

Patient-reported outcome measures and patient-reported experience measures

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Key points

- Patients' perceptions of their health and experiences are key to providing excellent patient-centred care.
- Patient-reported outcome measures (PROMs) are questionnaires measuring the patients' views of their health status.
- Patient-reported experience measures (PREMs) are questionnaires measuring the patients' perceptions of their experience whilst receiving care.
- The data sets can be used for: research, quality improvement projects, clinician performance evaluation, audit, and economic evaluation.
- Limitations in the PROMs and PREMs questionnaires must be considered before implementing these tools.

Improving quality, service, and patient outcomes is an important focus for health care providers. The NHS outcomes framework to improve quality of care can be broadly divided into clinical effectiveness, safety, and patient experience.¹ There is an increasing support for the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in measuring the quality of care across all three areas and to guide service improvement.

What are PROMs and PREMs?

Patient-reported outcome measures

PROMs are tools used to measure patient-reported outcomes (PROs). PROMs are standardized, validated questionnaires that

are completed by patients' during the perioperative period to ascertain perceptions of their health status, perceived level of impairment, disability, and health-related quality of life.² They allow the efficacy of a clinical intervention to be measured from the patients' perspective. Questionnaires are given to patients both pre and post operatively to allow comparison of outcomes pre and post procedure.³ In addition to outcomes relating to interventions, PROMs measure patients' perceptions of their general health or their health in relation to a specific disease. PROMs are a means of measuring clinical effectiveness and safety.³

PROMs can be classified as either generic or disease specific. The generic tools measure a variety of aspects of a broad range of medical conditions, allowing for the overall evaluation of care, quality of life, and cost effectiveness of interventions.⁴ The disease specific PROMs allow individual aspects of a condition and their impact on outcome to be examined.² A combination of the two types of PROMs is often used. The EQ-5DTM, discussed in detail later, is an example of a PROMs tool (see Fig. 1).

Patient-reported experience measures

PREMs gather information on patients' views of their experience whilst receiving care. They are an indicator of the quality of patient care, although do not measure it directly. PREMs are most commonly in the form of questionnaires. In contrast to PROMs, PREMs do not look at the outcomes of care but the impact of the process of the care on the patient's experience e.g. communication and timeliness of assistance. They differ from satisfaction surveys by reporting objective patient experiences, removing the ability to report subjective views.

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Health Questionnaire

English version for the UK

Fig 1 EQ-5D™ and EQ-VAS™ combined questionnaire.

PREMs can be classified as either relational or functional. Relational PREMs identify the patients experience of their relationships during treatment, e.g. did they feel listened to. Functional PREMs examine more practical issues, such as the facilities available. The CARE measure, a relational questionnaire, is an example of a PREMs tool (see Fig. 2).

Why we need PROMs and PREMs

The information gathered from PROMs and PREMs has a number of uses: research, quality improvement projects, audit, and for economic evaluation. Data gathered helps to improve and focus patient-centred clinical management but also provides vital feedback to health care providers to allow comparisons in clinical care.

PROMs provide insight into the impact of an intervention or therapy on the patient, whilst PREMs provide insight into the quality of care during the intervention. The two are often used in parallel to present the patients' perceptions of both the process and outcome of their care.

Black *et al.*³ have shown there is a positive correlation between experience and outcomes and that patients can distinguish between clinical effectiveness, safety and their experiences. 'Patient outcomes can increase patients experience ratings by 10%, similarly improving patient experience ratings will cause a 3% improvement on outcome scores'.⁵ This highlights how inherently linked PROMs and PREMs are and their importance in helping to provide superior quality of care.

How to develop a PROMs and PREMs questionnaire

Choosing the right questionnaire may be hard and developing a new one even more challenging. The systematic review by Barnett *et al.*⁶ found a number of questionnaires existed to measure PROMs and PREMs during the perioperative period. Many however lacked appropriate psychometric testing and design to be able to determine their validity as measures of patient satisfaction.^{6,7}

There are a number of satisfaction questionnaires that have gained popularity such as the Quality of Recovery Score 40 (QoR 40)⁸ looking at return to function after surgery and the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)⁹ survey used to assess patient experience during

hospital encounters. Despite some validated surveys being published in the literature, adoption into daily practice is unclear.

The construction of a successful tool requires a defined psychometric development process and validation in practice.⁶ In order to produce a questionnaire for patients, it seems sensible to involve patients in each step of the development. A recent white paper from the American Society of Anesthesiology (ASA) suggests the following steps are undertaken when building a patient questionnaire (as summarized in Table 1).¹⁰

It may seem simpler to utilize questionnaires that already exist and have been validated, however, selecting questions from statistically validated surveys does not guarantee production of a new equally valid survey. Equally there is also no guarantee that combining surveys will yield a new validated 'super survey'. When constructing a new survey, utilizing questions and themes from previously validated surveys is more likely to produce something reliable and robust.

Using the correct PROMs and PREMs measurement tool

A number of PROMs and PREMs questionnaires have been developed; therefore choosing the correct tool can be difficult. The target patient group, content, reliability, and validity of the questionnaire should be considered, in addition to its prior use in a similar patient demographic.¹¹ A pilot of the questionnaire prior to commencing the PROMs or PREMs data collection is vital to identify inappropriate questions for the population.

There are a number of specialties that employ the use of both PROMs and PREMs to evaluate their patient management: rheumatology, paediatrics, respiratory medicine, and cardiology.¹²⁻¹⁵ There are few validated tools available for use in anaesthesia. A systematic review of patient-satisfaction measures in anaesthesia by Barnett *et al.*⁶ highlighted that a number of studies continue to use non-validated instruments potentially leading to erroneous results. The data from the recent Sprint National Anaesthesia Project (SNAP-1) may help in providing validated patient-reported outcome and experience data after anaesthesia.¹⁶ Data from SNAP-1, such as postoperative nausea and vomiting (PONV) rates, may allow individual trusts and clinicians to reflect and adapt their practices to improve patient outcomes and experience.

How PROMs and PREMs data can be collected

The majority of PROMs and PREMs questionnaires are given to patients in preoperative clinics at the point of initial contact (on-site feedback), with the postoperative form being posted to each individual participating in the data collection (post-contact feedback). The data should be collected at a pre-specified time point in relation to the event or disease being studied.¹⁷ The optimal timing to complete the questionnaire will vary with each disease and procedure. The target data are independent, patient perceptions of their health status and care; therefore questionnaires should be completed away from health care professionals, only aided by a friend or relative if required.

PROMs and PREMs can be distributed via email, telephone calls, and more recently text messages, giving instant feedback on patient care. Online surveys and face-to-face interviews can also be used to collect data.

Under each heading, please tick the ONE box that best describes your health 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

Fig 1 Continued.

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

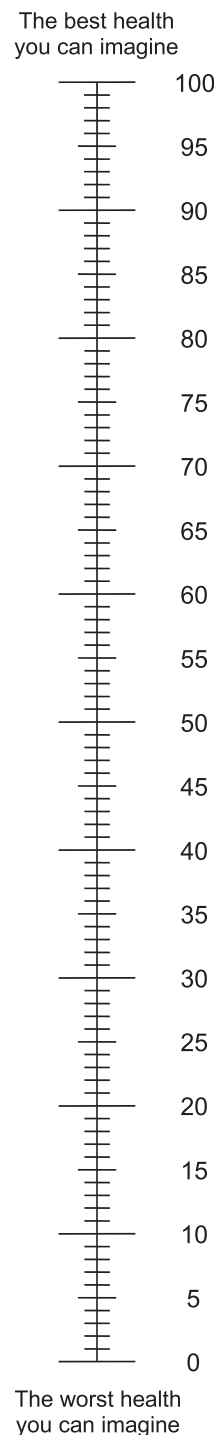


Fig 1 Continued.

How to use the PROMs and PREMs data sets

National use of PROMs

In 2009, the UK Department of Health launched a mandatory initiative to measure and improve clinical quality by collecting and reporting PROMs from four key surgical interventions: unilateral total hip and knee replacements, groin hernia repair, and varicose vein surgeries.¹⁸ In 2011, the government white paper 'Equity and Excellence: Liberating the NHS' highlighted that they would support clinicians to use PROMs across the NHS, recognizing that

patients' perception of their health and experiences are key to providing excellent patient-centred clinical care.¹⁹

A summary of uses for the PROMs and PREMs data sets can be found in Table 2.

How the current PROMs data set are measured

The patient's consent to participate in the PROMs questionnaire is obtained and the questionnaire given to the patient by hospital staff at the preoperative visit. The procedure should be

CARE Patient Feedback Measure for

Please write today's date here:

//

D D
M M
Y Y

Please rate the following statements about today's consultation.

Please mark the box like this with a ball point pen. If you change your mind just cross out your old response and make your new choice. Please answer every statement.

How good was the practitioner at...	Poor	Fair	Good	Very Good	Excellent	Does not apply
1) Making you feel at ease <small>(introducing him/herself, explaining his/her position, being friendly and warm towards you, treating you with respect; not cold or abrupt)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Letting you tell your "story" <small>(giving you time to fully describe your condition in your own words; not interrupting, rushing or diverting you)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Really listening <small>(paying close attention to what you were saying; not looking at the notes or computer as you were talking)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Being interested in you as a whole person <small>(asking/knowing relevant details about your life, your situation; not treating you as "just a number")</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Fully understanding your concerns <small>(communicating that he/she had accurately understood your concerns and anxieties; not overlooking or dismissing anything)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Showing care and compassion <small>(seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached")</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Being positive <small>(having a positive approach and a positive attitude; being honest but not negative about your problems)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Explaining things clearly <small>(fully answering your questions; explaining clearly, giving you adequate information; not being vague)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Helping you to take control <small>(exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing" you)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Making a plan of action with you <small>(discussing the options, involving you in decisions as much as you want to be involved; not ignoring your views)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: If you would like to add further comments on this consultation, please do so here.

© CARE SW Mercer, Scottish Executive 2004: The CARE Measure was originally developed by Dr Stewart Mercer and colleagues as part of a Health Service Research Fellowship funded by the Chief Scientist Office of the Scottish Executive (2000-2003).

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Fig 2 CARE (Consultation and Relational Empathy) measure questionnaire.

performed within 18 weeks of the questionnaire completion date, or a second questionnaire should be offered to the patient. The preoperative questionnaires are stored in a database by the contracted data suppliers responsible. The contracted data

suppliers are responsible for collecting the data and administering the postoperative questionnaires, working on behalf of the trust performing the PROMs procedure. Postal postoperative questionnaires are issued directly to the patient's home address

Table 1 ASA recommendations for building a patient questionnaire

Steps required for building a patient questionnaire	Method
Item generation	Gather the opinions of patient focus groups and relevant health care professionals. A literature search may be performed to help define what is considered important. Questions may be formulated and separated into dimensions within the questionnaire. A modified Delphi process may be used to help distil down relevant items and place them into dimensions
Construct a pilot questionnaire	The number of questions should be reduced to a pre-determined number. Questions should be amended for comprehensibility, skew and variability
Test the pilot questionnaire	The pilot questionnaire is tested for its reliability, validity and ease of understanding. There should be a clear description of how and when the questionnaire will be used. At this stage further questions may be removed that prove ambiguous or unnecessary
A revised pilot questionnaire	The revision is then written and tested in a different group of patients. This may be done by face-to-face interviews, written mail, over the telephone or electronically
Eliminate items that perform poorly	Reliability may be measured using statistical analysis such as Cronbach's alpha test, with an acceptable value of 0.7–0.95. Validity may be assessed utilizing multi-trait analysis and acceptability may be gauged looking at time to complete and response rates
Retest the final questionnaire	Once developed the questionnaire may be retested to determine that the scores continue to exhibit reliability and construct validity

Table 2 Summary of uses for the PROMs and PREMs data sets

How to use PROMs data set	How to use PREMs data set
To improve patients' ability to compare service providers quality of care	To provide feedback for health care professionals on quality of care
To determine the efficacy of clinical interventions	To improve the effectiveness of the processes of care
To determine the cost effectiveness of clinical interventions	To provide data to improve the current quality of service and offer patient-centred care
To identify triggers for surgery and potentially reduce burden on clinical services by limiting the numbers of unnecessary or ineffectual procedures	To allow management insight into patient expectations and redesign pathways accordingly to meet these
To provide clinician specific data sets on performance which support the revalidation process	
To allow comparisons of performance of trusts, thus allowing rewards for positive outcomes and quality care	
To provide data for clinical audit	

between 3 (for hernia and varicose vein surgeries) and 6 months (for hip and knee replacements) post procedure, to allow any effects from the operation to be identified. Reminders and repeat questionnaires are sent to patients that do not reply. A period of 6 months response time is allowed. Once received by the data supply contractors, the post-procedure questionnaires are linked to individuals' pre-procedure questionnaires in the database.

The Health and Social Care Information Centre, HSCIC, the body responsible for collating and publishing the PROMS data are updated on a monthly basis by the data supply contractors. The reports are published by HSCIC one year after the data collection period to allow time for all of the questionnaires to be collected. In all data sets for 2011–2012, 2012–2013, and 2013–2014 the response rates for both pre and postoperative PROMS questionnaires were over 70%.¹⁸ It has not been clearly defined what the minimum response rate should be for such surveys and more work needs to be undertaken in this area.

There is a specific set of questions offered to all patients' pre and postoperatively for the government mandated PROMs procedures (varicose veins, groin hernia, hip, and unilateral knee replacements). See Table 3.

Each patient is asked to complete a generic set of questions regarding their health status the EQ-5DTM and the EQ-VASTM. The EQ-5DTM is a standardized measure of health status and consists of a 5-stemmed descriptive system. The EQ-VASTM is a visual analogue scale allowing the patient to score their general health on a thermometer style scale. The EQ-5DTM and the EQ-VASTM can be seen as a combined document in Fig. 1. The descriptive system covers mobility, self-care, daily activities, pain, and anxiety.¹⁸ In addition, a condition specific questionnaire is given to each patient, e.g. The Oxford Hip Score (OHS) or Aberdeen Varicose Vein Questionnaire (AVVQ). The patient's perceptions of the outcome of the procedure and any complications encountered are also questioned in the postoperative data collection.

The OHS and the OKS were developed in 1996 and 1998, respectively. They were developed at the University of Oxford, to assess the outcomes of hip and knee replacements in randomized control trials, with their validity and reliability extensively tested over prospective studies. The now international use of OHS and OKS spans application to cohort studies, audit, and use in national registries. It is the most widely used patient-reported outcome measure in orthopaedics.

Table 3 National data set collected per PROMS procedure

Elective surgery (PROMS procedure)	Generic PROMS	Condition specific PROMS
Unilateral hip replacements	EQ-5D™ Index EQ-VAS™	Oxford Hip Score (OHS)
Unilateral knee replacements	EQ-5D™ Index EQ-VAS™	Oxford Knee Score (OKS)
Varicose vein	EQ-5D™ Index EQ-VAS™	Aberdeen Varicose Vein Questionnaire (AVVQ)
Groin hernia	EQ-5D™ Index EQ-VAS™	

EQ-Visual Analogue Scale (EQ-VAS).

The AVVQ was developed and validated by the health services research unit at Aberdeen Hospital, in conjunction with vascular surgeons. This tool allows patient self-assessment of varicose vein severity and appears in both national and international guidelines as key to case-by-case evaluation.

Limitations

The limitations of PROMs and PREMs must be considered by any health care organization embarking on implementing these tools to help guide their patient care. The correct measuring instrument, how the data are collected, the understanding by health care providers and cost are all key factors that need to be evaluated.

Choosing the correct tool to measure PROMs or PREMs for the specific population and the data to be collected is crucial. The tool must be validated for the data collected to have any meaning. A number of PROMs, in particular, have been originally developed for use in research methodology; their extrapolation to clinical practice may make interpretation of the data inaccurate.

Collecting the data poses additional challenges that should be considered. On site feedback collects data when the patients may not be in a physical or psychological state to give accurate opinions of their experience of health status, in addition to missing information relating to discharge and recovery. Patients may also be concerned about the negative impact of their answers on the care given by health care providers and adjust their responses accordingly. Post-contact feedback relies upon an adequate sample size of patients filling out the questionnaires, with potential for low-response rates. Time constraints may also affect the data collection process, with disruptions to outpatient and inpatient clinical encounters in order to distribute the questionnaires.²⁰ To reduce bias, completing the questionnaires at home, in the patient's own time may be beneficial.

Patient demographics can impact on the reliability of the data. The national PROMs data set collects patient identifiable information, however this is not used in analysis. In order to avoid skewed results nationally, statistical analysis is performed to adjust for variances in case-mix between providers.²

Translation of PROMs and PREMs questionnaires is frequently required to ensure all patients within our multicultural population are included in the data collection. However, the loss of meaning of the questions by literal translations, in addition to the cost of translation results in most questionnaires being translated for the patient by a translator or relative.¹⁷ Potential loss of data from certain patient populations as a consequence of this must be considered when interpreting results. In addition, surveys may exclude those with inadequate literacy, resulting in selection bias.

Identifying causal differences between patient groups can be difficult via questionnaires, with questions lacking depth to

allow thorough understanding and interpretation of the data collected.

Clinicians' knowledge and familiarity with PROMs, PREMs and how to use the data is important. Education programs may be needed to allow clinicians to utilize these instruments correctly and apply their data beneficially to their clinical practice.²⁰

Current health care resources are already stretched and so the cost of new data collection must be considered. Funding is required to develop the tool itself, provide training programs and implementation of these measuring instruments, as well as the cost of analysing the data. Cost maybe a limiting factor for some health care providers in using PROMs and PREMs.

Data collected from PREMs must be interpreted in conjunction with data from PROMs. Disparities in patient experience data compared to clinical effectiveness and safety data can occur and therefore it is important to remember patient experience is an indicator of quality, not a direct measure for it.

Experience in using PREMS and PROMS for service improvement

At University College London Hospital, we were recently awarded a grant by the Health Foundation as part of their 'Innovating for Improvement Programme', to develop a dedicated facility for the delivery of regional anaesthesia (Block Room).

As part of this new regional anaesthesia service we looked to deliver anaesthesia for our hand surgery service using nerve blocks alone with no sedation. Patients were offered the use of media for distraction, such as an iPad or music player, within the operating theatre as an alternative to sedation.

This change in service was assessed using a patient experience questionnaire, created and validated within our department. The result from our work indicated improved perioperative experience from patients receiving no chemical sedation, in comparison with patients that did receive sedation. The improvements were mainly as a result of earlier return to drinking/eating and a quicker time to discharge. Patients also expressed a greater feeling of control. As a result of this information, we now provide regional anaesthesia only hand operating lists, improving patient satisfaction and experience, in addition to delivering a more cost effective service. Utilizing PREMS and PROMS data in such a way can help to improve current clinical services and develop further services for both the benefit of the patients and the care providers.

Conclusion

PROMs and PREMs are useful tools that are increasingly being used to obtain data on patients' perceptions of their health and experiences whilst receiving care, with the aim of improving

quality of care. Choosing the correct measuring tool is vital to ensure validated, reliable data for the population is obtained. The limitations of PROMs and PREMs must be considered prior to implementing these tools.

Supplementary material

Supplementary material is available at *BJA Education* online.

Declaration of interest

None declared.

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MCQs

The associated MCQs (to support CME/CPD activity) can be accessed at <https://access.oxfordjournals.org> by subscribers to *BJA Education*.

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