Patient-Reported Outcome and Patient-Reported Experience Measures:

Exploring Opportunities for Valuing and Integrating the Voices of Patients to Improve HIV Care

Aug 23, 2021

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 data findings to continuously improve and foster engagement in and quality and effectiveness of HIV care.

This document outlines activities, recently conducted by CQII, to better understand the potential of PROMS and PREMS and the opportunities for integrating the voices of individuals with lived experiences to improve in HIV care.

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A) PROMS/PREMS Focus Groups

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Introduction

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 *Appendix*). Each focus group was transcribed. Detailed notes are not included in this report to preserve participant confidentiality.

PROMS/PREMS Focus Groups	
Date of Call	**Participants**
June 24 2021	Data Manager/QI Lead
June 29, 2021	Senior Manager Social Worker HCV Coordinator Program Coordinator
July 1, 2021	Quality Manager HCV Coordinator

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.

Focus Group 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

Focus Group Recommendations

Based on the conducted input provided by these 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**
  o Work with the Institute for Healthcare Improvement (IHI) and conduct an expert meeting with national content experts on this emerging topic
  o Conduct a literature search on PROMS and PREMS and widely disseminate the findings
  o 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
  o Provide training materials on how sites may increase knowledge and expertise on PROMS and PREMS among staff
  o Draft sample survey instruments, including HIV-specific PROMS and PREMS, that participants may tailor for implementation at their own sites
  o Develop a toolkit that summarizes real-world examples and best practices for Ryan White providers
  o 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**
    o 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
    o Set clear expectations for participation and define learning and implementation objectives
    o 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
    o Begin pilot activities in January 2022 for target end in June 2022
    o Collect best practices from participants in the pilot program and develop a toolkit based on their experiences

B) Preliminary Review of Patient Reported Outcomes and Experience Measures Literature DRAFT

Prepared: *Zainab Khan, Aria Chitturi*

Patient Reported Outcome Measures (PROMS)
Patient Reported Outcome Measures (PROMS) are commonly defined as the measurement instruments utilized to assess patient reported outcomes (PROs), which are usually standardized, validated questionnaires that are completed by patients to ascertain the reality of their "functional status, health-related quality of life, symptom and symptom burden, personal experience of care, and health related behaviors, such as anxiety and depression" (Kingsley, Patel, 2017) (Hodson et al., 2013). Other areas of focus include the patient's social wellbeing, cognitive functions, and role activities. Not only can the outcomes related to the patient's health, quality of life, and a patient's functional status be measured in absolute terms, but also allow for a more holistic "comprehensive assessment of the benefits and of the treatment under investigation" (Hodson et al., 2013). Popular PROM tools include patient-completed questionnaires, which patients use to score their perceived status against a statement with a pre-determined scale (Kingsley, Patel, 2017). PROMS are directly reported by the patients to gain their individualized insights rather than reported by a member of the health care team. While the importance of considering patient reported markers have been recognized, the health care field lags in routinely and fully assessing the impact of health care on individual patients using their perspectives and voices (Hodson et al., 2013).

Patient Reported Experience Measures (PREMS)
Patient Reported Experience Measures (PREMS) are defined as a "measure of a patient's perception of their personal experience of the health care they have received" (Hodson et al., 2013). PREMS focus and prioritize the aspects of care that matter most to the patient, facilitating a focus on patient-centered approach. PREM results 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" (Hodson et al., 2013). Increasingly, patient experiences with health care have become multifaceted since the "disease-specific healthcare experience of a patient may involve different facets of care that reflect different aspects of a patient pathway or journey, for example, a hospitalization for a severe exacerbation compared with a routine review in primary care" (Hodson et al., 2013). When used, PREMS have the potential to dramatically affect the interactions with the health care team by "altering the focus from what the clinician wishes to communicate to an interaction based upon what is important to the patient. In this context, a disease specific PREM is essential" (Hodson et al., 2013). It is important to note that PREMS go beyond patient satisfaction measures, as satisfaction surveys have a ceiling effect and mask the negative experiences in healthcare, failing to address the full spectrum of patient experiences. (Hodson et al., 2013). This is in part because satisfaction is where experience meets expectations; if the patient has low expectations for their care, then they will be satisfied with poor care.

In summary, PROMS measure the patients' report of their health status while PREMS measure the patients' report of their experience receiving care (Kingsley, Patel, 2017). Other commonly used terms include ePROM (electronic patient reported outcome measure), and ePREM (electronic patient reported experience measure).

PROMS and PREMS in HIV Care

People living with HIV may have medical or non-medical health concerns. Often in clinical encounters, the patient thinks 'the doctor or nurse will ask me about what's important', and the clinician is thinking 'if there is something of major concern, the patient will tell me' (Hughson, 2020). Thus, many of the patients issues never surface in the clinical encounter. This demonstrates the need for a mechanism to make clear that all kinds of problems are important and relevant in the clinical encounter (Hughson, 2020). By having an approach to collecting PROM ideally that is brief but measures status which can only be captured by asking the paitent can support providers can perform a full patient-centered assessment at every visit and the patient is enabled to identify what matters (Hughson, 2020). IMeasuring PROs allows providers to also focus on areas that matters to this patient in addition to the clinical examnation (Hughson, 2020). PROM questionnaires for people with HIV include the assessment of the patient's reports of physical, cognitive and psychological status including pain, frailty, quality of life, depression, memorymas we;; as issues such as sitigma, shared decision making, health determinants, and information needs (Hughson, 2020).

PROMS implementation in HIV care is essential because it can improve patient-clinician communication, symptom recognition, treatment adherence, and clinical decision-making including engaging in treatment options and choice. People with HIV have long reported that the focus on viral suppression and adherence to treatment is already well reflected within clinical consultations, but there exists a lack of attention and opportunity to discuss needs beyond antiretroviral therapy-related concerns. Not only does the incorporation of PROMS have the potential to improve quality and effectiveness of care on an individual level, but it can also be used to inform QI work needed to ensure that services are delivered equitably and with a high quality of care that matches the needs of various populations (Bristowe et al., 2019). The results can drive service quality improvement in clinical settings and provide support to patient assessment and care coordination. Care that is centralized to what matters to the individual and is respectful and responsive to their needs has the aptitude to improve care experiences and health outcomes.

To assess PREMS in an HIV clinical setting allows the patient to dsicuss the experiences of care and interaction with the health system, whether those needs, communication between the patient and the healthcare team may improve (Hughson, 2020). Many of these are already incorporated into orutime primary care (did we find this??) In a cross-national multicenter study by Bristowe, semi-structured qualitative interviews were conducted with adult people with HIV, HIV health care professionals, and government representatives. Some of the perceived benefits of utilizing PREMS in routine HIV care included "improved patient-centeredness, patient empowerment, fewer missed concerns, increased engagement with services, and informed planning of services" (Bristowe et al., 2019). Perceived potential challenges were the heterogeneity of people with HIV, literacy, and utility for individuals struggling to engage in care and stay retained in care.

Priorities, Problems, and Concerns for HIV Patients Highlighted in PROMS Domains of Need

Physical problems and concerns	Pain and discomfort (headache, neuropathy, pins and needles, joint pain) GI symptoms (bloating, constipation, diarrhea, lack of appetite, nausea, vomiting, reflux, dry mouth) Body and/or weight changes

	Fatigue Frailty and mobility Skin reactions (sweating) Other (warts or herpes, and eye problems from early HIV treatments) Problems taking ART
Cognitive problems and concerns	Dizziness Memory problems Sleep disturbance Difficulty concentrating
Psychological wellbeing	Negative experiences (anxiety, worry or fear, depression or low mood, stigma and discrimination, concerns around disclosure, shame, self-stigma, guilt, anger, unresolved issues relating to diagnosis or means of contracting HIV, body image, lack of confidence, low self-esteem) Positive experiences (self-esteem, self-worth, confidence, acceptance regarding diagnosis, happiness, meaningfulness, motivation, resilience, and coping)
Welfare, lifestyle and safety problems and concerns	Welfare (financial, housing, immigration, safety at home and in relationships) Self-care (diet and lifestyle, recreational drug use, alcohol consumption, smoking)
Social wellbeing - ability to live their life as they would like to	Relationship status (sex, intimacy, initiating new relationships and concerns about having a child) Social support (family, friends and community, support groups, organizations, faith groups) Isolation or marginalization Independence Impact of HIV on social wellbeing (socializing, employment, education, travel)
Information needs	Knowledge that HIV is under control Knowledge about the future, prognosis and aging with HIV Knowledge about HIV and treatments

(Bristowe et al., 2019)

PROMS/PREMS Frameworks
The goals of implementing PROMS and/or PREMS into routine care are to inform individual patient care and to evaluate care and improve quality. However, various barriers may impede the ability to fully implement these measures into routine care, and QI leading to a need for specific and tailored implementation strategies relevant to the context in which they are being implemented (Stover et al., 2020). A variety of implementation science frameworks exist to effectively integrate PROMS or PREMS implementation strategies. The following implementation science frameworks and theories related to PROMS and PREMS have been used to understand the implementation process and addressing various barriers and enablers in the process. The frameworks and theories include: Consolidated Framework for Implementation Research (CFIR), Theoretical Domains Framework (TDF), Integrated framework for Promoting Action on Research Implementation in

Health Services (i-PARIHS), Knowledge to Action (KTA), and Normalization Process Theory (NPT) (Stover et al., 2020).

Implementation Framework or Theory	Nilsen Classification	Constructs Influencing Implementation	Case Studies
Implementation framework or theory Consolidated Framework for Implementation Research (CFIR) www.cfirquide.org	Nilsen classification Determinant framework: categorizes implementation barriers/enablers	Constructs influencing implementation Characteristics of intervention or practice (e.g., evidence, complexity, cost) Outer setting (e.g., patient needs, policies) Inner setting (e.g., organization/clinic characteristics, culture, implementation climate) Characteristics of individuals (e.g., clinician knowledge, self-efficacy) Implementation process (e.g., engaging, evaluating)	Case stud(ies) Ahmed et al.: implementing ePROMS in a pain network van Oers et al.: implementing ePROMS in multiple pediatric and adult health clinics Manalili and Santana: implementing ePREMS for quality improvement in primary care
Theoretical Domains Framework (TDF)	Determinant framework: categorizes implementation barriers/enablers	Factors Influencing Clinician Behavior Change, e.g.: Knowledge, skills Professional role/identity Beliefs about capabilities Beliefs about consequences Reinforcement Intentions/goals Environmental context and resources Social influence Memory, attention, decision influences Behavioral regulation	Ahmed et al.: implementing ePROMS in a chronic pain network
Integrated framework for Promoting Action on Research Implementation in Health Services (i-PARIHS)	Determinant framework: categorizes implementation barriers/enablers	Successful implementation formula = Roberts et al. 1311: implementing paper and Fac?(l + R + Q electronic PROMS in a medical oncology Fac = facilitation outpatient department Person or organization assigned to do work of facilitation (implementation support) I = innovation Characteristics of innovation	Roberts et al.: implementing paper and electronic PROMS in a medical oncology outpatient department

		Degree of fit with existing practice and values Usability Relative advantage Trialability/observable results R = recipients Clinical experiences/perceptions Patient experiences, needs, preferences C = context Leadership support Culture, receptivity to change Evaluation capabilities	
Knowledge to Action (KTA) Kt.canada.org	Process model: describes practical steps in translating research to practice	Knowledge creation phases: Knowledge inquiry Knowledge synthesis Create knowledge tools Action phases: Determine the know/do gap Adapt knowledge to local context Assess barriers/facilitators to use Select, tailor, implement Monitor knowledge use Evaluate outcomes Sustain knowledge use	Manalili and Santana: implementing ePREMS for quality improvement in primary care
Normalization Process Theory (NPT) normalizationprocess.com	Implementation theory: specifies causal mechanisms	Coherence/sense-making (what is the work?) Cognitive participation (who does the work?) Collective action (how do people work together to get the work done?) Reflexive monitoring (how are the effects of the work understood?)	Manalili and Santana: implementing ePREMS for quality improvement in primary care

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C) Action Plan Moving Forward

The following action items outline CQII's vision in promoting the understanding and implementation of PROMS and PREMS in HIV/AIDS care settings.

- **September 2021 - Convene the Improvement Science Advisory Committee (ISAC)** and provide an update to a subcommittee of QI experts for further feedback. This feedback will help guide subsequent steps.

- **Fall 2021 - Plan and implement the Institute for Healthcare Improvement (IHI) Expert Meeting on PROMS and PREMS.** The meeting objectives are to outline and review existing recourses related to PROMS/PREMS, as well as to provide input and guidance to implement PROMS/PREMS in HIV care.

- **Fall 2021 - Develop a framework guide/white paper to outline a guide for implementing PROMS and PREMS in HIV care.** The guide should incorporate feedback from the ISAC and guidance provided at the IHI Expert Meeting.

- **December 2021 - Begin recruitment of up to 15 sites actively participating in the create+equity Collaborative for a PROMS/PREMS pilot project**. The pilot project will help guide sites to implement PROMS/PREMS in their local HIV programs in addition to their Collaborative activities.

- **January to June 2022 - The PROMS/PREMS pilot project.** The project will last 6 months to be concluding in June 2022.

- **July 2022 – Develop a PROMS and PREMS best practice guide.** This guide on best practices will serve as a companion to the framework guide/white paper to be developed in Fall 2021.

d) Appendix

<u>PROMS/PREMS Focus Group Questionnaire</u>

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 or PROMS or PREMS]
    o If any PROMS or PREMS are being captured, how did you choose these measures?
    o 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

- o 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?
  - o Can you give examples of what measures you use?
  - o Are these measures in your EHR or other data system you use?
  - o If part of a larger organization measuring PROMS or PREMS, does the organization provide your RWHAP clinic with the data?
  - o Are there any mandates (internal or external) to collect PROMS? PREMS?

- For those who have not used PROMS/PREMS:
  - o How hard would it be to implement them? What would be needed?
  - o 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?
  - o 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?
  - o 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?