



HRSA Ryan White HIV/AIDS Program

**CENTER FOR QUALITY
IMPROVEMENT & INNOVATION**

Elevating Patient Voices to Improve HIV Care: Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS)

An Introduction to Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) and their Importance, Implementation, and Application in HIV Care

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Introduction

This overview synthesizes published literature on Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) and highlights the processes to implement them, their potential barriers, and their application to quality improvement (QI) and HIV care. By exploring the value of PROMS and PREMS in healthcare settings and the impact of elevating patient perspectives, this review outlines the current state of PROMS and PREMS adoption while illustrating the need for more widespread use and further research. Accounts of successful QI projects are provided while noting potential challenges in measurement and implementation. Sources for this literature overview were retrieved from Google Scholar, PubMed, and the Institute for Healthcare Improvement (IHI).

Findings from the literature imply that, while PROMS and PREMS may be novel terms, the underlying concepts are not. There is history of successful implementation of various screenings, such as mental health, substance use, housing, among others, that have gathered patient-derived data to use for quality improvement and HIV care. Both PROMS/PREMS and QI share a special focus on the patient experience and the use of data. When the appropriate PROMS or PREMS tool is identified, piloted, and refined, the data collected can help support ongoing QI efforts and result in better health outcomes.

Patients and providers alike tend to have welcoming attitudes towards PROMS and PREMS use. While potential barriers exist for implementation, they can be circumvented by identifying available resources and applying an Implementation Science (IS) framework. Literature suggests that the use of IS can result in a higher likelihood that PROMS and PREMS are successfully adopted in clinics, yet there is a need for future research to explicitly test how implementation strategies impact PROMS and PREMS implementation, quality of care, and patient outcomes and experiences.

Other areas to consider for future research should be on PREMS adoption and its impact on the patient healthcare experience since much of the existing literature focuses on PROMS. While there is much literature regarding satisfaction surveys, content experts argue that PREMS are distinct from satisfaction surveys, warranting a need for further research on this topic, especially as it relates to QI and HIV care.

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Background

HIV advocacy has a long and rich history to ensure that people with lived experiences have a central voice in shared decision-making about directions in HIV policy and programming, and the health care that affect them. HIV activism was built on the principle of ‘Nothing About Us Without Us’ and are represented in the Denver Principles issued in 1983 (Jürgens, 2008).

The concept of integrating patient voices to improve care and services is gaining further traction in the greater healthcare community and a cornerstone in QI. It is vital to routinely assess the quality of HIV outcomes and experiences with the healthcare system using the insights of consumers.

As emerging topics in the field of performance measurement and quality improvement, Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) have value as additional measurement metrics to allow HIV providers to utilize these findings to continuously improve patients’ health outcomes and care/treatment experiences.

But how can patient voices be captured and utilized for quality improvement? And what role does their direct input play in advancing patients’ health outcomes and healthcare experiences? To start, capturing the voices of patients refers to gathering the perspectives and experiences of patients, and understanding how these viewpoints inform the medical care they receive and are used to improve the quality of care. These perspectives can be collected using PROMS and PREMS and their data results can inform future quality improvement activities.

PROMS and PREMS are prompting discussion in the fields of performance measurement, quality improvement, and public health because of their value to improve health outcomes and healthcare experiences. A relatively new topic, Hodson et al. (2013) describes PROMS and PREMS as standardized, validated measures that derive information directly from the patient regarding their health outcomes and their healthcare experiences. By utilizing the PROMS and PREMS data, healthcare providers can better understand the patient’s perspective of their health status, health goals, and the health care they receive. In other words, PROMS and PREMS enable patient-centered care. It is important to note that although closely related, PROMS and PREMS are two distinct measurements that capture different patient aspects.

Ryan White HIV/AIDS Program (RWHAP)-funded recipients/subrecipients (hereafter referred to as providers) are expected to engage in clinical quality management activities—a systematic process of assessing efforts, collecting and analyzing data, and engaging internal and external stakeholders, including people with HIV, to identify and implement improvement solutions; PROMS and PREMS fit this framework. At times, PROMS and PREMS are used interchangeably. The table below aims to draw the overall differences between these measurement concepts and metrics, and provide examples how these concepts are utilized in HIV care.

Table 1. Differences between PROMS and PREMS

Example of PROMS	Example of PREMS
<p>Multiple health systems have implemented PROMS across clinical settings in a variety of ways. One PROM in use across various settings is Cantril’s Ladder, a measure that assesses self-reported well-being. This measure consists of the following prompt and questions: <i>“Please imagine a ladder with steps numbered from zero at the bottom to 10 at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you. (1) On which step of the ladder would you say you personally feel you stand at this time? (2) On which step do you think you will stand about five years from now?”</i> The first item measures current life satisfaction and the second measures anticipated life satisfaction.</p> <p>In Delaware, healthcare settings have utilized the measure to identify patients who may be at higher risk of social hardship and adverse health outcomes. For example, when a patient reports a low number on either the first or second item, the care team engages in further dialogue to assess and respond to drivers of low well-being, which may include unmet basic needs, social isolation, or poor physical or mental health, among other drivers.</p> <p>In Ohio, a major children’s hospital and medical center has deployed Cantril’s Ladder across multiple community-based settings to assess and track population well-being as well as foster learning about the needs, hopes, and drivers of health and well-being of disadvantaged subpopulations for whom they provide care. When paired with appreciative inquiry practices, these items support person-centered understanding and priorities and fuel co-design and co-production.</p>	<p>Healthcare organizations have used PREMS across a wide breadth of clinical settings for some time now. The use of PREMS, such as patient satisfaction scores, however, has not always been leveraged systematically to improve clinical care and outcomes. When used strategically within an improvement science framework, PREMS can drive continuous learning and improvement in ways that matter to patients and improve their care and outcomes.</p> <p>For example, asking about the experience of perceived discrimination across the entire health care encounter, from first contact to post-encounter follow-up, could lead to insights into key potential barriers to trusted relationship, care-seeking behavior, and ultimately positive outcomes for patients.</p> <p>Alternatively, asking about the degree to which patients experience a sense of belonging within the clinic or their care team could yield actionable learnings that drive positive change in relationships with patients. This positive change, in turn, could yield meaningful improvement in patient care and outcomes.</p>

The data results of these measurement activities are intended to be acted upon. This patient-provided feedback is a tool for both providers and patients to identify areas for improvement beyond lab reports and other medical tests—whether it is revising a medication regimen to

minimize patient reported side effects or correcting an issue within a clinic that may make patients feel unwelcome or makes access more difficult. Measurement plays an important role in tracking progress and utilizing data to drive improvements, signaling to staff and patients what is important to the provider team. The ultimate goal of measurement helps providers evaluate the impact of changes made to improve the quality and systems of care. To this end, measurement should be designed to accelerate improvement, not slow it down. Also, consider that measurement alone is not quality improvement. To conduct quality improvement efforts using accepted quality improvement frameworks and tools, providers need to measure PROMS and PREMS in order to improve HIV care and the healthcare systems.

Patient-Reported Outcome Measures (PROMS)

“Patient-reported outcome measures (PROMs) are questionnaires measuring the patients’ views of their health status.”

Kingsley & Patel (2017)

Hodson et al. (2013) defines Patient-Reported Outcome Measures (PROMS) as self-reported health data generated by patients using questionnaires, surveys, etc., which seek to measure the patients’ perceptions of their health status and health-related quality of life. According to Lavalley et al. (2016), PROMS are defined as complementing existing examinations by providing standardized assessments of how patients function or feel with respect to their health, quality of life, mental well-being, or health care experience. For example, patient-reported outcomes can measure beyond lab reports and other medical tests. Examples include: health-related quality of life (such as functional status, medication side effects, decline in aging patients); symptoms and symptom burden (e.g., depression, pain, fatigue, medication side effects); health behaviors (e.g., medication adherence, diet, exercise, smoking, substance use); and social determinants of health that impact health outcomes (e.g., poverty, access to food). See **Table 2** for specific examples of PROMS. When these measures are incorporated into the health care visit, PROMS can fuel conversations between patients and providers that ultimately lead to shared decision-making and result in more individualized care. (Lavalley et al., 2016)

Lavalley et al. (2016) highlight the value that PROMS have in the healthcare setting. For instance, providers report that patient-reported outcomes enhance patient engagement and shared decision making when they are integrated into clinical care. Patient-reported outcomes can provide an assessment of the patient’s experience of illness (symptoms, functioning, and well-being), values and preferences, and goals for their health care over time. Accordingly, the authors illustrate that the value of patient-reported outcomes is to support patient-provider engagement by assessing the severity of symptoms, providing information to track the impact of treatments on patient outcomes, helping patients and providers set priorities for clinic visit

discussions, informing treatment decisions by making it possible to compare patient-reported outcomes to population norms, monitoring general health and well-being as part of routine visits, and connecting providers to patient-generated health data outside health care encounters. In summary, routine collection of PROMS related to general health and well-being provides important information about an individual's overall health. (Lavalley et al., 2016)

Hodson et al. (2013) add an additional perspective when longitudinally measuring PROMS where patients have had a positive or negative score over time. For example, a patient with knee arthritis who has low levels of pain following a joint replacement is unlikely to benefit using a PROM for their knee condition, such as the Oxford Knee Score (Dawson et al., 1998) unless there is a major functional disability. For example, after a knee replacement, a patient who gained little or no functional improvement may demonstrate a negative PROM score implying an adverse outcome for the patient, even though the operation may have been a technical success. In this way, providers will need to reconsider the impact of their technical inputs and additionally value the patient's perspective when assessing the overall health outcomes.

In recent years, many stakeholders are interested in expanding the capture and use of PROMS for direct patient care. Efforts to include PROMS in quality measurement, as well as calls by the patient community to advance shared decision making, have collectively created an environment that is increasingly ready for the widespread adoption of PROMS (Weldring and Smith, 2013). However, despite the widespread interest in and support for the use of PROMS to enhance clinical patient-centered care, efforts to put theory into practice have been met with mixed success. Lavalley et al. (2016) brings to light that the implementation of PROMS can be hampered by logistical concerns, measurement challenges (Boyce et al., 2014), technological barriers, and lack of focus on the end user.

With thoughtful planning to overcome potential barriers, the successful adoption of PROMS can result in rich patient-reported data and using this data for improvement has the capacity to improve patients' health outcomes. For example, Siniscalchi et al. (2020) articulates by implementing a PROM for depression screening, the University of Texas Southwestern Medical Center was able to identify patients diagnosed with depression, administer measurement-based care (follow-up, referral, treatment), and monitor patient responses, treatment effects, and remission of symptoms. Only 2.6% of screened patients refused treatment, while 87.4% began personalized treatment plans (Siniscalchi, 2020). Following the treatment plans for 14 weeks, patients demonstrated transformations in self-reported depression scores, dropping the mean score 14.89 to 9.58 (Siniscalchi, 2020).

CQII and IHI Expert Meeting

In October 2021, the Center for Quality Improvement & Innovation (CQII) partnered with the Institute for Healthcare Improvement (IHI) to host a two-day Expert Meeting on PROMS and PREMS. Meeting participants, comprised of content experts, clinical providers, and people with

lived experiences, were diverse in their familiarity with the patient-reported measurement tools. Each offered their perspectives on measurement instruments that were presented by IHI, including (1) ranking various PROMS and PREMS domains of importance for Ryan White HIV/AIDS Program-funded programs; and (2) strategies to overcome implementation barriers. In this context, ‘domain’ refers to the overarching subject area to be measured by a PROM or PREM, such as mobility or respect. Given a working list of possible domains, participants were asked to evaluate each domain while considering the following criteria:

- Is it important to measure? (To whom and for what?)
- Can you measure it?
- Would you actually use the information gained from measuring the domain?
- How heavy of a collection/reporting burden do you think this would be for a busy Ryan White HIV/AIDS Program-funded clinic?
- Can a measure in this domain be easily linked to quality improvement efforts?

Using the Delphi method, the domains were prioritized and resulted in the following “top 5” PROM domains of priority with respective examples (**Table 2**).

Table 2. Examples of PROMS

Priority Domain	Why it is Important	Example of Validated Tool Measures/Questions
<p>Well-being (e.g., overall health [not related to HIV], quality of life, impact of medication side effects, issues such as loneliness)</p>	<p>Research suggests that physical symptoms, ART, psychological well-being, social support systems, coping strategies, spiritual support, and psychiatric comorbidities are important predictors of quality of life for people with HIV.</p>	<p>100MLives Well-Being Assessment (validated). 12 question survey plus demographics</p> <p>Sample Questions/Answers</p> <p>Imagine a ladder with steps numbered from zero at the bottom to ten at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you.</p> <ol style="list-style-type: none"> 1. On which step of the ladder would you say you personally feel you stand at this time? 2. On which step do you think you will stand about 5 years from now? 3. Now imagine the top of the ladder represents the best possible financial situation for you, and the bottom of the ladder represents the worst. 4. In general, how would you rate your physical health? 5. How would you rate your overall mental health? <p>Note: This validated well-being assessment also has questions related to having a sense of purpose, loneliness, feeling a part of the local community, relationship with family and friends, positive emotions and negative emotions.</p>
<p>Housing Stability (whether the patient has stable housing, fears)</p>	<p>In 2019, almost 29,000 RWHAP clients reported unstable housing. People experiencing homelessness or</p>	<p>Veterans Administration Homeless Screening Tool: 5+ Question Survey</p> <p>Sample Questions/Answers</p>

<p>losing their housing)</p>	<p>unstable housing are more likely to delay entry into HIV care, more likely to experience interruptions in healthcare, less likely to be prescribed ART, less likely to reach sustained viral suppression, and overall have poorer health outcomes.</p>	<ol style="list-style-type: none"> 1. In the past 2 months, have you been living in stable housing that you own, rent, or stay in as part of a household? 2. Are you worried or concerned that in the next 2 months you may NOT have stable housing that you own., rent, or stay in as part of a household? 3. Where have you lived for MOST of the past 2 months? <ol style="list-style-type: none"> a. Apartment/ House/ Room - no government subsidy b. Apartment/House/ Room - with government subsidy c. With Friend/ Family d. Motel/Hotel e. Hospital, Rehab Center, Drug Treatment Center f. Homeless: Shelter g. Anywhere outside. e.g. Street, Vehicle, Abandoned Building h. Other 4. Would you like to be REFERRED to talk more about your housing situation?
<p>Mental Health (depression, anxiety, substance use)</p>	<p>People with HIV are at increased risk of developing mood, anxiety, and cognitive disorders. Depression is one of the most common mental health conditions facing people with HIV. Some medications used to treat HIV, including ART, may have side effects that affect a person's mental health.</p>	<p>PHQ9 – Depression Severity 10-question survey</p> <p>Sample Questions/Answers Over the <i>last 2 weeks</i>, how often have you been bothered by any of the following problems?</p> <ol style="list-style-type: none"> 1. Little interest or pleasure in doing things 2. Feeling down, depressed, or hopeless 3. Trouble falling or staying asleep, or sleeping too much 4. Feeling tired or having little energy 5. Trouble concentrating on things, such as reading the newspaper or watching television <p>Answers: (Not at all, several days, more than half the days, nearly every day)</p>
<p>Perceived Discrimination (lifetime history of discrimination, daily microaggressions, trauma and re-traumatization)</p>	<p>Research indicates that the number of discrimination events experienced over life was positively associated with the number of HIV-related symptoms experienced.</p>	<p>Everyday Discrimination Scale (Short Version) 9 questions plus a follow-up question on ‘perceived reasons</p> <p>Sample Questions/Answers In your day-to-day life how often have any of the following things happened to you?</p> <ol style="list-style-type: none"> 1. You are treated with less courtesy or respect than other people. 2. You receive poorer service than other people at restaurants or stores. 3. People act as if they think you are not smart. 4. People act as if they are afraid of you. 5. You are threatened or harassed.
<p>Food Security (lack of food, fear of not having enough</p>	<p>In 2020, 15.3 percent of RWHAP clients received food assistance through</p>	<p>USDA Food Security Brief Survey 6 question survey</p>

<p>food, lack of access to nutritional food)</p>	<p>the program. Studies indicate that food insecurity can lead to high levels of depression in people with HIV. Evidence also indicates lower rates of viral suppression, lower CD4 counts, and poorer health outcomes.</p>	<p>Sample Questions/Answers</p> <ol style="list-style-type: none"> 1. The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more. (Answers: Often true, Sometimes true, Never true, Don't Know, or Refused) 2. I/we) couldn't afford to eat balanced meals. (Answers: Often true, Sometimes true, Never true, Don't Know or Refused) 3. In the last 12 months, did (you/you or other adults in your household) ever cut the size of your meals or skip meals because there wasn't enough money for food? (Answers: Yes, No, Don't Know or Refused) 4. [IF YES ABOVE, ASK] How often did this happen? (Answers: almost every month, some months but not every month, or in only 1 or 2 months) 5. In the last 12 months, were you every hungry but didn't eat because there wasn't enough money for food? (Answers: Yes, No, Don't Know or Refused)
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While shared decision-making is assumed to be a “best practice,” some stakeholders believe that focusing on PROMS without involving patients in the measurement selection process may decrease the likelihood of having meaningful discussions about issues or concerns that are important to the patient (Concannon, 2018). Therefore, engaging patients in the implementation of these measures in healthcare settings will be necessary to ensure that patient-provider discussions are of value.

Patient-Reported Experience Measures (PREMS)

“Patient-reported experience measures (PREMs) are questionnaires measuring the patients’ perceptions of their experience whilst receiving care.”

Kingsley & Patel (2017)

Patient Reported Experience Measures (PREMS) are defined by Hodson et al. (2013) as a measure of a patient’s perception of their personal experience of the health care they have received. Examples include: patient-centered approach in delivering care (e.g., shared decision-making when the patient is a partner in making health care decisions); supportive/welcoming environment (e.g., respect and dignity when patients are treated with kindness by all staff); effective communication (e.g., privacy and confidentiality when patients can ask questions, their information is safe guarded their concerns are acknowledged and addressed); accessibility (e.g., services are accessible taking patients preferences in consideration); and efficient delivery of services. See **Table 3** for specific examples of PREMS. Ideally, PREMS should prioritize the aspects of the delivery of care and services that matter most to the patient, thus, facilitating a patient-centered approach. The authors summarize that the results of PREMS are commonly used to improve services and provide a perspective that moves away from the technological or economic model that is often employed in service design. Further, Weldring and Smith (2013) note that there is increasing international attention regarding the use of PREMS as a quality indicator of patient care and safety.

When optimally used, PREMS have the potential to move the focus away from how the healthcare provider wishes to unilaterally define the delivery of systems of care and towards what is important to the patient. Fernandes et al. (2019) discuss the significance of PREMS in detail by highlighting the recognized importance of PREMS across disciplines, from medical providers to economists. PREMS can be predictive of future patient behaviors, including the intent of patients to return for care, promptness in seeking help for further treatment, adherence to treatment, and quality of life.

Examples of PREMS

From the previously referenced CQII/IHI Expert Meeting on PROMS and PREMS and using the same evaluation criteria (see *Examples of PROMS*, **Table 2**), the domains were prioritized using the Delphi method and resulted in the following “top 5” PREM domains of priority with respective examples (**Table 3**).

Table 3. Examples of PREMS

Priority Domain	Why it is Important	Example of Validated Tool Measures/Questions
<p>Experience of Racism (has patient ever experienced racism while receiving care in the organization, does the patient not feel welcome [e.g., none of the educational materials look like me])</p>	<p>Research by the Center for AIDS Research of the University of Alabama at Birmingham found that people with HIV who experienced racism at clinic visits were two times less likely to adhere to ART.</p> <p>The National HIV/AIDS Strategy recognizes racism as a serious public health threat that directly affects well-being and drives and affects HIV outcomes.</p>	<p>Krieger Experiences of Discrimination (EOD) scale 30+ Question Survey (exact number depends on how many “Yes” answers)</p> <p>Sample Questions/Answers Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in getting medical care because of your race, ethnicity, or color? Answers Yes, No: For answers of “yes”, the follow-up question is: How many times did this happen? Once, Two or three times, Four or more times In the last year, how much did you worry about your experiencing unfair treatment because of your race, ethnicity, or color? Answers: Most of the time, Some of the time, Rarely or never How often do you feel that you, personally, have been discriminated against because of your race, ethnicity, or color? choose the number that best represents how you feel) Answers: Never, Rarely, Sometimes, Often Reference: Krieger et al. Experiences of discrimination: validity and reliability of a self-report measure for population health research on racism and health. Soc Sci Med. 2005 Oct; 61(7):1576-96.</p>
<p>Respect/Dignity (are patients treated with kindness by all staff, even in a busy clinic are they valued as a human being)</p>	<p>There are multiple variables related to respect and dignity (effective verbal communication, empathy, common courtesy, respect for privacy, modesty etc.). All these are important for patient-centered care.</p>	<p>CAHPS Home and Community Based Survey 100+ question survey based on experience of community-based care.</p> <p>Sample Questions/Answers In the last 3 months, how often did {insert staff role} treat you with courtesy and respect? Would you say . . . Never, Sometimes, Usually, Always, Don’t Know, Refused, Unclear Response</p>
<p>Privacy/Confidentiality (importance of privacy can be lost in a busy organization, even more important in smaller/rural organization)</p>	<p>Health Insurance Portability and Accountability Act is not enough. People with HIV emphasize that maintaining their privacy in clinical settings is still an issue. CQII has heard from patients that they often feel that their privacy/confidentiality has been violated by provider staff.</p>	<p>Ontario Outpatient Experience Survey 63 question survey</p> <p>Sample Questions/Answers Were you given enough privacy when discussing your condition or treatment? <input type="radio"/> Definitely <input type="radio"/> For the most part <input type="radio"/> Somewhat <input type="radio"/> Not at all (please tell us more in the open text box at the end of this survey)</p>

<p>Communication (do providers [and other staff] take the time to explain, do they allow patients to ask questions, do they recognize the value of questions and provide thoughtful responses [e.g., don't dismiss questions])</p>	<p>Effective communication between clinician and patient has been shown to positively influence health outcomes. It increases patient satisfaction, leading to greater patient understanding of health problems and possible treatments. This contributes to better adherence to treatment and provides support and reassurance to patients.</p>	<p>Ontario Outpatient Experience Survey 63 question survey</p> <p>Sample Questions/Answers Did doctors and/or health professionals ask you what was important to you in managing your condition or illness? Definitely; For the most part; Somewhat; Not at all; This was not necessary If you had important questions to ask him or her, did you get answers that you could understand? Definitely; For the most part; Somewhat; Not at all; I did not need to ask; I did not have an opportunity to ask</p>
<p>Shared Decision-Making (is the patient a partner in care, are their concerns acknowledged and addressed)</p>	<p>A process in which patients, clinicians and caregivers make treatment and other health-related decisions together based on clinical evidence and reflecting the patient's personal preferences.</p>	<p>Ontario Outpatient Experience Survey 63 question survey</p> <p>Sample Questions/Answers How often, during your most recent visit, were you involved as much as you wanted to be in decisions about your care and treatment? Always; Usually; Sometimes o Never</p>

Hodson et al. (2013) suggests that disease specific PREMS are essential in optimizing health care. Many PREMS are specific to one area of the patient experience, such as communicating with patients or demonstrating respect, which can help providers gain insight to that one specific aspect of care. However, Weldring and Smith (2013) claim that PREMS may be used to monitor patient feedback and focus on the general experience of customer service rather than experiences related to a specific disease. On the other hand, Fernandes et al. (2019) argues that disease-specificity makes general assessments and comparisons at a national or international level rather difficult. As a possible consequence, PREMS may not be routinely collected in many healthcare settings. Fortunately, by identifying these potential barriers, stakeholders are able to strategize solutions to ensure a successful implementation.

Implementing PROMS and PREMS

There is wide variation in how PROMS and PREMS are implemented. Prior literature has documented the limited uptake of PROMS and PREMS and barriers to their implementation in routine care settings.

Implementation science (IS) offers a potential way forward to address these barriers. As described by Stover et al. (2021), implementation science is the systematic study of methods to integrate evidence-based practices and interventions into care settings. IS aims to make the process of implementation more systematic, resulting in a higher likelihood that PROMS and PREMS are successfully adopted in clinics.

Stover et al.'s cross-study analysis (2021) demonstrate that IS approaches are largely harmonious with PROM and PREM implementation, although no single framework or theory fully captures their nuances. The authors suggest that multilevel frameworks and theories are necessary for PROM and PREM implementation, given their complexity.

Measurement of PROMS and PREMS

Before setting up data collection systems for gathering PROMS and PREMS data in a clinical practice, it is critical to clarify the goals of implementing the PROMS and PREMS and to assess the resources available for integrating these measures into routine data systems. Some resources include manpower, information systems, technical support, and financial investment (ISOQOL, 2015). However, the level of resources required depends on how the PROM or PREM is implemented.

When selecting the appropriate PROM or PREM tools, the target patient group, content, reliability, and validity of the questionnaire should be considered (Kingsley & Patel, 2017) as well as whether to use generic or disease-specific questionnaires, profile- or preference-based measures, single or multi-item scales, and static or dynamic questionnaires (ISOQOL, 2015). Prior to commencing the PROM or PREM data collection, piloting the questionnaire using a small sample size is vital to identify the appropriateness of measures for the targeted population. For example, many institutions have convened a working group of stakeholders to review and recommend measures that are relevant within a specialty, discipline, or subpopulation (NQF, 2021). At this stage, changes may be made to the questionnaire using stakeholder feedback to ensure the questions are relevant for the patients and providers and feasible to implement in the health care setting. Through this process, ISOQOL (2015) explains that a PROM can initially be collected for individual patient management, aggregated for quality evaluation, and then analyzed to inform quality improvement.

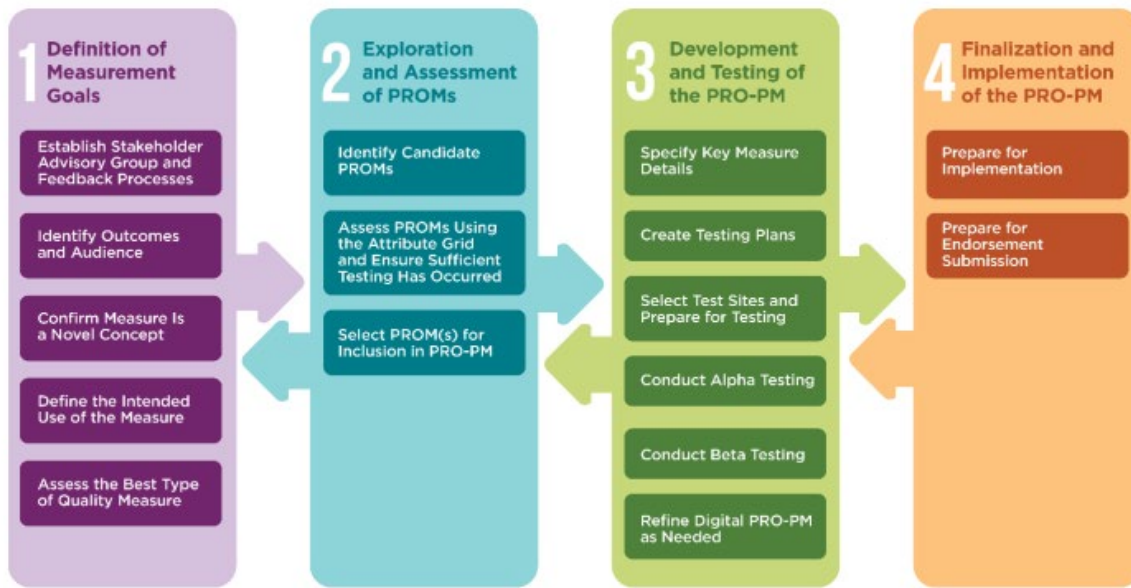


Figure 1. Implementation Roadmap (NQF, 2021)

The National Quality Forum (NQF, 2021) recognizes that there are many ways to get from identifying the need for a PROM to implementing patient-reported outcome performance measure (PRO-PM) and even submitting a fully tested PRO-PM for NQF endorsement. To clarify, PROMS are the tools/instruments to collect data, PRO-PM are a way to aggregate the information from patients into a reliable, valid measure of performance (CMS, 2021). It should be noted that although this illustration focuses on PROMS, all of its stages are also applicable to PREMS.

To collect the data, PROMS and PREMS can be distributed via pen and paper, face-to-face interviews, or using technology such as email, phone calls, or electronic tablets. To save time and reduce staff and patient burden, many systems offer multiple mechanisms for data collection, including tablet computers to use in collecting and scoring patient-reported outcomes while patients wait to see the provider (Lavalley et al., 2016). The use of peer navigators is also an effective strategy for reducing provider and patient burden; the provider can use their time to complete other tasks, while patients may be more likely to respond honestly to the questionnaire (Sheehan, 2019).

Fernandes et al. (2019) claim that most available PREMS are paper-based, making it challenging for professionals to obtain quality of care scores efficiently in real time. The questionnaires can often be too lengthy and fixed in content, such as asking the same questions to all patients regardless of their health characteristics, leading to a high survey burden for patients and to substantial problems with missing data (Fernandes et al., 2019). But while mobile tools may enhance patients' ability to complete PROMS and PREMS, Lavalley et al. (2016) argue that lack of access to technology may actually be a barrier for some patients. These patients may require

alternative modes of administration of the data collection, such as mail or telephone-assisted completion. In addition, people suffering from loss of vision or those in poor health may find completing the PROM or PREM burdensome or challenging. Thus, Lavellee et al. (2016) highlight the importance of designing systems to accommodate people with visual impairment or limited mobility, and how doing so can minimize such barriers and is an additional rationale for incorporating patients in the design and implementation of PROMS and PREMS.

Some of the logistical concerns about capturing PROMS include workflow barriers, such as the increased burden on staff members and patients to collect PROMS data and make them routinely available to the health care team. Also, the added time the provider needs to interpret the data and the increased duration of office visits to discuss them are additional barriers. In response to these concerns, health systems have developed several strategies to streamline the collection of patient-reported outcomes.

In all, the complete and timely capture of PROMS and PREMS is necessary and feasible but requires thoughtfulness to implement effectively. When the appropriate measurement tool is identified, piloted, and refined, the data collected can help support ongoing quality improvement efforts.

Quality Improvement

According to the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA), quality improvement (QI) consists of systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted patient groups (2011). When examining the inputs, processes, and outputs of QI, it is clear that QI and PROMS/PREMS are closely linked (Figure 2).

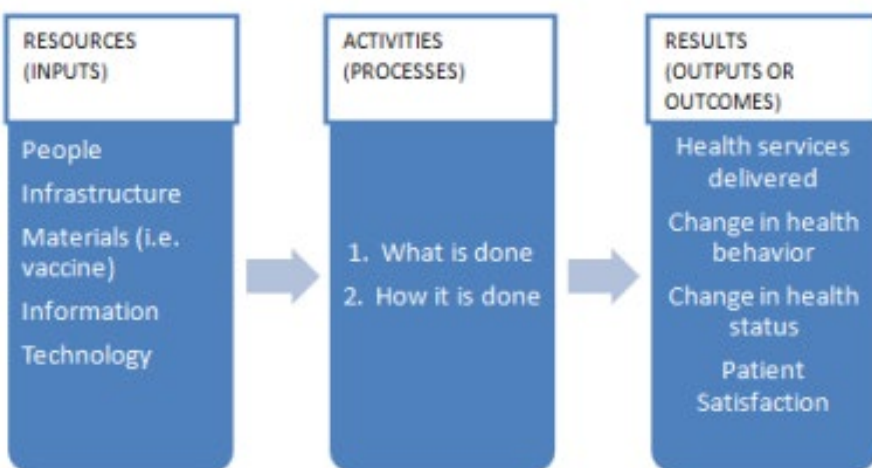


Figure 2: Inputs, Processes, and Outputs/Outcomes (Donabedian, 1980)

Both PROMS/PREMS and QI share a special focus on the patient experience and the use of data. Data are a vital prerequisite for quality improvement. The data collected from PROMs and PREMS questionnaires are used to improve patients' health outcomes and experiences, which can complement an agency's ongoing QI activities. In fact, PROMS and PREMS are powerful tools for quality improvement that the Centers for Medicare and Medicaid (CMS) and NQF have partnered for more than a decade to advance patient-reported outcome quality measurement (Raths, 2022).

Boyce et al. (2013) conducted a systematic review of qualitative studies to investigate the experiences of healthcare professionals with using PROMS and PREMS specifically for quality improvement. The authors found that when the healthcare professionals were able to collect and make sense of the data, or consumer responses, the data were used to make changes to patient care. For example, Beers et al. (2017) describes how routine mental health screening during annual visits can be used to identify concerns early and initiate appropriate interventions when collecting and analyzing the patient-reported data. Participating in a quality improvement learning collaborative can improve mental health screening practices, and in turn, lead to better health outcomes for patients (Beers et al., 2017). This is an example of how QI intersects with PROMS and PREMS to improve the consumer experience.

Another example of PROMS and PREMS in QI comes from Leggo et al. (2008) which demonstrates a QI project focused on the adoption of a nutrition screening tool. Following the patient responses, 15% of the patients who completed the questionnaire were identified as being at risk of malnutrition (Leggo et al., 2008). About half of those patients agreed to referral and assessment, revealing a malnutrition prevalence between 5% and 11% (Leggo et al., 2008). Further, of 34 malnourished clients receiving referred care from a dietician, 28 improved, with 17 generating high scoring PROMS.

Beyond serving as effective QI tools, the literature suggests that patients and providers alike find PROMS and PREMS important. Horowitz et al. (2013) piloted a suicide screening instrument to identify those at suicide risk. Patients who screened "positive" received further evaluation and no patient required an observational monitor (Horowitz et al., 2013). When surveyed about the screening tool, 87% of patients reported feeling comfortable with screening; 81% of patients, 75% of nurses, and 100% of social workers agreed that all patients in hospitals should be screened for suicide risk (Horowitz et al., 2013).

Conclusion

There are documented examples of PROMS and PREMS leading to improved health outcomes and experiences in HIV care. Due to the increasing conversation around PROMS and PREMS use and benefits, more providers and healthcare institutions are adopting patient-reported measures. For instance, Engler et al. (2017) suggests that incorporating PROMS in HIV care could, in turn, allow the provider to obtain a more patient-centered view of treatment success or failure than looking at biomedical markers alone, such as viral load and CD4 cell count. PROMS are also useful clinical tools to detect sensitive health outcomes, such as substance use, mental health, and housing instability (Engler et al., 2017). Similar to PROM use, the authors suggest using PREMS in HIV care to better engage patients, including better healthcare experiences to increase patient retention.

To better understand how PROMS and PREMS can be applied to HIV care, Monroe et al. (2018) set out to elicit stakeholder input on the integration on substance use and mental health screenings using computer-assisted PROMS. Two themes emerged: (1) providers felt that PROMS could help overcome stigma and might improve substance use/mental health disclosure and (2) patients indicated that PROMS and PREMS would help providers take better care of them. However, the support for PROMS was accompanied by a few concerns, mainly that it could be harder to disclose substance use or mental health status to a computer than to a person. On the contrary, there were also concerns of providing honest answers directly to the providers (Monroe et al., 2017). Despite these concerns around administration, Jabour et al. (2021) found success with computerized PROMS and PREMS in HIV care. The authors found that when patients completed a computerized PROMS for mental health and/or substance use before their HIV visit, 93.8% discussed substance use and/or mental health in their interventions with providers, and 40% of those patients accepted action plans made for them (Jabour et al., 2021).

Some current literature suggests that PROMS and PREMS feedback to HIV providers has an inconsistent impact on patient health outcomes, with one review of randomized controlled trials finding positive effects in only 41% of studies (O'Brien et al., 2019). However, these results could reflect ineffective implementation strategies and warrants a need for more robust research on the impacts of PROMS and PREMS in HIV care. Although the research of PROMS and PREMS use in HIV care is at a relatively early stage, most current literature on collecting PROMS data in routine HIV care suggests that it can be effective and feasible with minimal missing data, high completion rates, and modest financial investments. In addition, Jabour et al. (2021) found PROMS and PREMS to be highly acceptable to HIV patients, indicated by low refusal rates and a willingness to provide valuable, accessible, and current information on diverse patient health outcomes and experiences.

Steinbock et al. (2022) demonstrates how PROMS and PREMS complement quality improvement efforts to transform HIV care. During a 12-month learning collaborative,

participating agencies applied QI methods to improve screening rates and implement relevant interventions, resulting in an average increase of viral suppression by nearly 4%. By using PROMS and PREMS to screen HIV patients for areas of concern regarding their health, healthcare experience, and quality of life, providers can personalize health care accordingly to result in better patient outcomes.

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