

## A guide to Patient-Reported Outcome Measures

### Part one: Only the essentials

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Patients' can report their experiences with healthcare and assess the results that are achieved. These measurements can facilitate communication between patients and clinicians to develop care plans that are more likely to address individual needs. They can also assist managers and clinicians to continually improve systems of care. Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) focus on the outcomes and experiences that matter to patients - from their perspective. Different measurement options and tools exist to minimise the time and effort involved to collect and benefit from this important information.



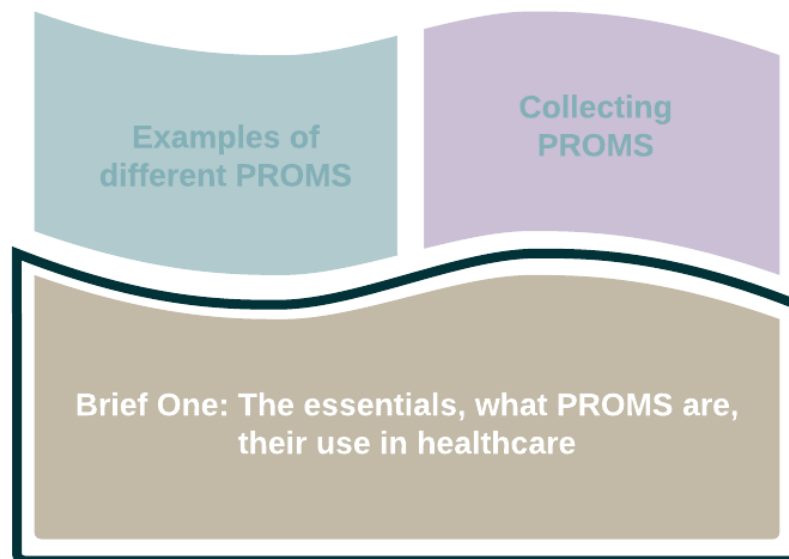
## Introduction

The collection, analysis, and reporting of patients' experience of healthcare, and of their self-reported health outcomes, is now a feature of more advanced healthcare systems around the world. This information is valuable for delivering, evaluating, and improving patient-centred healthcare.

**Incorporating this type of measurement into the South African healthcare system can facilitate shifts to value-based care. It sharpens the focus on patients' perspectives and priorities, producing data that can be utilised by frontline clinicians and by managers to improve both the healthcare system and patients' quality of life.**

This brief explores the purpose (the “**why**”) behind the measurement of Patient-Reported Outcomes (PROs) and describes the tools (the “**what**”) that are available. The intended audience, and the beneficiaries (the “**who**”), are clinicians, managers, and policymakers, working for and with patients and families. The context for this brief (the “**where**”) is Primary Healthcare (PHC) services in the South African public sector. Suggestions for getting started (the “**how**”) in our specific context are provided. This brief is the first in a series of three briefs.

**Figure 1: This brief in the context of the PROMs briefs series**



## “WHY” this is important

Patient-Reported Outcomes (PROs), Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) provide new insights into how healthcare services are being delivered, and into their effectiveness, at both a patient and a system level. This feedback enables adaptation and adjustment of everyday care, and of the system as a whole. It prioritises positive experiences and outcomes to make healthcare more person- or patient-centred.

**In clinical practice**, patient-reported outcome measurement can facilitate communication between patients and clinicians and the development of care plans that are more likely to address individual needs, preferences, and values.

PROs can also help identify patients who need additional support or a change in treatment regimen by assessing changes in symptoms and quality of life throughout the treatment process – the patient journey.

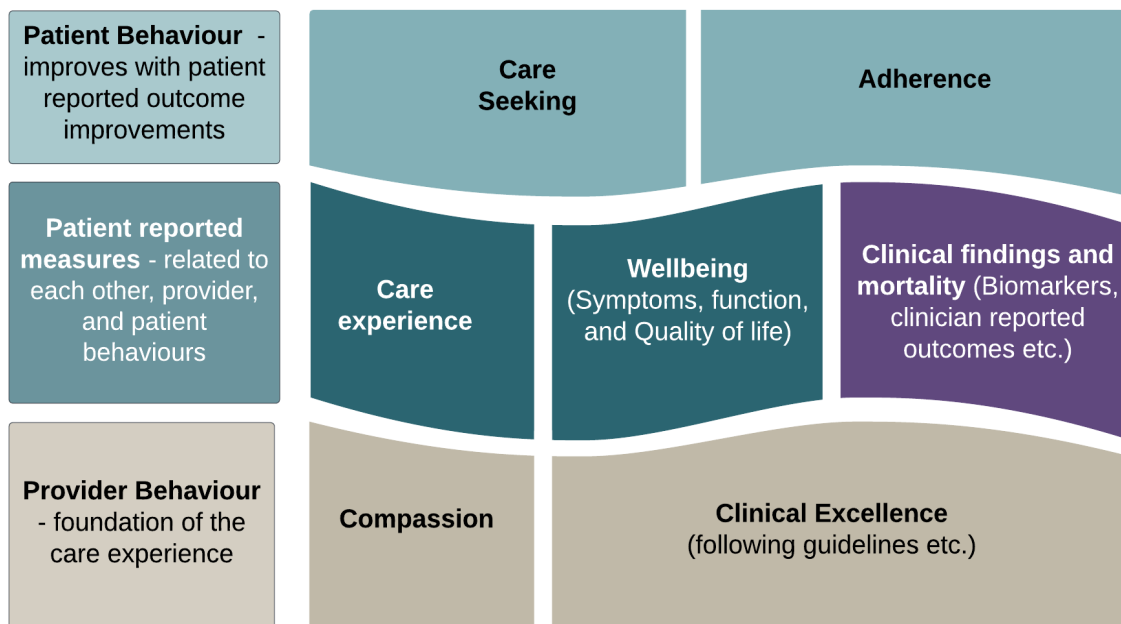


*Nurse Dlamini at CHC A reviews the two-question PHQ-2 that is completed by each new patient when they are initiated on ART and at monthly clinic visits during the first six months of treatment. She notices that Henry Radebe\*, a 35-year-old office worker has had a consistent dip in the score for the last two months and points this out to Doctor Gumede. In Henry's next clinic visit, Dr Gumede asks Henry whether he feels low; he confirms this. She asks more questions to assess the severity of the depressive state (e.g., suicidal ideation) and offers a referral to a mental health counsellor the following week which Henry gratefully accepts.*

**At a system level**, information from PROs enables bottom-up accountability and prioritisation of patient voices.

- It can help set policies for health service provision, payment and drive innovation, redesign, and quality improvement at all levels, from the clinic up
- Cost-effectiveness can improve; shared decision-making with well-informed patients is associated with lower rates of utilisation of low-value tests or procedures and higher rates of reliably beneficial care<sup>1</sup>
- Better care experiences are associated with greater adherence to prescribed treatment and may increase overall health service uptake, positively impacting health outcomes

**Figure 2: Patient-reported measures in the clinical space**



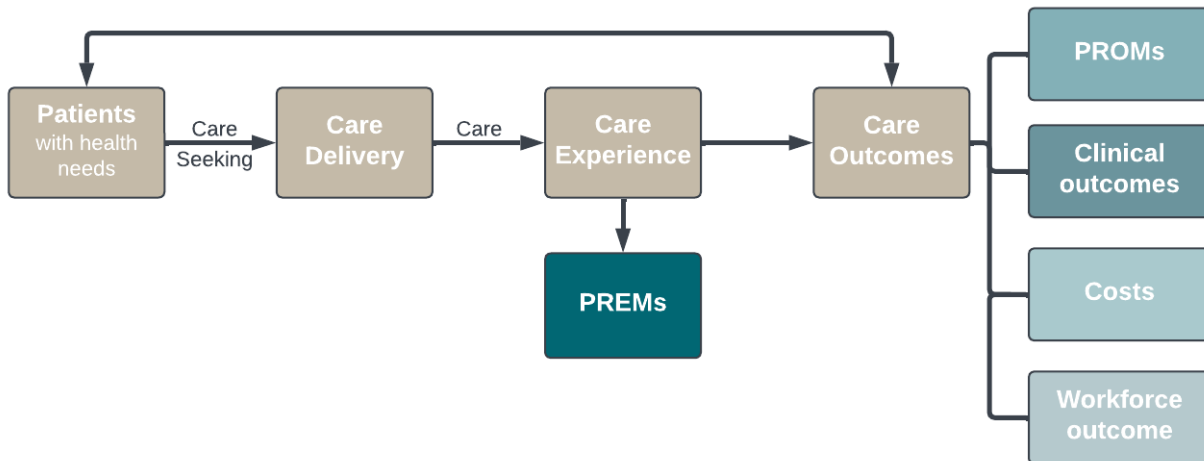
Patients are the start and end point of the healthcare flow diagram shown in Figure 3. They have health needs and seek medical assistance (“care delivery”) from healthcare providers - doctors, nurses, therapists, pharmacists, and others. “Care experience” represents patients’ perception of the care that is provided, including consultations, treatments, surgeries, and follow-ups. The care experience leads to “care outcomes”, which can be split into categories of clinical and patient-reported outcomes, cost and workforce outcomes, which are also critical; good healthcare relies on the wellbeing of the people who provide care, which is increasingly at risk, with high rates of burnout locally and globally. Budgets are finite and system managers are tasked with controlling them, and maximising value, defined as the ratio of health outcomes to the funds spent. Clinical outcomes include the tangible and measurable results of the healthcare provided such as

\*Pseudonym



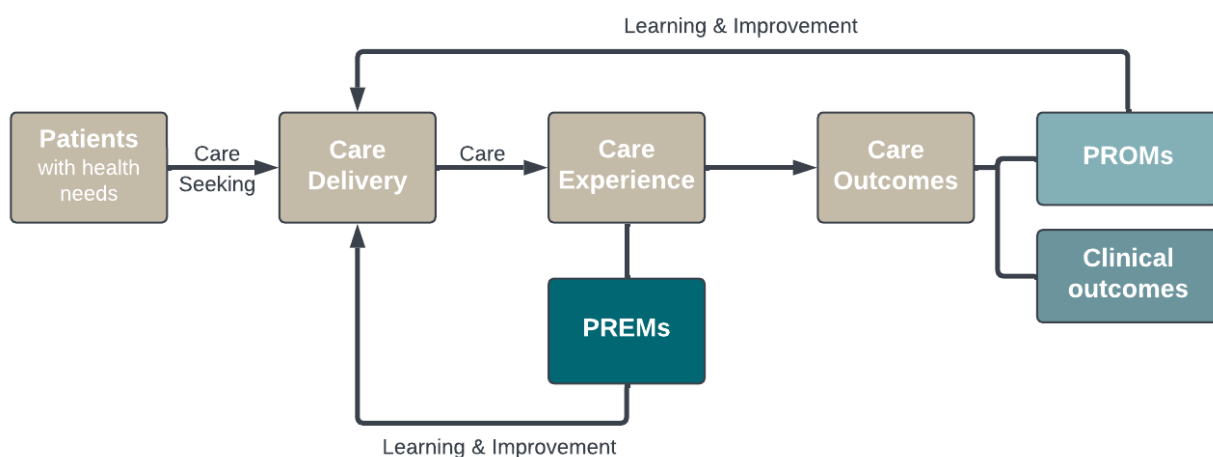
recovery rate, mortality rate, complication rate etc. Arrows leading back to the patient indicate that the outcomes of the care process ultimately affect patients' health status and future healthcare needs.

**Figure 3: Impact on health status and future healthcare needs**



The model in Figure 3 has other feedback loops shown in Figure 4. The arrow from outcomes back to care delivery indicates that studying and learning from the outcomes of services (“care outcomes”) is used to improve future healthcare delivery. The arrow from healthcare experience (and PREMs) to care delivery (healthcare providers) also represents feedback leading to improvement. This model simplifies a complex system, and many other elements could be included, such as policies, personnel and technologies. The key point is that measurement (PREMs and PROMs) is incorporated in workflow and used for learning and improvement of care delivery - both care for an individual patient and the organisation of care for groups of patients with similar needs.

**Figure 4: Further impact on health status and future healthcare needs**



## “WHAT” are PROs, PROMs and PREMs

**Patient-Reported Outcomes (PROs)** are about aspects of health that really matter, and are most meaningful, to patients. From a patient perspective, one can argue, only two health outcomes count – living longer and living better; PROs are about the living better part. By definition these things are observed and communicated by patients rather than by healthcare professionals.

**Patient-Reported Outcome Measures (PROMs)** are how we reliably measure PROs, quantifying key symptoms, their impact on daily living, and the physical or emotional burden of illness, including the overall



effect on health-related quality of life (HRQoL). Examples: EQ5-D and WHO-BREF (Table 1).

**Table 1: Examples of PROMs**

Patient-Reported Outcome Measures (PROM)	Description
<i>EuroQol Five-Dimension Questionnaire (EQ-5D)</i>	A generic measure assessing health-related quality of life across five dimensions.
<i>Short Form Health Survey (SF-12)</i>	A questionnaire measuring health status and quality of life across eight domains.
<i>Patient Health Questionnaire (PHQ-2 and PHQ-9)</i>	A self-administered diagnostic tool and severity measure for depression.
<i>Generalized Anxiety Disorder 7-item scale (GAD-7)</i>	A brief measure for screening and assessing the severity of generalised anxiety disorder.
<i>Visual Analogue Scale (VAS) for pain</i>	A simple scale for patients to rate their pain intensity.
<i>Functional Assessment of Cancer Therapy (FACT) scales</i>	A family of questionnaires evaluating health-related quality of life in patients with various types of cancer.
<i>Patient-Reported Outcomes Measurement Information System (PROMIS)</i>	A comprehensive set of tools measuring diverse health domains, such as physical function, emotional distress, and social well-being.
<i>Oswestry Disability Index (ODI)</i>	A questionnaire assessing functional disability in patients with low back pain.
<i>Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)</i>	A measure evaluating pain, stiffness, and physical function in patients with osteoarthritis of the hip or knee.
<i>International Prostate Symptom Score (IPSS)</i>	A questionnaire assessing the severity of lower urinary tract symptoms in men with benign prostatic hyperplasia (BPH).
<i>World Health Organization Quality of Life-BREF (WHOQOL-BREF)</i>	A shortened instrument measuring quality of life across four domains: physical health, psychological health, social relationships, and environment.

**Patient-Reported Experience Measures (PREMs)** assess patients' perceptions of the care received, i.e., the healthcare experience. They capture aspects such as communication, responsiveness, timeliness, the healthcare environment and overall satisfaction with care.

**Table 2: Examples of PREMs**

Patient-Reported Experience Measures (PREMs)	Description
<i>Consumer Assessment of Healthcare Providers and Systems (CAHPS)</i>	A family of surveys assessing patient experiences with healthcare providers and health plans in various settings, including hospitals, clinics, and home care.



Patient-Reported Experience Measures (PROMs)	Description
<i>Picker Patient Experience Questionnaire (PPEQ)</i>	A set of surveys designed to evaluate patient experiences across various healthcare settings, focusing on areas such as information provision, emotional support, and involvement in decision-making.
<i>Friends and Family Test (FFT)</i>	A simple feedback tool that asks patients whether they would recommend the healthcare services they received to their friends and family.
<i>Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)</i>	A standardised survey measuring patients' perspectives on hospital care, including communication with providers, responsiveness, and cleanliness.
<i>The Outpatient Experiences Questionnaire (OPEQ)</i>	A questionnaire assessing patients' experiences with outpatient care, focusing on areas such as waiting times, provider-patient interaction, and information provision.
<i>European Practice Assessment (EPA)</i>	A comprehensive evaluation tool for assessing quality and patient experiences in primary care practices, covering aspects like access to care, communication, and patient involvement.
<i>The National Cancer Patient Experience Survey (NCPES)</i>	A survey measuring the experiences of cancer patients in the UK, covering various aspects of care, including diagnosis, treatment, and support services.
<i>The Ambulatory Care Experiences Survey (ACES)</i>	A questionnaire assessing patient experiences with ambulatory care providers, focusing on aspects such as access to care, communication, and coordination of care.
<i>Net Promoter Score (NPS)</i>	A simple metric used to gauge patient loyalty and satisfaction by asking how likely they are to recommend a healthcare provider, facility, or service to others.

## Measurement Methods

The move toward routine implementation of PROMs and PREMs has been facilitated by two important technical advances:

- **Digital platforms**, including mobile applications and online surveys, which offer an efficient, cost-effective way to gather data. They afford convenience, versatility, and instantaneous feedback
- **Standardised, scientifically validated instruments** have become available for gauging symptoms, functional status, and overall wellness

Even in low-resource settings, networked mobile technologies (cellphone-based) are now available and relatively affordable. They facilitate a swift transition to this model.

Without digital tools, integration of patient-reported outcomes is still worth pursuing and can be done on **pen and paper**.

**Patient interviews**, whether structured or semi-structured, provide a valuable path to deeper insight into patients' health experiences and outcomes, however, these methods are not the focus here.

Lastly, it's important to say that measuring and sharing patient-reported outcomes is not intended to replace **human interaction, conversation, and careful listening**. The measurements are complementary and synergistic; clinical relationships can be enriched when this information is available for both patients and health professionals to consider.



# Are PROMs practical in a high-demand public health setting?

## Information Box 1: PROMs at work

*Adelaide Adams is a 55-year-old patient, recently widowed and struggling with obesity and type 2 diabetes. While waiting to see the doctor at the clinic, Adelaide completes a PROM questionnaire, a tool to tailor her care plan for her specific needs.*

*Adelaide's HbA1c level is significantly elevated and graphs show her blood glucose levels have been consistently high over the past 12 months. Her PROMs responses provide the doctor with more detailed information including her struggle to understand her condition and its management. Her responses suggest a lack of knowledge about the relationship between diet, exercise, and blood glucose levels. She mentions feeling overwhelmed with the dietary restrictions and unsure about how to incorporate regular exercise into her routine.*

*On enquiry, the doctor learns that Adelaide has been stressed at work in the last two months. Her PROMs responses also highlight some of the psychosocial aspects of living with diabetes management. In discussing her PROMs, Adelaide opens up to her doctor. Adelaide reports feelings of depression and isolation, which could be impacting her motivation to manage her diabetes effectively. She mentions feeling like a burden to her family, including her two adult children. Adelaide reveals she has been skipping or rationing her medication, because she hasn't had time to attend the pharmacy to collect them, which could explain her high HbA1c levels. She also says that purchasing healthy food often feels out of her budget, contributing to a diet that's not optimal for diabetes.*

*These insights from Adelaide's PROMs can support the doctor to create a more tailored, comprehensive care plan, bringing in the resources of the diabetes educator, psychologist, and social worker to support Adelaide in managing her diabetes more effectively.*

*At the regular weekly team meeting and monthly review of the PROMs for all the clinic's diabetes patients, the team become aware that Adelaide's challenges are common, and suggest a clinic initiative to provide more support to her and other patients. The social worker steps up, offering resources on assistance programs and coordinating with local NGOs. The psychologist suggests integrating mental health support into the care plans, providing a more holistic approach to patient care. The dietician reports that many patients struggle with managing their diet and exercise and proposes group classes or workshops which may not only be effective but also free up more time to devote to the individual patient visits to solve the more complex problems and build long term clinician-person relationships.*

*United in their mission, the team is dedicated to making a significant difference in their patients' lives, one step at a time.*

In the example in Information Box 1 we see a practical example of how PROMs questions can be used when treating diabetes. This only works if the PROMs are practically usable. In other primary care settings, such as the treatment of tuberculosis in India, PROMs have been used but had to be adjusted for practicality. Projects succeeded by developing their own tools to balance needed insightfulness with the feasibility of routine data collection. These tools were refined with extensive patient feedback in iterative field testing. While this appears to be a complex process it can be as simple as setting up the weekly team meeting and monthly PROM measure review shown in Information Box 1.

**Barriers to the adoption of PROMs in clinical practice have been noted<sup>2</sup> but experience is growing, along with enthusiasm for incorporating these measures into everyday practice. Some common criticism is explored below:**

### **1. Clinicians often believe they already have all the necessary information from their patients without the use of PROMs**

The literature suggests that a lot goes missing in the standard approach to practice; PROMs can reveal important information that is overlooked in a typical, hurried, consultation visit. In addition, patients may be reluctant to tell their doctor about certain symptoms or problems during a face-to-face conversation, and more likely to report them if asked in a format such as a PROM.



## 2. Clinicians find it difficult to assess meaningful differences when PROMs are measured

A recent poll of experts on PROMs found that patient-reported outcome measures are not very different from a whole range of clinical measures that people use all the time in practice, such as weight or blood chemistry values. However, unlike other measures, there is no single number or target value the measures should produce. This is because PROMs are by their nature subjective and depend on many factors that come from the patient. Additionally, a low score can tell you even more than a high score, so clinicians need to be interrogating the results, irrespective of the values achieved.

## 3. This is not research; these PROMs are too long and detailed

Shorter, more focused PROMs can be used to overcome some of the challenges associated with longer ones that often were created for clinical research rather than a clinical context.

## 4. Clinicians are uncertain about how to use PROMs

Clinicians can use PROMs as an entry point for conversations with patients, rather than as a definitive yes/no for intervention. By getting familiar with a set of questions that are meaningful to their practice and learning how they work best with different patients, PROMs can be used to improve alignment of the patient's goals with the physician's goals.

**Three take home messages for clinicians who wish to understand and implement PROMs in practice:**

1. Information from patients can easily be missed in patient-clinician visits that could turn up instead in a PROMs questionnaire
2. PROMs are best thought of as an entry point for conversations with patients rather than definitive calls for intervention
3. Get familiar with a set of questions that are meaningful to the individual practice and learn over time how they work best with different patients

**The suggested goal is to use PROMs as an entry point to conversations with patients and to learn over time how they work best with different patients. In this way, clinicians can improve the quality of care they provide and ensure that the patient's goals are aligned with the physician's goals.**

## Conclusion

In this brief, we have briefly described what PROMs and PREMs are and how they can benefit the patient, provider and system as a whole. PROMs need not take up lots of time and don't require digital tools, although digital systems make them easier to administer. In the second issue of this series, we provide examples of PROMs for the Western Cape's five priority areas (maternity, violence and trauma, tuberculosis, diabetes, and mental health) to support the Department in thinking through where and when to begin. In the third and final brief, we describe how to get started on implementing PROMs and PREMs.





## References

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