

## Patient-Reported Outcome and Patient-Reported Experience Measures: Exploring Opportunities for Integrating the Voices of Patients to Improve HIV Care

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*Prepared: Aria Chitturi, Marina Tian*

### A) Overview

The Center for Quality Improvement & Innovation (CQII) provides leadership and support in quality improvement (QI) to Ryan White HIV/AIDS Program-funded recipients and subrecipients nationwide. As emerging topics in the field of performance measurement and QI, Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) have value as additional metrics for assessing the quality of HIV care and healthcare experiences based on the individual insights of Ryan White clients. Local HIV providers can utilize these findings to continuously improve and foster engagement in HIV care.

To explore the understanding of, attitudes towards, and experience with PROMs and PREMs across Ryan White HIV/AIDS Program-funded providers of ambulatory care services, CQII hosted a series of focus groups with participants in CQII’s create+equity Collaborative. In total, three (3) calls with six (6) representatives were conducted between June and July 2021 (see *Table*) using a standardized interview guide (see *Attachment A: PROMs/PREMs Focus Group Questions*). Each focus group was transcribed. Detailed notes are not included in this report to preserve participant confidentiality.

<b><i>PROMs/PREMs Focus Groups</i></b>	
<b>Date of Call</b>	<b>Participants</b>
June 24 2021	Davone Singleton, Temple University Comprehensive HIV Program
June 29, 2021	D’Ontace Keyes, AIDS Foundation of Chicago Tammy Starr, Southeast Mississippi Rural Health Initiative Sarah Usher, Sun River Health Noreen Colon, Sun River Health
July 1, 2021	Aniam Iqbal, UPMC Pact Clinic Sarah Usher, Sun River Health

This report summarizes these conversations with participants by highlighting key findings and provides a list of recommendations for increasing awareness and integration of PROMs and PREMs in HIV care among Ryan White HIV/AIDS Program-funded recipients and subrecipients.

## B) Findings

The following findings summarize the conversations held with focus group participants.

1. **‘We are not familiar with PROMs/PREMs’** – while participants reported measuring patient health outcomes and gathering client feedback regarding their HIV care, they were not aware of these specific measurement frameworks.
  - a. All participants indicated that they were previously unaware of the concepts of PROMs and PREMs
  - b. Participants saw the potential benefits of using PROMs/PREMs for quality improvement and in gaining additional insights from direct input by HIV clients
  - c. Though each site routinely screens patients for health outcomes (e.g., mental health, substance use, etc.) and asks clients for feedback regarding their health care experience (e.g., satisfaction surveys, feedback forms, etc.), these measurement frameworks were new to them; however, the concepts were intuitive to participants for future use
  - d. The vocabulary and terminology of PROMs/PREMs were unfamiliar to them, resulting in varied understandings of the concepts and their potential applications
  - e. Though standardized definitions for PROMs and PREMs were provided to participants as part of the focus groups, the nuances of these concepts were often lost in discussion and reduced to specific instruments (e.g., “yes, we are doing PROMs since we are conducting depression screenings,” and “we are using PREMs, we have patient satisfaction surveys”)
2. **‘We want to learn more’** – participants expressed genuine interest in learning more and exploring the use of PROMs and PREMs at their sites.
  - a. Participants were genuinely open and interested in learning more about PROMs and PREMs
  - b. Clear definitions of PROMs and PREMs should be established and shared to promote consistent messaging around PROMs/PREMs and to clarify varied understandings of PROMs/PREMs
  - c. Clear examples of PROMs and PREMs, specifically for HIV care, should be provided to expedite the learning curve and allow providers to see their potential
  - d. Future learning and training materials should not only build awareness of PROMs and PREMs but provide rationale for these concepts and how they may be applied in their work
  - e. Trainings should include consistent language and terminology to reduce confusion
3. **‘We want guidance’** - participants were willing to engage in future activities to implement PROMs and PREMs in their HIV programs.
  - a. Strong interest in learning new skills and techniques to improve quality of care beyond approaches centering on viral suppression rates and patient satisfaction surveys
  - b. Participants indicated a desire to learn from real-world examples and have access to HIV-specific PROMs/PREMs examples

- c. Participants requested practical tools to help ground their understanding and to guide them forward
  - d. All participants indicated their interest to potentially participate in a PROMs/PREMs pilot program to learn from content experts and their peer HIV providers
  - e. Participants would feel more confident in implementing PROMS and PREMs if they were provided the necessary tools and support
  - f. Concerns were expressed by participants about finding time for properly implementing PROMs/PREMs due to time constraints and changing priorities (e.g., COVID-19)
4. **‘Should PROMs focus on health screening tools and quality-of-life assessments?’** – while health status screening tools are used, the focus of PROMs should also include the patient’s overall wellbeing and quality of life.
  - a. Many participants routinely reported patient screenings for depression, anxiety, substance use, etc. as examples of PROMs; results are documented in the medical records
  - b. Existing surveys could serve as groundwork for including PROMs by tailoring existing questions and adding several new questions
  - c. While many validated tools are available to assess patient health outcomes (e.g., Patient Health Questionnaire (PHQ-9)), standardized quality-of-life assessment tools are not routinely available or used by HIV programs
  - d. The need for standardized tools measuring more than just health status to capture the patient’s overall wellbeing was identified (e.g., quality of life, food access, etc.)
  - e. Quality-of-life discussions and barriers discussed with patients are often not fully documented in the patient’s medical records
5. **‘PREMs are more than patient satisfaction surveys’** – PREMs should embrace a variety of modalities to gather patient-reported experiences with HIV care beyond patient satisfaction surveys.
  - a. In general, there was a greater foundational knowledge and experience around PROMs than around PREMs
  - b. While patient experiences are not measured as easily as patient health outcomes, participants routinely conducted patient satisfaction surveys to ascertain the clients’ experiences with HIV care
  - c. The need for better delineating the difference between patient satisfaction and patient experience, particularly as it relates to PREMs, was identified
  - d. Standardized tools to measure patient experiences with HIV ambulatory care are not readily available; standardized questions and sample surveys should be widely shared to better demonstrate how to measure patient experiences beyond using patient satisfaction surveys

## C) Recommendations

Based on the conducted focus groups, the following recommendations outline CQII's role in supporting Ryan White providers to better understand PROMs and PREMs, their potential applications in HIV/AIDS care, and how to implement PROMs and PREMs instruments at their sites.

- **Establish QI resources on PROMs and PREMs for use by Ryan White providers**
  - Work with the Institute for Healthcare Improvement (IHI) and conduct an expert meeting with national content experts on this emerging topic
  - Conduct a literature search on PROMs and PREMs and widely disseminate the findings
  - Create technical assistance documents and multimedia tools that clarify the definitions of PROMs and PREMs, how they are used in QI projects, and best practices for implementation
  - Provide training materials on how sites may increase knowledge and expertise on PROMs and PREMs among staff
  - Draft sample survey instruments, including HIV-specific PROMs and PREMs, that participants may tailor for implementation at their own sites
  - Develop a toolkit that summarizes real-world examples and best practices for Ryan White providers
  - Conduct trainings with HIV providers to share expertise from content experts and promote peer sharing opportunities by Ryan White providers
  
- **Conduct initial 6-month PROMs/PREMs pilot among CQII create+equity Collaborative participants to build experience and further explore needs**
  - Recruit approximately 15 sites with the capacity to participate and engage in a pilot project to implement PROMs/PREMs in their local HIV programs in addition to their Collaborative responsibilities
  - Set clear expectations for participation and define learning and implementation objectives
  - This pilot program can serve as a PROMs/PREMs peer sharing group where participants can share experiences, lessons learned, and challenges encountered to align expertise and build a collective body of knowledge
  - Begin pilot activities in January 2022 for target end in June 2022
  - Collect best practices from participants in the pilot program and develop a toolkit based on their experiences

## Attachment A: PROMs/PREMs Focus Group Questions

The following questions are asked representatives across the AIDS Institute during informal outreach calls to better understand their quality improvement (QI) needs, QI expectations for funded providers, and suggestions how to build QI capacity among AIDS Institute staff. A brief overview of quality improvement will be provided.

Let's begin with a description of PROMS and PREMS, which are sometimes confused with other important patient reported measures, such as patient satisfaction.

Patient-reported outcome measures (PROMs) are defined as any measurement of patient's well-being or function which can only be determined by asking the patient. These are measured using standardized, often validated questions which are completed by patients to measure their self-report of their functional well-being and health status. Examples include depression, anxiety, pain, fatigue, etc.

A patient-reported experience measure (PREM) is a measure of the patient's report of their personal experience of the healthcare they have received. These include areas including respect, communication, privacy, engagement in shared decision making, as well as the environment in which care is being delivered.

The purpose of both tools is to assess the patient quality of life beyond patient satisfaction and therefore, taking a more holistic and patient centered approach to improve care and services.

- Based on these descriptions, how familiar are you with the concepts of PROMS? What about for PREMS?
- What other terminologies have you used to describe these concepts?

Please share any past experiences you or your agency had with using PROMS.

What experiences with PREMS?

[Invite any agencies with past PROMS and PREMS experiences for a subsequent call to collect their best practices for a potential guide]

- How does your agency incorporate patient reported experiences of care outcomes into the care you provide, either formally or informally?
- What about for patient reported outcomes?  
[Prompt for responses beyond patient satisfaction surveys]  
[It may be necessary for the facilitator to dialog with a participant to determine if an agency's current practices would qualify under our definitions of PROMS or PREMS]
  - If any PROMS or PREMS are being captured, how did you choose these measures?
  - Are any of the PROMS or PREMS used only by RWHAP-funded programs within the agency or are these measures used more broadly if you are part of a larger organization
  - For participants who do not report PROMS or PREMS: Has your agency considered use of PROMS or PREMS? If yes, can you tell us why use of PROMS or PREMS has not been implemented, if known?

- For those who have reported use of PROMS/PREMS: how do you collect the data?
  - Can you give examples of what measures you use?
  - Are these measures in your EHR or other data system you use?
  - If part of a larger organization measuring PROMS or PREMS, does the organization provide your RWHAP clinic with the data?
  - Are there any mandates (internal or external) to collect PROMS? PREMS?
- For those who have not used PROMS/PREMS:
  - How hard would it be to implement them? What would be needed?
  - How can we promote their data collection to improve HIV care?
- For those who have used PROMS/PREMS, how does your agency use the data? What is working, what is not?
  - Can you share an example how the PROMS or PREMS have been used to improve the quality of care and services for people with HIV?
  - How hard was it to start to use them (measurement and use)? What advice would you give?
- For all participants - How can we most effectively utilize PROMS or PREMS measurement and results data findings to improve HIV care? What are the potential uses?  
[Highlight the opportunities to look for patient wellness and quality of life, in addition to viral suppression rates; focus not only on HIV primary care but take a more holistic and patient centered approach to value the voice of patients.]  
[Note that this question is likely to pick up on some of the content from the prior bullet point. Be sure to acknowledge any HIV-related PROMS/PREMS successes that have already been highlighted. For participants from agencies successfully using PROMS/PREMS to inform HIV care, this question may end up focusing more on how use of such data can be enhanced.]

What suggestions do you have to engage participants of the CQII create+equity Collaborative to jointly explore this emerging topic of increasing the voice of patients through routinely measuring PROMS? What about PREMS?

[Please note that these efforts are in addition to other Collaborative expectations]

- How to explain the benefits?
- Would you participate? Why? Why not?
- What can we encourage others to join?

What suggestions do you have to further expand the understanding and use PROMS and of PREMS to other Ryan White HIV/AIDS funded agencies?

- What resources or documents should be developed to promote its adoption?
- How can we integrate them into other CQII activities?