Using patient-reported outcome measures to assess health-care quality

The transparency of surgical outcomes data and the drive for quality has been highlighted since the public inquiry, led by Professor Ian Kennedy, into children's heart surgery at the Bristol Royal Infirmary. This was formalized in Lord Darzi's 2008 report *High Quality Care for All*, that proposed the NHS should: 'systematically measure and publish information about the quality of care'. Subsequently the NHS White paper, *Equity and Excellence: Liberating the NHS* (Department of Health, 2010), set out the ambitions and aims of the NHS and in particular that it should provide: '...a service that offers care that is safe and of the highest quality.'

Patient-reported outcome measures are standardized, validated questionnaires that are completed by patients to measure their own functional status and general health. They were originally designed for use in clinical trials (Fitzpatrick et al, 1998). Since 2009, wider use of patient-reported outcome measures within the NHS has been proposed to augment mortality data from Hospital Episode Statistics, which are considered an insufficient measure of quality.

However, controversies exist regarding the widespread implementation, data collection and interpretation of patient-reported outcome measures within the UK and internationally (Dawson et al, 2010). This editorial considers some of the relevant issues inherent in collecting and analysing patient-reported outcome measures data.

Introduction of patient-reported outcome measures

Many scoring systems and questionnaires have been designed both to assess treatment effectiveness in the context of research and to quantify patient perspectives of care outcomes. The validity of this later use remains somewhat controversial (Judge et al, 2011). The outcomes-based definition of patient-reported outcome measures distinguishes them from questionnaires used to measure patients' experience of the care process.

To date, patient-reported outcome measures data have been used in clinical trials, national audits (Williams et al, 2002) and registers for joint replacement (Malchau et al, 2005). However, since April 2009, it has been mandatory for NHS hospitals to collect patient-reported outcome measures data for four separate surgical procedures in the first instance: inguinal hernia repair, varicose vein surgery, hip and knee replacements. The aim is to achieve a quantifiable and transparent improvement in quality.

With the use in the context of audit and 'registers' to inform individual care and manage the performance of health-care providers, patient-reported outcome measures data are now becoming increasingly widespread at a local level as well as national level (Greenhalgh et al, 2005; Marshall et al, 2006).

Components of patient-reported outcome measures data

There are two principal components of patient-reported outcome measures data:

1. A measure of a patient's perception of his/her general health ('generic' health status)
2. The patient's perceptions of his/her health in relation to pathology ('specific' health status).

Patients complete patient-reported outcome measure questionnaires by rating their current health status in response to individual questions. Commonly used generic questionnaires include Short form 36, EQ5D, ASCOT and Perceived Impact of Problem Profile. Commonly used specific questionnaires include the Parkinson's disease questionnaire, visual function questionnaire and Oxford hip and knee scores. The individual ratings are combined, usually one generic and one specific, to produce an overall score to represent an underlying phenomenon or 'construct', such as 'perceived level of pain' or 'anxiety'.

The analysis of patient-reported outcome measures tends to focus on the amount of change that has occurred in the patient's condition or his/her general health-related quality of life, as represented by a change in patient-reported outcome measure score following an intervention.

The collection of patient-reported outcome measures data outside the remit of clinical research risks a lack of clarity and focus, which may in turn result in suboptimal data interpretation. Therefore clinicians and managers should be aware that the quality of both processes and outcomes can be audited (*Table 1*).

Collection of patient-reported outcome measures data

It is essential that there is a cogent reason for data collection and a defined duration of follow-up when no clear hypothesis or research question exists. Clearly stated inclusion and exclusion criteria will aid the standardization of data collection and interpretation. In addition, the data points

Table 1. Specific examples of the processes and outcomes that may be quantified with patient-reported outcome measures data

Processes	Communication: improved communication between patient and health-care provider
	Concordance: agreement between patient and health-care provider about problems and solutions
	Provider behaviours: changes in health-care providers' diagnosis and treatment of patient conditions
	Patient behaviours: patient self-efficacy, adherence and behavioural change
Outcomes	Patient satisfaction: patient-reported satisfaction with the consultation, treatment or care overall
	Health status: patients' health and wellbeing as indicated by clinical measures or patient reports
	Resource use: patients' subsequent use of health and other services

need to be clearly specified, e.g. are the data patient-specific or pathology-specific (i.e. one patient may have two arthritic knees).

The logistics of data collection should be clarified before the widespread implementation of patient-reported outcome measures, preferably with the use of a pilot study. In essence who, how, when and where is the data to be collected? In particular, has informed consent been obtained, is a written protocol available and is all the relevant documentation available in a variety of languages?

In order to minimize bias, mechanisms need to be in place to ensure that only the patients are responding. Further, the means of patient recruitment needs to be considered, e.g. including only patients attending the outpatients department risks selection bias, as there is likely to be a greater proportion of patients with problems attending. A mechanism is needed to reduce non-responders, incomplete or duplicated data. Finally, as with all confidential patient information, data storage must be secure, while remaining easily retrievable for analysis.

Potential benefits of patient-reported outcome measures data

The appropriate implementation and interpretation of patient-reported outcome measures data collection has several potential benefits. It can have a diverse role in altering how health problems are perceived and managed by patients and health-care providers. Patients are stimulated to present problems that concern them in addition to symptoms elicited in traditional consultations. Health professionals are encouraged to think beyond the conventional limitations in identifying problems and selecting solutions jointly with patients. There is also improved identification of goals and priorities over time between health professional and patients faced with complex, evolving and multifaceted problems. However, to date few academic studies have validated the role of the questionnaires currently used for patient-reported outcome measures data against these potential benefits.

Potential problems with patient-reported outcome measures data

The interpretation of patient-reported outcome measures data has an inconsistent impact on health status depending on the actual questionnaire used. For any single condition, the choice of patient-reported outcome measure questionnaire used will influence the study results. To increase provider understanding of patient needs, priorities and/or preferences, the most appropriate patient-reported outcome measures should be applied to accurately reflect these issues. However, the most commonly used patient-reported outcome measures currently only capture a single facet of patient health or were created without the involvement of patients. Therefore, they may not actually accurately reflect patients' needs, priorities and preferences (Higginson and Carr, 2001). For example, questions relating to sports activity are not relevant to most elderly patients. While numerous measures are available (see www.proqolid.org), care is needed to ensure the most appropriate choice of data capture is used.

Constraints on the number and focus of questions imposed by standardization may prevent patient-reported outcome measures data from addressing the issues that are most important to patients. Furthermore, patient-reported outcome measures data should be evaluated against potential impacts beyond provider actions and patient health status, e.g. is there an impact on patient–clinician communication?

Conclusions

Clinicians should question what goals are achievable with the routine use of patient-reported outcome measures data for a specific patient population and whether all the potential benefits (processes and outcomes) are being used. More multidimensional and individualized measures, although more difficult to interpret, may help patient-reported outcome measures to optimize patient-centred care (Marshall et al, 2006). Careful and thorough evaluation of patient-reported outcome measures will be required to ensure these tools enhance patient involvement (Greenhalgh et al, 2005).

The widespread introduction and interpretation of patient-reported outcome measures data is not straightforward and will require auditing at local and national level since the definite advantages remain unclear. **BJHM**

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KEY POINTS

- Patient-reported outcome measures are standardized questionnaires that allow patients to measure their functional status and general health.
- Patient-reported outcome measures are being used throughout the NHS to evaluate health-care quality.
- Processes and outcomes may both be audited with patient-reported outcome measures.
- To afford valid information, the choice of questionnaire and the methods used to collect and interpret the data are critical.
- The definite advantages of patient-reported outcome measures remain unclear.