

PROMS+PREMS Pilot Study Summary Report

Findings from the CQII Pilot Project (January – June 2022)



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Executive Summary

The involvement of people with HIV in their care has been a hallmark of the Ryan White HIV/AIDS Program (RWHAP) since its inception. Their engagement takes many forms, from participation in community planning processes, involvement in quality improvement (QI) activities, to measurement of patient experiences with HIV care and their health outcomes.

While tracking viral suppression and other clinical measures is important to achieving improved health outcomes, other regional milestones (e.g., Ending the HIV Epidemic initiative goals) and national public health goals (e.g., National HIV/AIDS Strategy) have moved to incorporate additional measurement metrics that reflect domains that patients identify as important to their wellbeing, quality of life, and their experience with receiving healthcare.

Patient-reported outcome measures (PROMS) and patient reported experience measures (PREMS), indicators that can be used to improve health outcomes and experiences on an individual, organizational, and systemic level, are an emerging topic in the field of performance measurement and QI. They serve as complementary metrics for assessing the quality of healthcare, including HIV treatment, and the health care experience based on the individual feedback of patients. The use of PROMS and PREMS is a vital opportunity to elevate patient voices in the effort to improve health outcomes and the quality of health care services.

RWHAP recipients/subrecipients are required to engage in clinical quality management activities—a systematic process of assessing efforts, collecting, and analyzing data, and engaging stakeholders to identify solutions. PROMS and PREMS fit this framework. They 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. While PROMS and PREMS can identify areas for improvement, it is incumbent on provider staff (i.e., quality management team) to be able to interpret the findings and act on them — and then, importantly, let patients know how their feedback was used to make improvements.

The concept of PROMS and PREMS and the terminology may be new to some. However, many RWHAP-funded providers are already collecting data from patient-reported measures related to health outcomes and experiences with health care services, such as depression, quality of life, and satisfaction with care. It can be daunting to take on new measurement activities, especially when it comes to identifying measures and establishing new data collection processes. But, as they undertake these QI activities, most RWHAP providers will not be starting from scratch. Their existing QI activities already use the methodologies needed for PROMS and PREMS and may already be collecting key data. The Center for Quality Improvement and Innovation (CQII) — in partnership with the Institute for Healthcare Improvement (IHI) and HRSA HIV/AIDS Bureau (HAB) — has taken steps to support more patient-centered HIV care

through the incorporation of PROMS and PREMS into RWHAP providers' QI activities. CQII's initial activities to explore this emerging QI topic consisted of the following:

- Focus Groups: Exploring Opportunities for Valuing and Integrating the Voices of Patients to Improve HIV Care
 - In June/July 2021, CQII conducted a series of focus groups with participants in CQII's create+equity Collaborative. Participants represented RWHAP provider staff including data manager/QI lead, senior manager, social worker, HCV coordinator, program coordinator, and quality manager.
- Literature Overview
 - CQII compiled articles on various topics related to: PROMS; PREMS; PROMS and PREMS in HIV care; priorities, problems, and concerns for HIV patients highlighted in PROMS domains of need; and PROMS and PREMS frameworks.
- Institute for Healthcare Improvement (IHI) Expert Meeting
 - In October 2021, CQII and IHI convened a meeting of academic content experts, RWHAP providers, people with HIV, QI managers, and public health specialists. Participants explored a shared understanding of the measurement framework and initial ranking of the most important domains for PROMS and PREMS.
- National PROMS and PREMS Survey
 - CQII partnered with content experts to conduct a national survey to explore the understanding of attitudes towards, and experience with PROMS and PREMS measurement across RWHAP providers and patients.

The purpose of the PROMS+PREMS Pilot Project was for participating agencies to explore the value of these measures as a vital data source in HIV care and their feasibility for integrating the results in ongoing QI activities, identify best practices to measure PROMS and/or PREMS in HIV ambulatory care settings as additional QI measures and optimize agency-level strategies in the use of PROMS and/or PREMS data results to improve HIV care and complement ongoing QI efforts. CQII's expectations were that the findings of the Pilot Project will assist national efforts to increase the awareness of PROMS and PREMS among RWHAP and to further empower HIV providers to utilize findings to improve HIV health outcomes and patient experiences in HIV care.

In January 2022, CQII launched a six-month Pilot Project to explore the use of PROMS and PREMS in RWHAP settings. Ten (10) RWHAP providers were recruited from CQII's create+equity Collaborative. Each selected either a PROM or PREM domain for measurement and used the data results to inform QI activities. The eight participants that completed the Pilot in June 2022 realized the potential benefits of using PROMS and PREMS to listen to the voices of people with lived experience and utilize the findings to improve health outcomes and patient experiences in HIV care.

The Pilot Project showed that PROMS and PREMS have value as additional metrics for assessing the quality of HIV care delivered to people with HIV. Pilot participants not only realized the potential benefits of using PROMS and PREMS for QI, but also that QI is a continuous journey to being better stewards of the responsibility they are given to serve people with HIV.

Based on the experiences of this Pilot Project, CQII developed several resources for wider dissemination to the RWHAP community.

PROMS and PREMS Guide to increase awareness among RWHAP providers about the purpose of PROMS and PREMS as additional QI measures beyond viral suppression and how to use them to improve patients' outcomes and treatment experiences. Best practices from pilot participants were integrated in the Guide.

Ten (10) PROMS/PREMS measurement tool sets with specific patient questions (5 PROM and 5 PREM domains) to assist HIV providers with the adoption of already existing PROMS/PREMS measures.

PROMS and PREMS Video to introduce and widely promote the use of PROMS and PREMS among HIV providers and people with HIV.

All PROMS/PREMS resources are being made available on the CQII website housed at the TargetHIV site (<https://targethiv.org/cqii>)

Introduction

'We joined the pilot because we felt it would be good for our clients in the long run. Getting the patient perspective is important and we hope that it will allow us to provide even better care to our clients.'

PROMS+PREMS Pilot Project Participant

Integrating the voices of individuals with lived experiences is a cornerstone in quality improvement. Thus, it is vital to routinely assess the quality of HIV outcomes and experiences with the healthcare system using the insights of the clients we serve.

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 and services. PROMS and PREMS have the potential to fuel conversations between patients and providers that ultimately lead to shared decision-making and result in more individualized care.

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. 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 utilization of data to improve care. When the appropriate PROMS or PREMS tool is identified, piloted, and refined, the data collected can help support ongoing quality improvement efforts and result in better health outcomes. By utilizing the PROMS and PREMS data, healthcare providers can better understand the patients' perspective of their health status, health goals, and the healthcare 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 and subrecipients 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

patients, to identify and implement improvement solutions. PROMS and PREMS fit this framework. To this end, the Center for Quality Improvement & Innovation (CQII) collaborated with the Institute for Healthcare Improvement (IHI) and its federal funder, the HRSA HIV/AIDS Bureau (HAB), to implement a six-month PROMS+PREMS Pilot Project, which ran from January 2022 through June 2022.

The following definitions have been adopted by CQII as they help foster the understanding of PROMS and PREMS:

- **PROMS** are defined as any measurement of patient’s well-being or patients’ perceptions of their health status, which can only be determined by directly asking the patient. These are measured using standardized, often validated questions or instruments. Examples include depression, anxiety, pain, fatigue, etc.
- **PREMS** are measures of the patient's personal experience of the healthcare they have received. These include respect, communication, privacy, engagement in shared decision-making, as well as the environment in which care is delivered.

With support of national experts and people with lived experiences, participating agencies in the PROMS+PREMS Pilot Project explored the a) value of PROMS/PREMS as vital data sources in HIV care; b) testing the feasibility of measuring PROMS/PREMS in busy clinic settings; c) integrating the PROMS/PREMS results in ongoing quality improvement activities to advance HIV care and services; and d) identifying best practices to evaluate the measurement of PROMS and/or PREMS as complementary quality improvement measures.

In addition to the Pilot Project, CQII developed several resources for use by the wider RWHAP community, including ten PROMS/PREMS measurement tool sets with specific patient questions (5 PROM and 5 PREM domains), a PROMS and PREMS implementation guide with examples from participants in the PROMS+PREMS Pilot Project, an outline of literature related to PROMS and PREMS, and a brief video to introduce these frameworks.

It is the hope of CQII that the PROMS+PREMS Pilot Project will foster a national dialogue to increase the awareness of PROMS and PREMS among RWHAP recipients/subrecipients and to further empower HIV providers to utilize findings to improve health outcomes and patient experiences in HIV care.

Resources Developed | *PROMS/PREMS Literature Overview*
2021 Focus Group Report
2021/2022 National PROMS/PREMS Survey Report
2021 CQII/IHI Expert Meeting Report
Ten PROMS/PREMS Measurement Tool Sets
PROMS+PREMS Pilot Project Toolkit
PROMS/PREMS Video
CQII PROMS/PREMS Guide

Pre-Work Activities

Prior to the launch of the PROMS+PREMS Pilot Project, CQII engaged in several pre-work activities to set the stage and establish a foundational framework to measure these important additional indicators and use the data results to improve HIV care and experiences.

Literature Overview

A literature overview was conducted on PROMS and PREMS, which has resulted in a written report by CQII. This literature overview outlines the current state of PROMS and PREMS adoption while illustrating the need for more widespread use and further research.

Key findings include:

- 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.
- 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.
- Both PROMS/PREMS and quality improvement share similarities, including the focus on improving patient care and the use of data findings to support improvement efforts that result in better health outcomes and healthcare experiences.
- Applying an implementation science framework 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.

Resource Developed | *PROMS/PREMS Literature Overview*

2021 Focus Groups

To initially explore the understanding of, attitudes towards, and experience with PROMS and PREMS across RWHAP-funded providers of ambulatory care services, CQII conducted a series of focus groups with participants in the CQII's create+equity Collaborative. Participants represented RWHAP provider staff including data manager/QI lead, senior manager, social worker, HCV coordinator, program coordinator, and quality manager. In total, three (3) calls were conducted between June and July 2021 using a standardized interview guide.

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

- *'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. Participants saw the potential benefits of using PROMS/PREMS for quality improvement and in gaining additional insights from direct input by HIV clients.

- *'We want to learn more'* – participants expressed genuine interest in learning more and exploring the use of PROMS and PREMS at their sites. 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.
- *'We want guidance'* - participants were willing to engage in future activities to implement PROMS and PREMS in their HIV programs. Participants indicated a desire to learn from real-world examples of HIV-specific PROMS/PREMS examples and requested practical tools to help ground their understanding and to guide them forward.
- *'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. 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.)
- *'PREMS are more than patient satisfaction surveys'* – The need for better delineating the difference between patient satisfaction and patient experience, particularly as it relates to PREMS, was identified. PREMS should embrace a variety of modalities to gather patient-reported experiences with HIV care beyond patient satisfaction surveys. In general, there was a greater foundational knowledge and experience around PROMS than around PREMS

Resource Developed | *Focus Group Report*

2021 CQII/IHI Expert Meeting

To explore the understanding of, attitudes towards, and experience with PROMS and PREMS, CQII partnered with IHI to host a two-day expert meeting in October 2021. Participants consisted of academic content experts, RWHAP providers, people with HIV, QI managers, and public health specialists. A detailed meeting report is available.

The meeting objectives were to:

1. Develop a shared understanding of PROMS and PREMS and the value in using them to improve patient experience and/or outcomes within RWHAP-funded clinics.
2. 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.
3. Begin developing a strategy and technical assistance plan for addressing challenges/barriers for collecting, analyzing, and using PROMS and/or PREMS.

Using the Delphi method, participants worked in their respective PROMS or PREMS breakout groups to prioritize the provided list of possible domains using a set of agreed criteria, which resulted in the following “top 5” PROMS/PREMS domains.

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



Resources Developed | *2021 CQII/IHI Expert Meeting Report*
Ten PROMS/PREMS Measurement Tool Sets

2021/2022 National Survey

To further test the findings of the Focus Groups and the CQII/IHI Expert Meeting, CQII conducted a PROMS and PREMS National Survey, announced in December 2021, which included questions about the current use of PROMS and PREMS in HIV program settings, as well as perspectives on implementation barriers and feasibility of measurement. The main goal of the survey was to validate if the domains of PROMS and PREMS selected during the IHI Expert Meeting were relevant to HIV care and if those domains were perceived to be feasible to measure and implement in busy HIV ambulatory care settings and use the results to inform and drive quality improvement.

The online survey link was emailed to RWHAP providers across the United States and CQII received 126 responses over 6 weeks. Most respondents were either “familiar” or “somewhat familiar” with both PROMS and PREMS, although most indicated that they did not have prior experience implementing them in healthcare settings, including HIV care settings. Each domain prioritized by the expert meeting for both PROMS and PREMS was ranked independently among participants as having “high” relevance to HIV care. However, several domains for both PROMS and PREMS received “moderate” or “low” rankings for perceived difficulty to be measured and implemented, including Patient Wellbeing, Mental Health, Discrimination, Self-Efficacy for Managing Chronic Conditions, and Adolescents and Young Adults for PROMS. For PREMS, this includes Racism, Shared Decision-Making, Perceived Importance of Services, and Continuity/Coordination of Care.

The results suggest a lack of experience in measuring and using PROMS and PREMS in RWHAP-funded settings, which supported the need for a pilot study to measure the feasibility of implementing PROMS or PREMS in real time and to use results to improve quality of care and

health outcomes. A detailed report of the findings of this National PROMS/PREMS Survey is available.



Resource Developed | *National PROMS/PREMS Survey Report*

PROMS+PREMS Pilot Study

To better measure the feasibility of implementing and measuring these domains in local HIV care settings and effectively use the results to improve health outcomes and patient care experiences, a pilot study with RWHAP clinics was evident. With the support of the HRSA HIV/AIDS Bureau, CQII collaborated with IHI to plan and implement this six-month PROMS+PREMS Pilot Project, which ran from January 2022 through June 2022.

The overall goals of the PROMS+PREMS Pilot Project were to explore the

- a) value of PROMS/PREMS as vital data sources in HIV care
- b) testing the feasibility of measuring PROMS/PREMS in busy clinic settings
- c) integrating the PROMS/PREMS results in ongoing quality improvement activities to advance HIV care and services
- d) identifying best practices to evaluate the measurement of PROMS and/or PREMS as additional quality improvement measures

The pilot participants were RWHAP recipients or subrecipients who concurrently participated in the CQII create+equity Collaborative and who were interested in exploring the emerging topic of PROMS and/or PREMS in their agencies. Prior knowledge or experience with PROMS and/or PREMS was not requisite for participation in the PROMS+PREMS Pilot Project.

The following criteria were used to select pilot participants:

- Active participation in all aspects of the PROMS+PREMS Pilot Project
- Ability to continue to fully participate in the create+equity Collaborative and other HRSA-funded obligations while participating in the PROMS+PREMS Pilot Project
- Demonstrate existing capacities for performance measurement and quality improvement in HIV care
- Ability to implement one PROMS or PREMS at the agency-level using the provided measures and utilization of the data results in the agency to improve HIV care or the experiences of people with HIV
- Availability to share experiences in implementing PROMS or PREMS with faculty members and for inclusion in the PROMS/PREMS implementation guide

Interested agencies were asked to complete a brief online application to determine interest and ability to fully engage in the PROMS+PREMS Pilot Project.

Initially, 10 participating sites were selected in the PROMS+PREMS Pilot Project. Two sites were part of the same cooperative and were consolidated into one and one site dropped out due to competing priorities. Eight participating agencies completed the Pilot Project in June 2022.

Benefits of Participating in the Pilot

- Opportunities to jointly explore this emerging quality improvement topic with CQII staff and consultants
- Access to national content experts from IHI, and their coaching support and individualized technical assistance
- Access to standardized PROMS/PREMS tools and measures for use beyond the pilot project, including sample measures, topic-specific literature review, findings from a CQII/IHI Expert Meeting, and focus group findings with RWHAP recipients/subrecipients
- Contributions of lessons learned to be documented in the PROMS/PREMS Guide

Expectations to Participate in the Pilot

- Participate in monthly one-hour webinars with presentations by national experts and updates by other PROMS+PREMS Pilot Project participants
- Participate in monthly coaching calls with assigned faculty members to provide one-on-one support to guide implementation
- Implement at least one PROMS or PREMS in the agency
- Use the results in current QI activities
- Share the implementation strategies during monthly reflection calls
- Contribute to the development of the PROMS and PREMS implementation guide by identifying best practices

Faculty Support

To support each participating agencies, the following key faculty support roles were identified and filled by CQII and IHI staff and consultants/experience experts.

Faculty	Roles
Lead: Clemens Steinbock, Paul Howard	<ul style="list-style-type: none"> ○ Provide general guidance and direction for Pilot Project ○ Facilitate Orientation and Group Sessions ○ Point person to update HRSA
Manager: Aria Chitturi/Dennis Pearson	<ul style="list-style-type: none"> ○ Coordinate the development of content and resources ○ Point person for Pilot Project activities and communication with all participation/coaches ○ Coordinate Planning Group Meetings
Data Analyst: Stephen Weinberg	<ul style="list-style-type: none"> ○ Develop tracking tools ○ Set up reporting systems ○ Summarize all site collected data ○ Summarize all site collected data
Experience Expert: Adam Thompson, Melissa Curry, Martha Cameron	<ul style="list-style-type: none"> ○ Support participants in their engagement of people with HIV ○ Support participants in their PROMS/PREMS implementation efforts

PROM/PREMS Coach: Carley Riley, Aleya Martin	<ul style="list-style-type: none"> ○ Facilitate Coaching Sessions ○ Provide support and TA to implement PROMS and PREMS measures ○ Provide content for PROMS and PREMS presentations ○ Document and track assigned sites
QI Coach: Amanda Norton, Christina Clarke, Justin Britanik, Stephanie Hedepeth	<ul style="list-style-type: none"> ○ Provide QI support and technical assistance to assigned sites ○ Provide content presentations to link PROMS/PREMS data to improvement activities ○ Document and track assigned sites
Support: Michelle Pendill, Shaymey Gonzalez, Teaka Isaac	<ul style="list-style-type: none"> ○ Set up meeting schedules and send out reminders ○ Maintain all sharing and communication platforms ○ Communicate with all sites and faculty members ○ Record minutes
Writer: Paula Jones	<ul style="list-style-type: none"> ○ Facilitate the Group Reflection Sessions ○ Document lessons learned and best practices ○ Develop the PROMS/PREMS Guide based on Pilot Project experiences

Pilot Sites

The table below list sites and their assigned PROMS/PREMS coaches and experience experts.

Pilot Site	State	Coach	Experience Expert
AIDS Ministries	IN	Aleya Martin, Stephanie Hedepeth, Amanda Norton	Adam Thompson
AIDS Project of the Ozarks	MO	Aleya Martin, Stephanie Hedepeth, Amanda Norton	Adam Thompson
Harris County Public Health	TX	Aleya Martin, Stephanie Hedepeth, Amanda Norton	Adam Thompson
UPMC Presbyterian Shadyside	PA	Aleya Martin, Stephanie Hedepeth, Amanda Norton	Martha Cameron
Centro Ararat Inc	PR	Carley Riley, Justin Britanik, Christina Clarke	Martha Cameron
Cook County HIV Integrated Programs	IL	Carley Riley, Justin Britanik, Christina Clarke	Martha Cameron
Eau Clair Cooperative Health	SC	Carley Riley, Justin Britanik, Christina Clarke	Melissa Curry
Tarrant County HIV Administrative Agency	TX	Carley Riley, Justin Britanik, Christina Clarke	Melissa Curry

Project Timeline

Over the course of the pilot’s six-months a step-by-step timeline of activities was provided to both pilot participants and PROMS/PREMS faculty. The table below outlines a charted timeline of the pilot project.

	January	February	March	April	May	June
A) Group Session	<i>Getting Started</i>	<i>Pick your PROM or PREM Domain</i>	<i>Select your PROMS and PREMS Measures</i>	<i>Integrating and Implementing Your Measure</i>	<i>PROMS and PREMS in Practice</i>	<i>Putting Data into Action</i>
B) Individual Coaching Call	<i>Send email to establish relationship</i>	<i>Selecting a domain</i>	<i>Prioritizing measures from selected domain</i>	<i>Guide implementation</i>	<i>Guide sites to take action in response to data findings</i>	<i>Discuss actions in response to data</i>
C) Best Practice Reflection Session		<i>How to select a domain</i>	<i>How to prioritize PROM PREM measure</i>	<i>How to integrate and implement PROM PREM measure</i>	<i>How to take action in response to data findings</i>	<i>Lessons learned and best practices</i>

A) Group Sessions

- Description: monthly 60-minute group sessions of all pilot participants, PROMS/PREMS coaches/faculty and people with lived experience.
- The Group Sessions served to bring all pilot participants together in an open forum of peer sharing and learning facilitated by both a coach and/or a person of lived experience. In addition, coaches and/or experience coaches took turns delivering didactic presentations on topics specific to the implementation of PROMS/PREMS. Topics covered included: *How to engage people with lived experience in the selection of PROMS/PREMS measures, Integrating & implementing PROMS/PREMS measures, How to Use Data for Results? Putting PROMS and PREMS results in QI practice and Putting data into action (how to continue using PROMS+PREMS to improve HIV care).*

B) Individual Coaching Calls

- Description: monthly 60-minute individual coaching calls were provided to each PROMS+PREMS pilot site by assigned coaches and individuals with lived experience to assist with pilot project implementation.
- This space allowed for pilot participants to individually share their progress (and challenges) implementing PROMS/PREMS. In so doing they received expert technical assistance tailored to their specific needs and circumstances. A focus area was suggested for each monthly call.

C) Best Practice Reflection Sessions

- Description: Three 30-minute Reflection Sessions were held each month on consecutive days to accommodate scheduling conflicts. Pilot project participants were only expected to select one of three monthly sessions.
- The best practice Reflection Sessions focused on predetermined monthly content areas and focused on key questions outlined in the PROMS+PREMS Pilot Project Toolkit. These Reflection Sessions allowed CQII to document the experiences of pilot participants that contributed to the development of the CQII PROMS+PREMS Guide. Detailed notes were taken at each call and shared with the assigned coaches and experience experts.

In addition to the formalized structure outlined for pilot participants, weekly internal planning calls were held each Wednesday with PROMS+PREMS coaches/faculty to debrief and strategized on how to guide participants to effectively implement their PROMS/PREMS pilot project. The coaches with lived experience played a key role on this planning body as their thoughts and insights provided a unique perspective that was at the core of every decision and activity undertaken. For example, their advice and guidance to pilot sites particularly, on issues of engagement of people with HIV with PROMS/PREMS survey completion was invaluable.

Resources Developed | *Ten PROMS/PREMS Measurement Tool Sets*
PROMS+PREMS Pilot Project Toolkit
PROMS/PREMS Website on TargetHIV

PROMS/PREMS Domains and Measures

CQII looked at ways to support RWHAP providers in incorporating patient-reported outcomes and experiences. It became clear that many providers were already collecting patient-reported data and using them in their QI activities. In response, CQII sought to identify priority areas, also referred to as domains, that could be incorporated into ongoing QI activities. This approach was designed to allow RWHAP providers to build on existing efforts, utilize established data collection processes, and gradually build a more robust use of patient-reported outcome and experience measures.

The 2021 CQII/IHI Expert Meeting suggested domains participants could use for the Pilot Project. It is worth noting that these were not the only domains participants could use as the characteristics of the organization and their patient population would drive what issues to prioritize. Prior to selecting a PROM/PREM domain pilot participants were advised to consider whether they are:

- *Relevant* – are the PROM/PREM domains relevant to the patients they serve? Do they generate the necessary momentum and interest among staff?
- *Measurable* – to the extent possible, can existing data collection system be utilized?
- *Actionable* – Does the organization have the capacity to address the issue that will be identified?
- *Sustainable* – Can data be collected over time and integrated in ongoing QI efforts?
- *Tailorable* – Do potential findings allow considerations of differences within the organization, patient population, geographic region, etc.

By February 15, 2022, pilot participants had selected their PROM/PREM domain. The table below list the sites and selected domains.

Pilot Site	Selected Domain	PROM/PREM
AIDS Ministries	Housing Stability	PROM
AIDS Project of the Ozarks	Communication	PREM
Centro Ararat	Quality of Life/Well-being	PROM
Cook County HIV Integrated Programs	Housing Stability	PROM
Eau Clair Cooperative Health	Housing Stability	PROM
Harris County Public Health	Quality of Life/Well-being	PROM
University of Pittsburgh Medical Center, Presbyterian Shadyside	Food Security	PROM
Tarrant County HIV Administrative Agency	Quality of Life/Well-being	PROM

In addition to the suggested domains, detailed domain-specific PROMS/PREMS survey questions were provided to each participating team to serve as an initial assessment tool.

Participants were free to use all or some of the questions. Some questions do not constitute a validated measure, but they were drawn from existing measures and references for each tool were provided.

The table below provides examples of **PROMS** domains and sample questions shared during the CQII/IHI Expert meeting.

Patient-reported Outcome Measures [PROMS] Domains		
Priority Domain	Why is Important	Example of Validated Tool Measures/Questions
<p>Quality of Life/Well-being (e.g., overall health [not related to related to HIV], quality of life, impact of 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) Twelve (12) question survey plus demographics</p> <p>Sample Questions/Answers <i>Imagine a ladder with steps numbered from zero at the bottom to ten at the top. The step of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you.</i></p> <p><i>On which step of the ladder would you say you personally feel you stand at this time?</i></p> <p><i>On which step do you think you will stand about 5 Years from now?</i></p> <p><i>Now imagine the top of the ladder represents the best possible financial situation for you, and the bottom of the ladder represents the worst possible financial situation.</i></p> <p><i>In general, how would you rate your physical health?</i></p> <p><i>How would you rate your overall mental health?</i></p> <p><i>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</i></p>

		<i>and friends, and positive and negative emotions.</i>
Housing Stability (whether the patient has stable housing, fears losing their housing)	In 2019, almost 29,000 RWHAP clients reported unstable housing. People experiencing homelessness or 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>Veterans Administration Homeless Screening Tool Five (5) question survey</p> <p>Sample Questions/Answers: <i>In the past 2 months, have you been living in stable housing that you own, rent, or stay in as part of a household?</i></p> <p><i>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?</i></p> <p><i>Where have you lived for MOST of the past 2 months?</i></p> <ul style="list-style-type: none"> • Apartment/ House/ Room - no government subsidy • Apartment/House/ Room - with government subsidy • With Friend/ Family • Motel/Hotel • Hospital, Rehab Center, Drug Treatment Center • Homeless: Shelter • Anywhere outside, (e.g., Street, Vehicle, Abandoned Building) • Other <p><i>Would you like to be REFERRED to talk more about your housing situation?</i></p>
Mental Health (depression, anxiety, substance use)	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>PHQ9 – Depression Severity Ten (10) question survey</p> <p>Sample Questions/Answers <i>Over the last 2 weeks, how often have you been bothered by any of the following problems?</i></p> <ul style="list-style-type: none"> • Little interest or pleasure in doing things. • Feeling down, depressed, or hopeless • Trouble falling or staying asleep or sleeping too much. • Feeling tired or having little energy.

		<ul style="list-style-type: none"> • <i>Trouble concentrating on things, such as reading the newspaper or watching television.</i> <p><i>Answers: (Not at all, several days, more than half the days, nearly every day).</i></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) Nine (9) questions plus a follow-up question on ‘perceived reasons</p> <p>Sample Questions/Answers <i>In your day-to-day life how often have any of the following things happened to you?</i></p> <ul style="list-style-type: none"> • <i>You are treated with less courtesy or respect than other people</i> • <i>You receive poorer service than other people at restaurants or stores</i> • <i>People act as if they think you are not smart</i> • <i>People act as if they are afraid of you</i> • <i>You are threatened or harassed</i>
<p>Food Security (lack of food, fear of not having enough food, lack of access to nutritional food)</p>	<p>In 2019, 12.6 percent of RWHAP patients received food assistance (i.e., food bank, home-delivered meals) through the program. Studies indicate that food insecurity can lead to high levels of depression in people with HIV.¹² Evidence also indicates lower rates of viral suppression, lower CD4 counts, and poorer health outcomes.</p>	<p>USDA Food Security Brief Survey Six (6) question survey</p> <p>Sample Questions/Answers <i>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 (DK) or Refused)</i></p> <p><i>(I/we) couldn’t afford to eat balanced meals. (Answers: Often true, Sometimes true, Never true, DK or Refused)</i></p> <p><i>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, DK or Refused)</i></p> <p><i>[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)</i></p>

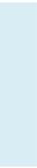
		<i>In the last 12 months, were you ever hungry but didn't eat because there wasn't enough money for food? (Answers: Yes, No, DK or Refused)</i>
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The table below provides examples of **PREMS** domains and sample questions shared during the CQII/IHI Expert meeting.

Patient-reported Outcome Measures [PREMS] Domains		
Priority Domain	Why 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 feel unwelcome [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 wellbeing and drives and affects HIV outcomes.</p>	<p>Krieger Experiences of Discrimination (EOD) scale Thirty (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</p> <p>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</p> <p>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</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 with over 100 questions based on experience of community-based care</p> <p>Sample Questions/Answers <i>In the last 3 months, how often did {insert staff role} treat you with courtesy and respect? Would you say: never, sometimes,</i></p>

		<i>usually, always.</i> Interviewee would also indicate don't know, refused, unclear response
Privacy/Confidentiality (importance of privacy can be lost in a busy clinic, even more important in smaller/rural organizations)	Health Insurance Portability (HIPAA) 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.	Ontario Outpatient Experience Survey Survey has 63 questions Sample Questions/Answers <i>Were you given enough privacy when discussing your condition or treatment?</i> <ul style="list-style-type: none"> • Definitely • For the most part • Somewhat • Not at all (please tell us more in the open text box at the end of this survey)
Communication (do clinicians [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 [i.e., don't dismiss questions])	Effective communication between clinician and patient has been shown to positively influence health outcomes, It increases patient satisfaction and supports greater patient understanding of health problems and possible treatments. This contributes to better adherence to treatment and provides support and reassurance to patients.	Ontario Outpatient Experience Survey Survey has 63 questions Sample Questions/Answers <i>Did doctors and/or health professionals ask you what was important to you in managing your condition or illness?</i> <ul style="list-style-type: none"> • Definitely • For the most part • Somewhat • Not at all • This was not necessary <i>If you had important questions to ask him or her, did you get answers that you could understand?</i> <ul style="list-style-type: none"> • Definitely • For the most part • Somewhat • Not at all • I did not need to ask • I did not have an opportunity to ask
Shared Decision-Making (is the patient a partner in care, are their concerns acknowledged and addressed)	Shared decision-making is 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.	Ontario Outpatient Experience Survey Survey has 63 questions 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? <ul style="list-style-type: none"> • Always • Usually • Sometimes

		• Never
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Resources Developed | *Ten PROMS/PREMS Measurement Tool Sets*
PROMS+PREMS Pilot Project Toolkit
CQII PROMS/PREMS Guide
PROMS/PREMS Website on TargetHIV

Assessment of Pilot Project and Lessons Learned

Assessment of Pilot Study

Overall, the PROMS+PREMS Pilot Project met its pre-established goals for this national initiative. Several opportunities for improvement and further refinement were noted.

Value of PROMS/PREMS as vital data sources in HIV care

- This PROMS/PREMS Pilot Project confirms the value of measuring PROMS and PREMS by HIV providers funded by the RWHAP. Participants saw the vital importance of capturing patient voices to better understand their self-reported outcome and experiences with their HIV programs. This finding is consistent with previously conducted focus groups and national surveys.
- Established measurement frameworks should be widely shared to avoid duplication of efforts and expedite the measurement process.
- The integration of PROMS/PREMS into existing data systems is critical. Best practices should be shared, and early adopters are critical in this process for national dissemination.
- CQII has developed a PROMS/PREMS Guide as an important step to highlight PROMS/PREMS as vital data sources in HIV care. Best practices by pilot site participants are outlined in this resource.

Testing the feasibility of measuring PROMS/PREMS in busy clinic settings

- The Pilot Project strongly affirms the feasibility of integrating PROMS/PREMS in busy RWHAP care settings and their integration as additional measurement concepts. Pilot sites welcomed the opportunity to look beyond viral suppression rates as their key performance measure.
- Individual support and technical assistance by subject matter and experience experts are needed. Peer learning and exchange provided an important additional source of ideas to overcome measurement and implementation challenges.
- Best practices need to be widely shared with other RWHAP sites to assist their efforts into measuring PROMS/PREMS in their HIV clinic environments.

Integrating the PROMS/PREMS results in ongoing quality improvement activities to advance HIV care and services

- The PROMS/PREMS Pilot Project had an additional goal to utilize the PROMS/PREMS data results for advancing HIV care and services using QI methodologies and tools. While all pilot sites were able to set up effective measurement systems for PROMS/PREMS and receive results, several sites did not have the necessary time during the six-month pilot to fully integrate the PROMS/PREMS results in ongoing QI activities.
- Using the PROMS/PREMS results in QI efforts take time. Implementers need to be reminded that measurement of patient-reported outcomes and experiences alone is not enough to make a difference in patient lives.

- Real-world examples how to integrate PROMS/PREMS results in QI activities are needed to assist RWHAP recipients/subrecipients. Providers with successful past experiences should be made visible to other providers to learn from their experiences.

Identifying best practices to evaluate the measurement of PROMS and/or PREMS as additional quality improvement measures

- The Pilot Project routinely identified and documented best practices from all pilot sites during each step of the measurement and QI integration process.
- The Reflection Sessions - monthly 30-min calls facilitated by CQII to interview and document the experiences of all pilot participants - provided an important source to document best practices. This model was a novel process, which should be adopted in similar projects.
- Notes from the Reflection Sessions were routinely shared with all faculty to keep everyone involved in the project well informed on each pilot site.
- CQII developed a PROMS and PREMS Guide to increase awareness among RWHAP providers about the purpose of PROMS and PREMS as additional QI measures beyond viral suppression.

Lessons Learned

Pilot participants gained significant insights through the many lessons learned from this feasibility study, which will undoubtedly position them to better manage any challenges that may arise as they consider making PROMS and PREMS a permanent part of their performance measurement and quality improvement efforts. Additionally, other HIV care providers will also benefit from the experiences of the PROMS and PREMS pilot participants in their own PROMS and PREMS implementation. Some of the lessons learned are listed below and are also featured in the PROMS+PREMS Guide.

PROMS/PREMS may seem challenging and complex at first, but they can be done. It can be done with basic quality improvement skills

- Some participants made 'the perfect the enemy of good' and made it too complicated than needed. These activities are like other quality improvement projects – think big and start small.

Patient involvement is critical in all steps

- People with HIV should be involved in all aspects of planning and implementing PROMS/PREMS, especially in selecting the domain and the related measures.
- Inform people with HIV about the reason questions are being asked (i.e., purpose of the survey) and how answering the questions will benefit them and other patients.
- People with HIV wants continued feedback. Participating in the PROMS/PREMS survey process and providing their feedback, they are invested in it and want to know their input is acted upon.

It takes a team

- Some pilot sites' projects were initially driven by a single person. As they implemented the project, they quickly learned that it was not possible without the additional support from others in their organization. Especially important was the involvement of staff with direct experiences related to the domain (e.g., if the domain was housing, include the housing case manager).
- It is important to communicate clearly and consistently to staff about goals, timeframe, and expected milestones and outcomes. Engagement of staff in this process generates ownership and buy-in.

Use data for PROMS/PREMS selection

- Qualitative and quantitative data should be used to confirm the selection of the PROMS/PREMS before starting. Be aware that sometimes staff may perceive an issue that is not supported by data results.

Different domains require different actions

- Housing stability requires more intervention than quality of life, which can vary according to site's resources.
- A domain that captures the interest of people with HIV should be selected. There should be a reason beyond the data---will the domain make a difference in their lives and their well-being?
- Select a domain that staff are passionate about, since they will be involved in the implementation of the measures and more importantly, making subsequent improvements.
- Involve staff representing various disciplines and role (e.g., front desk staff, peer navigators) in all aspects of planning and implementing PROMS/PREMS. Often, engagement by staff creates their ownership in the process.

Test early and often

- Selected measures should be appropriate for people with HIV and feasible in existing workplan before incorporating them in any form of EMR.

Data should be actionable

- Data collection should be worthwhile for both staff and people with HIV by channeling responses into action.

Acknowledge survey fatigue by both staff and patients

- The survey should be kept short. The use of volunteers proved to be a good work around to staffing challenges. Incorporating survey into the people with HIV visit can be strategically significant.

'A lesson learned for everyone is to meaningfully implement PROMS and PREMS you must ask patients the right questions and ask at the right time.'

PROMS+PREMS Pilot Project Coach

Case Studies and Testimonies

Case Study – Eau Clair Cooperative Health

Eau Clair Cooperative Health in Columbia, South Carolina wanting to formalize and sustain the process of asking patients about their housing status, took an ambitious step by moving towards integrating measure into their EMR so that every patient will be asked about their housing situation. Given the short timeframe of the pilot this approach not only was a challenging undertaking, but it also slowed down the process of rolling out the measure and collecting data. Undeterred and committed to the pilot, the team at Eau Claire regrouped and began exploring where in the workflow they could best administer the survey as a temporary solution until it was fully incorporated into the EMR. While the delay was somewhat frustrating for the team, their work was recognized by senior leadership so much so that the medical director encouraged the collection of PROM data on multiple social determinants of health in the EMR so that the clinic can gain a more comprehensive view of patients' life challenges.

Case Study - AIDS Ministries

AIDS Ministries in northern Indiana selected housing as their domain because it is a significant problem for their patients as they have difficulty finding permanent housing, even with support from their organization. The initial survey questions focused on the stability of housing, including where a patient was sleeping. Based on a short test cycle of the measures, AIDS Ministries found that the data they were collecting did not align with what was in their database about patients' housing situations. In response, they revised the survey questions and focused on the financial issues that might result in patients becoming unhoused. They included a definition of housing stability in the survey, so patients understood what they meant when they asked about unstable housing. They also included questions on financial stability, such as inability to pay power bills and other utilities, and on situations that could lead to unstable housing. As a result of what they found AIDS Ministries is considering offering financial literacy training to their patients.

Testimonies by Pilot Participants

'There are two perspectives when it comes to quality improvement activities, the providers analysis and the patients' response to their analysis. When you integrate the two, so that both parties have shared decision-making capacities, you illuminate a deeper understanding of the data. The data no longer translates as numbers or figures, but instead become the narrator of the untold stories for those with lived experience. Because the fact is, that the

outcomes of your practice are directly related to the voices of your patients. Listen to your patients, even through the silence, they are speaking.'

'When you think of quality improvement you tend to have a clinical focus. The project made us look at the bigger picture—what is going on in our clients' lives. While our clinicians are good at checking in with clients adding these measures on a permanent basis will formalize our processes.'

'Within our jurisdiction there were many providers that were not familiar with PROMS/PREMS but now there is a lot of interest. When you look at issues like quality of life, everyone is interested, especially frontline providers.'

'Gathering the data gave me a clearer view of areas that we can focus on for improvement. Honing the questions help me better understand the issues.'

'We've learned that responses can be complex. Patients indicate satisfaction in one area, such as having a purpose, or support from family and friends, but then say they feel lonely. We now need to craft a response to these needs.'

'We joined the pilot because we felt it would be good for our clients in the long run. Getting the patient perspective is important and we hope that it will allow us to provide even better care to our clients.'

'I think this is one of the most relevant and critical pilots that focuses on patient experiences and outcomes. As a person living with HIV and former consumer of Ryan White Service, I can honestly say that this pilot, and any future collaboratives around PROMS+PREMS will be one of the most important contributions to quality of care and services there has ever been – thank you for finally elevating the consumer experience.'

Next Steps

With the assistance of the PROMS+PREMS Pilot Project faculty and participants, CQII brainstormed potential next steps to allow the exploration of the PROMS/PREMS measures as vital data sources in HIV care and their feasibility for integrating the results in ongoing QI activities. These options will be discussed with the HRSA HIV/AIDS Bureau for further exploration.

- Encourage PROMS+PREMS Pilot Project participants to submit request for technical assistance from HRSA HIV/AIDS Bureau for additional support.
- Run a second pilot with an increased number of pilot sites (~25 sites) to further explore the opportunities for RWHAP recipients/subrecipients.
- Run a national learning collaborative that focuses on implementing PROMS/PREMS and invite sites across the United States to join.
- Integrate specific PROMS/PREMS in upcoming CQII learning collaboratives as additional performance measures.
- Conduct a series of national TA Calls that addresses all major steps of implementing PROMS/PREMS, is open to all RWHAP providers, and include best practices from initial pilot sites.
- Put together a series of Quality Academy Tutorials for asynchronous learning addressing all major steps of implementing PROMS/PREMS and using the data results in QI efforts.
- Create a mentorship program where pilot sites mentor other RWHAP sites that are starting this journey.
- Integrate PROMS/PREMS into existing Learning Labs.
- Publish a paper on the first pilot and submit abstracts to national conferences (e.g., IHI Forum).