

A guide to Patient-Reported Outcome Measures

Part two: How to get started

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This second brief of the series delivers a starting point to implement patient-reported measures. Design principles and considerations, as well as the challenges they may give rise to, are further explored. Finally, practical approaches to bridging such challenges are explored.



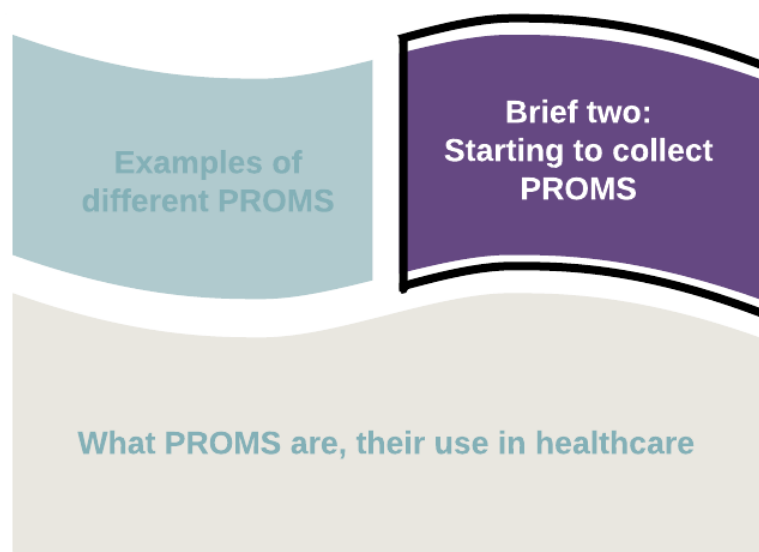
Introduction

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 second brief explores how to start using PROMs in the South African public primary healthcare setting.

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



Getting started

Developing a vision

Primary care services could develop a set of aims, and a vision statement, to highlight the potential impact of incorporating patient-reported outcomes into their clinical and management activities.

*The measurement and use of patient-reported outcomes will be used **to support and improve systems:***

- *Supporting innovation, design and improvement, and surfacing of best practice*
- *System managers using PROMs to respond to population needs and expectations*
- *Supporting assessment of the quality and value of healthcare*
- *Designing and monitoring effects of large-scale system reforms*

*The measurement and use of patient-reported outcomes will be used **to improve patient care:***

- *Clinicians will use PROMs to identify and treat groups of patients with common healthcare needs*
- *PROMs will be used alongside data from clinically assessed outcomes*
- *Complementing and supporting therapeutic relationships that remain at the heart of personalised, careful and compassionate medical care*



*The measurement and use of patient- and staff-reported outcomes will help be used **to rebuild professional purpose and wellbeing:***

- PROs and PROMs will help rebuild trust and motivation of HCWs by aligning the system's performance goals with their professional purpose

*The measurement and use of patient-reported outcomes will **give patients their voice and promote value that is aligned with patient needs:***

- Empower health-seekers (patients) to drive quality
- Ensure that financial decisions (cost cutting, or spending) align with results valued by patients

The measurement and use of patient-reported outcomes will be part of routine healthcare delivery for individual patients and populations, and become an essential contributor to healthcare system assessment, innovation and improvement.

Design considerations and principles

Make it easy (and free!) for patients to complete PROMs and PREMs. This may mean a guarantee of zero cellphone data costs for patients. Additionally, high response rates to the surveys used to collect PROs are most likely when patients understand that this data is used by their own doctors and nurses to improve their care.

Make it easy for clinicians. The aim, minimal or zero involvement and effort required from clinicians: “seamless workflow”. The measurements should be available to every health professional with whom the patient interacts, in an effortless way; like a lab result with the data presented because it is important for clinical decision making. Taking visible action on the information that is provided helps build trust. “Close the loop” with patients. Collecting data (“feedback”) which is not acted upon erodes trust. Continually explain the “why” to patients - give feedback or health information at every interaction. Explain that the doctors and nurses need this information.

Use existing resources for the “logistics”. Work with the provincial data centre. Patient/facility identifiers including QR codes for each clinic/facility. Work with the Provincial call centre. Unique identifiers for each individual.

The ideal PROMs tools are open source. Choose existing, open-source measures such as those offered by WHO, PROMIS and public agencies. PROMs licensed for commercial use can have high license costs, but public health systems may qualify for use without charge. Keep quality high by using the COSMIN criteria to evaluate measures.

Design for inclusion and equity to include vulnerable patients, patients with low literacy and low service expectations.

Permit health proxies – family members or other caregivers – but record when they are the source of data.

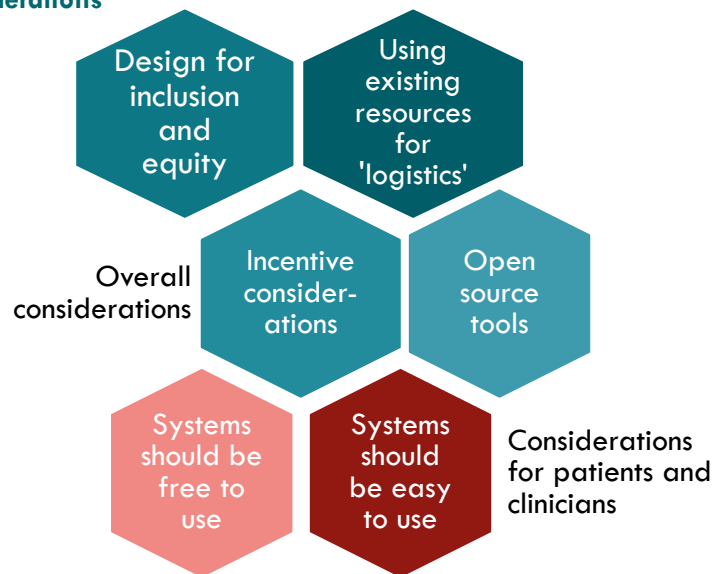
Include in the programme **simple measures that could be applied at scale** regardless of disease or health status such as one simple question - “Did we meet your need for care today” or the Net Promoter Score (NPS) - used in “exit surveys”.

Think about incentives (e.g. free data) but watch out for unintended consequences - the risk of gaming the system and contamination of the measurement.

These design considerations and principles are summarised at the patient, clinician, and overall level in Figure 2.



Figure 2: Design considerations



Test in one area, plan for more

Learn quickly and at low risk by starting small. Design a pilot/model for learning in one key area, with willing clinicians and managers collaborating.

Define upfront how to use the data – for quality and value improvement. Benefit from PROMs is most likely when they are built into quality (QI) and value improvement (VI) activities that are already underway.

Develop and test the model before spread or scale-up.

Choose priority focus areas

Any or all of the Province's five priority areas - diabetes, maternity, trauma, mental health, and tuberculosis – could be good places to start; together with major elective surgery and cancer which are both common, costly and have a high impact on patients and the system. In the priority cohorts, choose condition-specific measures together with a measure of health-related quality of life (HRQoL). It's an advantage to choose a cohort where at least some outcomes data – clinical and cost – already exist. The expanded data set will enable better care and better system management by gaining insights into the needs of the patients in the cohort, adjusting services to match those needs, and improving service integration. Using an episode grouper could help.

Improvement is work. When selecting and using measures for improvement, focus on aspects where the resulting change is valued.

Overcoming implementation challenges

There are several challenges to bringing patient-reported experience and outcome measurement to the South African public healthcare sector.

Low service expectations, cultural differences, and individual risk factors (such as age and literacy level) need to be considered. They affect how patients from economically deprived groups experience and report care. Experience in India suggests that people from underprivileged backgrounds will often rate services higher than their own more detailed qualitative feedback suggests is the case.

In some circumstances, it may be a good idea to **use a third party** to collect the data and to emphasise that the use of the PREM data will be in aggregated and anonymised form and have no repercussions on service availability.

Selecting **appropriate measures and collection methods** is crucial for obtaining reliable and meaningful



data. Factors to consider include the target population, purpose of data collection, available resources, and cultural relevance of the tools used.

Measures should be **adjusted to the context**, and potential differences in local, cultural and geographic settings need to be considered. Language translation, and validation of measures in varying contexts may be necessary.

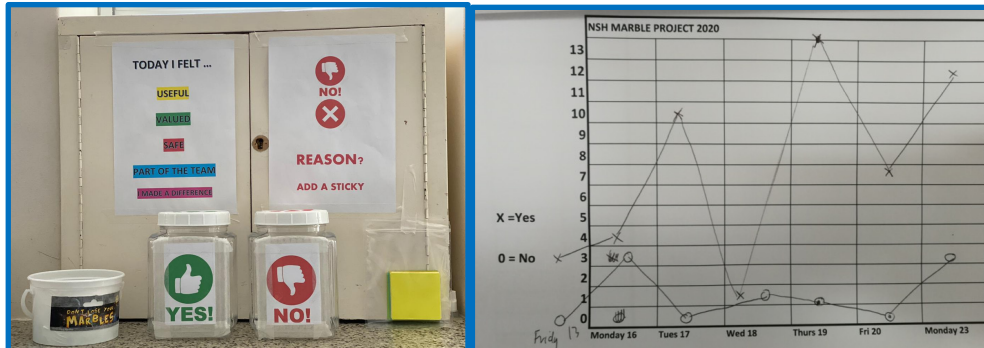
Beyond the measures themselves, successful implementation of PROMs in different healthcare contexts is more likely if three things are in place: (1) agreed, **value-based and improvement-oriented aims** for which PROMs provide needed measurement, (2) **technical infrastructure** to collect and report the data, and (3) **integration into standard work** of clinicians and managers.

Establishing clear aims and shared purpose for both clinicians and managers is essential. To do so, it is helpful to present PROs and PREMs as **improvement-oriented “laboratory tests”** of patient experience and outcomes rather than as performance management tools, which can be perceived by staff as judgemental or even punitive.

Infrastructure requirements include affordable patient-facing technology, such as mobile phones, that are likely to be the primary mode of data collection. Implementation involves technical challenges of data collection, storage, analysis and reporting, preserving confidentiality and privacy, and minimising costs.

Information Box 1: Staff reported measures use example

Although cellphone ownership rates are high, and platforms for PROMs collection already exist in equivalent LMIC settings, technical obstacles to digital implementation in SA can't be ignored. “Low-tech” means of collecting PROMs, including pen-and-paper, can be explored. At New Somerset Hospital, theatre staff report their daily experience at work by placing a marble in a “good day” or “bad day” jar, with notes to explain why or provide suggestions. Data is tracked on paper, on an annotated run chart. [Used with permission: Dr Anthony Reed, New Somerset Hospital]



PROMs can be used for time-limited improvement projects or for longer-term assessment. In either case, they are best **integrated into daily work, and workflows** – just as laboratory test results are – aligning and integrating with other forms of measurement, avoiding data collection burden on clinicians, and targeting priority areas where measurement adds the most value.

Patients who know that their doctors and other members of the care team use the data provided via PROMs typically show **high response and completion rates** to the questionnaires or surveys used to administer PROMs. This may be a key factor facilitating the integration of PROMs into routine care for both clinical and management purposes. Preventing or reducing inequity due to language barriers or low health literacy will also be important in local settings.

Conclusion

In this second brief, we have described how to get started implementing PROMs and PREMs and some of the common pitfalls and challenges with implementation. Thinking of PROMs as a mechanism for improvement (both quality and value) can be helpful to frame and ‘place’ these new measures. PROMs can be started on a very small scale, allowing the system, clinicians, and patients to understand the value and buy into the process.