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

Exploring Opportunities for Elevating and Integrating Patient Voices to Improve HIV Care - Findings from the 2021 National PROMS/PREMS Survey

Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) in HIV care: A Ryan White HIV/AIDS Program Perspective

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Executive Summary

In partnership with the HRSA HIV/AIDS Bureau, the Center for Quality Improvement and Innovation (CQII) conducted a national survey about the experiences of Ryan White HIV/AIDS Program-funded providers to examine their familiarity with and experiences in using Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS). The PROMS and PREMS National Survey, announced in December 2021, included questions about the current use of PROMS and PREMS in HIV care, as well as perspectives on implementation barriers and feasibility of measurement. The main goals of the survey were to validate if various domains of PROMS and PREMS were relevant to HIV care, if those domains were perceived to be feasible to measure and implement in busy Ryan White ambulatory care settings and used to inform quality improvement. The PROM domains were Patient Well-Being, Housing Stability, Mental Health, Discrimination, Food Security, Self-Efficacy for Managing Chronic Conditions, and Adolescents and Young Adults. The PREM domains were Racism, Respect/Dignity, Privacy/Confidentially, Communication, Shared Decision-Making, Perceived Importance of Services, Accessibility, and Continuity/Coordination of Care. In addition, questions were asked to gather perspectives on the PROMS and PREMS domains, previously prioritized by an interdisciplinary group, as well as to gauge interest in a PROMS and PREMS Pilot Project about implementing these measures for quality improvement.

The online survey was emailed to HIV providers around the United States, and announcements to complete the survey were distributed 4 times. We received 126 responses over 6 weeks. The majority of respondents reported being 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 interdisciplinary group was independently ranked among participants as having “high” relevance to HIV care. However, several domains for both PROMS and PREMS received “moderate” or “low” rankings for perceived ability to be measured and implemented, including the PROMS Patient-Well Being, Mental Health, Discrimination, Self-Efficacy for Managing Chronic Conditions, and Adolescents and Young Adults. For PREMS, this included 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 Ryan White HIV/AIDS Program-funded settings. In response to interest and need, a pilot study with Ryan White HIV/AIDS Program clinics is indicated to measure the feasibility of implementing PREMS or PROMS in real time and using their results to improve quality of care and health outcomes.

CQII plans to implement the PROMS+PREMS Pilot Project in 2022.

Background

Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) are emerging topics in the fields of performance measurement, quality improvement, and public health. These measures are standardized, validated questions that derive information directly from the patient regarding their health outcomes and their healthcare experiences.[1] In turn, PROMS and PREMS help healthcare providers understand the patients' perspectives of their health status, health goals, and experiences with the healthcare they receive. Although closely related, PROMS and PREMS are two distinct measurement tools that measure different patient aspects.

Patient-Reported Outcome Measurements, or PROMS, are tools used to evaluate a patient's perspective of their health status and quality of life and can only be measured by asking the patient.[1] PROMS can measure holistic areas such as physical functioning, psychological wellbeing, and cognitive functioning.[2] They can also measure disease-specific aspects, such as pain, mobility, or ability to complete daily tasks.[3] Because of these attributes, PROMS are a means of measuring clinical effectiveness and safety.[2]

Patient-Reported Experience Measures, or PREMS, measure the patients' perspectives of the experiences of care they receive and can only be measured by asking the patient.[1] PREMS can assess areas like respect, privacy, communication, and other aspects of the patients' healthcare experience. It is important to note that PREMS go beyond patient satisfaction surveys. This is because PREMS report objective patient experiences, whereas satisfaction surveys often lead patients to report subjective views.[2] For instance, a patient could receive poor healthcare and still report high satisfaction with their care if they are not accustomed to receiving a higher standard of healthcare. [2]

Both PROMS and PREMS can be collected at several points during a healthcare visit, such as before the visit online or by phone, in the waiting room prior to the appointment, in the exam room while waiting for the provider, by the provider during the clinical encounter, or during the checkout process or after the patient has left (again by mail, phone or online). The information gathered from PROMS and PREMS has several uses, particularly in research and quality improvement, while PROMS are also a core component of clinical care.[2] Thus, PROMS and PREMS data help to improve clinical quality management while also providing vital feedback to healthcare providers and pateints.[2]

[1] 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
[2] CMS. (2021) Patient-Reported Outcome Measures. https://www.cms.gov/files/document/blueprint-patient-reported-outcome-measures.pdf
[3] Hospital for Special Surgery. (2021). Patient-Reported Outcome Measures (PROMs). https://www.hss.edu/proms.asp

CQII conducted 3 focus groups in July 2021 with Ryan White HIV/AIDS Program (RWHAP) providers who were also participating in CQII's create+equity Collaborative. The focus groups concluded that there was genuine interest in learning more about PROMS and PREMS, including how to implement PROMS and/or PREMS in their local programs. Additionally, CQII produced a preliminary review of PROMS and PREMS literature.

In October 2021, CQII partnered with the Institute for Healthcare Improvement (IHI) to host a two-day Expert Meeting on this emerging topic. Meeting participants, comprised of content experts, clinical providers, and individuals with lived experiences, were diverse in their familiarity with PROMS and PREMS. They offered their perspectives on the measures, including (1) ranking various PROMS and PREMS domains for importance for Ryan White programs and (2) strategies to overcome implementation barriers. In this context, **domain** refers to the overarching subject area to be measured by a PROM or PREM, such as mobility or respect.

To this end, CQII implemented the online PROMS/PREMS National Survey in December 2021 to measure the validity of the information produced in the CQII/IHI Expert Meeting across Ryan White HIV/AIDS Program-funded providers, including the importance of each PROM and PREM domain and the perceived feasibility of measuring each domain. Collectively, the survey results are intended to help guide future PROMS and PREMS activities conducted by CQII.

Based on the current understanding of PROMS and PREMS, CQII is in the process of developing additional resources to help Ryan White HIV/AIDS Program recipients implement PROMS and PREMS in their care settings and use the results to improve healthcare. Further exploring this important topic, CQII plans – with the support of the HIV/AIDS Bureau – to conduct a formal literature review on PROMS and PREMS; develop a PROMS and PREMS implementation guide with best practices; and implement the PROMS+PREMS Pilot Project, a collaborative learning opportunity for RWHAP-funded providers to explore and implement at least one PROM or PREM into their local program.

Survey Methodology

The participants for this survey were Ryan White HIV/AIDS Program-funded providers in the United States and its territories. The survey was built on SurveyMonkey.com and announcements were distributed online via email announcements. The survey purpose and weblink for completion were announced a total of 4 times. Each announcement resulted in 3,508 e-mail deliveries. Of these deliveries, 126 responses were collected during the period between December 6, 2021 and January 7. 2022. Participants were asked to answer 19 survey questions, 16 of which asked about familiarity with PROMS and PREMS and perspectives on the PROMS and PREMS domains previously prioritized at the CQII/IHI Expert Meeting. The types of questions varied and included multiple choice, open response, and Likert scales (rating scales). The final 3 questions gauged interest in CQII's PROMS+PREMS Pilot Project. To view the survey tool itself, see *Appendix A: PROMS/PREMS National Survey*.

Results

Patient-Reported Outcome Measures (PROMS)

The majority of respondents reported being "somewhat familiar" with PROMS. However, when asked about using PROMS in a healthcare setting, 39% indicated they did not use PROMS and 18% were unsure. Respondents who answered "yes" shared their past experiences using PROMS in their agencies, including the use of PHQ-9,[4] GAD-7,[5] and pain level assessments. For all open-ended responses regarding past experiences using PROMS, please see *Appendix B: Responses to Question #3.*

Respondents were asked to assess the 7 domains of PROMS prioritized during the Expert Meeting in terms of the PROMS' relevance to HIV care and its ability to be measured/implemented. The domains included: Patient Well-Being, Housing Stability, Mental Health, Discrimination, Food security, Self-Efficacy for Managing Chronic Conditions, and Adolescents and Young Adults. Each of these domains were overwhelmingly ranked as "high" for relevance to HIV care, especially Housing Stability and Mental Health. See the data table ranked by high relevance below.

Relevance to HIV Care	HIGH		MODERATE		LOW		NONE	
	%	n	%	n	%	n	%	n
Housing Stability	85.7%	108	8.7%	11	1.6%	2	4.0%	5
Mental Health	84.0%	105	11.2%	14	1.6%	2	3.2%	4
Food Security	77.0%	97	16.7%	21	4.0%	5	2.4%	3
Patient Well-Being	77.0%	97	17.5%	22	1.6%	2	4.0%	5
Self-Efficacy	65.9%	83	28.6%	36	2.4%	3	3.2%	4
Discrimination	57.1%	72	34.9%	44	3.2%	4	4.8%	6
Discrimination	54.8%	68	30.7%	38	7.3%	9	7.3%	9

However, when asked about the ability to measure these domains, the majority of respondents ranked Well-Being, Mental Health, Self-Efficacy for Managing Chronic Conditions, and Adolescents and Young Adults as "moderate." The majority of respondents ranked the Discrimination domain as "low" ability to measure. See the table below.

Ability to Measure	HIGH		MODERATE		LOW		NONE	
	%	n	%	n	%	n	%	n
Housing Stability	60.5%	75	29.0%	36	5.7%	7	4.8%	6
Food Security	52.0%	65	29.6%	37	12.8%	16	5.6%	7
Mental Health	40.2%	49	42.6%	52	13.9%	17	3.3%	4

[4] Pfizer Inc. (1999) *PHQ-9 Patient Depression Questionnaire*. https://integrationacademy.ahrq.gov/sites/default/files/2020-07/PHQ-9.pdf

[5] Spritzer, R.L., Williams, J.B.W., Kroenke, K., & Lowe, B. (2006). Generalized Anxiety Disorder 7-Item (GAD-7) Scale. https://www.crossroadscounselingcenters.com/pdf/Generalized%20Anxiety%20Disorder.pdf

Patient Well-Being	29.8%	37	47.6%	59	15.3%	19	7.3%	9
Adolescents and Young Adults	27.1%	33	34.4%	42	26.2%	32	12.3%	15
Self-Efficacy	21.6%	27	47.2%	59	23.2%	29	8.0%	10
Discrimination	19.2%	24	29.6%	37	37.6%	47	13.6%	17

For visual results, view *Chart 1: Ranking of PROMS Domains, Relevance to HIV Care and Ability to Measure.*

Following the domain ranking, respondents had an opportunity to add domains that were not included in the survey but believed were important to measure. Some of these domains included Transportation and Personal Safety, Access to Care, Financial Stability, Substance Abuse. For the full list of responses, see *Appendix C: Responses to Question #5*.

About 85% of respondents said that measuring some or all of the PROMS domains listed in the survey could "somewhat likely" or "very likely" result in actionable interventions to improve HIV care at the respondent's agency. However, only about 58% felt their agency was "equipped" or "somewhat equipped" to implement PROMS. The remaining respondents were either "unequipped", "somewhat unequipped", or "unsure". *(Chart 3)* When asked what technical assistance and/or tools would be needed to implement a PROM in the respondent's agency, answers varied from wanting training tools, seeking validated assessments for data collection, or needing additional staff members. Others commented on streamlining workflow processes to prevent staff turnover and conduct PROM surveys. To view all the open-ended responses, please view *Appendix D: Responses to Question #8*.

Patient-Reported Experience Measures (PREMS)

When asked about familiarity with PREMS, most respondents indicated being "somewhat familiar" with PREMS. When asked about using PREMS in any healthcare settings, 51% answered "yes," 32% answered "no," while the rest of respondents were unsure. Respondents who answered "yes" in response to past experiences using PREMS in their agencies indicated they used patient satisfaction surveys and CAHPS[6] surveys. To view all open-ended responses to previous experience using PREMS, please see *Appendix E: Responses to Question #11.*

Similar to the PROMS section of the survey, respondents were asked to assess 8 provided PREMS domains in terms of their relevance to HIV care and their ability to be measured and implemented, including: Racism, Respect/Dignity, Privacy/Confidentiality, Communication, Shared Decision-Making, Perceived Importance of Services, Accessibility, and Continuity/Coordination of Care.

Each of these domains were overwhelmingly ranked as "high" for relevance to HIV care, especially Privacy/Confidentiality.

[6] Centers for Medicare and Medicaid Services. *Consumer Assessment of Healthcare Providers & Systems (CAHPS).* https://www.cms.gov/research-statistics-data-and-systems/research/cahps

Relevance to HIV Care	HIGH		MODERATE		LOW		NONE	
	%	n	%	n	%	n	%	n
Privacy/Confidentiality	91.2%	104	3.5%	4	2.6%	3	2.6%	3
Respect/Dignity	84.1%	95	10.6%	12	2.7%	3	2.7%	3
Accessibility	84.1%	95	11.5%	13	1.8%	2	2.7%	3
Communication	83.3%	95	14.0%	16	0.9%	1	1.8%	2
Continuity/Coordination of Services	76.3%	87	17.5%	20	2.6%	3	3.5%	4
Racism	72.3%	81	17.0%	19	6.3%	7	4.5%	5
Shared Decision-Making	66.1%	74	27.7%	31	2.7%	3	3.6%	4
Perceived Importance of Services	62.0%	70	31.9%	36	3.5%	4	2.7%	3

However, when asked about the ability to measure these domains, the majority of respondents ranked Racism, Shared Decision-Making, Perceived Importance of Services, and Continuity/Coordination of Care as "moderate."

Ability to Measure	HIGH		MODERATE		LOW		NONE	
	%	n	%	n	%	n	%	n
Privacy/Confidentiality	68.1%	77	23.0%	26	5.3%	6	3.5%	4
Accessibility	54.9%	62	32.7%	37	8.0%	9	4.4%	5
Communication	51.3%	58	37.2%	42	8.9%	10	2.7%	3
Respect/Dignity	46.0%	51	38.7%	43	6.3%	7	9.0%	10
Continuity/Coordination of Services	40.2%	45	45.5%	51	8.9%	10	5.4%	6
Perceived Importance of Services	32.1%	36	43.8%	49	17.9%	20	6.3%	7
Shared Decision-Making	28.8%	32	51.4%	57	12.6%	14	7.2%	8
Racism	25.9%	29	38.4%	43	24.1%	27	11.6%	13

For visual results, see *Chart 2: Ranking of PREMS Domains, Relevance to HIV Care and Ability to Measure*.

Respondents also had the opportunity to add PREMS domains that were not listed in the survey but believed to be important to measure. The most referenced domain was Stigma. To view all the domains provided by respondents, see *Appendix F: Responses to Question #13.*

About 85% of respondents said that measuring some or all of the PREMS domains listed in the survey could "somewhat likely" or "very likely" result in actionable interventions to improve HIV healthcare at the respondent's agency – the same results as PROMS. However, only about 66% felt their agency was "equipped" or "somewhat equipped" to implement PREMS, which was 6% more than for PROMS. The remaining 28% respondents were either "unequipped", "somewhat unequipped", or "unsure." *(Chart 4)* When asked what technical assistance and/or tools would be needed to implement a PROM in the respondent's agency, answers varied from

engaging in peer learning at other clinics to needing general staff education on PREMS. Many responses were similar to PROMS in that respondents feel they would need more staff, designated staff members, workflow improvements, and general staff training tools. One respondent commented on introducing a call line designated for patients to file grievances about their care, as the only designated person is the agency's program supervisor and the respondent feels that the patients are not open to transparent communication with the supervisor. To view all the open-ended responses, please view *Appendix G: Responses to Question #16* .

PROMS+PREMS Pilot Project

A third and final section of the survey was introduced to gauge the interest of the greater Ryan White community about joining CQII's PROMS+PREMS Pilot Project. When asked how likely respondents would be to participate in a PROMS/PREMS pilot project, 49% were either "likely" or "very likely" to participate. The other half were either unsure (33%) or "unlikely" or "very unlikely" (18%) they would participate.

Conclusion

The survey data indicate that the suggested PROMS and PREMS domains that were prioritized at the CQII/IHI Expert Meeting are seen as highly relevant to HIV care. However, there appears to be concern about the feasibility of measuring many of these domains. These results indicate a moderate familiarity with the underlying concept of incorporating patients' voices to assess health outcomes and patient experiences, but also emphasize the general lack of experience in measuring PROMS and PREMS in Ryan White HIV/AIDS Program-funded settings. Roughly 50% of respondents had either not used PROMS or PREMS or were unsure if they had. It seems plausible that the measurement feasibility for several domains was ranked "moderate" or "low" because respondents are unaware of existing, validated tools to measure the presented domains.

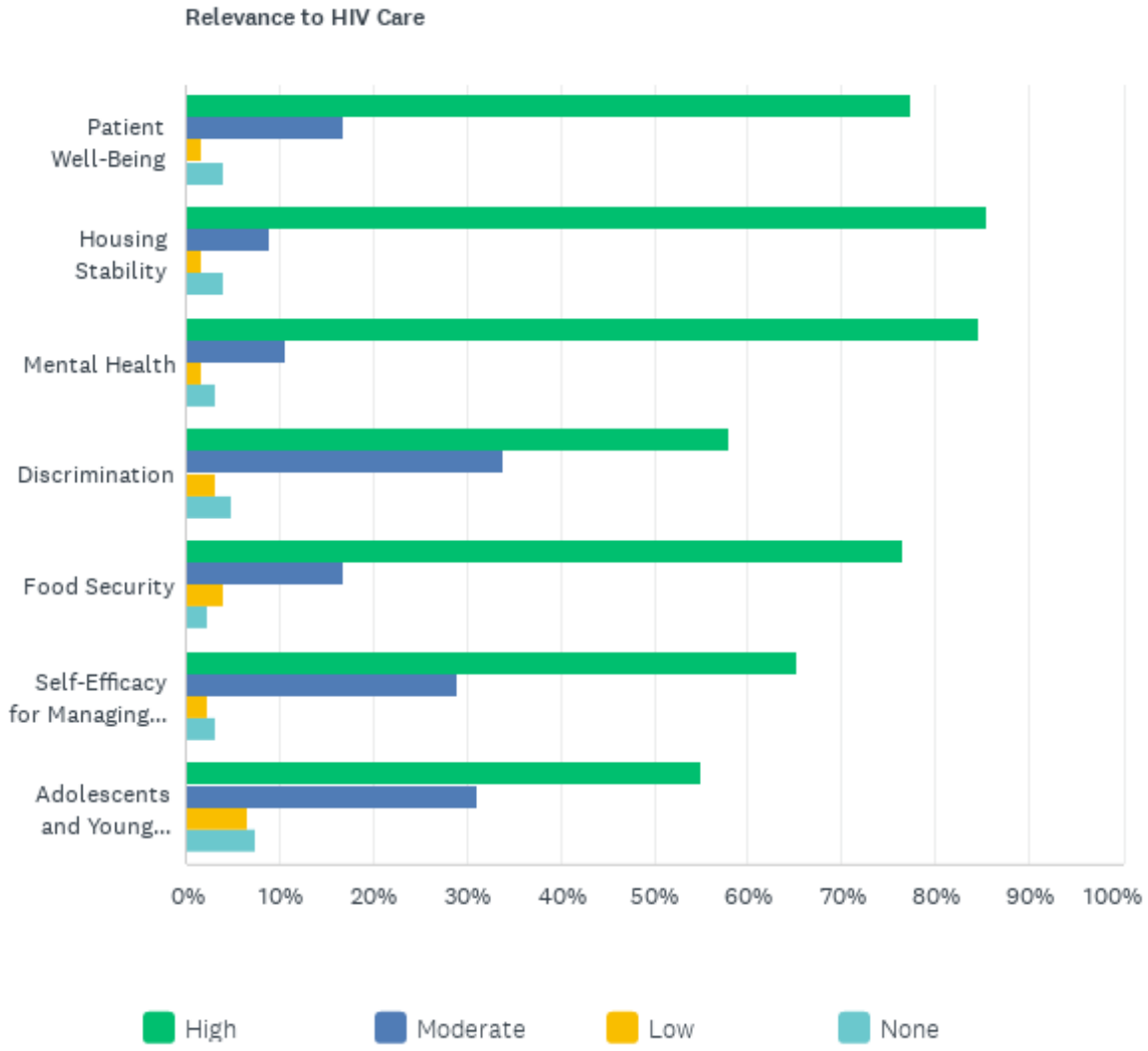
The survey results agree with the proposed PROMS and PREMS domains as initially prioritized during the CQII/IHI Expert Meeting. Thus, these domains should be included for exploration and implementation in the PROMS+PREMS Pilot Project. However, one significant limitation of the methodology is that the survey was distributed to providers but failed to reach patients. Considering that PROMS and PREMS are tools that utilize patient voices, it is important to include patients in the implementation process. Equally so, patient perspectives should have been collected to affirm the domains' relevancy to HIV care.

To better measure the feasibility of implementing these domains in local HIV care settings with patient involvement and using the results to improve health outcomes and experiences, a pilot study with Ryan White HIV/AIDS Program clinics is indicated. In partnership with the HRSA HIV/AIDS Bureau, CQII plans to conduct a PROMS+PREMS Pilot Project in 2022. It is possible

that respondents who were “unsure” about participating in a pilot project simply need more information about the project and evidence that peers have successfully measured these domains. Given that most respondents expressed interest in joining a pilot program, CQII is optimistic about the wide interest to further explore and implement these measures in a collaborative environment.

Data Charts

Chart 1: Ranking of PROMS Domains, Relevance to HIV Care and Ability to Measure.



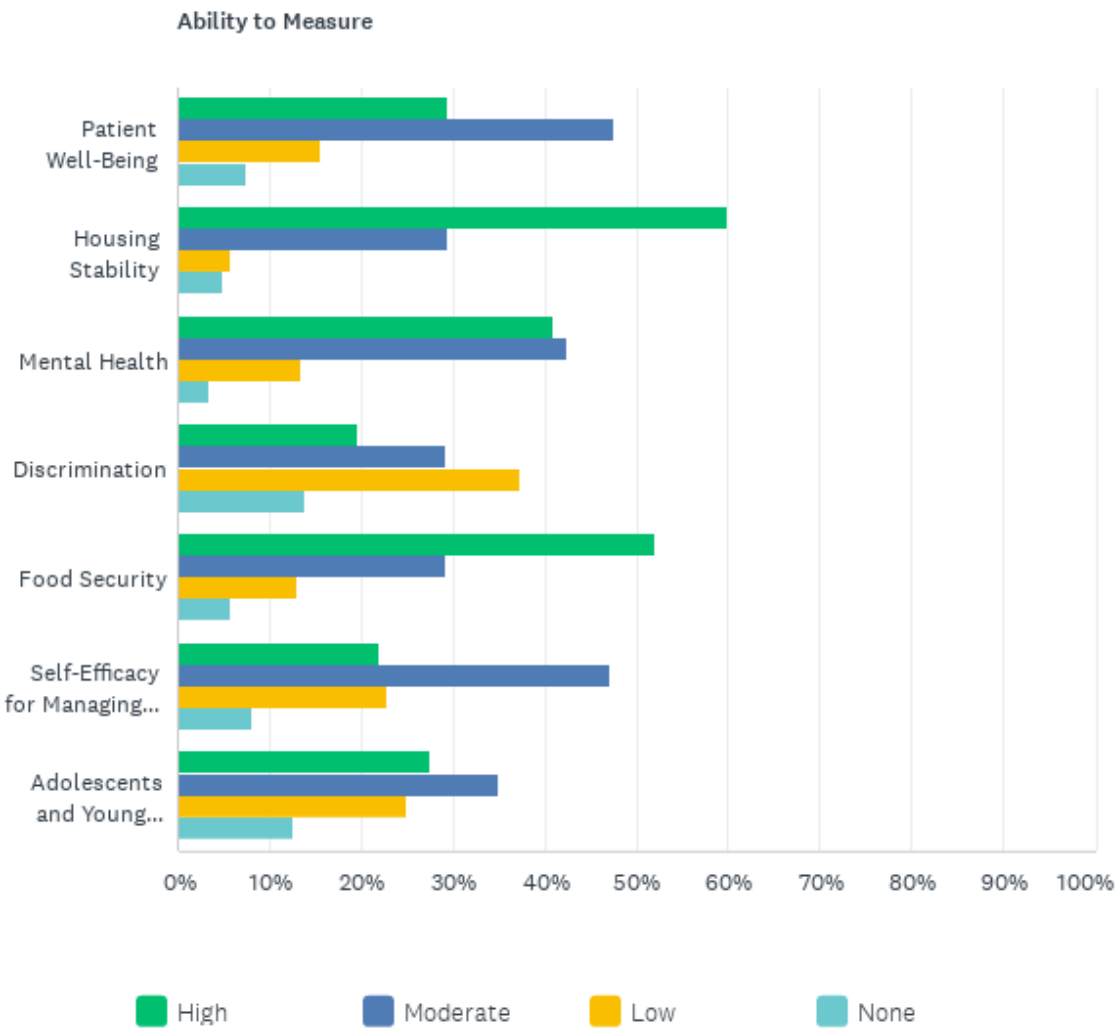
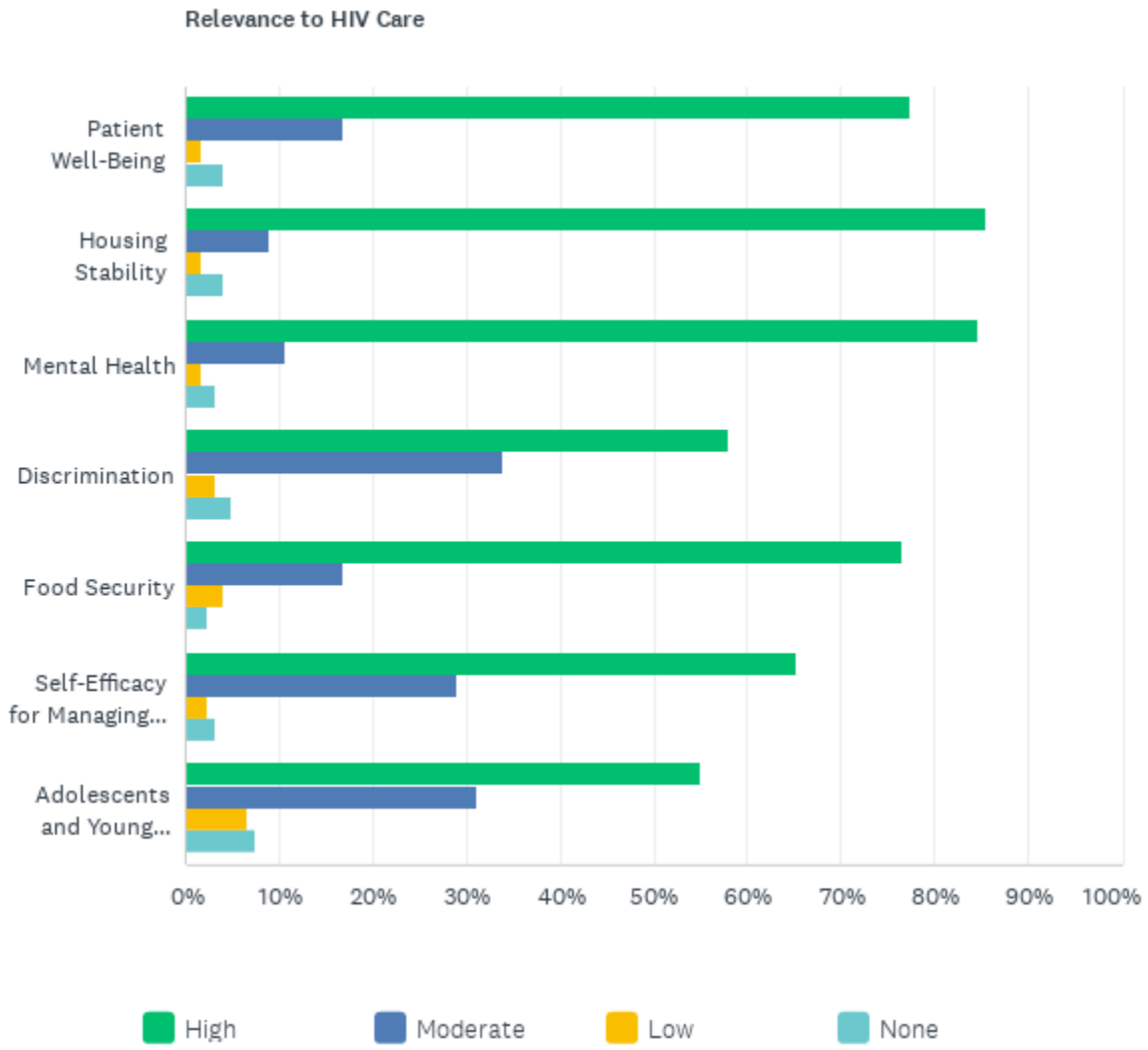

Ability to Measure
Patient Well-Being
Housing Stability
Mental Health
Discrimination
Food Security
Self-Efficacy for Managing...
Adolescents and Young...
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
High
Moderate
Low
None

Chart 2: Ranking of PREMS Domains, Relevance to HIV Care and Ability to Measure



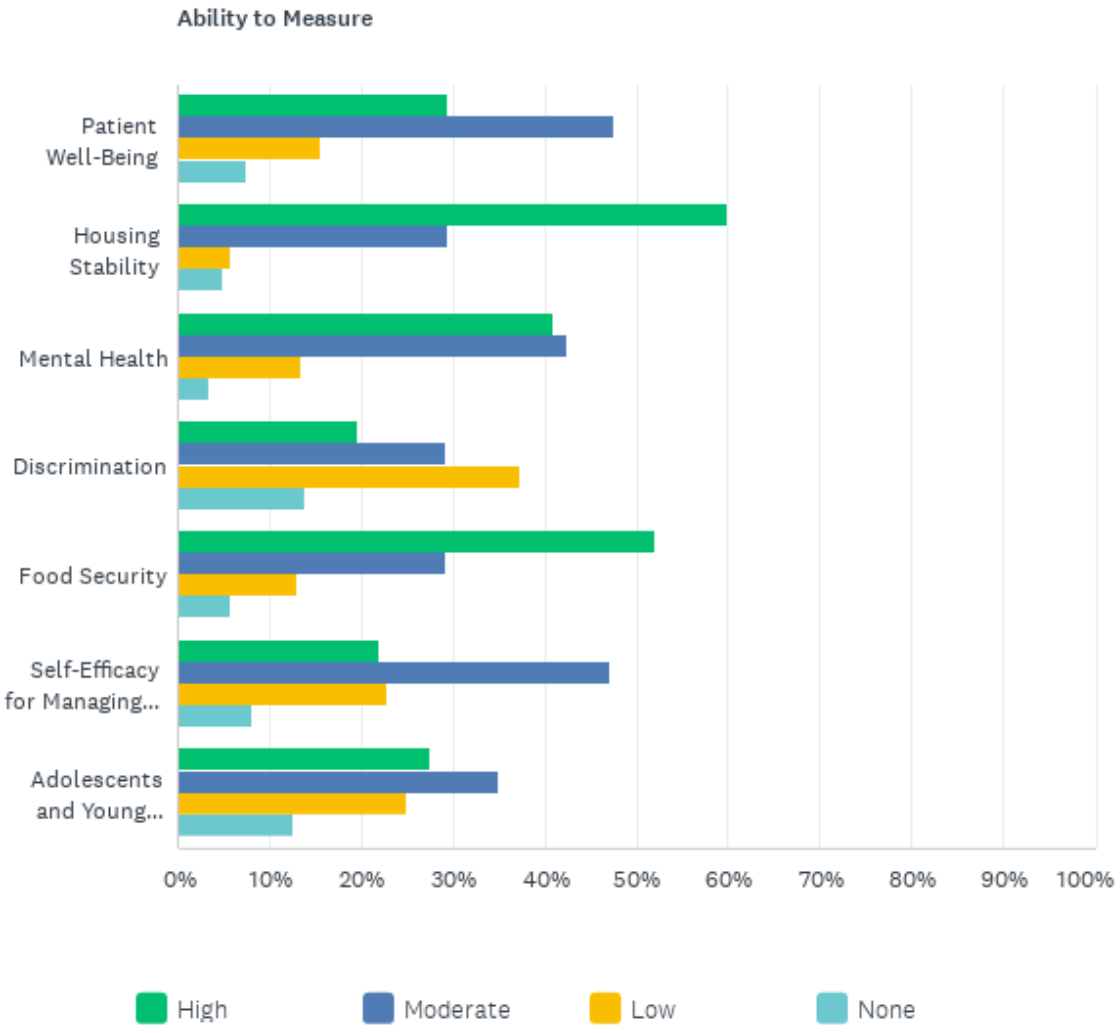

Ability to Measure
Patient Well-Being
Housing Stability
Mental Health
Discrimination
Food Security
Self-Efficacy for Managing...
Adolescents and Young...
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
High
Moderate
Low
None

Chart 3: How likely do you think measuring some or all of the PROMS domains listed above could result in actionable interventions to improve HIV healthcare at your agency?

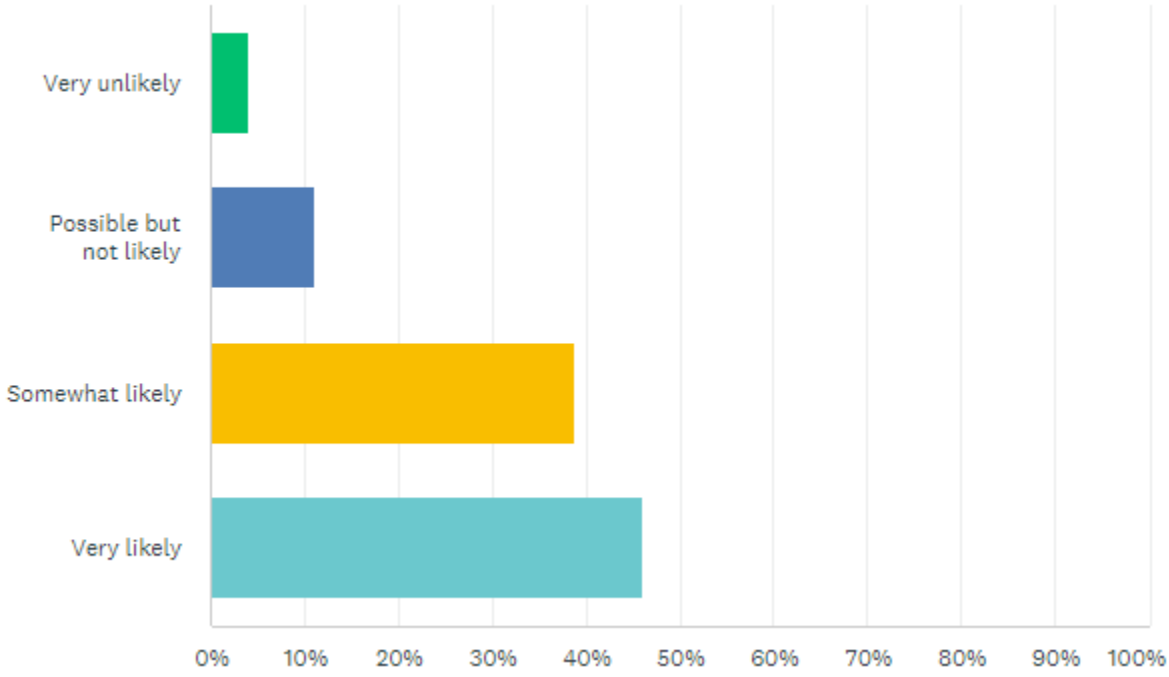
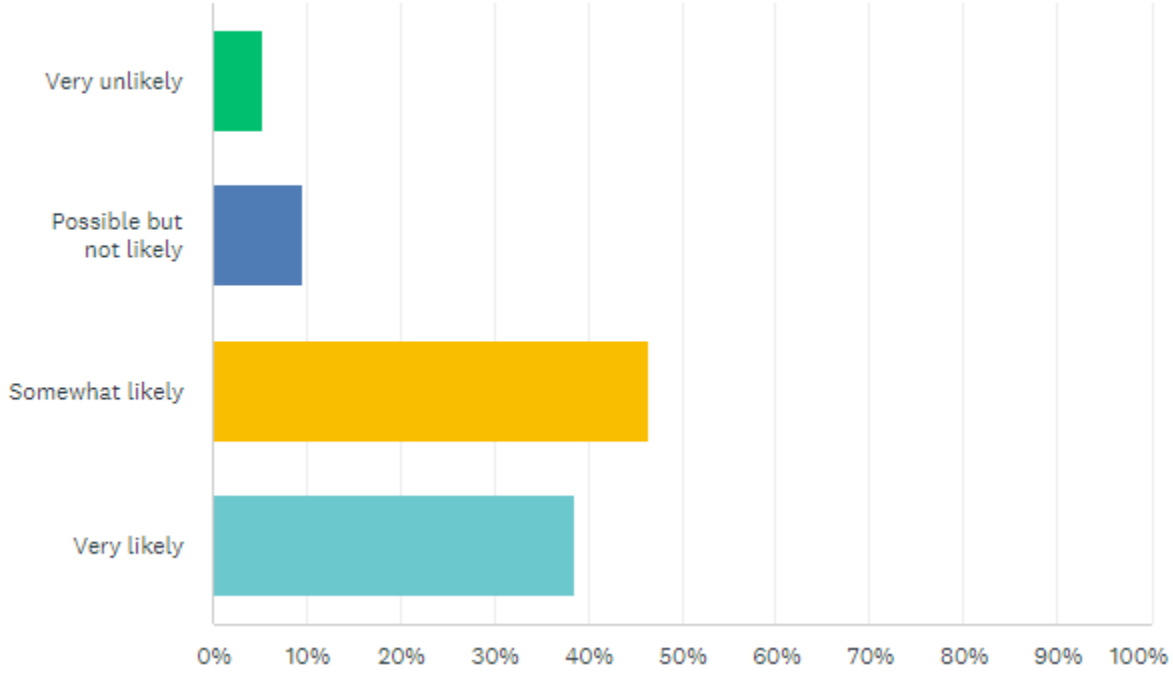


Chart 4: How likely do you think measuring some or all of the PREMS domains listed above could result in actionable interventions to improve HIV healthcare at your agency?



Appendices

Appendix A: PROMS/PREMS National Survey

PROMS/PREMS National Survey

Patient-Reported Outcomes and Experiences: A National Survey

Integrating the voices of individuals with lived experiences is a cornerstone in quality improvement. It is vital to routinely assess the quality of HIV outcomes and experiences with the healthcare system using the insights of 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.

To explore the understanding of, attitudes towards, and experience with patient-reported outcomes and experiences across Ryan White HIV/AIDS Program-funded providers, CQII partnered with the Institute for Healthcare Improvement (IHI) to conduct a national survey on this important topic.

We hope to capture the voices of all RWHAP-funded providers and appreciate your voluntary feedback.

If you have questions about this survey or PROMS/PREMS in general, please contact Aria Chitturi at Aria.Chitturi@health.ny.gov.

PROMS/PREMS National Survey

A) Patient-Reported Outcome Measures (PROMS)

Please review the following definition for Patient-Reported Outcome Measures (PROMS):

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

The purpose of Patient-Reported Outcome Measures (PROMS) is to directly query the patient about their health outcomes, which would otherwise be not accessible to the healthcare team.

* 1. Based on this description, how familiar are you with the concept of PROMS? (select one)

- ○ Unfamiliar
- ○ Somewhat unfamiliar
- ○ Unsure
- ○ Somewhat familiar
- ○ Familiar

* 2. Have you used PROMS in any healthcare settings? (select one)

- ○ No
- ○ Unsure
- ○ Yes

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

* 4. Please rate the following domains of PROMS using the provided criteria.

	Relevance to HIV Care	Ability to Measure
Patient Well-Being		
Housing Stability		
Mental Health		
Discrimination		
Food Security		
Self-Efficacy for Managing Chronic Conditions		
Adolescents and Young Adults		

5. Please add a domain that you think is important to measure but was not included in this list.

* 6. How likely do you think measuring some or all of the PROMS domains listed above could result in actionable interventions to improve HIV healthcare at your agency? (select one)

- Very unlikely
- Possible but not likely
- Somewhat likely
- Very likely

* 7. At this point, do you feel equipped to implement PROMS in your agency? (select one)

- Unequipped
- Somewhat unequipped
- Unsure
- Somewhat equipped
- Equipped

8. What technical assistance and/or tools would you need to implement a PROM in your agency?

PROMS/PREMS National Survey

B) Patient-Reported Experience Measures (PREMS)

Please review the following definition for Patient-Reported Experience Measures (PREMS):

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

The purpose of Patient-Reported Experience Measures (PREMS) is to comprehensively assess a patient's experiences with and perceptions of their care. These measures offer a more holistic and patient centered approach to improve care and services.

* 9. Based on this description, how familiar are you with the concepts of PREMS? (select one)

- ○ Unfamiliar
- ○ Somewhat unfamiliar
- ○ Unsure
- ○ Somewhat familiar
- ○ Familiar

* 10. Have you used PREMS in any healthcare settings? (select one)

- ○ No
- ○ Unsure
- ○ Yes

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

* 12. Please rate the following 5 commonly used domains of PREMS using the provided criteria.

	Relevance to HIV Care	Ability to use/implement
Racism		
Respect/Dignity		
Privacy/Confidentiality		
Communication		
Shared Decision-Making		
Perceived Importance of Services		
Accessibility		
Continuity/Coordination of Services		

13. Please add a domain that you think is important to measure but was not included in this list.

* 14. How likely do you think measuring some or all of the PREMS domains listed above could result in actionable interventions to improve HIV healthcare at your agency? (select one)

- Very unlikely
- Possible but not likely
- Somewhat likely
- Very likely

* 15. At this point, do you feel equipped to implement PREMS in your agency? (select one)

- Unequipped
- Somewhat unequipped
- Unsure
- Somewhat equipped
- Equipped

16. What technical assistance and/or tools would you need to implement a PREM in your agency?

PROMS/PREMS National Survey

C) PROMS+PREMS Pilot Project Feasibility

CQII is developing a 6-month PROMS+PREMS Pilot Project to explore the feasibility for implementing PROMS and PREMS in Ryan White HIV/AIDS Program-funded agencies.

* 17. How likely would you participate in a PROMS/PREMS Pilot Project? (select one)

- ○ Very likely
- ○ Likely
- ○ Unsure
- ○ Unlikely
- ○ Very unlikely

* 18. Are you currently participating in the create+equity Collaborative? (select one)

- ○ Yes
- ○ No

19. If you have interest in participating in this pilot, please indicate your name and contact information below.

First name	
Last name	
Email	
Agency	

Appendix B: Responses to Question #3

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

In the clinic, we ask questions screening for depression, social determinants of health, and for over wellbeing, such as their current mood and pain on a visual analog scale.
We learned quickly that there needs to be a support mechanism around the use of PROMS. People Living with Expertise need to be involved in the design of the questions and process. Once the questions and process are established, PLWH need to be oriented to the new process and the purpose of the PROMS. PLWH need dedicated staff to ask questions to as they are completing the PROMS.
Too Many to name… as Black HIV positive woman, Community Advocate positioned at multiple local, State, & Federal tables with direct interfaced with more than 10,000 PLWHA including RWPC, DHTF, Fast-Track Cities, DSHS, Tx HIV Syndicate, Achieving Together, EHE, etc. / I find common responses, e.g. I'm so tired cause I don't feel those in power actually care, especially during the pandemic when it's difficult to reach the right people to help/ I can't get my meds/ there is an underground barter system for meds/!17 much needed meds were taken off the formulary/ I feel my health is worse/ I feel I'm going nuts & desperately need mental health assistance.
We use the PHQ9 assessment at each visit to identify depression or the GAD 7 to identify anxiety. We also evaluate pain under questions. or changes in condition through self-management questionnaires of your medical condition. It helps us to be able to know and identify changes in condition or if the patient is following medical recommendations.
When checking in patients, they are asked for their pain scale and then they complete a depression screening. When patients meet with case managers, they are asked about mental health, housing stability, and food security.
social determinants of health surveys
Annual behavioral health assessment that screens for anxiety, depression, PTSD, alcohol, tobacco, and drug use; Also includes a cognitive screen for patients 50+
In prior agencies, challenges have centered around standardizing the protocol so questions are asked at the same time period, in the same manner, and are done at all.
In a previous job I utilized the National Outcomes Measures Survey with behavioral health patients through a grant with SAMHSA. We also used PROMS in our annual patient evaluation.
At enrollment and then annually for clients who have a high acuity, clients are asked questions about use of alcohol and drugs using questions from the Screening, Brief Intervention and Referral to Treatment (SBIRT) to determine if the client then needs to complete the Alcohol Screening Questionnaire (AUDIT) and/or the Drug Abuse Screening Test (DAST). Our Mental Health Screening is a compilation of several questionnaires.
I was involved in creations of consumer's surveys, and a few national level household survey designs in my previous job.
Self reported BP for Health Plan HEDIS
PhQ-2, PhQ-9, Pain level assessments, Smoking, diet, exercise
We have a number of assessment tools that patient's complete electronically when they come to a clinic appointment. A number of our research protocols include PROMS
Pain Scale
We use PROMS for charting patients viral load and CD-4 counts. Completed Lab results and tobacco use.
Our Medical Case Managers ask questions to gather this information from our patients
Medicare member health outcome surveys and CAHPS surveys
Have not had the experience with it being called PROMS. Do use standardized tools to assess client's current mental, physical and social health.
1. SDOH Screening 2. HTN-RPM – Patients are self-reporting their BP readings through Remote Program Monitoring in an effort to improve their Hypertension and Blood Pressure Control 3. Pain Scales are used in our EMR to assess and manage patient's pain (i.e. what is your pain on a scale of 0 to 10?). 4. BH Assessment Tools are used, scored, and reassessed over time to determine outcomes (Depression Screening and Depression in Remission at 12 months) 5. Tobacco Screening & Cessation is a quality measure that is self-reported and managed by health care provider. 6. BMI, Diet, Exercise – I believe that Wendy Hedrick was working on revamping our Kids in Motion program that would include patient reported outcomes/progress for childhood obesity (in the works)
Screening tools for depression/anxiety, substance use.
mental health, housing
We routinely use PROs for newly Dx HIV+ patients and at routine visits as well as PrEP visits.
As a Medical Case Manager, I ask these questions on a daily basis.
I've used PROMS in RW work both at a CBO and at a small clinic, using MI to gather outcome data, as well as at a BH facility to work at preventing inpatient recidivism.

If screening tools count, then many experiences (PHQ-9, GAD-7, SAMISS, HITS, HARK, ACES, etc.)
we do health literacy assessments to adjust understanding of care
Press Ganey surveys are mailed out post appointments for general satisfaction with the patients experience. patients are asked about social determinants of health and are screened for mental health needs at the clinic.
Assessing PROMS is an integral part of our services. We have to know where the Patient is already at, so we can best assess how to meet them there.
I have not had specific experience with PROMS but am familiar and is similar to CGCAPS and patient surveys.
In my past work I asked clients about depression.
We do a one question patient reported outcome question in our assessment for RWHAP case management, and as a student of social work I have learned about the importance of qualitative data.
Mental health and substance use screenings. General wellbeing scales.
Used in Provider and CM visits to discuss Risk Reduction, Mental Health Screening, Substance Abuse, Oral Health Care, etc.
PHQ9
Our agency is not a direct service provider. We fund and provide monitoring and oversight to direct service providers.
Maybe I'm not understanding the question. But in healthcare these are subjective questions. So when we use validated screening instruments, pain assessments etc. we are using PROMS.
We use Depression screenings for all patients, Fall risk screenings in some cases, Pain scales
With the Administrative Agency and hired consultant, and I'm not sure they understood what they were doing, i.e. Transportation questions that asked about services that clearly were not offered/funded or legally authorized by Ryan White funds. When providers brought this up, we were told we didn't understand the concept. So not a great impression.
Medication Adherence, Depression, Pain
PROMS has been utilized during client assessment for services and care.
TICS (Two-Item Conjoint Screen) Questionnaire, PHQ9,McGill Quality of Life Question, Food Insecurity Screening.
WE have several assessments asking about mental health. Not sure we are using those for measurement however
Mental Health Professionals use different Beck Inventories to learn about patients health and needs. HIV Specialists use medical history and Case managers use another type of historical to identify health and more type of needs. We also conduct a Needs Assessments Study.
PHQ-9
Throughout COVID-19 clients complain about anxiety, fatigue they went through not being able to reach out affects their daily life.
Each visit patients are screened for mental health issues, depression, drug abuse and pain index.
We use the PHQ-2 and the GAD questions for our Mental Health assessments.
Used basic screening tools to assess depression, anxiety, etc., pain indices, to gather data.
Currently patient reported outcome measure information is obtained via client satisfaction surveys conducted by RW B providers.
screening for falls

Appendix C: Responses to Question #5

Please add a domain that you think is important to measure but was not included in this list.

Transportation and/or Personal Safety
Partnership with their healthcare/health provider, Access to care (ability to get same day appointments if needed OR referral to specialists when needed)
Transportation, Financial Stability, Support System, revised approach to Medication adherence (utilizing an approach like the MARS 10)
The degree to which you feel your voice is valued
trust/comfort w/staff
Substance Abuse and Screening
client retention racial disparities
Self-reported quality of life
Advanced age, pregnancy
gender dysphoria, safety (violence, hate crime victimization), employment/employability, patient centeredness
SUD, How would you rate your overall health?, Support System (social, family, community)
Stigma, Loneliness, Support system, Resilience
Patient motivation to be engaged in care
Medication adherence
Diet and exercise, pain, fatigue, functional level after injury or surgery or different medications, domestic violence
Childcare or adult care (care givers)
community/isolation
Social environment - i.e. part of town they live in; physical environment - i.e. air pollution/sound pollution levels in their area of town
Patients tobacco use
Quality of Life
Social isolation
overall financial status
Access to high quality, cost effective, on demand health care
History of Alcohol and/or Substance Use
Education, Employment, Transportation
health literacy
Any other social determinants of health
More about quality of life - discrimination / stigma beyond HIV (race, sexual orientation/gender identity, substance use...), emotional/spiritual/social well-being
Gender/Sexual Identity, by which I mean of course gender concerns but also WRT sexual identity, I'm referring to the ability to be comfortable in one's own skin in any setting or a particular prescribed setting.
Substance Use (could be under Mental Health), Transportation Access, Adherence - medication, appts, care plans, Stigma, Domestic Violence, Human Trafficking, Trauma, Activities of Daily Living (ADLs) & Instrumental Activities of Daily Living (IADLs), Childcare, Social support and family life, Dementia/cognitive deficit, Financial stability/self-sufficiency, Cultural barriers, Language barriers, Immigration, Education/Knowledge/Health Literacy, Risky Behaviors/Survival Sex/Risk Reduction, Trust of Healthcare System/Service Providers, Sexual and Gender Minority Barriers, Healthcare Fatigue, Quality of Life, Time/Competing Priorities/External Obligations, Fear/Confidentiality/Information Disclosure, History of Criminal/Civil/Legal Barriers, Migrant/Seasonal Status and Continuity of Care
Substance Use Treatment Readiness Assessments, Access to appointments (transportation for limited range of motion, motion compromised or deficient patients) or immobile persons, Respectful Treatment in the clinic/clinical setting, Level of Engagement in Care Planning with their providers/being invited to be partake in decision making regarding the treatment and care plans, Safety, Support
Care Continuation
Support and Education
IPV
Health literacy; understanding of HIV; comfort with/confidence in health care provided; understanding of legal/confidentiality rights; sexual wellness/health.
Overall Health
Intimate partner violence
social outlets- does pt have social network or family or anyone who is aware of status, they can speak openly with?

Sexual Health
Something related to stigma and HIV
Support network
Older adults/Advance age
Income, transportation, health insurance
Financial security
Employment
Safety in relationships
Spiritual
Transportation needs.
Cognitive abilities
Poverty

Appendix D: Responses to Question #8

What technical assistance and/or tools would you need to implement a PROM in your agency?

Might be helpful to see what measures or metrics others use and/or are suggested.
Suggestions on how to market and distribute to ensure that there is a lot of participation by patients across the demographic spectrum.
Help with the identification of validated screening tools as a starting point. Video On Demand training resources for the various domains, their impact on PLWH overall wellbeing, and the use of screening tools.
Self care education tools which build self esteem
refreshment course after hours
May be in measure in the EHR
We would not need any additional tools because we already ask this information of our clients.
Trainings and tools we could use
whatever technical element that will be used to implement PROM
Practical tools on how to implement within current workflows
someone to monitor measurements and assessments to compile dashboards for team members
Training on process for implementation of screening
Performance measures and indicators to track that do not require manual chart abstraction
Might be helpful to see what measures or metrics others use and/or are suggested.
tools within EMR to collect this as data (flowsheets, for example) and systems/procedures/training for asking having meaningful conversations about these areas
Make some adjustments into our EHR (Athena)
Examples of tools used in ADAP and Part B HIV Case Management.
Some sort of curriculum or class since I am not familiar with PROM. Data to show what the effects of using PROMs.
Benchmarks
some of the PROMs are not easily measurable, i.e. well-being, mental health, etc.
assessment tools that measure the above areas. We utilize a number of mental health assessments, but I would love to have access to assessments in the other categories.
actions to take since there's very limited options for things like housing as an example
A way to incorporate into EHR and tangible measures
A form with all the different PROMS that includes definitions.
General guidelines, data collection tools, modifiable patient screening tools
Standardized forms and staff training
Electronic survey tools to integrate into Medical and Case Management systems
We have no tools at present. We would need the tools and staff needed to implement it and then staff who would be able to address the survey outcomes.
The majority of these measures should have an actionable referral or intervention. In a healthcare setting with almost no social support (social work, mental health on site), limited community workers, difficult to implement.
Staff trainings
Assistance in how best to integrate the tool in our practice.
LRMC does not use/have access to any of the CMS recognized tools such as PROMIS, HOS, or FOTO for reporting PROMS.
I think it's important to consider workflows for assessing PROM's. In the workflow, it's critical to consider who will be doing the assessment and whether the tool is consistent with that person's training and qualifications. Workflows must also have plans for action taken as a result. There has to be a good reason for assessing as well as clear guidelines for follow up -- don't just measure to collect data.
Validated assessments for data collection, reporting and monitoring. Intervention material/training.
Some training materials and the questions in written form.
I might just need some guidance on crafting a specific tool streamlined to conduct said measurements in an overall BH inpatient setting administrating with RW clients.
A database/EMR provider who can implement the individualized Comprehensive Assessment, Retention and Evaluation (iCARE) Tool. We have the tools, the scoring, the plan of how it would inform action plans and referrals, but have a service provider for our database/EMR that is unwilling to implement in a timely manner due to competing priorities and complexity of the project.
more detailed project reports

Innovative methods for screening patients in an automated way would remove the barrier of staff turnover, which impedes the conduct of these critical screenings.
Work flows, EMR integration, MCM and support staff training
Staff training
Development of a short easy to administer/use survey.
Well designed questionnaire that is "inviting," not the drudgery of another piece of paper to fill out. The ability to conduct PROMs electronically via texted, confidential, online surveys/polls. The ability to do repeated tests over a stated period of time/provider visits to measure if improvement actions are making a difference--possibly even before a visit and after a visit to see if the visit makes a difference in patient outcomes.
Guidance on the performance measures, selection of these.
We have a structure in place that would allow for the eventual collection of PROMS but it would take time to review data elements to add to the data system with program staff and work with IT to get it added. Currently IT is prioritizing work that is required per federal mandates so it may take additional time for the database changes.
The challenge is addressing measures, especially housing. If there is no housing available, it's difficult to provide hope for the client.
what is necessary to monitor and report?
Case examples
Best practices from other agencies. Information on evidence based tools. Tips for integration into already crowded workflows.
To learn of PROM and how to implement in practice
I think we have PDSA's to assist in this
Additional training/guidance for us to facilitate PROM trainings with our providers and provide ongoing TA.
Training and admin/staff buy-in
software, buy-in, data entry
We would need to have a focus group to discuss these gaps and to formalize/standardize a template to use during clinic visit and incorporate it into the electronic medical record notes
A tiered training program w/hands on experience
Many are already being done within the EMR or verbally with the providers.
database consultation, upgrade; TA in development and implementation.
Checklist and upper management assistance
A training manual.
To have a PROMS survey format to be use with our clients.
To develop ways to get info from client level to overall accumulative data
Drafting of proper forms and questions to be asked of clients.
Editable documentation drafts for EMR uploads
Presentation for providers
Spanish tools

Appendix E: Responses to Question #11

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

We survey our patient around patient experience and their care every year.
As a RWD Recipient, we have used PREMS as a basis of our engagement programs for two decades (though we have not called them PREMS). We have developed a multi-pronged approach to collecting PLWH experiential feedback including advisory board that are facilitated by people living with experience, physical surveys, internet surveys, and annual interviews with PLWH as part of program monitoring. Each of our funded clinics have site-specific systems to collect PREMS.
Sorry I have blended the 2 Types of patient reported issues like respect & self esteem, etc.
Patient survey in regards to patients total experience while at their appointments.
We use Focal Group to Know the experience of the patient in different area.
Included in our programs rights and responsibilities, is the information for patients to file grievances about their care that they have received.
Harm reduction focus groups evaluating the quality of provider interaction Planetree interviewing of patients regarding environment, respect, care, Trauma Informed Care Project environment assessment and cultural assessment
Press Ganey patient satisfaction surveys
interviews to find out trends. Male patients reported a lack of male staff to talk to.
We conduct a patient evaluation annually utilizing a national standardized tool and it includes the information mentioned above.
We have created our own outreach tool for our QI project for clients who are virally unsuppressed, but we did not use a standardized tool
some of the CAB surveys
CAHPS surveys in many settings
information is shared by patients on the patient satisfaction survey is used to make changes in our center
Our entire team asks clients for their help in their healthcare experience.
We have used very broad satisfaction surveys but I don't think they provided valuable information back to us. We also us a national program that our hospital uses but this doesn't seem very helpful wither. On both of these the comments that people write seem to be the most helpful.
Patient Satisfaction Surveys, CAHPS, Grievances
We've conducted patient satisfaction but it has had limited utility since most rate it fairly high and its difficult to determine anything actionable from the surveys we have conducted
CAHPS Surveys, organization specific patient surveys
We use a mixture of needs assessments and patient satisfaction surveys and then act according to the results.
Health care system and program-- patient satisfactions surveys.
Our health center regularly collects patient experience reported data through a 3rd party vendor.
larger agency asks these questions of a sample of patients
Press Gainey surveys, patient satisfaction surveys, interviews following rapid ART
The agency has done surveys in the past. We also have CAB meetings.
In our planned individualized Comprehensive, Assessment, Retention and Evaluation Tool, we have domains of stigma and social support, barrier matrix for care and adherence, patient satisfaction survey for HIV ambulatory care (from New York), and access and quality. Nearly all of the questions we are asking are validated, and all have been asked before in other jurisdictions.
We have used data reported in group settings as PREMs data to improve processes. This was not structured thusly, but an action that came into play based on an intuitive acceptance of the reality of the importance of PR data.
Community Advisory Boards
Teach back method
As a patient advocate, I am always dealing with issues of respect, privacy, and the environment where care is provided.
We tend to get overwhelmingly positive responses with little actionable feedback.
I do not recall a PREMS measure being done at my agency. If it was done at some point in the past, it was not memorable enough to have made any impression on me as a valuable tool or measure.
We do yearly surveys of our patients. We also do quarterly CAB meetings and ask the same questions.
In my last work experience, we had clients rate their experience as they proceeded through their visit. They wrote the staff person's name and rated them as soon as they left them to move on to the next person.
conducting focus groups and interviews; surveys (not individual data, but rather aggregate data)
Satisfaction surveys, out of care surveys.

Our agency is not a direct service provider; however, we have used PREMS questions in previous client satisfaction surveys, and our providers include them in theirs.
Client surveys
Patient satisfaction questionnaires
With the Administrative Agency and hired consultant, and I'm not sure they understood what they were doing, i.e. Transportation questions that asked about services that clearly were not offered/funded or legally authorized by Ryan White funds. When providers brought this up, we were told we didn't understand the concept. So not a great impression.
Patient Satisfaction Surveys, Consumer Advisory Board, Focus Groups, Support Groups
PREMS comes up during client assessment for services and therapy sessions.
WE obtain individual assessments of care through annual patient surveys.
We conduct Patient Satisfaction Surveys and a Complaints and Grievances Protocol.
Client Satisfaction Survey (Post-Interaction)
We have a suggestion box located in the waiting room that patients are able to make suggestions to staff as well as an annual survey to asses their care and satisfaction with the clinic.

Appendix F: Responses to Question #13

Please add a domain that you think is important to measure but was not included in this list.

Satisfaction with provider (patient might like the clinic staff and services but want to see a different provider for whatever reason), as well as satisfaction with availability of appointments (would they like to have clinic appointments at a different time then offered)
Commitment/Engagement to provider, willingness to follow-through on goals, level of understanding of information shared
EDU/ we don't empower; we should be creating environment where people can empower themselves
comfort in having access to all staff and resources
stigma
transportation; eligibility procedures (they can be a bit undignified); and time (intakes and recertifications can be time consuming and involve a half or full day of the patient's time. HIV is far more manageable, people have jobs, and might find it cumbersome/unaffordable to take a day off work.
Relationship with agency staff - from front desk to provider
Pharmacy
Housing Stability
Accessibility should include access for persons disabled and for language access
Stability of healthcare provider and team
Racism is what we are trying to eliminate. All other terms are more positive framed. Maybe use cultural, gender, historical humility (trauma informed lens), Peer Support, Physical/environment space, trust
Stigma, social support, barrier matrix for care and adherence, patient satisfaction survey for HIV ambulatory care (from New York), and quality.
Consistency or clinical and supportive staff. In other words, does the agency retain staff or have a high turnover rate to the extent the patient does not consistently see the same staff.
Support Systems
Medication adherence
Amount of time needed to complete visit/appointment.
wait times in clinic.
patient autonomy; barriers present
gender inclusivity; emotional health services; age-friendly services
cultural humility
Stigma, Inclusion
Welcoming environment; facility in which services are provided.
Education
Confidence in caregivers

Appendix G: Responses to Question #16

What technical assistance and/or tools would you need to implement a PREM in your agency?

I think being able to work with other agency to compare and create standards that helps understand what actionable steps need to be taken.
locating validated screening tools to adapt
Tools, resources, EDU
Some PREMS are discussed during our initial enrollment to our clinic.
I think that a separate call line or a designated person for patients to file grievances about their care would be better perceived by the patients. As of today, the only designated person is our program supervisor. Patients are not as open to communicate with her because they are scared of repercussions from providers or case managers; and she is very unapproachable.
Trainings/tools to we could use
whatever technical assistance it would take to implement PREM
same as previous answer-- someone to compile data, prepare dashboards and discuss implementation strategies.
Standardized, validated tools, Dashboards for data analysis, Capacity building funding
training to tools and implementation process
Performance measures to track
All staff training
data collection tools, time, training and procedures.
Training tools practice
We would need examples of tools used for ADAP and Part B HIV Case Management
Patient experience is faulty at best. If we could teach patients how to feel good about their illness and set expectations- maybe patient experience would be reliable. Just too many entitled people out there and it's getting worse.
educating staff members
Tools/assessments that are evidenced based or at least tried and true.
A form with the definitions of all the different PREM's
guidance and tools on measuring the domains listed above
We don't provide healthcare services, but could use standardized forms and training to implement PREM for additional data collection, or to eventually train subrecipient healthcare providers
Figuring out a methodology that is easy to implement across a large system, allows easy access to program level data, and ensures actionable data
Electronic data collection and reporting tools so feedback to staff and providers is routinely (frequently) produced and reviewed.
these are touted by the healthcare system but not often monitored or implemented with follow up.
Develop a HIV specific patient experience survey.
Validated assessments for data collection, reporting and monitoring. Intervention material/training.
Collecting information is one step, designing interventions, of course, is a much larger/ongoing process.
Have seen nothing on this. Perhaps some training materials
Same barrier as listed before -- we do not have a responsive database/EMR programmer that is willing to implement these questions into our database/EMR system. We already have questions, skip patterns, etc. waiting to be programmed.
Innovative approaches to conducting these surveys are needed so agencies are not relying on human resource to complete them. Agencies and institutions will not assess an area they are not prepared to address in advance. That is the reality. Training, TA, interventions, protocols and/or guidance on how to address these must be developed and provided first. The agency/org must then assess the feasibility to produce the interventions, then, if they are cost effective interventions AND there are staff available to assess and follow up, then they might consider assessing PEMS.
Workflows, staff training, EMR integration
client satisfaction surveys in place
Assistance with getting buy-in from the higher powers!
Same response as that for the same PROM question. Additionally, a real-time online option for patient's to rate each visit/encounter, via text/email (patient choice of preferred contact method) and via having an electronic kiosk/computer in the waiting room/at check out for patients to share responses immediately.
Assistance selecting measures

Same note as with PROMS re: have the infrastructure in place but would take time to review and implement any PREMS elements. Tools that would be helpful is a list of PROMS or PREMS to choose from (ones already established like the HRSA HAB performance measures)
Some of the measures are so entrenched and some institutions are resistant to change. How many service providers want to be open until 9pm and on the weekend?
I think is would be challenging to implement all of the PREM domains, but programs could choose the top three in any given grant year; having case examples and a toolkit would help guide programs in addressing PREMs to ultimately inform quality improvement projects.
Examples from other agencies. Evidence based screening examples.
Education on programs and how to implement
More training in order to provide training and ongoing TA to providers.
Training and admin/staff buy-in
A neutral party to assess this.
software, buy-in, data integrity
Staff/Provider education, competing responsibilities among staff, staff turnover
TA on development, creation, implementation, and data processes.
How to develop the strategy
Cultural competency