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## **Utilising Patient Reported Outcome Measures (PROMs) in Improving Patient Care**

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## **Utilising Patient Reported Outcome Measures (PROMs) in Improving Patient Care**

### **Abstract**

There is continual pressure on healthcare providers to improve the quality of care and the effectiveness and efficiency with which clinical care is delivered. Patient Reported Outcome Measures (PROMs) are an effective mechanism for discerning high quality care and areas for improvement. Information obtained from PROMs is useful for gauging the patient experience as well as whether patients perceive their health outcomes have been achieved. Gastrointestinal nurses are well placed to determine the type of PROM to be used with their patient population as well as implementing changes to healthcare delivery subsequent to PROM data collection, assessment and evaluation.

### **Key words**

Quality of life, outcome measures, patient experience, questionnaires, quality care

### **Key phrases**

It is essential that the patient's perspective is discovered so that the quality of healthcare can be understood and improved.

Gastrointestinal nurses have a direct influence on patient experiences and outcomes of care and are in a prime position to lead on and contribute to the use of PROMs in improving patient care.

PROMS aim to capture and measure the patient's perspective of health status or health-related quality of life in a reliable, valid, acceptable and feasible way.

PROMs can be generic or specific.

The systematic use of PROMs can enable gastrointestinal nurses to improve patient outcomes.

## **Introduction**

There is continual pressure on healthcare providers to improve the quality of care and the effectiveness and efficiency with which it is delivered. These components are essential ingredients in improving the patient's experience. Quality of care, and how it should be measured and maintained, is a subject that has been actively addressed in the nursing literature since the 1980s (Hyrkäs & Paunonen-Ilmonen 2001). A number of clinical measurements are frequently utilised in measuring clinical effectiveness such as readmission rates, length of stay, infection rates and mortality and morbidity. This information, whilst useful, does not tell healthcare providers directly about the patient experience or whether the patient's health outcomes have been achieved. It is essential that the patient perspective is discovered in order that the quality of healthcare can be understood and improved (Hibbard 2003, Hermann et al 2004, Haywood 2006).

In 2008, the Department of Health announced that for the first time, patients personal assessments of the success of their treatment and the quality of their experiences would have a direct impact on the way hospitals are funded. As of 2008, funding has been based on a range of quality measures, including patient safety (safe, clean environments, reducing rates of hospital acquired infections etc), patient experience (the *quality* of caring e.g. compassion, dignity and respect) and the effectiveness of care both measured on key clinical indicators (mortality rates, complication rates

etc) and also from the patient's perspective (DoH 2008a). It is through the use of Patient Reported Outcome Measures (PROMs) that this data regarding the patients experience can be obtained. Gastrointestinal nurses have a direct influence on patient experiences and outcomes of care (Cox and Hall, 2007; Reay 2010) and are in a prime position to lead on and contribute to the use of PROMs in improving patient care. It is therefore vital that gastrointestinal nurses have an understanding of what PROMs are, how they are best utilised and importantly, how the data gathered can be used to discern ways to improve the patient experience.

### **PROMs**

PROMs aim to capture and measure the patient's perspective of health status or health-related quality of life in a reliable, valid, acceptable and feasible way (Fitzpatrick et al 1998, DoH 2008b). Most commonly they are standardised, validated questionnaires that are completed by patients to measure their perceptions of their own functional status and well being at a single point in time. It is definition of 'outcome measures' that differentiates them from PREMs (Patient Reported Experience Measures) which measure the patients experience of the care process (Dawson et al 2010, Reay 2010). Where questionnaires are not appropriate, other formats may be used such as interviews or focus groups (Reay 2010).

Until recently, PROMs have been used primarily in clinical trials (Grant et al 2008), national audits (Williams et al 2002) and national registers for conditions such as joint replacements and other conditions. Now the routine use of PROMs is beginning to be used more in healthcare at a local level. Since April 2009 all patients undergoing unilateral hip and knee replacements, inguinal hernia repair or varicose vein surgery are expected to be invited to complete a pre-operative PROMs questionnaire. The data are being used to improve the clinical quality of care.

A number of uses have been presented for PROMs in routine practice that may increase the nurse's awareness and ability to address patients concerns. Such uses include screening tools (Higginson & Carr 2001), as methods to identify patient preferences and inform decision making (Higginson & Carr 2001) and as a means to improve the nurse-patient relationship through communication (Higginson & Carr 2001, Gilbody et al 2003, Haywood et al 2006). A study by Velikova et al (2004) found an improvement in patient-provider interaction following the routine assessment of health related quality of life in cancer patients. Results such as these should encourage nurses to participate in investigations of PROMs as a method for enhancing the nurse-patient relationship (Haywood et al 2006).

Nurses working in gastrointestinal settings are taking on many advanced and autonomous roles (Cox and Hall, 2007). It is the implementation of these roles and continuous evaluation of their success which needs to be measured and maintained (Whiteing 2008). The challenge for the profession regarding these advanced roles and responsibilities is to put in place management systems that demonstrate their outcomes are as good as, or better than, those of doctors. PROMs are a way of doing this and could also protect nurses who are becoming involved in minor surgery and endoscopy (Maynard, 2006).

Box 1 illustrates the potential wider application of PROMs data to healthcare teams.

Insert Box 1 here.

### **PROMs tools**

Several types of PROMs tools are described in the literature. Perhaps the most useful distinction between tools are those that are *generic* and those that are *specific*. Generic tools are those that are widely applicable to patient populations and patients perceptions of their general health ('generic' health status). A widely used generic tool is the short form 36 [version 2](http://www.sf-36.org/) (SF-36v2) health survey which comprises 36 questions that assess self perceived health status relating to eight broad areas or dimensions of physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, vitality, pain and general health perceptions (<http://www.sf-36.org/>).

Generic tools have several advantages: they are suitable for use across a wide range of health problems and conditions. The data gained can be used to make comparisons between treatments for different patient groups and to compare effectiveness which is also useful in assessing the positive and negative effects of a new intervention. The generic tools can also be used to gather normative data in comparing different patient groups (<http://www.phi.uhce.ox.ac.uk>). This broad applicability means that specific data as related to a disease or condition is not obtained. Therefore generalisability to a specific population is limited.

Specific tools relate to a particular health problem or population. These tools can be broken down into disease/condition specific tools (measuring the patients perceptions of a specific disease or health problem), population specific tools (designed to be appropriate to particular demographic groups such as children or the elderly) and dimension specific tools (assessing one particular aspect of health status e.g. cognitive functioning or psychological well being) (Marshall et al 2006, <http://www.phi.uhce.ox.ac.uk>).

There are numerous PROMs tools that are designed specifically for use in gastrointestinal diseases including; celiac disease, neoplasms, faecal incontinence, gastroesophageal reflux, gastroparesis, inflammatory bowel disease, irritable bowel syndrome, liver diseases and peptic ulcer. Table 1 provides a few examples of specific tools that can be utilised for these diseases. These specific tools for gastrointestinal diseases enable clinically important changes in health resulting from interventions to be assessed. Only items or health dimensions that are relevant to the disease/condition are included. As these tools have a clear relevance to the patient it is felt that patients accept their use far more readily (Glise & Wiklund 2002, Greenhalgh et al 2005). One of the disadvantages to using such a specifically tailored tool is that health status scores cannot be compared with those for the general population as the tool can only be administered to those with the specific condition/disease. Subsequently the impact of the disease on general health status cannot be made. In addition the restricted focus of disease specific tools may prevent them from detecting side effects to treatments or unforeseen effects of treatment (<http://www.phi.uhce.ox.ac.uk>).

### **Choosing a PROM**

A number of factors must be considered when selecting a tool to be used. Factors include item content and appropriateness for the proposed application and population group (Haywood et al 2005, Dawson et al 2010). It is important to apply the necessary criteria to select the most suitable tool. Box 2 illustrates the eight criteria that should be considered in the selection of a PROM (Fitzpatrick et al 1998). PROMs are developed using clear processes and as such it is important that they are not altered in any way as even a small change in wording can make a considerable difference to the meaning of the questions and consequently the measurement properties (Dawson et al 2010, Reay 2010). If changes need to be made the tool must be retested against the eight key criteria for rigour. An appropriate tool is one which is supported by published evidence that



demonstrates it has met the eight criteria and will therefore be more likely to maximise the response rate (Dawson et al 2010).

Insert Box 2 here.

Choosing the right PROM can be challenging as there are a number of tools available. It may be that none seem entirely appropriate or they may consist of questions that are not relevant to your population group. It may be that in these circumstances the use of both a generic tool and a population or disease specific tool is required. Caution should be exercised in this approach as the importance of obtaining rich data from patients needs to be weighed against the risk of missing data owing to patients feeling overburdened by lengthy questionnaires and then not completing them fully (Dawson et al 2010).

### **Collecting Data**

The literature has indicated who is best placed to undertake formal PROMs assessment. Nurses are consistently seen as being the most appropriate practitioners to lead on PROMs due to their positive attitude to using and acquiring health related quality of life data (Gough & Dalgleish 1991, Meadows et al 1998, Greenhalgh et al 2005). PROMs are completed by patients by rating their health in response to individual questions which are scored according to the level of difficulty or severity reported by the patient. An overall score is obtained and represents an underlying experience such as perceived levels of pain or anxiety. It is not usually sufficient to collect PROMs data as a one off occurrence as this does not enable practitioners to monitor changes in the patient's health related quality of life (Greenhalgh et al 2005). Even when used for screening purposes, as suggested by

Higginson & Carr (2001), it assumes that treatment decisions can be made during a single consultation (Greenhalgh et al 2005). The analysis of PROMs tends to focus on the amount of change that has occurred in the patient's condition or their general health related quality of life that is demonstrated by a change on the overall PROMs score following an intervention (Dawson et al 2010). When using PROMs for patients undergoing a surgical intervention for example, it is important that there is consistency in when the PROM is administered. There should be a specified time for collecting preoperative data such as at the pre-assessment clinic or a week prior to surgery (etc) and post-operatively at certain time points such as 3 month and 6 monthly intervals, depending on the condition and procedure. Whilst some PROMs data are obtained at the patients' out-patient appointment this does pose several problems. Firstly, appointments are rarely organised to occur at precise points after a treatment or intervention and are frequently changed by either the patient or organisation. A higher attendance at out-patient appointments by patients with continuing problems may mean that more data is obtained from patients with poorer outcomes (Dawson et al 2010). All of these factors introduce bias to the data obtained. The DoH (2008) gives clear guidance as to when PROMs should be collected for the four previously specified areas. Patients may ask whether they should rate questions on how they are feeling on a 'good' day or a 'bad' day. Here again there needs to be consistency in instructions given by staff requesting the PROM be completed (Reay 2010).

PROMs questionnaires can be self-administered, interviewer-administered or telephone-administered. It is important that the user ensures that the tool is administered in the way for which it has been developed or validity will be affected. McColl et al (2001) found that interviewer and telephone administered questionnaires produced a higher response rate and lower levels of missing data than self administered postal questionnaires; however self administered questionnaires have a much lower cost.

Whilst PROMs are generally collected through the use of questionnaires, for some patient groups such as those that are unable to read or write or are housebound, and unable to post a questionnaire, this is not the best approach to gaining information. In these circumstances structured, semi-structured or unstructured interviews or focus groups can be used (Reay 2010). An advantage of interviews is that the practitioner may be able to gain much more in depth information of patients' outcomes or experiences.

It is important that PROMs collected truly represent the patient's views and not those of the healthcare team. Therefore staff should not be involved in the completion of questionnaires and caution should be exercised when using family members and friends to assist patients to respond to questionnaires. Assistance from a friend or relative is not ideal (due to the potential for introduction of bias) but may be unavoidable and indeed may be helpful at times. Dawson et al (2010) are quite clear that a patient's inability to understand a questionnaire, for reasons of impaired cognition or difficulty with the language in which it is available, should constitute exclusion criteria. PROMs are not widely available in a variety of languages as the cost of translation and re-evaluation is high. This can be problematic in areas serving populations with diverse language preferences. Furthermore, utilising an English language questionnaire and having a relative translate it is not acceptable as a true translation that maintains the correct meaning cannot be guaranteed (Dawson et al 2010). Despite these issues, PROMS as a whole, serve as a good means of assessing perceived outcomes so that changes to healthcare can be made where necessary.

## **Conclusion**

Obtaining patients views is vital if quality healthcare is to be ensured. Outcome measurement should not just be about the identification of potentially poor performance but should be about learning from and disseminating good practice between departments and facilities both locally and nationally. PROMs are a good mechanism for discerning good practice.

The evidence available on PROMS is generally positive, from both patients and providers, of healthcare. Therefore the Department of Health is encouraging their widespread use (DoH, 2008b). The systematic use of PROMs can enable gastrointestinal nurses to improve patient outcomes. Patient outcomes improve through information giving, changes in services, resource allocation and through greater communication which enhances the nurse-patient relationship. It is essential that PROMs are used appropriately so that useful, reliable and valid data are obtained. Gastrointestinal nurses need to ensure that they are equipped with the knowledge and skill necessary to participate in the selection, development and implementation of PROMs and to act on the information gained to improve patient care.

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**Box 1: the potential wider application of PROMs data (DoH 2008b:6)**

PROMs data can be used to:

- Evaluate the relative clinical quality of providers of elective procedures. PROMs data can be used by clinicians, managers, regulators and PCT commissioners to benchmark providers performance. It can be used for clinical audit and it can be used by patients and GPs exercising choice.
- Research what works. Efficacy and cost-effectiveness of different technical approaches to care can be evaluated using PROMs in association with other measures.
- Assess the appropriateness of referrals to secondary care. PROMs data can be used to establish whether referrals for elective procedures are appropriate by examining variation in baseline PROMs scores across the country.
- Support the reduction of inequalities
- Empower commissioners. PCT commissioners can use the data to establish the quality of services, which they are contracting with providers for.

**Box 2: PROM tool selection criteria, Fitzpatrick et al (1998).**

**Appropriateness:** is the instrument content appropriate to the questions which the application seeks to address?

**Acceptability:** is the instrument acceptable to the patients?

**Feasibility:** is the instrument easy to administer and process?

**Interpretability:** how interpretable are the scores of the instrument?

**Precision:** how precise are the scores of the instrument?

**Reliability:** does the instrument produce results that are reproducible and internally consistent?

**Validity:** does the instrument measure what it claims to measure?

**Responsiveness:** does the instrument detect changes over time that matter to patients?

**Table 1: Examples of digestive system disease specific PROM tools**

<b>Disease</b>	<b>Abbreviation</b>	<b>Full Name of Tool</b>
<b>Generic for digestive system diseases</b>	DHSI	Digestive health Status Instrument
	GIQLI	Gastrointestinal Quality of Life Index
<b>Celiac disease</b>	CDQ	Celiac Disease Questionnaire
<b>Digestive System Neoplasms</b>	GSRS	Gastrointestinal Symptom Rating Scale
<b>Faecal incontinence</b>	FISI	Faecal Incontinence Severity Index
<b>Gastroesophageal Reflux</b>	NBD Score	Neurogenic Bowel Dysfunction Score
	QOLRAD	Quality of Life in Reflux and Dyspepsia
	PAGI-QOL	Patient Assessment of Upper gastrointestinal Disorders-Quality of Life
<b>Gastroparesis</b>	GCSI	Gastroparesis Cardinal Symptom Index
<b>Inflammatory Bowel Disease (IBD)</b>	RFIPC	Rating Form of IBD Patient Concerns
<b>Irritable Bowel Syndrome (IBS)</b>	IBS-36	IBS-36
<b>Liver diseases</b>	CLDQ	Chronic Liver Disease Questionnaire
<b>Peptic Ulcer</b>	GSRS-self	Gastrointestinal Symptom Rating Scale-self-administered version

### Case Study

A group of nurse specialists working in a Colorectal Unit were experiencing pressure from senior management to demonstrate that they were providing efficient, effective high quality of care to the patients that were being seen in the Unit. The PET tracker was being used to monitor the patient experience throughout the Hospital; however monthly monitoring reports were not demonstrating the changes senior management wanted to see. It was essential that the patients' perspective was discovered so that the quality of healthcare the nurses were providing could be understood and where necessary improved.

The specialist nurses knew that efficient and effective high quality care were essential ingredients in improving the patient's experience. They also knew that there are a number of clinical measurements that are frequently used to measure clinical effectiveness such as readmission rates, length of stay, infection rates and mortality and morbidity. However this information, whilst useful, was not demonstrating whether the care they were providing contributed to improving the patient experience or whether the patient's health outcomes were being achieved – although the nurses knew anecdotally that the care they were providing did make a difference. They felt that they were well placed to implement use of a PROM with their patients in the Unit.

Following a review of the literature, the nurses decided that all patients with inflammatory bowel disease (IBD) would be asked to complete the SF-36v2 form before being seen by the nurse specialist and administered treatment, four weeks after being seen by the nurse and one year later. A one week recall could have been chosen as this provides more sensitivity to recent health changes, but the nurses knew that colorectal disorders like IBD can require long term treatment. The research administrator for the Hospital was consulted and following guidance from the administrator a research proposal was developed and submitted to the Hospital's Research Ethics Committee.

Following Committee review, approval was obtained to undertake the study. All patients with IBD were invited to take part in the study. An information sheet was provided for each patient indicating that they would be completing the SF-36v2 form. The sheet provided information on how confidentiality would be maintained and that they should not feel obligated to participate and could withdraw from the study at any time without giving a reason. If they chose not to take part in the study their care would not be compromised in any way. Each patient that chose to take part in the study was asked to sign a consent form indicating that they understood what the study involved and that they were happy to participate.

Over the period that the research was undertaken, 433 patients agreed to participate in the study. Each SF-36v2 form that was completed was given to the Hospital statistician who entered the data into the statistical data analysis package designed for analysing the SF-36v2. Results obtained from the analysis were compared with published data. The comparisons indicated that the nurse specialists' care was having a direct influence on the patients' experiences and outcomes of care. The SF-36v2 made it possible to capture and measure the patients' perspective of health status and health-related quality of life in a reliable, valid, acceptable and feasible way. Use of the SF-36v2 also provided a mechanism to review nursing care delivery in the Unit so that the nurses could focus on improving patient outcomes.