | | |
| Gender | Male ☐ | Female ☐ | Not Known ☐ | Not Specified ☐ |
| Date of Birth | DD/MM/YYYY | | | |
| Patient Postcode | | Overseas Address ☐ | | |
| NHS Number (if available) | | | | |

### OPERATION DETAILS

| | | |
|---|---|---|
| Hospital | | |
| Operation Date | DD/MM/YY | |
| Anaesthetic Types | General ☐ Regional - Epidural ☐ | Regional – Nerve Block ☐ Regional – Spinal (Intrathecal) ☐ |
| Patient ASA Grade | 1 ☐   2 ☐   3 ☐   4 ☐   5 ☐ | |
| Operation Funding | NHS ☐   Independent ☐ | |

### SURGEON DETAILS

| | |
|---|---|
| Consultant in Charge | |
| Operating Surgeon | |
| Operating Surgeon Grade | Consultant ☐   SPR/ST3-8 ☐   F1-ST2 ☐   Specialty Doctor/SAS ☐   Other ☐ |
| First Assistant Grade | Consultant ☐   Other ☐ |

### HIP PRIMARY PROCEDURE DETAILS

| | |
|---|---|
| Side | Left ☐   Right ☐ |
| Indications for Implantation (select all that apply) | Osteoarthritis ☐ Trauma – Chronic ☐ Inflammatory Arthropathy ☐ Previous Hip Surgery – ☐ Congenital Dislocation / Dysplasia of the Hip ☐ non Trauma related Avascular Necrosis ☐ Previous Arthrodesis ☐ Trauma – Acute (Neck of Femur) ☐ Previous Infection ☐ Failed Hemi-Arthroplasty ☐ Other ☐ |

### SURGICAL APPROACH

| | |
|---|---|
| Patient Procedure | Primary Total Prosthetic Replacement Using Cement ☐ Primary Total Prosthetic Replacement Not Using Cement ☐ Primary Resurfacing Arthroplasty of Joint ☐ Primary Total Prosthetic Replacement Not Classified Elsewhere (eg Hybrid) ☐ |
| Consultant in Charge – Default Technique used? | Yes ☐   No ☐ If Yes, ensure the relevant Surgeon Default Technique is recorded on the Data Entry system. The Surgeon's Default Technique is made up of several data fields. |
| Patient Position | Lateral ☐   Supine ☐ |
| Approach | Hardinge ☐   Trochanteric Osteotomy ☐ Posterior ☐   Other ☐ |
| Minimally Invasive Technique Used? | Yes ☐   No ☐ |
| Computer Guided Surgery Used? | Yes ☐   No ☐ |

### THROMBOPROPHYLAXIS REGIME (intention to treat)

| | |
|---|---|
| Chemical | Aspirin ☐ Warfarin ☐ None ☐ LMWH ☐ Direct Thrombin Inhibitor ☐ Pentasaccharide ☐ Other ☐ |
| Mechanical | Foot Pump ☐ Other ☐ Intermittent Calf Compression ☐ None ☐ TED Stockings ☐ |

### BONEGRAFT USED

| | |
|---|---|
| Femur | Yes ☐   No ☐ |
| Acetabulum | Yes ☐   No ☐ |

### SURGEON'S NOTES

### INTRA OPERATIVE EVENT

| | |
|---|---|
| Untoward Intra Operative Event | None ☐ Shaft Fracture ☐ Other ☐ Calcar Crack ☐ Shaft Penetration ☐ Pelvic Penetration ☐ Trochanteric Fracture ☐ |
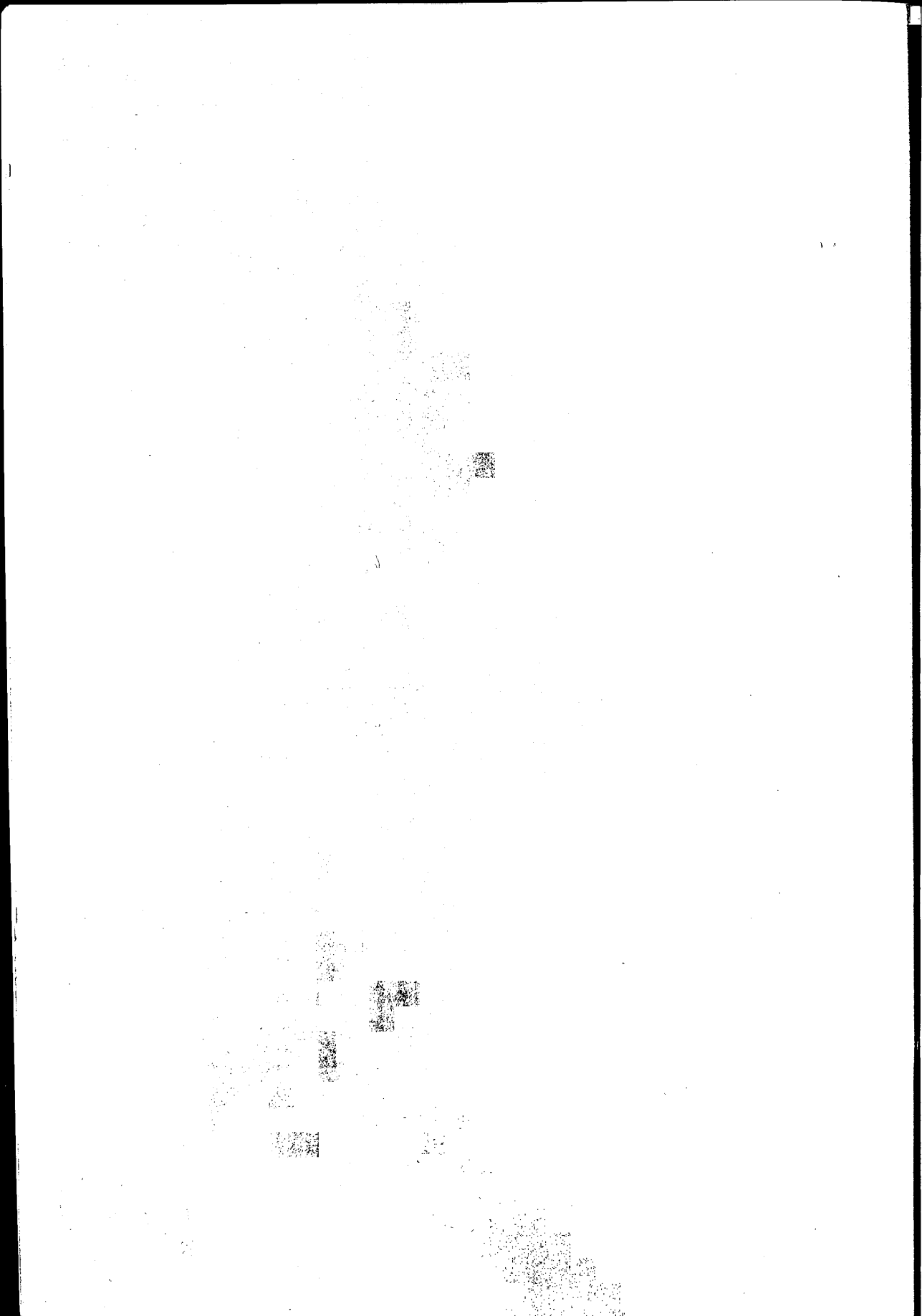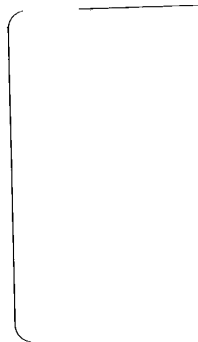
# The King's Fund>

**Ideas that change
health care**

More than 100 years ago Florence Nightingale suggested a health-related
outcome measure for her patients: relieved, unrelieved and dead. Despite the
developments in medical technology since then, attempts to measure the
positive outcomes of health care have been slow in coming. An important step
forward was made in 2009 when the English NHS began collecting patient-
reported outcome measures (PROMs) for four elective procedures. Using a
series of structured questions that ask patients about their health from their
point of view, PROMs are intended to enable the patient perspective to inform
decision-making at all levels of the NHS.

Evaluating the outputs of health care services is not straightforward as services
must be looked at in terms of their effects and not simply 'added up' to measure
what is produced. Traditional clinical ways of measuring health and the effects
of treatment are increasingly accompanied by PROMs. Although it is argued
PROMs should supplement, rather than replace, existing measures of quality
and performance, they are likely to become a key part of the way health care is
funded, provided and managed.

The aim of this report is to provoke and encourage thinking about the wide
range of ways in which PROMs data can be used to inform decisions. It draws on
Bupa's example to discuss how providers can use PROMs data to improve clinical
performance. It also offers practical advice for commissioners in using PROMs
data to assess value for money and decide how to purchase health care
systems. The report concludes by showing how measuring outcomes from the
patient perspective has the potential to lead to important improvements in
service delivery and patient health.