HRSA Ryan White HIV/AIDS Program
CENTER FOR QUALITY
IMPROVEMENT & INNOVATION

2021 CQII/IHI Expert Meeting Executive Summary:
Patient-Reported Outcome Measures (PROMS) and
Patient-Reported Experience Measures (PREMS)

A) Overview

PROMS/PREMS | CQII/IHI Expert Meeting
Day 1: October 25, 2021 | 12:00pm – 5:00pm ET
Day 2: October 27, 2021 | 12:00pm – 5:00pm ET

As emerging topics in the quality improvement (QI) field, Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) have potential value as QI data sources to improve care for clients served by Ryan White HIV/AIDS Program-funded providers. To explore the understanding of, attitudes towards, and experience with PROMS and PREMS, CQII partnered with the Institute for Healthcare Improvement (IHI) to host a two-day expert meeting focused on the emerging topic.

B) Meeting Objectives

The following meeting objectives were jointly developed with the IHI:

- Develop a shared understanding of PROMS and PREMS and the value in using them to improve patient experience and/or outcomes within Ryan White HIV/AIDS Program-funded clinics
- Begin the journey to create a prioritized list of domains of existing PROMS and/or PREMS to inform next steps to test and refine the process of their implementation by current CQII Collaborative participants and ultimately to other Ryan White HIV/AIDS Program-funded clinics
- Begin developing a strategy and technical assistance (TA) plan for addressing challenges/barriers for collecting, analyzing, and using PROMS and/or PREMS together with QI methods to improve patient outcomes and/or patient experiences
- Brainstorm about next steps to implement these PROMS/PREMS concepts in Ryan White HIV/AIDS Program-funded clinics

C) Meeting Participants

The 2021 IHI Expert Meeting participants consisted of academic content experts, Ryan White providers, people with HIV, QI managers, and public health specialists. Participants were diverse in terms of location and racial identity. Participants were divided into two groups – PROMS or PREMS – to develop a shared understanding, explore barriers to improve patient experiences and outcomes, develop strategies for implementation, identify barriers, and collectively rank their most important five (5) domains of PROMS and PREMS.

The following individuals participated in the 2021 IHI Expert Meeting:

Name/Organization	PREMS	Name/Organization	PROMS
Paul Howard (IHI)	PREMS	Carley Riley (IHI)	PROMS
Teaka Isaac (IHI)	PREMS	Marianne McPherson (IHI)	PROMS
Lisa Hirschhorn	PREMS	Clemens Steinbock (CQII)	PROMS
Paula Jones	PREMS	Aria Chitturi (CQII)	PROMS
Michelle Pendill (CQII)	PREMS	Marlene Matosky (HRSA)	PROMS
Chris Redwood (HRSA)	PREMS	Dawn Trotter	PROMS
Jim Tesoriero (CQII)	PREMS	Adam Thompson	PROMS
Dottie Dowdell	PREMS	Kathleen Clanon	PROMS
D'Ontace Keyes	PREMS	Cecilia Chung	PROMS
Travis Barnhard	PREMS	Tonya Green	PROMS
Reachelian Ellison	PREMS	Aaron O'Brien	PROMS
Julie Saber	PREMS	Khalil Hassam	PROMS
Pam Klein	PREMS	Mulamba Lunda	PROMS
Wayne Steward	PREMS		

D) Agenda Overview

This two-day agenda was developed with the intention of providing participants with an introduction to PROMS and PREMS while creating spaces to hear everyone's voices. Thus, the meeting contained several presentations and five (5) breakout sessions. The meeting was facilitated by Paul Howard (IHI). A detailed agenda is available upon request.

Day 1 (all times are ET)		Day 2 (all times are ET)	
12:00 – 12:15	Welcome and Getting Started	12:00 – 12:10	Welcome and Getting Started
12:15 – 1:00	Introductions and Overview of the Expert Meeting	12:10 – 1:00	Breakout 3: Top 5 PROMS and PREMS Domains
1:00 – 1:05	Break (5 min)	1:00 – 1:20	Challenges and Barriers to using PROMS and PREMS
1:05 – 1:55	Overview of PROMS and PREMS (Pat Franklin and Lisa Hirschhorn)	1:20 – 1:30	Break (10 min)
1:55 – 2:25	Break (30 min)	1:30 – 2:15	Breakout 4: Strategies for Addressing Challenges
2:25 – 2:45	PROMS and PREMS in Other Settings (Carley Riley and Marianne McPherson)	2:15 – 2:45	Break (30 min)
2:45 – 3:30	Breakout 1: Developing a strong list of "Domains" for PROMS and PREMS	2:45 – 3:05	Report Outs from Breakout Groups
3:30 – 3:40	Break (10 min)	3:05 – 3:50	Breakout 5: Technical Assistance and Resources Needed
3:40 – 4:00	Operationalizing the Collection and Use of PROMS and PREMS	3:50 – 4:00	Break (10 min)
4:00 –	Breakout 2: How to Implement	4:00 –	Report Outs from Breakout Groups

4:35	PROMS and PREMS at Ryan White-funded Clinics	4:20	
4:35 – 4:50	Report Outs from the Breakout Groups and Discussion	4:20 – 5:00	Next Steps, Evaluation, and Wrap-Up
4:50 – 5:00	Preparing for Day 2 and Wrapping up Day 1		

E) Prioritized Domains

Participants worked in their respective PROMS or PREMS breakout groups to review and discuss various domains that were presented to them and had the opportunity to add additional domains (see **Appendix A:** *Additional Domains to Consider).* Given a working list of possible domains and examples of domain measures, 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?; How heavy of a collection/reporting burden do you think this would be for a busy Ryan White-funded clinic?; and Can a measure in this domain be easily linked to quality improvement efforts?.

Each of these criteria were to be scored on a scale of 1-5, with 1 being very difficult to measure and 5 being very easy to measure. Participants then shared their initial reaction to each domain before individually selecting 5 domains that were important to them. Using the Delphi method, the domains were prioritized and resulted in the following "top 5" PROMS/PREMS domains.

Prioritized PROMS and PREMS Domains	
PROMS	**PREMS**
1. Well-being	1. Experience of Racism
2. Housing Stability	2. Respect/Dignity
4. Mental Health (tie)	3. Privacy/Confidentiality
4. Perceived Discrimination/Everyday Discrimination (tie)	5. Communication (tie)
5. Food Security	5. Shared Decision-Making (tie)

F) Considerations for High-Level Implementation Strategies

In their respective breakout groups, the participants were then asked to think about various considerations for implementing their PROMS or their PREMS into practice in busy HIV clinics. High-level implementation strategy examples were provided. To make them more actionable, participants were asked to add more detail. The following notes summarize these action items by each group.

1. **PROMS - Considerations for Implementation**
   a. Standardize processes to facilitate the implementation: use of standardized tools and workflows (best practices, collection tools, reporting).
   b. Identify where there might be room for clinics to tailor questions/tools specific to them and then track it.
   c. Develop workplan for implementation and data collection.

d. Specify that PROMS are part of agency's evaluation plan (both to ensure PROMS measures are still relevant and point of accountability if action was taken from findings).

e. Shared purpose & meaning: Ensure everyone who interacts with the PROMS, especially patients, understands *why* a PROM is being collected.

f. Ensuring the workflow includes how all team members, especially patients, can be informed and act on the information.

g. In the spirit of giving as much guidance as possible to Ryan White providers, recommend they develop a formal training & change management model to ensure strong implementation and data collection building on upon existing QI infrastructures.

2. **PREMS - Considerations for Implementation**

a. Engage people beyond the written word - sit down and talk with people. This is beyond the pen and paper and check boxes. Incorporate this mindset and approach and feel their emotion.

b. The importance of listening and letting people know they are heard.

c. Send out reports to clients (annual meeting and/or other venues so they can see that their words/thoughts matter. Different methods (consumer meetings, reports) - find multiple ways to disseminate.

d. The amount of questions and the format - you never want to overwhelm a person. Think about how much you are asking them in one sitting.

e. Evaluate the implementation process in real-time - make changes as needed – and build on existing PREMS infrastructures.

G) Discussion Points on Potential Barriers or Challenges

Reflecting upon their list of considerations for implementation, participants were asked to brainstorm barriers or challenges. Among the PROMS and PREMS breakout groups, participants developed some strategies to address these barriers with the goal of having at least a few potential strategies for the barriers and challenges listed. The following notes summarize these potential barriers or challenges to implementation.

1. **PROMS - Thoughts on Barriers or Challenges to Implementation**

a. Not a one-size fits all -- will depend on staffing, resources of each clinic

b. Upper management aren't in the day-to-day; they need to understand what it takes and what the challenges are so they can support clearing barriers, bringing forward resources

c. Multiple systems within an organization can cause challenges because not all the systems, even within the same clinic, may be interfaced. This means staff are often documenting things in multiple systems and that's a source of staff fatigue.

d. Select the few measures you feel relevant to the clinic -- avoid the "useful many"

e. To the extent that we can, we need to provide tools, workflow, different languages, and "spoon-feed" so this becomes a package presented to the clinic. This way, there's no reinvention, just adaptation

2. **PREMS - Thoughts on Barriers or Challenges to Implementation**
    a. Need to consider the challenges that come from working within larger institutions. Decisions by larger institutions to do things like change an EHR can greatly affect the best laid plans and undo all of the work one had done to date.
    b. Balancing qualitative and quantitative data. The former are needed to better get at the individual experience and nuances, but are harder to collect. The latter are better for easily documenting change over time (e.g., performance measures).
    c. PREMS may be harder to make a change for a specific patient - but can be used to find some system challenges.
    d. Making sure that we show possible improvements or changes/adoptions to agency or consumers. This eases folks into wanting to be a part of this.
    e. Within large healthcare systems, they have to get approval to make any changes (and this can take time); check feasibility for large scale implementation.

H) Conclusion

This meeting provided CQII and IHI with a shared understanding of PROMS and PREMS, the identification of prioritized domains, and the foundation of a technical assistance plan to address challenges and barriers to implementation. As PROMS/PREMS could be a valuable tool for quality improvement in HIV/AIDS care, it was essential to gather these perspectives for its application. These perspectives will also serve as the foundation for CQII's next steps in PROMS and PREMS activities.

H) Next Steps

- **December 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 CQII Improvement Science Advisory Committee and guidance provided at the IHI Expert Meeting.

- **December 2021 – Conduct a national survey to gather additional input from the larger Ryan White community.**

- **December 2021/January 2022 - 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.

- **December 2021 – Reach out to HRSA funded entities who work on consumer engagement, such as TAP-IN**

- **January 2022 – Review the NQF and CMS frameworks for developing and implementing performance measures.**

- **January to June 2022 - The PROMS/PREMS pilot project.** The project will last 6 months to be concluding in June 2022 with potential involvement from IHI to guide the pilot.

- **May 2022 – Consider developing a brief video to introduce PROMS/PREMS and to promote their use.**

- **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.

I) Contact Information

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Appendix A: *Additional Domains to Consider*

What are other additional domains that are critical to consider?

PROMS	PREMS
Access to basic needs	Access to other healthcare service options
Financial - ability to pay for Rx, transportation to med appts, etc.	Maybe one general question on asking what we can do to improve your experience?
Criminal Justice System Involvement (patient or someone close to patient)	Support Systems (i.e., Peer Support, Support Groups)
Language, literacy and technology barriers	Measuring other 'isms' in addition to racism and ageism, particularly related to sexual orientation and gender identity.
	Another one around how HIV stigma impacts willingness to walk into a service provider known to serve PWH.
	Health literacy & stigma
	Stigma associated with accessing services e.g., mental health, substance abuse, etc.