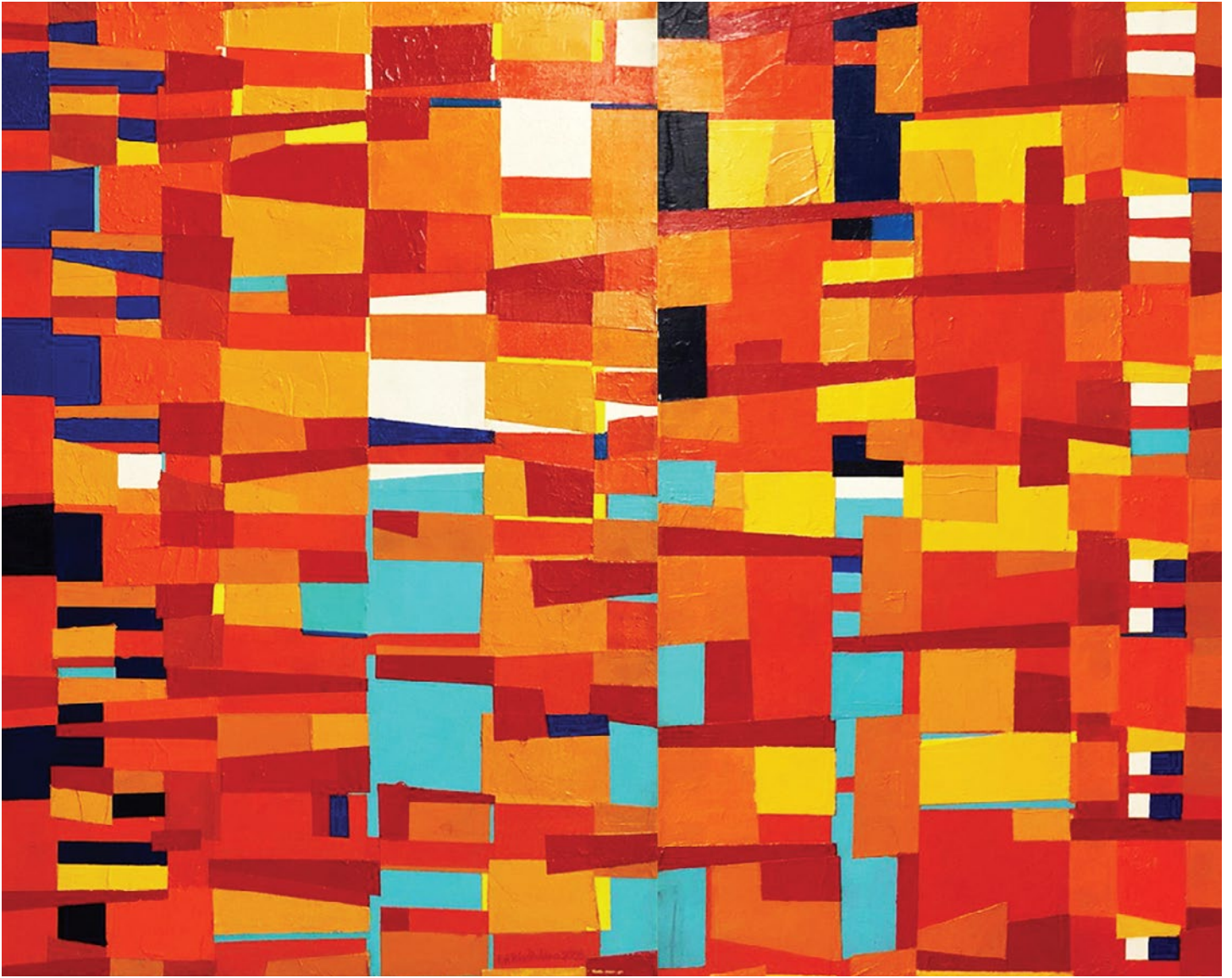


“Untitled diptych” by Fabián H. Ríos Rubino a.k.a. blitiri — HIV-positive artist



Patient-Reported Outcomes and Experiences

Elevating Patients' Voices to Improve the
Quality of HIV Treatment and Care

New York State Department of Health AIDS Institute
Health Resources and Services Administration HIV/AIDS Bureau



HRSA Ryan White HIV/AIDS Program
**CENTER FOR QUALITY
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Patient-Reported Outcomes and Experiences

Elevating Patients' Voices to Improve the Quality of HIV Treatment and Care

Developed by the
New York State Department of Health AIDS Institute
Center for Quality Improvement & Innovation (CQII)

For Health Resources and Services Administration
HIV/AIDS Bureau

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Introduction

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. — **Pilot Project Site**

The patterns of your practice are directly related to the silent voices of your patients. What are your patients not saying? Is it evident in their actions and your outcomes? — **Melissa Curry, Pilot Project Coach**

The involvement of patients, also referred to as people with lived experience, clients, or consumers, has been a hallmark of the RWHAP since its inception. Their engagement takes many forms, from participation in community planning processes, involvement in quality improvement (QI), to encouraging and supporting patients as partners in their own care. The concept of patient involvement extends beyond patients partnering with clinicians in their own care to providing feedback on the quality and scope of services to the actual design of services, referred to as co-design.^{1,2} Involving people with HIV, along with other factors, has yielded impressive results in terms of clinical outcomes. According to the *2021 RWHAP Annual Client-Level Data Report*, 89.7 percent of RWHAP clients receiving outpatient ambulatory health services achieved viral suppression.³

While tracking viral suppression and other clinical measures is important to achieving improved health outcomes, other regional milestones (e.g., *Ending the HIV Epidemic in the U.S. (EHE)* initiative goals) and national

public health goals (e.g., National HIV/AIDS Strategy) have moved to incorporate additional metrics that reflect other factors that patients identify as important to their well-being, 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 additional 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 an additional opportunity to elevate patient voices in the effort to improve health outcomes and the quality of health care services.

RWHAP recipients/subrecipients (hereafter referred to as providers) are required to engage in clinical quality management (CQM) activities—a systematic process of assessing efforts, collecting and analyzing data, and engaging stakeholders to identify solutions. PROMs and PREMs fit this framework. They provide another opportunity to collect patient information beyond laboratory-based data with a patient-centered approach. 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

¹ Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opiari-Arrigan, L., & Hartung, H. (2016). Coproduction of healthcare service. *BMJ quality & safety*, 25(7), 509–517. <https://doi.org/10.1136/bmjqs-2015-004315>

² Turakhia, P., & Combs, B. (2017). Using Principles of Co-Production to Improve Patient Care and Enhance Value. *AMA journal of ethics*, 19(11), 1125–1131. <https://doi.org/10.1001/journalofethics.2017.19.11.pfor1-1711>

³ Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2021. Published December 2022. <https://hab.hrsa.gov/data/data-reports>.

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. (Section 1 provides more details on PROMs/PREMs)

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 data.

The Center for Quality Improvement & Innovation (CQII) — in partnership with the Institute for Healthcare Improvement (IHI) and Health Resources and Services Administration's (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 are listed below.

- **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, hepatitis C (HCV) coordinator, program coordinator, and quality manager.

- **Review of Literature.**

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. Articles will be added as they are identified.

- **Institute for Healthcare Improvement (IHI) Expert Meeting.**

In October 2021, CQII and IHI convened a meeting of experts: academic content experts; RWHAP providers; people with HIV; QI managers; and public health specialists. For both PROMs and PREMs, participants explored developing a shared understanding of the measurement framework; implementation strategies for measurement; barriers to improving patient experiences and outcomes; implementation strategies; 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 in December 2021.

- **CQII PROMs and PREMs Pilot Study.**

In 2022, CQII conducted a six-month pilot study 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.

CQII Focus Groups on PROMs and PREMs: Key Findings

- Participants saw the potential benefits of using PROMs and PREMs for QI and in gaining additional insights from direct input by HIV patients.
- Though focus group participants' sites routinely screen patients for health outcomes (e.g., mental health, substance use) and ask clients for feedback regarding their health care experience (e.g., satisfaction surveys, feedback forms), the PROMs and PREMs measurements frameworks are new to them.
- For focus group participants, the concepts were intuitive, based on their previous and current works, and could be incorporated into current improvement activities.
- Participants showed 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.
- Clear examples of PROMs and PREMs, specifically for HIV care, should be provided to show how they are implemented in the real world and the benefits of doing so.

How to Use the Guide

It takes a village of providers and clients to address PROMs and PREMs in clinic settings.
Do not try to do it by yourself! — Clemens Steinbock, Pilot Project Coach

This Guide may be used both as an introduction to measuring patient-reported outcomes and experiences and for helping to develop strategies for planning and implementing the collection of these data and then acting on them. If you are new to these types of measurements, you may want to read the Guide in its entirety as it provides a step-by-step approach and suggests domains for both PROMs and PREMs. For the more experienced, this Guide provides real world examples and useful resources that can be used to refine existing activities.

Goal

The goal of this Guide is to increase awareness among RWHAP providers about the purpose of PROMs and PREMs as additional QI measures, beyond viral suppression, and show how to use them to improve patients' health outcomes and treatment experiences.

Purpose

This Guide provides a framework for integrating PROMs and PREMs into existing clinical quality management program activities conducted by RWHAP providers and offers an array of tools/resources that can be used to collect patient-reported outcome and patient-reported experience data and utilize the findings to improve HIV care and experiences.

Audience

This Guide is designed for all RWHAP stakeholders focused on improving the quality of HIV care and treatment, the health outcomes of RWHAP patients, and the quality of

life of patients served by the RWHAP. It focuses on those who will be involved in the planning and implementation of activities to measure patient-reported outcomes and experiences and developing strategies to respond to the data findings. These include quality management staff, clinicians and other frontline staff, administrators, and most importantly, people with HIV.

What to do with PROMs/PREMs Findings

Measurement is just one aspect of quality improvement to track your improvement progress and utilize these data to drive improvements. Measurement helps you to evaluate the impact of changes made to improve the quality and systems of care. Remember that measurement is only the first step on your improvement journey.

This Guide specifically focuses on the measurement of patient-reported outcomes and experiences. These go beyond process and clinical measures to focus on what matters to patients. The findings of these efforts should be used — as any other performance data you collect in your CQM activities — to inform your improvement efforts. The important next improvement steps mirror the same as you do with any other QI project.

Many QI resources are already available to guide your improvement project. If you are not familiar with CQM or QI, CQII has many resources focused on QI activities to respond to the PROMs/PREMs findings. These resources can be found on the [CQII page](#) on the TargetHIV website at www.CQII.org.

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Section 1:

What are PROMs and PREMs?

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. — Pilot Project Site

Many think the key to bringing an end to the global HIV epidemic is the UNAIDS 95/95/95 targets⁴ (95% of all people with HIV know their HIV status, 95% of all people with HIV infection receive antiretroviral therapy (ART), and 95% of all people on ART achieve viral suppression). In the United States, the *Ending the HIV Epidemic in the United States* initiative has similar goals. Many in the HIV community have advocated for adding another metrics to complement these established measurement frameworks⁵—one more focused on quality of life and experience with receiving health care services. Examples of the domains that would be addressed by such efforts include patient-provided feedback on HIV treatment and care; well-being; impact of symptoms and side effects; mental health; social determinants of health; and experience with stigma and discrimination.

The purpose of PROMs and PREMs is to help ensure that patients' health outcomes are aligned with patients' health goals and that their treatment and care experiences support the achievement of these goals. Formalizing the process of collecting patient-reported outcomes and experiences—and incorporating these activities into the overall clinical quality management program—emphasizes to patients that their goals and experiences are important and relevant and that these data should be systematically collected (i.e., collected on a regular, ongoing basis). Tracking these

⁴ UNAIDS. 2025 AIDS Targets. Available from: <https://aidstargets2025.unaids.org/>

⁵ Lazarus, JV, Safreed-Harmon K, Barton SE, et al. Beyond viral suppression of HIV—new quality of life frontier. *BMC Med* 2016; 14: 94. <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-016-0640-4>

outcomes and experiences communicates to patients that the health care team cares about what matters to them. In addition, given high national viral suppression rates, new outcomes measures are necessary to continue to advance improvements in HIV care.

For this Guide, CQII adopted definitions of PROMs and PREMs from the available literature and by input of content experts, providers, and patients.⁶ (See text box on the following page for these definitions.)

Integrating PROMs and PREMs into care delivery amplifies patient voices in the delivery of HIV care at the patient, clinic, and systems levels. Key to the successful implementation of PROMs and PREMs is patient involvement throughout the process—from planning to the collection and analysis of data, to the identification of improvements. Patients are partners throughout the process.

Enhancing Quality Improvement Activities

As stated in CQII's *Measuring Clinical Performance: A Guide for HIV Health Care Providers*,⁷ “Performance measurement is a method to identify and quantify the critical aspects of care within your facility. When you measure important aspects of care, you not only create a valuable source of data

⁶ Adopted from: Kingsley, C., & Patel, S. (2017). Patient-reported outcome measures and patient-reported experience measures. *BJA Education*, 17(4), 137–144. <https://doi.org/10.1093/bjaed/mkw060>; and Hodson, M., Andrew, S., & Michael Roberts, C. (2013). Towards an understanding of PREMs and PROMs in COPD. *Breathe*, 9(5), 358–364. <https://doi.org/10.1183/20734735.006813>.

⁷ Center for Quality Improvement & Innovation. *Measuring Clinical Performance: A Guide for HIV Health Care Providers*. <https://targethiv.org/sites/default/files/file-upload/resources/MeasuringClinicalPerformance2006.pdf>

Definitions

Patient-Reported Outcome Measures (PROMs):

A measurement of the 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 may include depression, anxiety, pain, fatigue, etc. The purpose of these measures is to directly query the patient about their health outcomes, which would otherwise not be accessible to the health care team.

Patient-Reported Experience Measure (PREMs):

A measurement of the patient's report of their personal experience of the healthcare they have received, including respect; communication; privacy; engagement in shared decision making; as well as the environment in which care is being delivered. The purpose of these measures is to comprehensively assess patients' experiences with and perceptions of their care. These measures offer a more holistic and patient-centered approach to improve care and services.

regarding your facility's greatest areas of competence, but also identify those areas that require improvement and that will produce the greatest benefit for patients and staff when adequately addressed.”

The systematic collection of patient-reported outcomes and experiences adds important metrics to a provider's QI activities. Because these measures are based on what patients identify as important to them, responding to the data can help to support engagement in care and adherence to treatment.

While these measures are designed to focus on individual patients and their needs, they also can be used as part of a provider's overall QI activities. Tracking measures longitudinally, such as side effects, depression, social isolation, and food and housing insecurity, in addition to clinical performance measures, can help guide responses to address these issues that have a significant impact on health outcomes. Collecting these data can help to improve overall performance (i.e., required performance measures) as well as health outcomes and patient experience.

Measurement plays an important role in tracking progress and utilizing data to drive improvements. Measurement and sharing results signals to staff and patients what is important to the provider. The goal of measurement helps HIV providers evaluate the impact of changes made to improve the quality and systems of care. To this end, measurements should be designed to accelerate improvement, not slow it down. Also, consider that measurement alone is not QI but to conduct QI efforts, you need to measure.

When considering measurement of patient-reported outcomes and experiences, it is important to assess what current performance measurement and QI activities can be leveraged or expanded. Processes may already be in place to engage patients in QI activities (e.g., community/consumer advisory boards [CABs], participants on QI committees). Data collection and analysis may already be underway.

CQII Resources

[Guide to Consumer Involvement: Improving the](#)

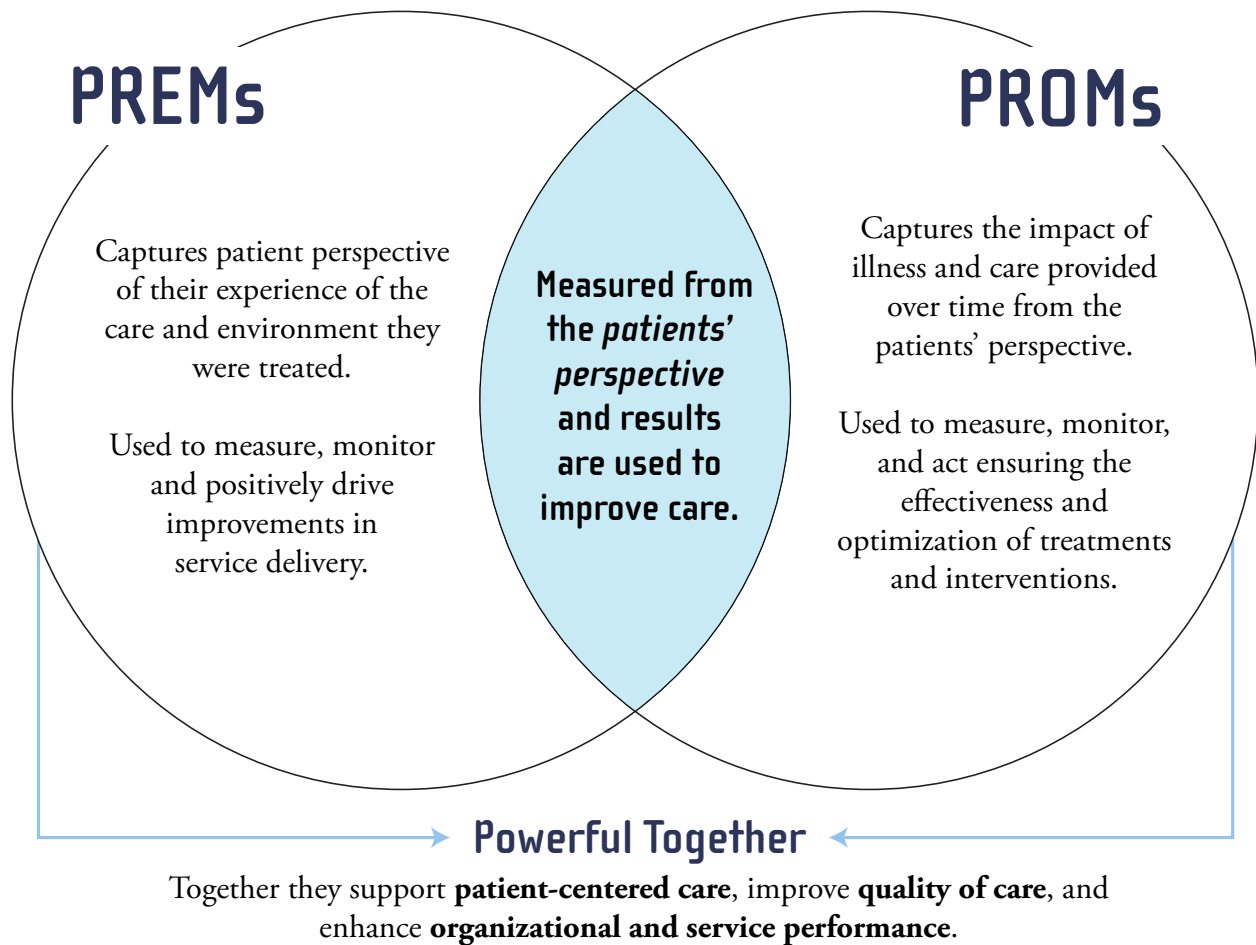
[Quality of Ambulatory HIV Programs](#)

[NQC Action Planning Guide](#)

[Measuring Clinical Performance: A Guide for HIV](#)

[Health Care Providers](#)

The following graphic is based on a graphic by Paul Millet ([How do PREMs and PROMs Work Together?](#) Cemplicity. 2020, November 13).



PROMs vs PREMs

<i>PROMs</i>	<i>PREMs</i>
Capture a person’s perception of their health (overall and/or specific areas of health and well-being).	Capture a person’s perception of <i>their experience receiving care and services</i> (overall and/or specific aspects of the care they receive).
Generally <i>standardized, validated self-reporting instruments</i> , which use a patients’ views and opinions to assess their health status and overall well-being.	Self-reporting instruments that measure a patients’ perception of their experience of receiving care and services.
Outcome measures are generally connected to a specific individual (and can be aggregated and segmented as needed).	Experience measures are generally reported anonymously and so may not be connected to a specific individual.
Data can be used to improve health outcomes for a specific individual, a group of individuals with similar characteristics, and/or the entire patient population.	Data can be used to improve the experience of receiving care and services for a group of individuals with similar characteristics and/or the entire patient population.
Individual patient data are generally tracked in the electronic health records (EHR) to document patient responses over time and allow other providers to access the data for follow-up.	Patient-reported data are often aggregated, and these reports are shared with the provider team and the QI team to improve specific aspects of the health care experience.

Lessons from the Pilot: Expanding the Focus on What Matters to Patients, Eau Claire Cooperative Health (Columbia, South Carolina)

Wanting to formalize and sustain the process of asking patients about their housing situation, Eau Claire Cooperative Health worked to including their measure in their EHR. Every patient will be asked about their housing situation. Given the short timeframe of the pilot, making changes to the EHR slowed down the process of rolling out the measure and collecting data. The team explored work arounds in terms of where best in the workflow they could administer the survey until it was incorporated into the EHR. While the delay had been frustrating for the team, their work was recognized by senior leaders. The medical director saw the value of collecting these data and encouraged data collection on multiple social determinants of health in the EHR so that the clinic can have a more comprehensive view of patients’ life challenges.

Best Practices from the Pilot: General

- PROMs/PREMs may seem challenging and complex at first but they can be implemented with basic quality improvement skills. Don't let 'perfect be the enemy of the good' and make the project more complicated than necessary. Think big and start small.
- Set a realistic timeline. It can take time to get leadership buy in, form a project team, engage patients in a meaningful way, and formulate a workplan.
- Manage expectations for implementing PROMs/PREMs over time. Consider integrating measures on an ongoing basis. To track results over time, the measurement of PROMs/PREMs must be sustained over time.
- It takes a team to complete a successful project—a single staff person cannot do it alone. Especially important is staff with direct experience related to the domain (e.g., if the domain is housing, engage the housing case manager).
- Acknowledge survey fatigue by both staff and patients. There are many ways to streamline the data collection process. These include using volunteers; incorporating surveys into patient visits; using online surveys; and incorporating questions into an annual patient survey.
- In the initial stages, create a plan about how patients will be involved in the planning and implementation of the project. Ideally, patients will be part of the project team.
- Plan to survey patients (e.g., focus groups, surveys, interviews). These are “patient reported” data, not data collected from other sources (i.e., clinicians).
- Consult staff who have direct patient contact as they can provide insight into how best to design and administer measures.
- Run data reports using existing data sets.
- Use benchmarking data to compare performances with others.
- Select a domain that captures the interest of patients. Have a reason beyond the data—will the domain make a difference in their lives and well-being?
- Select a domain that staff are also passionate about, since they will be involved in the implementation of the measures and more importantly, making subsequent improvements.
- Involve staff representing different disciplines and roles (e.g., health care teams, clinical quality management, case management, front desk staff, peer navigators) in all aspects of planning and implementation of PROMs/PREMs. They will bring different perspectives, based on their roles. This engagement of staff also creates investment in and ownership of the project.
- Accept the possibility that you may not get the results you expect or want.

Best Practices from the Pilot:

Plan and Implement PROMs/PREMs

- Use qualitative and quantitative data to confirm the selection of the PROMs/PREMs before you start (e.g., data from previous client surveys). Also consult patient advisory committees. Be aware that sometimes staff may perceive an issue that is not supported by data results.

Best Practices from the Pilot:

Involve Patients from the Beginning

- Look for ways that patients can be involved in the project. This could be consulting a patient advisory group about the project or including patients who are members of the quality management committee on the project team. Staff with lived experience can also be included on the project team or provide feedback on various aspects of the project.

- Feedback from patients on various aspects of the project can be informal (e.g., “hey, what do you think of this survey?”) Don’t be afraid to engage patients in various ways.
- Patients can be effective in administering surveys to their peers. This can reduce burden on staff.
- Disseminate findings to patients so they know their input has been heard. Possible strategies include posters in the waiting room; flyers; presentations at advisory board meetings where patients are members or attend.
- Involve patients in identifying solutions and subsequent quality improvement projects in response to findings.

Section 2: CQII PROMs + PREMs Pilot Project

Collecting and using PROMs and PREMs has tremendous potential for improving individual and population health and it's exciting to be part of a project where teams are learning how to do just that. Collecting and using PROMs and PREMs is somewhat nuanced and doing it with a community of improvers makes a huge difference! — **Christina Clarke, Pilot Project Coach**

CQII worked in close collaboration with IHI to support 10 sites participating in the PROMs + PREMs Pilot Project, starting in January 2022 and concluding in June 2022.

Purpose of the Pilot Project

Participating agencies in the PROMs + PREMs Pilot Project explored the value of these measures as vital data sources in HIV care and their feasibility for integrating the results in ongoing QI activities. The aims of the pilot project were to:

- 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 providers and to further empower HIV providers to utilize their findings to improve HIV health outcomes and patient experiences in HIV care.

CQII evaluated all aspects of the pilot project—using both quantitative and qualitative data.

Benefits of Participating in the Pilot

Participation in the PROMs + PREMs Pilot Project allowed for:

- Opportunities to jointly explore this emerging QI topic with CQII staff and consultants;
- Access to national content experts from IHI and their coaching support and technical assistance;
- Access to standardized PROMs and 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 groups with RWHAP providers; and
- Contributions of lessons learned to be documented in the upcoming PROMs and PREMs implementation guide.

Pilot Project Sites

AIDS Ministries, South Bend, Indiana
AIDS Project of the Ozarks, Springfield, Missouri
Centro Ararat, Ponce, Puerto Rico
Cook County HIV Integrated Programs, Chicago, Illinois
Harris County Public Health, Houston, Texas
Eau Claire Cooperative Health, Columbia, South Carolina
Tarrant County HIV Administrative Agency, Fort Worth, Texas
UPMC Presbyterian Shadyside, Pittsburgh, Pennsylvania

Expectations

Starting in January 2022, each participating agency was asked to complete the following activities:

- 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 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.
- Contribute to the development of the PROMs and PREMs implementation guide by identifying best practices.
- Participating in monthly reflection sessions to share updates.

Pilot Project Support

Key support positions are listed below. These positions were filled by CQII and IHI staff and consultants.

<i>Position</i>	<i>Roles</i>
PROMs and PREMs Coach	<ul style="list-style-type: none"> • Facilitate coaching sessions • Provide support and technical assistance to implement PROMs and PREMs • Provide content for PROMs and PREMs presentations • Document and track assigned sites
QI Coach	<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
Data Analyst	<ul style="list-style-type: none"> • Develop tracking tools • Set up reporting systems • Summarize all site collected data • Prepare reports and analyze data

Timeline

	<i>January</i>	<i>February</i>	<i>March</i>	<i>April</i>	<i>May</i>	<i>June</i>
<i>Group Session</i>	Getting Started	Pick your PROM or PREM domain	Select your PROMs and PREMs measures	Integrating and implementing your measure	PROMs and PREMs in practice	Putting data into action
<i>Individual Coaching Call</i>	Send email to establish relationship	Selecting a domain	Prioritizing measures from selected domain	Guide implementation	Guide sites to take action in response to data findings	Discuss actions in response to data
<i>Best Practice Reflection Session</i>		How to select a domain	How to prioritize PROM/ PREM measure	How to integrate and implement PROM/ PREM measure	How to take action in response to data findings	Lessons learned and best practices

Domains Selected: PROMs + PREMs Pilot Project

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

Section 3:

PROMs and PREMs Domains and Measures

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. — **Pilot Project Site**

As CQII began exploring ways to support RWHAP providers in incorporating patient-reported outcomes and experiences, it became clear that many providers are already collecting patient-reported data and using them in their QI activities. In response, CQII sought to identify priority areas that RWHAP recipients could address to improve patient outcomes and experiences, 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 construct a more robust use of patient-reported outcome and experience measures.

In this section, we present suggested domains for both PROMs and PREMs, identified at the 2021 IHI Expert Meeting. The meeting included academic content experts, RWHAP providers, people with HIV, QI managers, and public health specialists, who all participated in identifying the domains.

RWHAP providers can use the domains to initiate these activities. It is important to note that these are not the only domains that providers can explore. As with all QI activities, the characteristics of the organization and their patient population drive what issues should be prioritized.

In addition to presenting the suggested domains, we provide questions that can serve as a mini survey (i.e., the measure). Providers can use all or some of these questions. These questions do not constitute a validated measure, but they are drawn from existing measures.

Finally, at the end of each section we present some “big picture” issues to consider prior to implementing either PROMs or PREMs.

Patient-Reported Outcome Measures (PROMs)

Domains include health-related quality of life (such as functional status, side effects, decline in aging patients [note: these examples are components of quality of life measures but could also be a stand-alone measure]); symptoms and symptom burden (e.g., pain, fatigue); health behaviors (e.g., medication adherence, diet, exercise, smoking, substance use); and social determinants of health. These domains are examples of the many patient outcomes that can be measured.

Considerations: Selecting Domains and Measures

- **Relevant** — Are they relevant to the patients you serve? Do they generate the necessary momentum and interest among staff?
- **Measurable** — To the extent possible, can you utilize existent data collection systems?
- **Actionable** - Does your organization have the capacity to address the issues that will be identified?
- **Sustainable** — Can data be collected over time and integrated in ongoing QI efforts?
- **Tailable** — Do potential findings allow consideration of differences within the organization, patient population, geographic region, etc.

The following table includes the domains selected during the IHI Expert Meeting.

<i>Examples of Patient-Reported Outcome Measures (PROMs) Domains</i>		
Priority Domain	Why it is Important	Example of Validated Tool Measures/Questions
<p>Well-being (overall health [not 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.⁸</p>	<p><u>100MLives WellBeing Assessment</u> (validated). Twelve (12) question survey plus demographics.</p> <p>Sample Questions/Answers</p> <p><i>Imagine a ladder with steps numbered from zero at the bottom to ten at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you.</i></p> <ol style="list-style-type: none"> 1. <i>On which step of the ladder would you say you personally feel you stand at this time?</i> 2. <i>On which step do you think you will stand about 5 years from now?</i> 3. <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> 4. <i>In general, how would you rate your physical health?</i> 5. <i>How would you rate your overall mental health?</i> <p>Note: This validated well-being assessment also has questions related to having a sense of purpose, loneliness, feeling a part of the local community, relationship with family and friends, and positive emotions and negative emotions.</p>
<p>Housing Stability (whether the patient has stable housing, fears losing their housing)</p>	<p>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,</p> <p><i>(continued on next page)</i></p>	<p><u>Veterans Administration Homeless Screening Tool:</u> Five (5) question survey.</p> <p>Sample Questions/Answers</p> <p><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>(continued on next page)</i></p>

⁸ Basavaraj, K. H., Navya, M. A., & Rashmi, R. (2010). Quality of life in HIV/AIDS. *Indian journal of sexually transmitted diseases and AIDS*, 31(2), 75–80. <https://doi.org/10.4103/0253-7184.74971>

	<p>more likely to experience interruptions in healthcare, less likely to be prescribed ART, less likely to reach sustained viral suppression, and overall have poorer health outcomes.</p>	<ol style="list-style-type: none"> 1. <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> 2. <i>Where have you lived for MOST of the past 2 months?</i> <ol style="list-style-type: none"> a. <i>Apartment/ House/Room — no government subsidy</i> b. <i>Apartment/House/ Room — with government subsidy</i> c. <i>With Friend/Family</i> d. <i>Motel/Hotel</i> e. <i>Hospital, Rehab Center, Drug Treatment Center</i> f. <i>Homeless: Shelter</i> g. <i>Anywhere outside, (e.g., Street, Vehicle, Abandoned Building)</i> h. <i>Other</i> 3. <i>Would you like to be REFERRED to talk more about your housing situation?</i>
<p>Mental Health (including depression, anxiety, substance use)</p>	<p>People with HIV are at increased risk of developing mood, anxiety, and cognitive disorders. Depression is one of the most common mental health conditions facing people with HIV. Some medications used to treat HIV, including ART, may have side effects that affect a person's mental health.⁹</p>	<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> <ol style="list-style-type: none"> 1. <i>Little interest or pleasure in doing things.</i> 2. <i>Feeling down, depressed, or hopeless.</i> 3. <i>Trouble falling or staying asleep, or sleeping too much.</i> 4. <i>Feeling tired or having little energy.</i> 5. <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>

⁹ National Institutes of Health. HIV and Mental Health. January 2022. <https://www.nimh.nih.gov/health/topics/hiv-aids>

<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 correlated with the number of HIV-related symptoms experienced.¹⁰</p>	<p><u>Everyday Discrimination Scale</u> (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> <ol style="list-style-type: none"> <i>1. You are treated with less courtesy or respect than other people.</i> <i>2. You receive poorer service than other people at restaurants or stores.</i> <i>3. People act as if they think you are not smart.</i> <i>4. People act as if they are afraid of you.</i> <i>5. 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. Evidence also indicates lower rates of viral suppression, lower CD4 counts, and poorer health outcomes.¹²</p>	<p><u>USDA Food Security Brief Survey</u> Six (6) question survey.</p> <p>Sample Questions/Answers</p> <ol style="list-style-type: none"> <i>1. The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more. (Answers: Often true, Sometimes true, Never true, don't know (DK) or Refused)</i> <i>2. (I/we) couldn't afford to eat balanced meals. (Answers: Often true, Sometimes true, Never true, DK or Refused)</i> <i>3. In the last 12 months, did (you/you or other adults in your household) ever cut the size of your meals or skip meals because there wasn't enough money for food? (Answers: Yes, No, DK or Refused)</i> <i>4. [IF YES ABOVE, ASK] How often did this happen? (Answers: almost every month, some months but not every month, or in only 1 or 2 months)</i> <i>5. 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>

¹⁰ Braksmajer, A., Simmons, J., Aidala, A., & McMahon, J. M. (2018). Effects of Discrimination on HIV-Related Symptoms in Heterosexual Men of Color. *American journal of men's health*, 12(6), 1855–1863. <https://doi.org/10.1177/1557988318797790>

¹¹ Ayano, G., Tsegay, L. & Solomon, M. Food insecurity and the risk of depression in people living with HIV/AIDS: a systematic review and meta-analysis. *AIDS Res Ther* 17, 36 (2020). <https://doi.org/10.1186/s12981-020-00291-2>

¹² Weiser, S. D., Sheira, L. A., Palar, K., Kushel, M., Wilson, T. E., Adedimeji, A., Merenstein, D., Cohen, M., Turan, J. M., Metsch, L., Adimora, A. A., Ofookun, I., Wentz, E., Tien, P. C., & Frongillo, E. A. (2020). Mechanisms from Food Insecurity to Worse HIV Treatment Outcomes in US Women Living with HIV. *AIDS patient care and STDs*, 34(10), 425–435. <https://doi.org/10.1089/apc.2020.0009>

To Consider...

As you think about choosing a PROMs domain, keep the following in mind...

- Domain should be a priority to patients and the HIV community. Is the domain relevant to the patients you serve? Can you use it to make a difference in the quality of life and health outcomes?
- Domain should measure concerns that can be addressed. Are the provider team and patients able to address the issue by offering new or modifying existing treatment options? Can they engage other clinicians (e.g., specialty care, social workers) or support services?
- Domain should have validated assessment tools available — do validated tools and indicators exist to measure the domain and does the agency have access to them?
- Domain should be easily measured — can the

information be routinely and effectively gathered from patients prior to their arrival at the clinic (e.g., through a patient portal survey), at the clinic prior to the appointment (e.g., in the waiting room), or during the appointment itself, and the results incorporated in the existing medical record systems?

Patient-Reported Experience Measures (PREMs)

The following table includes the domains selected during the IHI Expert Meeting. These examples are just some of the many domains related to patient experience. When selecting domains related to patient experience, important considerations include patient-centered approach (especially patients as partners in care); supportive/welcoming environment; efficient delivery of services; and comprehensive services. *(Note: Many of the measures listed below are quite long. Consider selecting the most relevant questions and compiling a shorter survey.)*

Examples of Patient-Reported Experience Measures (PREMs) Domains		
Priority Domain	Why it is Important	Example of Validated Tool Measures/Questions
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>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.¹³</p> <p>The National HIV/AIDS Strategy recognizes racism as a serious public health threat that directly affects well-being and drives and affects HIV outcomes.</p>	<p>Krieger Experiences of Discrimination (EOD) scale</p> <p>Thirty (30) question survey (exact number depends on how many “Yes” answers)</p> <p>Sample Questions/Answers</p> <p><i>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?</i> 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><i>(continued on the next page)</i></p>

¹³ Boerner, H. Racism in medical settings may reduce willingness to take HIV meds. POZ. 2021 Nov 26. <https://www.poz.com/article/racism-medical-settings-may-reduce-willingness-take-hiv-meds>

Section 3: PROMs and PREMs Domains and Measures

		<p><i>In the last year, how much did you worry about your experiencing unfair treatment because of your race, ethnicity, or color?</i> Answers: Most of the time, some of the time, rarely or never.</p> <p><i>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.</i> 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.¹⁴</p>	<p><u>CAHPS Home and Community Based Survey</u> 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, usually, always.</i> Interviewee would also indicate don't know, refused, unclear response.</p>
<p>Privacy/Confidentiality (importance of privacy can be lost in a busy clinic, even more important in smaller/rural organizations)</p>	<p>HIPAA is not enough. People with HIV emphasize that maintaining their privacy in clinical settings is still an issue. CQII has heard from patients that they often feel that their privacy/confidentiality has been violated by provider staff.</p>	<p><u>Ontario Outpatient Experience Survey</u> Survey has 63 questions.</p> <p>Sample Questions/Answers <i>Were you given enough privacy when discussing your condition or treatment?</i></p> <ul style="list-style-type: none"> <input type="radio"/> Definitely <input type="radio"/> For the most part <input type="radio"/> Somewhat <input type="radio"/> Not at all (please tell us more in the open text box at the end of this survey)
<p>Communication (do clinicians [and other staff] take the time to explain, do they allow patients to ask questions, do they recognize the value of <i>(continued next page)</i></p>	<p>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 <i>(continued next page)</i></p>	<p><u>Ontario Outpatient Experience Survey</u> Survey has 63 questions.</p> <p>Sample Questions/Answers <i>Did doctors and/or health professionals ask you what was important to you in managing your condition or illness?</i> <i>(continued next page)</i></p>

¹⁴ Cascella, L. Promoting patient dignity in healthcare. Medpro Group. <https://www.medpro.com/promoting-patient-dignity>

<p>questions and provide thoughtful responses [i.e., don't dismiss questions])?</p>	<p>problems and possible treatments. This contributes to better adherence to treatment and provides support and reassurance to patients.¹⁵</p>	<ul style="list-style-type: none"> <input type="radio"/> Definitely <input type="radio"/> For the most part <input type="radio"/> Somewhat <input type="radio"/> Not at all <input type="radio"/> This was not necessary <p><i>If you had important questions to ask him or her, did you get answers that you could understand?</i></p> <ul style="list-style-type: none"> <input type="radio"/> Definitely <input type="radio"/> For the most part <input type="radio"/> Somewhat <input type="radio"/> Not at all <input type="radio"/> I did not need to ask <input type="radio"/> I did not have an opportunity to ask
<p>Shared Decision-Making (is the patient a partner in care, are their concerns acknowledged and addressed)</p>	<p>Shared decision-making is a process in which patients, clinicians and caregivers make treatment and other health-related decisions together based on clinical evidence and reflecting the patient's personal preferences.</p>	<p><u>Ontario Outpatient Experience Survey</u> Survey has 63 questions.</p> <p>Sample Questions/Answers</p> <p><i>How often, during your most recent visit, were you involved as much as you wanted to be in decisions about your care and treatment?</i></p> <ul style="list-style-type: none"> <input type="radio"/> Always <input type="radio"/> Usually <input type="radio"/> Sometimes <input type="radio"/> Never

¹⁵ Duke Center for Personalized Health Care. The Importance of Physician-Patient Relationships Communication and Trust in Health Care. 2019 March 11. <https://dukepersonalizedhealth.org/2019/03/the-importance-of-physician-patient-relationships-communication-and-trust-in-health-care/>

¹⁶ Tamirisa, N. P., Goodwin, J. S., Kandalam, A., Linder, S. K., Weller, S., Turrubiate, S., Silva, C., & Riall, T. S. (2017). Patient and physician views of shared decision making in cancer. *Health expectations: an international journal of public participation in health care and health policy*, 20(6), 1248–1253. <https://doi.org/10.1111/hex.12564>

To Consider...

As you think about choosing a PREMs domain, keep the following in mind...

- Domain should be actionable — can the barriers identified by the domain be reasonably addressed by the agency (e.g., are they within your control?) and can the agency make measurable improvements for patients?
- Domain should be addressed with structural changes to the clinic flow and staff capacities and attitudes — is the agency staff prepared to deal with unearthing patient emotions and criticisms and able to address them with openness and empathy?
- Domain should have validated assessment tools available — do validated tools and indicators exist to measure the domains and does the agency have access to them?
- Domain should be improved with the support of staff and agency leadership — does the organization and its leadership have the necessary level of commitment to address systemic changes?
- Domain should be easily measured — can the information be routinely and effectively gathered from patients shortly after the visit (e.g., during the sign-out processes, post-visit survey, through a patient portal survey) or prior to next visit at the clinic (e.g., in the waiting room)?

Best Practices from the Pilot: Domain Selection

- Team approach — involve quality improvement managers, clinicians (multiple disciplines), case managers, patients, and others.
- Use the domain selection process to dive deeper into where data indicate there is a problem or where you suspect there is a problem.
- Consult existing internal staff or patient groups to gain their insights.

- Select a domain to standardize in screening process (e.g., housing and food insecurity).
- Select a domain that aligns with existing performance measures or data collection procedures.
- Involve consumer advisory board in selecting a measure.
- Involve subrecipients and planning councils in the process (i.e., Part A or B jurisdictions).

Best Practices from the Pilot: Measure Selection and Testing

- Consider how measures fit into existing survey activities, (e.g., who will be doing the asking, how will the survey be administered).
- Assess how easy it is for designated staff to administer the measure (e.g., are the questions easy to read to patients).
- Find questions that resonate with patients and address questions that matter to them.
- Test questions with patients on a small scale using the Plan, Do, Study, Act (PDSA) cycle (e.g., are the questions appropriate, phrased in a way patients understand, getting the information you need).
- Consider multiple PDSA in testing the measure. One PDSA to test literacy level, one PDSA on who should ask the questions, one looking at when to ask the questions, one on using culturally relevant language.
- Ensure that you have a clear sense about the patients you want to focus on for PROMs/PREMs and the number of patients to be asked each measurement cycle.

Section 4: How to Plan and Implement PROMs or PREMs

A lesson learned for everyone is to meaningfully implement PROMs and PREMs you must ask patients the right question and ask at the right time. — Clemens Steinbock, Pilot Project Coach

This section suggests ways to implement patient-reported outcome and experience measures. Challenges and possible solutions are identified but it is important to note that these may need to be modified depending on circumstances unique to the organization.

Initiating PROMs and PREMs: Get Buy In

Having an enthusiastic and invested leader of the consumer advisory board made consumer engagement much easier. - Pilot Project Site

As with any new improvement project, it is necessary to be transparent—this means informing staff and patients about the goals, processes, and expected outcomes. Providing this information is essential for gaining “buy in” from key stakeholders. For staff and patients, an understanding of the purpose and potential benefits can increase the likelihood that they will participate in data collection and related improvement activities. Gaining the support of leadership is critical as they can convey from the top that the project is a priority for the organization and are also instrumental in securing the resources necessary to carry out the project

and respond to the findings. Leadership must agree to the project and give their permission to move forward.

Considerations: Buy In

- Involve leadership from beginning. Getting their support can result in necessary resources that ensure the project is sustainable.
- Foster shared purpose and meaning. Everyone who interacts with the measure, especially patients, must understand why the data are being collected and how they will be used.
- Inform all staff about goals of project and processes. Engaging them creates ownership.
- Reach out to staff directly involved (as planners and participants).
- From the beginning provide regular feedback to staff and patients.
- Expect possible staff pushback. Gaining their input at the beginning and regular feedback can help to reduce pushback.
- At the beginning and throughout the process recognize the contribution of staff.

Lessons from the Pilot: Leadership Support, Centro Ararat

Centro Ararat’s leadership was very supportive of the domain selected for the project—well-being—since it aligns with the organization’s priorities and is sensitive to cultural issues. The organization’s patients are experiencing multiple mental health stressors. The rate of poverty is high, hurricanes have devastated many local communities, and COVID-19 has only added to the stress. In the Latinx culture, there is a significant stigma related to mental health issues and people are reluctant to access needed services. Addressing mental health in the context of “well-being” is more acceptable to patients—there is not the stigma of a diagnosis or being told “you need help.” Leadership was regularly informed about the project’s progress and early findings, which helped keep the team on track and brought leadership in on how to respond to the findings.

Early findings indicated that older patients are very concerned about their future in terms of health and financial outlook. Based on the data, Centro Ararat is considering support services and education focused on financial literacy. In addition to addressing patients' mental health needs, leadership is also interested in improving Centro Ararat's medical visit performance measure. Patients often cancel or are no shows when they are suffering from mental health issues. Using project findings to improve services related to mental health will hopefully impact other aspects of care, such as keeping medical appointments.

Planning and Implementation Team

For successful projects, your team should represent various positions within your organizations and bring together multiple skills and experiences.

From within your organizations, be sure to include administration, clinical providers, non-clinical staff, information technology (IT), social work, support staff, and clinical quality management. Tailor teams based on the issues to be addressed. For example, if you are exploring patients' experience during intake (a PREM), you will want to include front office staff in planning and implementing the project. If you are exploring patients' housing situation (i.e., unstable housing), include social workers.

Patients (yes, more than one) play an important role in planning and implementing PROMs and PREMs—from selecting the domains to how best to collect the data, to providing findings back to stakeholders beyond the project team (i.e., patients, clinicians, and other staff), and formulating a response to the findings. They bring their expertise, their lived experience, to this work. Patients should be thoroughly integrated into the work of the project team and included from the beginning. One, or a small number of individuals, cannot represent a patient community. The more patients involved, the more patient

perspectives can be included, and community voices can be heard.

Key Roles

Key functions within the team include:

- Project lead
- Data collection and analysis
- Documentation (document the planning, implementation, and results of the project)
- Training of clinicians and other staff (e.g., interview protocol, data collection)
- Communications (informing staff/patients prior to start of project, informing staff/patients of findings and organization's response)
- Responding to findings (ensuring that the organization initiates change in response to findings and engages CQM staff, if not already involved)

Considerations: Involving Patients

- Make an effort to recruit patients who will contribute to the team. Do not just post an announcement on a bulletin board or newsletter. Patients already involved in QI activities can be effective recruiters.
- Orientation and/or training maybe necessary so that patients possess a basic understanding of the activities. This doesn't have to be extensive, but it can lay the foundation for more valuable contributions.
- Remove barriers to participation. Provide support (e.g., transportation) to facilitate involvement. Schedule meetings when it is convenient for patients (e.g., evenings).
- Acknowledge their contribution and investment of time (e.g., gift card, etc.). Patients bring their expertise—lived experience—to the project as well as other skills. These should be recognized and valued.
- Provide opportunities for growth. Be mindful about helping patients gain skills that could lead to employment in your organization or elsewhere. Let them know that they are developing valuable skills.

More information on effectively engaging patients in QI can be found in CQII's [Guide to Consumer Involvement: Improving the Quality of Ambulatory HIV Programs](#). HRSA HAB also provides more clarification in the [February 2023 program letter on community engagement](#).

The only way we address improvements to client reported outcomes and experiences is by meaningfully including people with HIV in all aspects of selecting and implementing a measure, and most importantly, in making changes to the status quo. - Clemens Steinbock, Pilot Project Coach

HIV/AIDS Bureau Implementation Science (IS) Framework

Consider using the HRSA HAB Implementation Science Framework. The HAB IS framework, developed in collaborations with the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH), includes effectiveness criteria for three categories of intervention strategies: evidence-based interventions, evidence-informed interventions, and emerging strategies.

<p>Evidence-Based Interventions (EBIs)</p> <p>Published research evidence supporting these interventions meets established CDC criteria for being evidence-based.</p>	<p>Evidence-Informed Interventions (EIIIs)</p> <p>Published research evidence meets HRSA HAB evidence-informed criteria but does not meet CDC criteria for being evidence-based. May also meet CDC criteria for being evidence-informed.</p>	<p>Emerging Interventions (EIs)</p> <p>Innovative and responsive to emerging priorities. Real world validity and effectiveness demonstrated at least at the local level, but evidence has not yet been published.</p>
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These interventions inform your QI projects and the selection of the improvement ideas the QI team implements. For more information on [HAB IS](#).

Tool: Pre-Implementation Checklist

Initiation

- Include PROMs and PREMs projects in QI program activities. Include in organization's quality management evaluation plan (to ensure relevancy and accountability) and quality management efforts.

Identify project leadership

- Develop a concept paper (presents the basic elements of a project—goal, objectives, outcomes, impact, timeline, required resources).

Stakeholders

- Brief leadership and obtain buy-in.
- Identify key staff that will be integral to conducting the project (IT, key clinical staff, peers, support staff, allied health).
- Identify role for patients (on project team, in collecting data, in disseminating findings, and promoting organization's response).
- Identify and recruit other stakeholders (e.g., if project extends beyond the organization, such as housing).

Planning

- Develop work plan with specific milestones for implementation, data collection, analysis, and organization's response.
- Ensure workflows include all team members, especially patients.
- Use standardized processes to facilitate the implementation, such as use standardized tools and workflows (e.g., best practices, collection tools, reporting).
- Tailor tools/questions to the needs of the organization as necessary.
- Develop training plan.

- Recognize contributions to the project to promote participation on the project team.

Resources

- Identify existing organizational resources and whether they can be utilized for project.
- Explore options for gaining additional resources (from inside and outside organization).
- Consult with leadership about resource needs.
- Revise project based on available resources.

Burden

- Be mindful of survey burden on clinicians, other staff, and patients.
- Determine how to manage data given staff and IT infrastructure.
- Will staff have sufficient time to address findings? For PROMs, during clinical encounters and on an ongoing basis? For PREMs, to engage in QI activities to address identified issues?

Identify, Prioritize, and Select PROMs and PREMs Domains and Measures

Selecting Domains

Previously (Section 3) we presented suggested PROMs and PREMs domains for HIV providers. As noted, these were identified during the 2021 IHI Expert Meeting and are intended to help RWHAP providers initiate their improvement projects.

There are various ways to go about selecting a domain. Various QI tools are available to assist QI teams to prioritize those domains that are suggested by the team members. The use of the prioritization matrix might be particularly helpful in this process. Further, you might want to ensure that all team members agree that your organizations' circumstances make a particular domain a clear priority. However, it is most likely that people will have different opinions in terms of priority domains. Before you start any selection process, ensure that all participants have a full understanding of the domains; some staff or patients may require a brief orientation.

We suggest using a **modified-Delphi process**, which is what was used during the IHI Expert Meeting. This is a structured communication technique used for systematic, interactive forecasting. Over the course of multiple

Considerations: Selecting Domains

- Domain should reflect a top priority for the patient population.
- Domain(s) should align with the organization's QI goals and activities.
- Consider focusing on a subpopulation of your patients (e.g., women, youth), if appropriate.
- Organization must be able to address the issue (i.e., are the findings be actionable).
- Addressing findings may require the involvement of multiple disciplines.
- Identify possible resources in your organization or community (e.g., other service providers) that could address the needs.

rounds (2-3 is probably sufficient), participants rate their selections using a Likert scale (0 being not important, 5 being most important). After each round, participants can engage in discussion about the domains, which can inform selections made during the next round. At the end of the agreed upon number of rounds, the domain with the highest score is selected.

Lessons from the Pilot:

Selecting a Domain, University of Pittsburgh Medical Center

As they considered which PROMs/PREMs domain to select, the University of Pittsburgh Medical Center team initially thought all domains were important. During the subsequent decision-making process, it came down to selecting a domain which generated data that were actionable. Food insecurity had increasingly become an issue during COVID-19. While clinicians may ask patients about food insecurities, there is no standard protocol for referrals. The expectation is that by standardizing the process, all patients will be screened and will result in more consistent referrals to support services, including a dietitian. Leadership has shown interest in expanding PROMs/PREMs measures to more social determinants of health and in capturing these data in the EHR so that it can be tracked over time.

Selecting Measures

For many domains there are existing measures that are both reliable and validated. Some of these measures are quite long (i.e., numerous questions) and cover multiple domains. Be mindful of the burden you are creating for both staff and patients (e.g., number of questions, amount of time required to answer questions).

For each of the domains we identified in Section 3, we have identified questions that HIV providers can use to collect data. Providers can select which questions to include in their surveys as they launch their PROMs and PREMs projects—starting small while becoming familiar with the process. These activities can be expanded, and additional measures identified as staff build their expertise.

Considerations: Selecting Measures

- Assess what data are already being collected and determine if it is sufficient for your selected domain.
- Collect only the data you need for your selected domain.
- Consider expense of using the measure (i.e., is it proprietary).
- Balance qualitative vs. quantitative data. Quantitative is easier to collect but qualitative may provide greater insights.
- If data are not already available, determine how easy it will be to collect the data and if IT support will be required.

Lessons from the Pilot:

Selecting a Measure, AIDS Project of the Ozarks

The AIDS Project of the Ozarks selected the communications domain, since it would provide greater insight into how patients interact with clinicians, such as whether they understand discussions with their providers or their lab results. When they tested their survey, they discovered the survey questions were so similar to each other that later questions did not add useful information. The project team went back to the original survey tool and selected different questions that helped them better understand communications between providers and patients. Specifically, they wanted to know if patients: received test results and medical information in a way that they understood, and felt there was enough time during the visit for them to ask questions and get answers. They also felt that it was important to identify the provider who interacted with the patient. The project team also thought of ways to proactively solicit feedback via an open-ended question to get at other elements of communication that could be improved. Had they not conducted this small test before they rolled out the measure to all patients, the data they received would not have been helpful.

How to Collect Data

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.

– Pilot Project Site

In developing a data collection strategy there are several key questioned to addressed.

- Are there existing data that can be used and how to access these data?
- Are there resources to support data collection or will you have to work within existing data collection infrastructure and with existing staff?
- How will surveys be administered (e.g., data entered into EHR, patient portal, paper, tablets, telephone surveys, smart phone)?
- When will surveys be conducted (before, during, or after appointment)?
- Who will collect the data (clinician, other staff, peer, patient)?
- How often will surveys be administered (every appointment, one-time, every six months)?
- Consider literacy levels, language barriers, and other communication needs (American Sign Language, braille) when designing data collection method.

Involve IT Staff

Understanding data collection capacity and available technology is critical to making informed decisions about designing and implementing a data collection process. IT staff can provide input on the feasibility of various data collection methods.

Be creative and flexible. There is a lot of survey fatigue on the part of staff and patients. With the focus on patient outcomes, they seem more engaged. More willing to take the survey. – Pilot Project Site

Considerations: Selecting Measures

- Using the EHR to collect data makes it readily available to staff to track data over time (longitudinally).
- Explore the possibility of providing incentives to patients to participate in surveys (given at the time of participation). Ask patients what would be a meaningful incentive.
- Explore data collection methods besides surveys. Engaging in conversations (e.g., key informant interviews, focus groups) can also provide rich information.
- Make data collection easy for patients (e.g., drop down menus instead of open-ended questions).
- Understand how findings will be used. For PREMs, patients may want to be anonymous (they may fear retaliation). For PROMs, data must be tied to the patient.

Data Collection Methods: Advantages and Disadvantages		
Method	Advantages	Disadvantages
Electronic Health Record (EHR)	<ul style="list-style-type: none"> • Members of the HIV care team can complete survey during appointment • Able to track data over time • Highest response/participation rate • Accessible to clinicians across clinic 	<ul style="list-style-type: none"> • Adding fields to EHR may be challenging (e.g., barriers within the organization, expensive for vendor to modify) • Requires health care staff to administer measures to patients • Patients will lack anonymity in responding which may compromise data quality (i.e., patients may feel pressure to provide socially desirable responses)
Patient Portal	<ul style="list-style-type: none"> • Patients have direct access and can complete survey prior to appointment • Patients may feel less pressure to provide socially desirable responses as opposed to being asked the question in person • Patients can take their time to complete, which may translate to higher quality data 	<ul style="list-style-type: none"> • Patients may not have Internet access • Patients may require training in how to navigate the portal • Reminders to complete the survey may be necessary (via email or phone) • Portal may not interface with EHR, making data difficult to access • ADA compliance • Lower response rate compared to other methods of data collection
App/Phone Survey	<ul style="list-style-type: none"> • Patients have direct access and can complete survey prior to appointment • Can be completed onsite in advance of the appointment (patients can be reminded to do so at check in) • Higher response rate possible compared to patient portal method 	<ul style="list-style-type: none"> • Some apps must be purchased and are expensive to maintain on an ongoing basis • Patients may require training in how to use the app • Reminders to complete the survey may be necessary (via email or phone) • App may not interface with EHR, making data difficult to access

<p>Paper Survey</p>	<ul style="list-style-type: none"> • Some patients (especially older patients) prefer paper surveys • Can be completed onsite in advance of the appointment • Patients may feel less pressure to provide socially desirable responses as opposed to being asked the question in person • Higher response rate possible compared to patient portal method 	<ul style="list-style-type: none"> • Data must be entered by hand • Database may not interface with EHR so data (longitudinal) are not accessible to clinicians during appointment
<p>Tablet Survey (e.g., completed by patient in waiting room)</p>	<ul style="list-style-type: none"> • Can be administered onsite, prior to appointment • Patient does not need to use their own device • Peers can assist patients—provides an opportunity for peers to interact with patients • Patients may feel less pressure to provide socially desirable responses as opposed to being asked the question in person 	<ul style="list-style-type: none"> • Expense of purchasing survey, if proprietary • Patients may require assistance in using tablet and completing survey • Need database or other method to maintain data • May not interface with EHR, making data difficult to access • Staff time for data entry and analysis

Lessons Learned from the Pilot:

Administering the Measure, Harris County Public Health/Thomas Street Health Center

While Harris County was interested in implementing PROMs/PREMs across all funded subrecipients, it initially enlisted a subrecipient to participate to gain first-hand experience about exploring patient well-being. Thomas Street Health Center in Houston had concerns about survey fatigue on the part of both staff and patients. Their response was to rely on volunteers and college and graduate students in health-related fields. All volunteers went through the same onboarding as staff—so they knew about confidentiality and other issues. The volunteers had a cart, decorated with balloons, and they stationed themselves at various locations throughout the clinic. They also had candy to distribute. Patients completed the paper measures. The volunteers then uploaded their data to a shared site. The response was very positive. Thomas Street also learned that in the early days, most respondents were men and older patients. To reach more women, the plan was to station the cart outside the OB-GYN clinic. A similar flexible strategy will be used to reach younger patients.

Lessons Learned from the Pilot:

Collecting Data, Tarrant County

Exploring a jurisdiction-wide approach, Tarrant County had to be prepared to collect data from multiple agencies that they funded. To do so, the project director and an outreach officer visited various agencies in the jurisdiction for a day. During their visits, they engaged patients one-on-one and completed the survey with them—making a connection with that patient.

Lessons Learned from the Pilot:

Data Management, Pilot Project Sites

Sites used various methods to capture data from the pilot. Some relied on a spreadsheet, where they would enter data from paper surveys. Others hoped to capture data in the EHR. This presented some challenges, first in terms of getting the fields added to the EHR and then getting providers to ask the questions and check the boxes. Another site established a shareable site that allowed survey administrators to upload data in real time and staff to access the data. Sites also had to address issues related to coding the data, especially those related to open ended questions, which some sites opted for because they provided more insight into the patient experience.

Staff Training

Education and training for staff are critical for the implementation of PROMs and PREMs. This must be done at various levels within your organization.

- Basic orientation to the project—who, what, why, when (all staff)
- Training on the data collection process (select staff)
- Training on how to discuss outcomes with patients (select staff)

Providing information about the project to all staff will help to secure buy in. Staff who are not directly involved in the project need to understand why time, effort, and resources are being devoted to the project and how it can improve the clinic's performance and potentially, health outcomes. Existing methods of communicating with staff can be used to convey this information, such as staff

updates/newsletters or short presentations during staff meetings.

Training staff directly involved in the project on how to carry out their role helps to ensure the quality and consistency of activities, such as the collection and analysis of data, and that established protocols are followed. Consider using QI language and examples in the training to thoroughly test the project within other QI activities.

Patients participating on the project team may need additional training on the basics of QI, data collection, confidentiality, and other topics related to the project. Providing this foundational training provides them the understanding so that they can fully participate in the project.

CQII has numerous tools to assist in providing training to clinicians and patients. In particular, the [Quality Academy](#) has numerous online modules available.

Project Communications and Providing Feedback to Patients

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. – [Pilot Project Site](#)

Project Communications

Throughout the project it is necessary to be transparent with both patients and staff. This includes:

- Informing patients about why the questions are being asked (i.e., purpose) and how answering the questions will benefit them.
- Clearly communicate to staff about goals, timeframe, and expected milestones and outcomes.
- Establish a single point of contact (i.e., a specific staff person) that will address questions/concerns about the project (if necessary, involving the entire project team).
- Be consistent in messaging and provide training to staff so that they can effectively convey these messages.
- Use multiple methods of communication, especially for patients. Make materials easy to understand (e.g., use plain language) and consider translating materials if many patients speak a language other than English.

Providing Feedback to Patients

By participating in the survey process and providing their feedback, patients are invested in the project. They want to see that there is action on their input.

For PROMs, this feedback is much more tangible. Patients and their clinicians use the data to make care-related decision or address challenges in patients' lives that are impacting their health outcomes (e.g., unstable housing or food insecurity). While patients may see change on an individual level as a result of the improvements informed by findings from the PROM, it is also important to inform the whole patient population (as well as staff) about improvements in the quality of care and health outcomes overall.

For PREMs, this type of communication is especially important. Given that patient experiences are often the result of complex structural factors resistant to easy or quick change, patients may not perceive any changes have been made even though steps have been taken.

Effective communication of findings and the resulting QI activities are critical to ongoing patient engagement and overall transparency. Many organizations already have vehicles in place to communicate with patients and staff. These include:

- Organizational newsletters;
- Bulletin boards; and
- Meetings/advisory groups of patients and people with lived experience.

Communicate findings to patients in a clear manner—make the presentation of data easy to understand. Graphics can be a more effective way to communicate findings, especially when presenting changes over time (i.e., longitudinal data). Also, engage consumer in this process of how best communicate findings and results as they will be able to provide insight on what messaging will resonate with patients.

Lessons Learned from the Pilot:

Presenting Findings to Staff and Patients, Pilot Project Sites

Participants had various strategies for keeping staff informed. Most participants relied upon regular staff meetings, where they could let staff know about the project and the role they might play (e.g., administering measures or questions in EHR). Other ways were to communicate with staff through specific work groups or the quality management committee. One site worked with their local Disparity Workgroup to craft questions and review the subsequent data. Plans to communicate findings back to patients included: working with the consumer advisory boards for suggestions to reach the broader patient population; using the organization's patient newsletters or listserv; and posting story boards or other information in the lobby or waiting room about the project and findings, something that was used for other quality improvement projects. Also, pilot participants noted that there was a lot of interest generated in just asking the questions. Patients knew about what was going on and there has been lots of interest.

Lessons Learned from the Pilot:

Revising a Measure, AIDS Ministries

AIDS Ministries has selected housing as their domain despite limited housing options because it is a significant problem for their patients. While they have two buildings to provide transitional housing, patients 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 measure, 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 re-considered 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 know what they mean when they ask about unstable housing—not just living on the street but perhaps living with relatives, couch surfing, or fearing eviction. They also focused on financial stability, such as inability to pay power bills and other utilities, and on situations that could lead to unstable housing. AIDS Ministries is looking into provided financial literacy training to address some of these issues.

Revising Domains, Measures and Data Collection

As with any QI project, it is necessary to assess and make revisions over the course of activities. As you make these modifications, be transparent with staff and patients and take steps to make sure they are smoothly implemented (e.g., training, changes to protocol).

Best Practices from the Pilot: Data Collection

- Have systems in place how data are collected (i.e., paper form, iPad, interviews).
- Ensure the roles are clearly defined who collects the information (e.g., case manager, patient, provider, front staff).
- Clarify where the reported results are tracked (e.g., spreadsheet, medical record).
- Adding the selected measure to the EHR and other existing data systems.
- Be creative and use technologies to collect data, (e.g., use Survey Monkey and upload data directly to Excel spread sheet).
- Most importantly, use the data results for improvement activities.

After Measurement: What's Next?

PROMs and PREMs are all about measurement—it is the focus of this Guide. Once you have collected the data from your PROMs and PREMs project, what do you do with the findings? Your findings are utilized as with any other QI project using established improvement frameworks, such as the Model for Improvement. The local project team looks at what can be done at the patient, clinic, or system level (as appropriate) and identifies possible interventions. The team works with others inside the organization and patients to implement these interventions. Ongoing collection of data can help determine if interventions are resulting in the desired changes.

Quality Improvement Projects: Key Steps

- Prioritize area for improvement based on data
- Form a QI team (if one is not already in place)
- Develop a project workplan/timeline
- Identify the sequential processes of the chosen system
- Implement changes
- Modify as needed
- Share strategies and best practices with others

CQII Resources

CQII has a wide range of resources to help organizations carry out QI activities. These include how-to guides, training guides, archived webinars, and materials designed for patients (e.g., what they need to know to actively participate in QI activities). These resources can be found on the [CQII page](#) on the TargetHIV website.

- CQII Quality Academy
- CQII Technical Assistance Call Series
- CQII Learning Lab
- CQII Advanced Training Programs
- HIVQUAL Workbook: Guide for Quality Improvement in HIV Care
- CQII Subcontractor Guide: Partnering with Subcontractors to Improve HIV Care
- CQII Cross-Part Quality Management Guide: Using Collaboratives across Ryan White HIV/AIDS Program

Section 5: Implementation Checklist

Selecting Domain

- Assess data collection and analysis requirements related to potential domain.
- Engage wide group of stakeholders (e.g., patients, caregivers, clinicians, leadership, peer workers, other staff) in selection process.
- Select a domain that aligns with organization's QI priorities.
- Draw on the findings from previous patient surveys when selecting a domain. What have patients said in the past about their needs and priorities?
- Use modified Delphi or other participatory process to ensure that many voices are heard and that it is an iterative process.

Selecting Measure

- Assess if data are already being collected and determine if they are sufficient for the selected domain.
- Identify existing measure based on selected domain—don't reinvent the wheel.
- Modify measure as necessary (e.g., selected only a few questions to make it easier to administer in clinical settings).
- Test measure on small number of patients (i.e., pilot test).

Getting and Maintaining Buy In

- Involve leadership (from beginning) to ensure their support.
- Inform all staff about goals of the project and process.
- Inform patients about the project.
- Provide regular updates to leadership, staff, and patients.

Training

- Identify who on project team needs training (e.g., clinicians, IT staff, peer workers, data entry, patients, others).
- Determine areas for training (e.g., data collection, privacy/confidentiality, sharing findings with patients).
- Determine training methods (e.g., in person, online) and frequency of training.
- Establish a way to train new staff if they have a role in the project.
- Design evaluation process for the training.

Collecting Data

- Design data collection process (e.g., entered into EHR, paper survey).
- Engage IT and other key staff.
- Develop data collection tool (e.g., survey, interview protocol, etc.).
- Ensure privacy/confidentiality of data.
- Use existing or create new data management system.
- Develop data entry process, if necessary.

Using Findings to Improve HIV Care and Patient Experience

- Integrate project into existing QI activities.
- Assess if the findings meet patients' expectations and are valuable.
- Identify areas for improvement at the clinician, organization, and system level (as appropriate).
- Involve multiple disciplines to address findings (e.g., clinicians, social workers, others).

Providing Feedback to Patients

- Integrate the provision of feedback into existing clinical protocols and workflows (e.g., with PROMs, from clinician to patient).
- Develop tools to guide clinicians in engaging patients about the findings.
- Identify appropriate communication tools that already exist (e.g., newsletters, bulletin boards).
- Develop patient education materials (e.g., explaining the meaning of the findings).
- Track that findings are provided to patients.

Section 6: Resources

PROMs Resources (Select Articles)

- [Using an implementation science approach to implement and evaluate patient-reported outcome measures \(PROM\) initiatives in routine care settings](#)
- [The development and cognitive testing of the positive outcomes HIV PROM: a brief novel patient-reported outcome measure for adults living with HIV](#)
- [Towards person-centered care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centered qualitative study with key stakeholders](#)
- [Measuring what matters: the patient-reported indicator surveys](#)
- [PaRIS survey of Patients with Chronic Conditions](#)
- [PROMIS® \(Patient-Reported Outcomes Measurement Information System\)](#)

PREMs Resources (Select Articles)

- [We Respect Their Autonomy and Dignity, But How Do We Value Patient-Reported Experiences?](#)

Notes

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