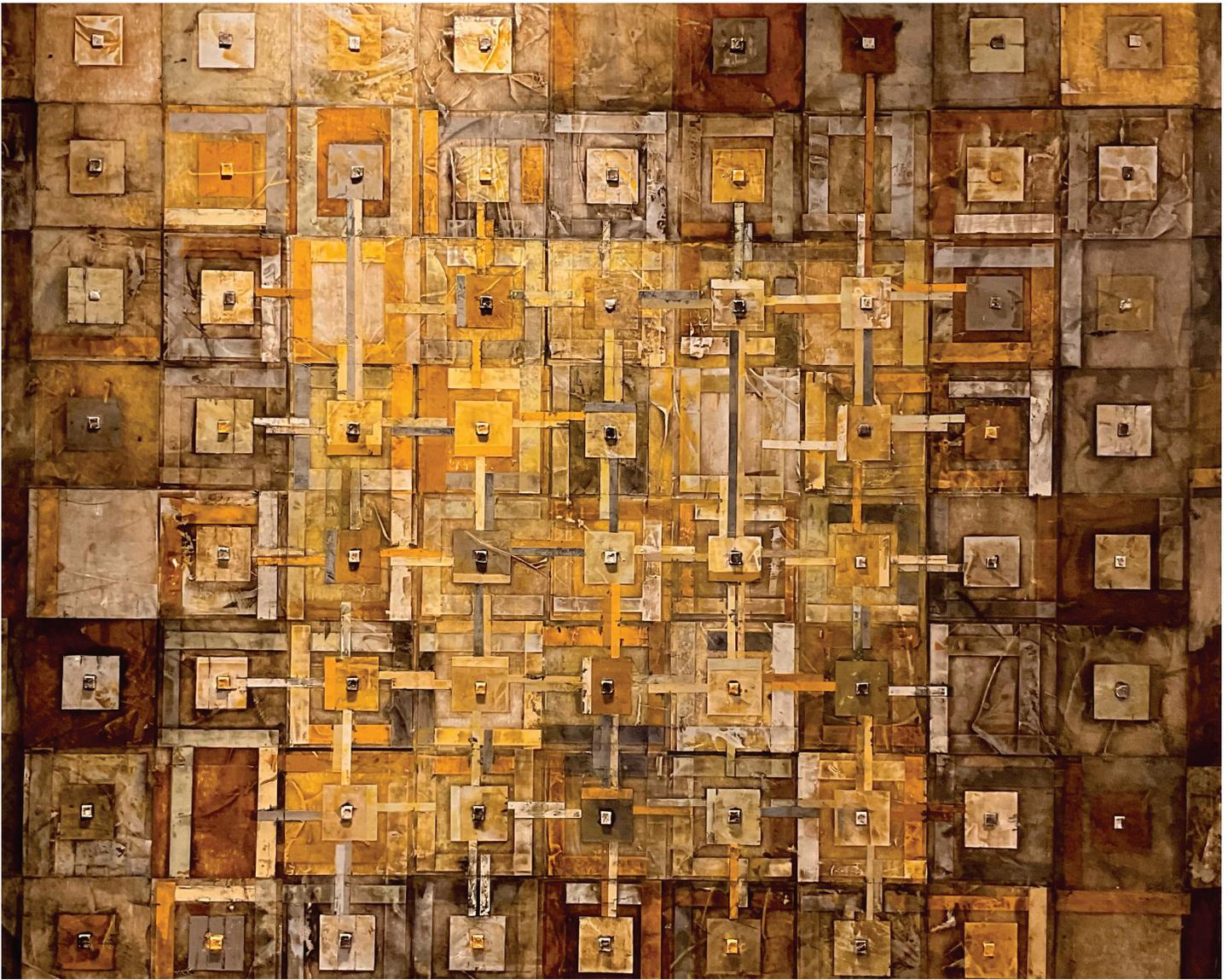


“Nápoles #1” by Fabián H. Ríos Rubino a.k.a. blitiri—HIV-positive artist



A Guide to Patient Involvement in Quality Improvement

Building Meaningful Partnerships to Improve HIV Care

New York Department of Health AIDS Institute

Health Resources and Services Administration HIV/AIDS Bureau



HRSA Ryan White HIV/AIDS Program

**CENTER FOR QUALITY
IMPROVEMENT & INNOVATION**

www.cqii.org

A Guide to Patient Involvement in Quality Improvement

Building Meaningful Partnerships to Improve HIV Care

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

For Health Resources and Services Administration
HIV/AIDS Bureau

January 2024

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$1.5M. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.



Table of Contents

Introduction to Guide

Rationale for the Guide.....	<u>7</u>
Audiences.....	<u>8</u>
Terminology Used.....	<u>8</u>
Existing Training Resources.....	<u>9</u>

SECTION 1. Getting Ready: Why Patient Involvement Matters

Research Supporting Patient Involvement	<u>14</u>
Common Barriers to Patient Involvement	<u>15</u>
Benefits of Patient Involvement in Quality Improvement: Why Patients’ Voices Matter	<u>17</u>

SECTION 2. Patient Involvement Spectrum

Why Patient Involvement Matters and What it Looks Like: Driver Diagram.....	<u>24</u>
Guiding Principles: Patient Involvement	<u>24</u>
Patient Involvement Spectrum	<u>26</u>
Domain: Empathic Listening.....	<u>27</u>
Domain: Gathering Perspectives and Insights.....	<u>32</u>
Domain: Engagement in Quality Improvement Activities	<u>36</u>
Domain: Co-Producing and Leading.....	<u>40</u>

SECTION 3. Key Elements of Effective Patient Involvement

Things to Consider Before You Start.....	<u>48</u>
Integrating Patient Involvement	<u>50</u>

Patient Involvement Implementation Steps	<u>50</u>
Recruiting and Retaining Patients in Quality Improvement and Other Activities.....	<u>50</u>
Recruitment.....	<u>51</u>
Retention.....	<u>51</u>
Setting Boundaries for Patients and Staff	<u>53</u>
Training and Capacity Building.....	<u>55</u>
Support, Incentives, and Other Recognitions	<u>57</u>
Patient Self-Care.....	<u>60</u>
Documenting and Evaluating Patient Involvement	<u>62</u>
Sharing Data/Outcomes with Patients.....	<u>62</u>
Facilitating Effective Patient Involvement Activities....	<u>64</u>
Set Goals for Patient Involvement in Quality Improvement Activities.....	<u>64</u>
Identify Appropriate Activities to Initiate Patient Involvement.....	<u>64</u>
Avoid Tokenism, Ensure Multiple Voices	<u>64</u>
Power Dynamics.....	<u>65</u>
Timely Engagement.....	<u>65</u>
Ensure the Necessary Skills to Partner in Shared Quality Improvement Efforts ...	<u>65</u>

Appendices

Appendix 1: Quality Improvement Terms	<u>67</u>
Appendix 2: Quality Improvement Acronyms and Abbreviations.....	<u>69</u>
Appendix 3: Consumer Involvement Quality Award Winners and Acknowledgements	<u>70</u>



Using the Guide: Where to Find What You Need



SECTION 1. Getting Ready: Why Patient Involvement Matters

1. Working definition of patient involvement (page [13](#))
 - Learn the who, what, why of patient involvement
2. Barriers to effective patient involvement (page [15](#))
 - Challenges that can limit the effectiveness of patient involvement
 - Patients should know these to manage expectations and be better prepared for this work
3. Benefits of patient involvement (page [17](#))
 - How it helps providers
 - How it helps patients
4. Beyond tokenism (page [21](#))
 - Learn about a comprehensive approach by New York State Department of Health AIDS Institute

SECTION 2. What Does Patient Involvement Look Like? The Patient Involvement Spectrum

5. Guiding principles for patient involvement (page [24](#))
 - A reference for what patient involvement should look like
6. Patient involvement spectrum (page [26](#))
 - Organizations can move up and down the spectrum depending on the situation and local challenges
 - The four domains are: empathic listening; gathering perspectives and insights; engaging in quality improvement activities; and co-producing and leading
7. Patient involvement journey: check list (page [44](#))
 - Tools for patients and providers to plan and implement their patient involvement journey

SECTION 3. Key Elements of Effective Patient Involvement

8. Considerations for organizations/agencies (page [48](#))
 - Size of organization
 - Integrating the patient voice
 - Patients as peers (i.e., equal partners)
 - Value differences
 - Acknowledge limitations
 - Manage expectations
 - Quality improvement
 - Evaluation
9. Patient involvement implementation steps (page [50](#))
 - Recruitment and retention
 - Setting boundaries
 - Training
 - Support, Incentives, and Other Recognitions
 - Patient self-care
 - Documentation and evaluation
 - Sharing findings with patients

Introduction to the Guide



The goal of this Guide is to increase the impact of federally funded HIV providers to meaningfully involve people with HIV (i.e., patients) in quality management activities to improve HIV care outcomes, quality of life, and health care experiences. Many of these providers are funded through the Ryan White HIV/AIDS Program (RWHAP), which is administered by the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB).

The Guide is designed to provide a framework for patient involvement in quality improvement across a spectrum of engagement opportunities by:

1. Defining vital domains for patient involvement, the steps providers can take to implement them, and the various roles patients have in addressing each domain;
2. Identifying the skills needed for these roles and how to build the necessary capacities;
3. Strategies for initiating and sustaining patient involvement in quality improvement and other activities; and
4. Sharing best practices and examples to further provide real-world guidance on effective patient participation in quality improvement activities.

The Guide is intended to help staff in organizations providing healthcare to people with HIV as well as people with HIV to meaningfully participate in a person-centered care environment (or move toward a more person-centered care environment)—an environment where everyone's voice is encouraged, valued, and improvement actions are taken in response.

For this Guide we use the term “patient” since we are focusing on the role people with HIV play in quality improvement to improve HIV and other health-related outcomes—that is, they are providing their perspectives as recipients of, or ideally partners in, care.

This Guide was created with direct involvement and guidance of people with HIV in all phases of development—a key aspect of effective quality improvement activities that CQII strives to ensure in all projects.

Rationale for the Guide

Given the activism of people with HIV from the early days of the epidemic, it is only fitting that the statute authorizing the RWHAP mandates that RWHAP-funded HIV providers incorporate the voices of people with HIV into various aspects of their programs, including planning bodies and planning councils.

Opportunities for people with HIV to engage with RWHAP recipients include:

1. Planning bodies/planning councils;
2. Consumer or community advisory boards (CABs);
3. Boards of directors; and
4. Clinical quality management committees and quality improvement project teams.

For example, Part A recipient planning councils/planning bodies set HIV-related service priorities and allocate Part A funds based on the number of people with HIV, their demographics, and their needs. At least 33 percent of members must be unaligned (i.e., not affiliated with a service provider) and persons living with HIV.

Specific to quality management, HRSA HAB [Policy Clarification Notice \(PCN\) #15-02](#) clarifies HAB's expectations for clinical quality management (CQM) programs. A CQM program is the coordination of activities aimed at improving patient care, health outcomes, and patient satisfaction. This PCN specifically includes the involvement of people with HIV as a component of an ideal CQM program's infrastructure. It defines involvement by people with HIV as:

Involvement of people with HIV that reflect the population being served to help ensure that the needs of people with HIV are being addressed by clinical quality management activities.

Additionally, HIV providers may face pressure from other funding requirements, their patient population, or the community. Whether it is in response to a requirement, or the impetus comes from staff, patients, or others, quality improvement-related activities can be enhanced by including people with HIV in the process.

Sometimes, their involvement is an afterthought in quality improvement; in other instances, people with HIV are involved, but not in a meaningful way that uses their input and guidance to have a measurable impact on patient care. The focus of this Guide is to provide:

1. A framework for patient involvement that recognizes the challenges facing busy HIV providers;
2. Practical examples and guidance for successful integration of people with HIV in quality improvement-related and other activities;
3. A road map for people with HIV to be active partners to improve HIV care, health outcomes, quality of life, and health care experiences.

This Guide emphasizes how individuals with lived experiences can be meaningfully involved at multiple levels and was designed so that it is equally valuable to patients and provider staff.

Audiences

This Guide is designed to meet the needs of both staff and patients; those new to quality improvement and those with more experience. Some may read this resource from start to finish while others may focus on specific topics. We encourage both to jointly review the Guide in its entirety so that they can see the many ways in which quality improvement-related activities are strengthened from

patient involvement. We hope that the real-world examples provided throughout the Guide inspire all parties involved to take on active roles in improvement activities.

Providers should take the lead and ensure that this Guide is shared (in an accessible format) with people with HIV wanting to engage in advocacy to improve HIV care. Note that some individuals with lived experiences and staff members may also need additional support in understanding parts of this Guide.

A variety of provider staff are involved in initiating and enhancing patient involvement. Each has a different perspective and a unique set of opportunities to engage people with HIV in the process. This Guide can be used by:

1. Adherence counselors
2. Administrative support staff (e.g., receptionists)
3. Clinical staff (physicians, nurses, nurse practitioners, physician assistants)
4. HIV program administrators
5. Medical directors
6. Outreach workers
7. Patients (and family members, support networks)
8. Peer educators
9. Quality improvement staff
10. Social workers and case managers
11. Treatment educators

Two important tools are included in the appendices, which will help you as you use this Guide.

1. Quality Improvement Terms: Appendix 1
2. Quality Improvement Acronyms and Abbreviations: Appendix 2

Terminology Used

Since the beginning of the HIV epidemic there has been much discussion about the terms used to describe people

with HIV. Commonly used terms include patient, client, and consumer—each term has its supporters. For example, some people may dislike the term “consumers,” feeling that it reflects the passive receipt of services as opposed to an active partnership between the individual and the provider team. HRSA HAB uses the term “client” unless discussing people receiving direct health care services. Then, the term patient is used.

It is important to also acknowledge that people with HIV who engage in quality improvement, clinic-based positions, leadership roles, and HIV prevention activities (e.g., outreach, testing) have a variety of titles. Some of these are listed below:

1. Peer counselor/peer navigator
2. Advocate
3. Patient quality improvement partner
4. Patient experience expert
5. Person with lived experience

Existing Training Resources

People with HIV are the key to patient involvement—their participation can help make healthcare better and improve health care outcomes. However, this Guide focuses on multiple players in the quality improvement process. Know that this Guide does not attempt to be “all things to all people,” which is why we recognize that more tailored approaches are necessary to help people with HIV fully participate in the process.

CQII has multiple resources for people with HIV to help them engage in quality improvement activities. Since its inception in 2004, CQII—formerly known as the National Quality Center—has prioritized increasing the involvement of patients in quality improvement efforts and promoting patient self-care. CQII, with the input of people with HIV as staff, consultants, trainees, and participants in CQII initiatives (i.e., learning collaboratives), has carried out a wide range of activities.

About the Ryan White HIV/AIDS Program (RWHAP) and the Center for Quality Improvement & Innovation (CQII)

RWHAP. For three decades, the RWHAP has provided a comprehensive system of HIV primary medical care, medication, and support services to approximately 50 percent of people with diagnosed HIV in the United States. An indication of the quality of these comprehensive services is that 89.7 percent of RWHAP clients reached HIV viral suppression in 2021.

1. More information on [RWHAP](#).
2. For more information on clients served by RWHAP see the [2021 Ryan White HIV/AIDS Program Annual Client-Level Data Report](#).

CQII. Funded by the HRSA HIV/AIDS Bureau through a cooperative agreement with the New York State Department of Health AIDS Institute, CQII provides technical assistance on quality improvement to RWHAP-funded entities across all Parts. CQII’s aim is to build the necessary capacity among RWHAP recipients and subrecipients to improve the quality of HIV care and services across the United States.

1. More information on [CQII](#).

1. [A Guide to Consumer Involvement: Improving the Quality of Ambulatory HIV Programs](#) (2006)—This guide grew from the work of New York State Department of Health’s Consumer Advisory Committee (CAC). The CAC interviewed and visited clinical sites in New York State that reported having effective patient involvement activities to gain their insight into the factors that contributed to meaningful and effective patient involvement.
2. [Quality Academy Modules](#)—These online training tutorials provide 24/7 access to key quality improvement content areas. They are designed to guide people with HIV as well as HIV care providers through fundamental concepts in quality improvement and to teach skills necessary to create and implement quality improvement projects.

3. **CQII Training for Consumers on Quality Plus (TCQPlus)**—Advanced training to further build the skills of consumers to participate in quality improvement activities. It was developed to meet the demand for local Training of Consumers on Quality (TQC) trainings and the recognition of the need for another level of training to involve individuals more deeply with lived experiences in clinical quality management programs.
4. **CQII Technical Assistance Call Series**—CQII holds routine webinars for people with HIV to build their capacity for quality improvement. Those sessions are recorded and accessible on the CQII website.
5. **Making Sure HIV Patient Self-Management Works: A Training Workshop for HIV Care Providers**—This interactive curriculum with exercises to train HIV providers aims to help support patients as they advocate for their clinical care. This enables them to play a pivotal role in the management of their personal care. This resource includes a facilitator guide, handouts, slides on self-management, and findings from a literature review.
6. **Making Sure Your HIV Care is the Best It Can Be**—This resource outlines the content of a patient quality of care training workshop and contains a facilitator guide in English and Spanish, handouts, a workshop brochure, and findings from a literature review.

Additional RWHAP-Supported Resources on Patient Involvement

ELEVATE, conducted by NMAC, prepares people with HIV to meaningfully engage and take on leadership roles in planning bodies, advocacy actions, and the HIV workforce.

For more information on [ELEVATE](#).

7. **CQII Experience-based Co-Design (EBCD) Quality Improvement Learning Lab**—CQII designed an online training course to build capacity among people with HIV and providers to utilize a co-design methodology to understand and improve the experience of HIV care and services, by both those who provide care and receive care.
8. **Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS)**—Integrating the voices of individuals with lived experiences is a quality improvement cornerstone. It is vital to routinely assess the quality of HIV outcomes and experiences with the healthcare system using the insights of patients served. PROMS and PREMS have value as additional measurement metrics to utilize these findings to continuously improve patients' health outcomes and care/treatment experiences.

SECTION 1. Getting Ready: Why Patient Involvement Matters





In this Section...

- The following definition was adopted from **Carman et al, 2013** to describe patient involvement for the purpose of the Guide.

Patients, families, their representatives, and health professionals are working together in active partnerships at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health care, health outcomes, and care experiences.

- Being aware of key barriers to patient involvement:

Unequal Power	Dual Focus
Limited Menus	Insufficient Representation
Critical Mass	Lacking Necessary Skills
Flat-Footed	Managing Expectations
Closed Doors	

- The benefits of patient involvement in quality improvement activities:

Insight into Patient Experience	Identify Emerging Issues
Support Transparency	Link to Community
Focus Needs Assessments	Demonstrate Commitment to Patient Voices

Check List: Patient Action Steps

- ➔ Ask about patient involvement opportunities in your organization where you receive services; consider inviting a peer for this journey.
- ➔ Advocate for and create new opportunities for patient involvement (learn more about advocacy from CQII resources).
- ➔ Understand your role and expectations; ask for help and assistance to be a more prepared partner to improve HIV care.
- ➔ Learn about patient involvement from CQII resources and **TargetHIV.org**, the technical assistance resources repository for the RWHAP.
- ➔ Regularly update your resume with the skills you have learned and the activities you have participated in.
- ➔ Become a mentor to other patients who want to be involved.

The Girl with HIV, By Melissa Curry

When they see me all they see is the girl with HIV,
 Little do they realize there is so much more to me you see.
 I can calm a storm with the words uttered from my lips,
 When I walk into a room the energy just shifts.
 My mind is a wonder with the thoughts that are consumed,
 My ideas can frustrate scholars with my profoundness I presume.
 My lived experience only adds to the breadth of my skills,
 And my passion for humanity ignites my purpose to fulfill.
 I give birth to new ideas like I'm a mother in labor.
 Pardon the confidence I exude, it was fueled by my anger.
 The anger that developed when they tried to box me in,
 So sorry if my portrait doesn't fit your description.
 I will not fail nor will I falter I declare and I decree
 Because from here on out I refuse to be bound by the terms
 of my disease.
 So when you look at me, don't see me as the girl with HIV

Since the very beginning of the HIV epidemic, people with HIV demanded to be an integral partner in making decisions about their care. This took many forms, from street protesting, to forming buyers' clubs to access medications, or to being experts in their own care and advocating for treatments through organizations such as Project Inform.

In 1983, a small group of activists living with HIV drafted the *Denver Principles*. This document outlines the rights and responsibilities for health care professionals, people with HIV, and others concerned about the epidemic. The AIDS Coalition to Unleash Power (ACT UP) was made up of people with HIV and other activists. Through protests and advocacy, ACT UP pushed policymakers to take action on both medical research and care as well as support services for people with HIV. The work of these activists helped lay the groundwork for the RWHAP legislation and is reflected in many of the provisions.

Patient involvement in healthcare is a commonsense approach that challenges people to ask, “why isn't everyone doing this?” Patients can provide individual experiences about their quality of care and health outcomes—reporting on service delivery at the point of care and providing their own assessment of their health and well-being. They are also in

a unique position to provide valuable feedback to providers from the community perspective about how care is provided.

The move toward increased patient involvement is closely aligned with recognition of the importance of patient-centered healthcare. The World Health Organization (WHO) refers to patient-centered care as “people-centered care” and defines it as,

...an approach to care that consciously adopts individuals,' carers,' families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences.

Key elements of patient-centered care include education, training, and support necessary for patients to make decisions and partner in their own care as well as time and support for providers to engage in these relationships.

Patient-centered care goes well beyond clinical encounters and stresses the importance of including patients, families, and community representatives in development of health policy and the design of health services.¹

Working Definition: Patient Involvement

For the purposes of this Guide, the following working definition of patient involvement was adopted.

Patients, families, their representatives, and health professionals are working together in active partnerships at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health care, health outcomes, and care experiences.^a

^a Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health affairs (Project Hope)*, 32(2), 223–231. <https://doi.org/10.1377/hlthaff.2012.1133>

¹ World Health Organization. Framework on integrated, people-centred health services. Geneva: WHO; 2016 Apr (Report No.: A69/39). Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1

WHO's *Framework on Integrated People-Centered Health Services* identifies five pillars of health care improvement including, “empowering and engaging people” as partners in their own care, in their daily lives, and in improving the quality of the care provided.

While WHO's framework is persuasive in articulating the importance of patient involvement and presents concrete strategies for achieving patient-centered care, health care providers, and policymakers often struggle to achieve meaningful involvement of people with HIV in the design and provision of healthcare. Both research and anecdotal accounts indicate that there remains much work to be done to meaningfully and systematically integrate the patient voice into the way we deliver healthcare. A study of over 100 patient-centered medical homes in the U.S. found that less than one-third had formal, ongoing engagement of patients in quality improvement.²

There is minimal research about how to effectively involve patients in quality-related activities and the effectiveness of these activities has not been well documented.³ For the best intentioned, this can make their efforts very challenging. It can be difficult to get buy-in from others in the organization in order to incorporate patient involvement at various levels. For those who have not yet bought into the

For Quality Improvement Partners: Qualities for Success

1. Trust
2. Commitment
3. Cultural competence
4. Recognition of differences
5. Appreciation of lived experience
6. Acknowledgement of effort
7. Understanding of limitation

² Han E, Scholle SH, Morton S, Bechtel C, Kessler R. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. *Health Aff*; 2013 Feb;32(2):368–75. <https://pubmed.ncbi.nlm.nih.gov/23381530/>

³ Concannon TW, Friedberg MW, Hwang A, Wiitala K. Engaging Consumers in the Quality Measurement Enterprise. RAND Corporation. 2017. Available from: https://www.rand.org/pubs/research_reports/RR1760.html

Patient Involvement: The Body of Research

Search PubMed using the terms “patient involvement” or “patient engagement” and you will find a wide range of studies outlining how patients are involved in care. These include how researchers, in the design of clinical trials, shared decision making, safety, and other important areas of clinical care. Many of these studies found that involving patients supports engagement, increases satisfaction, and in some cases improves outcomes.

concept, the skeptics, the lack of clear guidance can serve as a reason to take a “wait and see” approach. Others may take one or two small steps but resist substantive changes to increase patient involvement.

However, for those who make the commitment to patient involvement, the rewards can be significant.

Research Supporting Patient Involvement

The body of research on patient involvement goes back more than a decade. While small, it is growing and documents multiple models.

In 2006, Paul Bates and Glenn Roberts published their article, “Experience-Based Design: From Redesigning the System Around the Patient to Co-Designing Services with the Patient.” They explored how experienced-based design of services views users (i.e., patients) as “...integral to the improvement and innovation process.” Their continuum of patient influence includes five domains:

1. Complaining
2. Giving information
3. Listening and responding
4. Consulting and advising
5. Experienced-based co-design

Bates and Roberts go on to suggest five possible impacts on healthcare as a result of patient involvement and using experienced-based co-design.

1. Patients provide input, suggest changes, and work with health care professionals/planners throughout the change process.
2. Patient involvement can put the focus on the patient experience—not just that the services were delivered, but how the patient perceived them in terms of where they met the patient’s needs and whether it was a good experience.
3. Focusing on patient experience, not the process or system, incorporates the subjective (i.e., what individuals perceive). This prioritizes the service touch points, what the patient experiences throughout the interaction, as opposed to what designers intended (e.g., workflows).
4. Collecting and analyzing patient experiences should be a formal process—analytical frameworks are necessary (e.g., as with focus groups, analysis of participants’ feedback is necessary). Once patient experiences have been collected and analyzed, these data can be used in the subsequent change process.
5. A focus on function will ensure that services are both user friendly (i.e., the patient had a good experience) but also the design of services reflect safety and functionality.

Another important article is, “[Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies](#).”⁴ The framework presented in the article is often used in patient involvement activities. It breaks down patient involvement in three categories: consultation; involvement; and partnership. It explores how these three domains can impact direct care, organizational design/governance, and policy making.

The article identifies factors that influence the process at various levels.

⁴ Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health affairs (Project Hope)*, 32(2), 223–231. <https://doi.org/10.1377/hlthaff.2012.1133>

For patients, motivation, willingness, and ability to engage are key considerations. These considerations may present greater challenges for marginalized populations who have rarely been invited to participate and/or are intimidated by the process.

For organizations, there should be policies and practices that encourage patient involvement and are responsive to and facilitate this input. They should make it easy for patients to participate in these activities and importantly, be transparent in terms of what patients can expect from their participation in these activities. At the systems level, making patient voices heard may be challenging—they may feel they are not heard at all. However, at this level their input may be most essential as this is where important decisions are made about access, what services are provided, and how services are provided. Providers and other advocacy organizations can help patients make their voice heard.

Common Barriers to Patient Involvement

The approaches discussed in this Guide were developed, in part, in response to many of the issues identified in the article “[Barriers to Elevating the Consumer Voice in Quality Improvement: Findings](#)” from the Rand Corporation Report *Engaging Consumers in the Quality Measurement Enterprise*.⁵ Based on conversations with people with HIV and advocates about their experience with quality-related activities, the authors identified barriers for patient involvement. The publication also discussed possible solutions, which are included in the article.

This table is adapted by Concannon et al and includes additional barriers based on the experience of CQII and its advisory committee members.

⁵ Concannon, Thomas W., Mark W. Friedberg, Ann Hwang, and Kris Wiitala, *Engaging Consumers in the Quality Measurement Enterprise*. Santa Monica, CA: RAND Corporation, 2017. https://www.rand.org/pubs/research_reports/RR1760.html.

SECTION 1. Getting Ready: Why Patient Involvement Matters

Barrier	How it Plays Out
<i>“Unequal Power”</i>	<ol style="list-style-type: none"> 1. Unequal time and resources (i.e., patients do not have the time or the resources to participate in quality activities due to other commitments and needs) 2. Power dynamics (i.e., patient input is minimized or ignored as providers are the dominant voices in decision making) 3. Not an equal partner (i.e., patients are included in the process, but their experience and opinions do not carry the same weight as other stakeholders)
<i>“Limited Menus”</i>	<ol style="list-style-type: none"> 1. Opportunities for input are limited since most decisions have been made (i.e., invitations are made after key decisions are made, or when only a limited input can be provided) 2. Measures do not address patient priorities (i.e., nothing in the quality improvement activities address what is important to patients) 3. Involvement after the fact (i.e., patients are asked for feedback—that is “react”—after all decisions are made)
<i>“Critical Mass”</i>	<ol style="list-style-type: none"> 1. No seat at the table (i.e., patients are not invited since patients are not believed to be interested in being at the table for conversations about quality measurement) 2. Lone voice (i.e., a single or a handful of patient advocates are expected to represent the diverse perspectives of all patients)
<i>“Flat-Footed”</i>	<ol style="list-style-type: none"> 1. No clear role (i.e., patients are invited to participate but not given a clearly defined role—they are not told what is expected of them) 2. Highly technical request for input (i.e., patients are asked to provide input on highly technical topics with which they are not entirely familiar or lack the technical expertise to respond quickly to requests) 3. Inadequate training, preparation, and time to respond (i.e., limited or no training opportunities are provided to patients, and they are expected to hold their own with seasoned professionals)
<i>“Closed Doors”</i>	<ol style="list-style-type: none"> 1. Shut out of planning-related exchanges (i.e., negotiations may be taking place behind closed doors, including informal channels, across colleagues, between partners) 2. Not included in the launch of new services (i.e., surprised with new services that may or may not meet their needs)
<i>“Dual Focus”</i>	<ol style="list-style-type: none"> 1. Balancing big system perspective with individual patient experiences (i.e., patients asked to comment on system wide issues where they lack content expertise [although their care experience could inform these discussions]) 2. Problems stemming from implementation issues (i.e., patients come to the table with strong ideas about what is needed just to realize that the implementation fell short)
<i>“Insufficient Representation”</i>	<ol style="list-style-type: none"> 1. Few people with HIV are involved in quality improvement process and are expected to be the voice of all communities with HIV 2. Relying on a small group of patients not only limits the breadth and quality of input but also increases the likelihood of burnout
<i>“Lacking Necessary Skills”</i>	<ol style="list-style-type: none"> 1. Patients may lack the expertise in public health and data analysis to fully engage in improvement activities 2. The necessary training or background materials are not offered in advance to prepare patients in their role
<i>“Managing Expectations”</i>	<ol style="list-style-type: none"> 1. The process of decision making is not transparent, and the mode of decision making is unclear to patients 2. Patients are not clear about their roles to make decision

The following table breaks downs barriers to patient involvement that occur at various levels in the health care system and was developed by CQII’s advisory committee that is comprised of patients, provider representatives, and content experts.

Level	Barrier
<p>System Level (Macro) (e.g., patients have a voice in policy making)</p>	<ol style="list-style-type: none"> 1. Minimal body of evidence that patient involvement improves health outcomes 2. Inadequate representation of the patient population (i.e., tokenism) 3. Process is not transparent, leading to distrust and misunderstanding 4. Needs/changes identified by patients cannot be addressed through policy changes/at system level 5. Changes are not communicated to the patient community and beyond, making patient involvement appear ineffective
<p>Organizational Level (Meso) (e.g., ensuring multiple patient voices are heard and acted upon)</p>	<ol style="list-style-type: none"> 1. No process/system for collecting input 2. Reluctance to modify workflows to allow clinicians time to engage with patients around quality 3. Inadequate training infrastructure (i.e., no process to build staff/patient quality improvement skills) 4. Lack of resources to support patient involvement (e.g., stipends, support for transportation) 5. No buy in from leadership (which can impact staff/patient buy in)
<p>Patient Level (Micro) (e.g., patient/clinician interaction during appointments, effective communication for partnering in care)</p>	<ol style="list-style-type: none"> 1. Lack of time during patient encounter 2. Clinician reluctance (reluctant to recognize patient as partner, bias stigma) 3. Patient distrust of medical system/providers 4. Lack of communications skills (both patient and clinician)

Benefits of Patient Involvement in Quality Improvement: Why Patient Voices Matter?

Patients have a role in many aspects of service delivery, including quality improvement. Their insights and involvement can support their fellow peers but also help to improve many programmatic aspects, such as service enhancements, outreach, evaluation activities, cultural responsiveness, and stigma reduction. This expertise can be invaluable to providers and should be recognized and incorporated.

Insight into Patient Experience. Information on the patient experience—how welcome they feel, whether they feel valued as partners in care, experiences with stigma and discrimination (both within the organization and in their lives), and how easy it is to access and navigate services—can be invaluable to a service provider in terms of improving services and improving health outcomes and other quality metrics. This insight has value across service planning, delivery, and evaluation.

Support Transparency. People with HIV help to ensure that the purpose and outcomes of quality improvement

activities are clearly communicated to patients and the broader community. They can help to identify how best to inform the patient population and others about quality improvement activities, such as why specific service delivery issues are focused, how patients were involved in the planning process, how patients were involved in identifying solutions, and what changes were made in response to their feedback.

Focus Needs Assessments. Involving people with HIV in all aspects of the needs assessment process (i.e., design, data collection, analysis) can help to ensure the process addresses the needs and concerns of the patient populations and can incorporate a broad range of patient perspectives (e.g., reflecting geographic considerations, needs of different subpopulations). Patients can also provide insights into barriers to accessing services, retention in care, and adherence to treatment.

Identify Emerging Issues. Patients can help providers to identify both internal and external emerging issues that can impact access to and engagement in services. For example, providers may not fully understand the access issues related to external support services, which in turn, can optimize treatment outcomes in the community. Or they may not be aware of changes outside their organization, such as cutbacks in federal benefits.

Link to Community. Patients, their families, and their social networks are part of the broader community and serve as an ongoing link to the community and its various subpopulations (e.g., race, gender, age, sexual orientation). While it is not realistic to expect a few people with HIV to be the “voice of their community,” they can provide anecdotal information based on interactions with those in their network and other patients. Patients can also serve as a link to others, such as:

1. Engaging members of their social network in care
2. Providing information to the community
3. Engaging other patients in quality improvement activities such as surveys, focus groups
4. Asking others about the barriers to accessing and staying in care

Demonstrate Commitment to Patient Voices. Actions speak louder than words. Involving people with HIV in quality improvement and other aspects of planning, service delivery, and evaluation speaks to the value an organization puts on patient experience, lived expertise, and the contributions they can make as partners in the patient/provider relationship. It conveys to patients and the broader community that there is a commitment to patient-centered care and to acting on the input of patients to improve services and health outcomes.

Before We Begin: A Word About Support, Incentives, and Other Recognitions

As CQII developed this Guide, with help from our patient advisors, the message was loud and clear: patients should be incentivized and supported for their input and expertise in quality improvement efforts. As one advisor said recently, “My meaningful involvement is not a gift card.” Another advisor stated, “If I am doing the same work as everyone else on the quality committee and bringing my expertise as a person with lived experience, then pay me just like everyone else on the committee.”

HRSA HAB’s PCN 16-02, *Ryan White HIV/AIDS Program Services: Eligible Individuals & Allowable Uses of Funds*, provides guidance about allowable costs related to patient involvement. It is important for recipients to review this document to ensure that they are in compliance in terms of their expenditures related to patient involvement. In February 2023, HRSA HAB released additional guidance on community engagement in a program letter outlining ways the RWHAP can support community engagement efforts.

While there is direct guidance on the use of RWHAP funds related to patient involvement, patient advisors have emphasized that this should not be a deterrent for engaging patients. Other non-RWHAP funding sources can potentially be used, such as to buy pizza for a focus group, to cover costs not allowable by RWHAP.

Hiring people with HIV as staff or contracting them as content expert consultants is a viable option for organizations receiving RWHAP funds, certainly with the proper safeguards in place. In some organizations, bureaucracy can be a challenge, such as requiring that all positions are posted or multiple levels of review. In such cases, using stipends or honoraria may streamline the process.

Despite the challenges, RWHAP recipients should explore ways to incentivize, support, and recognize patients in alignment with RWHAP requirements. Their voices are essential to the quality improvement process and financial support should be provided to demonstrate that their expertise and efforts are valued.

Patient Involvement in Practice: A Comprehensive Approach

The New York State Department of Health (NYSDOH) has worked for many years to meaningfully engage patients in multiple aspects of quality management through various initiatives. Using a multidimensional framework for patient involvement, NYSDOH’s efforts engaged people with HIV at three levels:

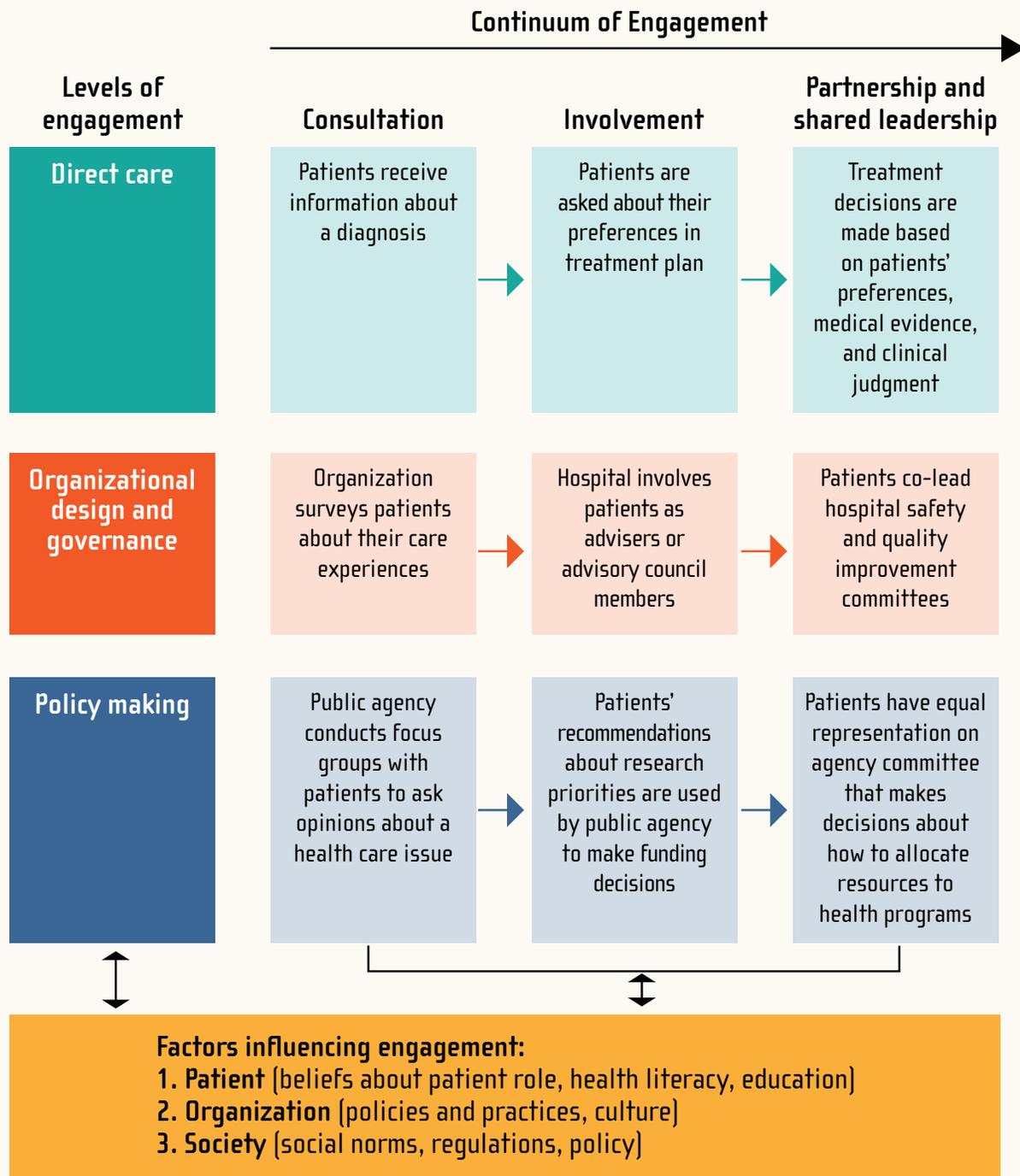
1. As partners in their direct care (individual level);
2. Shaping and improving care delivery (organizational level); and
3. Policy decisions that impact health and wellbeing (system level).

Below are examples of activities and their benefits.

Activity	Elements	Examples of Benefits
Statewide Consumer Advisory Committee (CAC)	<ol style="list-style-type: none"> 1. Members are people with HIV, recruited to ensure representation from key subpopulations (e.g., race/ethnicity, age, risk, sexual orientation, various geographic regions, rural areas) 2. CAC meets quarterly 3. Members also participate in NYSDOH guidelines and policy committees 4. CAC works closely with HIV Quality of Care Clinical Advisory Committee 	<ol style="list-style-type: none"> 1. CAC has prioritized mental health and wellbeing over other clinical indicators (e.g., viral suppression) 2. CAC has emphasized the importance of patient-provider communication in supporting engagement 3. Person-centered language has been identified as a way to reduce stigma and labeling
Patient Education	<ol style="list-style-type: none"> 1. <i>A Consumer’s Guide to Quality of HIV Care in New York State</i>, available in English and Spanish, was produced with input from patients 	<ol style="list-style-type: none"> 1. Promotes greater health literacy and understanding of numeracy 2. Describes performance data in patient-friendly language
Assessing Patient Involvement in Quality Activities	<ol style="list-style-type: none"> 1. <u>Organizational Performance Assessment of Patient Involvement</u> (externally validated) 	<ol style="list-style-type: none"> 1. Technical assistance is available from NYSDOH. Quality coaches work with sites to better address the domains on the assessment where they had low performance. Coaches also conduct organizational assessments with sites to ensure there is routine assessment of patient experience and patient advisory bodies are in place
Healthcare Stories Project (HCSP)	<ol style="list-style-type: none"> 1. It is rooted in experienced based co-design and co-production; patients share their health care experiences. The stories are portrayed visually (e.g., maps of patients’ care journeys) within clinics. [More on HCSP is provided in Section 2] 	<ol style="list-style-type: none"> 1. HCSP allows patients to tell their stories and visualize the results 2. Assistance was available to sites to jointly develop the healthcare stories
Living Cascade	<ol style="list-style-type: none"> 1. It captures patients’ narrative descriptions of their care across the HIV care continuum 	<ol style="list-style-type: none"> 1. These stories complement the clinic’s quantitative HIV continuum data and provide qualitative data that can be used in quality improvement activities



A more detailed description of these activities is provided in the article, “[Beyond Tokenism in Quality Management Policy and Programming: Moving from Participation to Meaningful Involvement of People with HIV in New York State](#),” which was published in the *International Journal for Quality in Health Care* (February 2021).⁶



⁶Coren F, Brown MK, Ikeda DJ, Tietz D, Steinbock C, Baim-Lance A, Agins BD. Beyond tokenism in quality management policy and programming: moving from participation to meaningful involvement of people with HIV in New York State. *Int J Qual Health Care*. 2021 Feb 20;33(1):mzab004. doi: 10.1093/intqhc/mzab004. PMID: 33415331.

SECTION 2.

Patient Involvement Spectrum: What Does Patient Involvement Look Like?





In this Section...

1. The following guiding principles can serve as a reference for what patient involvement should look like:
 - Make patients equal partners on quality improvement teams
 - Involve multiple patient voices to have broader representation
 - Include patients from the very beginning and not after critical decisions
 - Look for pro-active and innovative ways to gain input
 - Involve patients in providing feedback on specific patient populations
 - Provide training so that patients can participate fully in quality improvement activities
 - Provide patients with incentives to participate in quality improvement activities such as focus groups or to complete a survey (e.g., gift cards vouchers, coupons) as allowable per PCN 16-02⁷
2. Encourage patients to add their quality improvement experiences to their resumes so that they can pursue employment opportunities within the organization (e.g., as peers) or in other organizations
3. Hire or contract with patients as consultants who are bringing their expertise and devoting a considerable amount of time to quality improvement activities
 - Recognize that there are various levels of involvement
4. The domains of the patient involvement spectrum outline different approaches to improve care and experiences
 - **Emphatic Listening:** Cultivating empathy among staff members and creating ways to collect and listen to patient experiences and stories help to integrate these qualities into the organizational culture.
 - **Gathering Perspectives and Insights:** Actively soliciting information from patients about their current lives, individual needs, expectations, aspirations, and experiences receiving care with the goal to improve their lives, health outcomes, and health care experiences.
 - **Engaging in Quality Improvement Activities:** Patients participate as equal members in quality improvement activities, including local quality improvement teams and clinical quality management committees.
 - **Co-Producing and Leading:** Patients are involved in decision making in the organization as equal partners in design and implementation, including the development of policies/programs and the decisions of the organization

Check List: Patient Action Steps

- ➔ Learn about the domains to involve patients in quality improvement activities.
- ➔ Understand the level of commitment and skills required for each activity.
- ➔ Work with providers to see what the most effective way is to get engaged.
- ➔ Know that as you engage in activities and build your skills you can move along the professional spectrum. Some patients get paid for their time as consultants or employees within the organization.

⁷HRSAs HAB Policy Clarification Notice 16-02 Ryan White HIV/AIDS Program Services: Eligible Individuals & Allowable Uses of Funds <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/service-category-pcn-16-02-final.pdf>.

Patient involvement in quality improvement activities will look different in every organization depending on the characteristics of the agency and the type of quality activities it is engaged in.

Why Patient Involvement Matters and What it Looks Like: Driver Diagram

Driver diagrams present a graphic framework of the drivers (factors) that have major impacts on achieving the preferred outcome of a specific activity—in this case, patient involvement. These outcomes are reflected in the “Aim” statement. The drivers focus on the issues and steps that can be taken to facilitate achievement of the

aim. Primary drivers are the major factors driving the outcome—they are the “how to” steps at a higher level. The secondary drivers are the detailed activities and structures that make up the primary drivers.

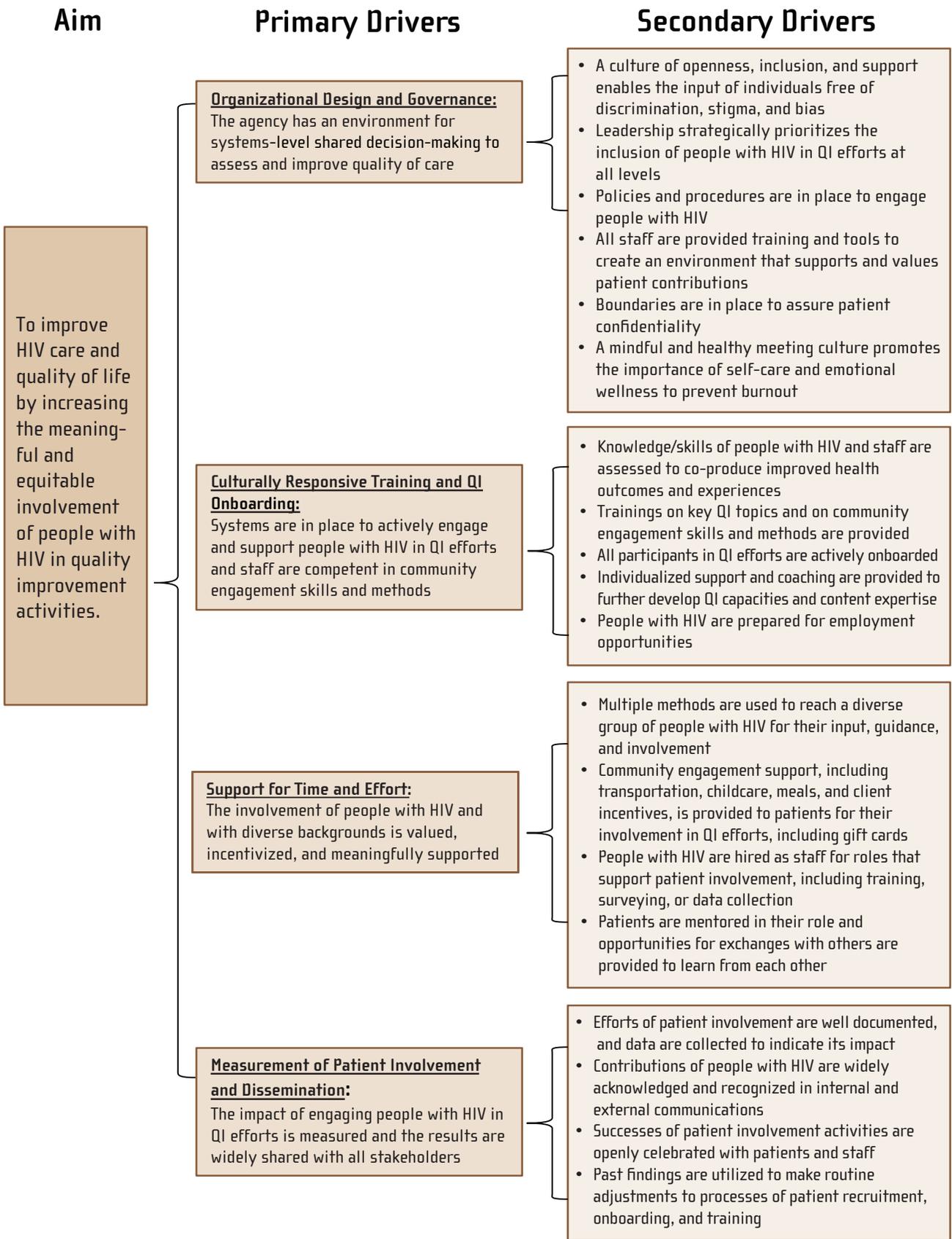
To facilitate the involvement of patients in quality improvement activities among HIV providers, the following driver diagram has been developed by CQII’s content experts with lived experiences. It helps to conceptualize change ideas that allow patients and providers to work in unison to improve HIV care and health care experiences. It also reflects the steps presented in this Guide.

Guiding Principles: Patient Involvement

Based on quality improvement work and with the input of patient experts, the following guiding principles for patient involvement provide some underlying reference points for planning and implementing efforts to engage patients as equal partners in quality improvement efforts.

1. Patients are equal partners on quality improvement teams—their insights and opinions are valued and considered in the same way as those of any other member of the team.
2. Involve multiple patient voices to have broader representation. One patient cannot speak for all communities.
3. Include patients from the very beginning (formative input) and not after critical decisions have been made; patients do not want to provide “feedback” on decisions that are already made.
4. Look for pro-active and innovative ways to gain patient input (e.g., informant interviews by peers, focus groups, online surveys, and other methods).
5. Involve patients in providing feedback on projects to patient population (e.g., crafting messages, materials, recruit other patients).
6. Provide training (basic public health concepts, social determinants of health, quality improvement basics, data basics, program planning/strategic planning, as appropriate) so that patients can participate fully in quality-related activities.
7. Facilitate and support involvement (e.g., travel support, meetings held at convenient times, childcare/support is provided).
8. Provide patient incentives (e.g., gift cards) as allowable per PCN 16-02.⁸ Additional guidance is provided in HRSA HAB’s program letter on community engagement.
9. If patients are getting paid for their time by the organization, they need to have a formal agreement with the organization as a consultant or as an employee.
10. Acknowledge that patients are building professional skills and encourage them to build their resumes and seek out employment opportunities in your organization or others in the community.
11. Recognize that there are various levels of involvement. Utilize and value them.

⁸ <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/grants/service-category-pcn-16-02-final.pdf>.



Patient Involvement Spectrum

The underlying framework for this Guide is a spectrum of patient involvement activities that organizations can use to navigate their engagement. The four domains (Empathic Listening; Gathering Perspectives and Insights; Engaging in Quality Improvement Activities; and Co-Producing and Leading) represent increasing levels of patient involvement along the agency’s quality improvement activities. Each patient involvement domain is equally important, and organizations will move up and down this spectrum based on their needs.

More information on each domain and steps to implement them is provided in the following section.

The Importance of Cultural Competence

Given the critical involvement of patients, it is important for all involved to have an awareness of and practice cultural competence. This means that the organization (and its members) value diversity; can assess their attitudes toward others; can interact effectively and with empathy with others from different cultures; and adapt to the cultural contexts of the people they serve. For more information on [cultural competency](#).



Empathic Listening	Gathering Perspectives and Insights	Engaging in Quality Improvement Activities	Co-Producing and Leading
<p>Cultivating empathy among staff members and creating ways to collect and listen to patient experiences and stories helps to weave these qualities into the organizational culture, resulting in a more welcoming environment where patient experience is heard and valued.</p>	<p>Actively soliciting information from patients about their current lives, individual needs, expectations, aspirations, and experiences receiving care with the goal to improve their lives, health outcomes, and health care experiences. Depending on the circumstances, anonymity may be required.</p>	<p>Patients participate as equal members in quality-related activities, including local quality improvement teams and clinical quality management committees. Patients are active participants in planning improvement activities, collecting data, and developing solutions to improve patient care processes and experiences.</p>	<p>Patients are involved in decision making in the organization as equal partners in design and implementation, including the development of policies/programs and the decisions of the organization.</p>

For each domain, specific tasks and activities should be selected based on the optimal and appropriate level and extent of patient involvement dependent on the organizational priorities and patient interests. The following table provides an overview of activities for each patient involvement domain, which are explained in the subsequent sections. Note that the qualities/capacities and building skills/training pertain to whoever is participating in the activities, including staff or patients.

Domain	Examples of Actions/Activities
Empathic Listening	<ol style="list-style-type: none"> 1. Understanding individual biases 2. Empathy mapping (patients “map” their experience with care so providers can learn more about patients’ actual experience) 3. Collecting and sharing patients’ stories
Gathering Perspectives and Insights	<ol style="list-style-type: none"> 1. Surveys (needs assessments, satisfaction) 2. Focus groups 3. Qualitative interviews or informant interviews
Engaging in Quality Improvement Activities	<ol style="list-style-type: none"> 1. Member of quality improvement project team (as employee, consultant, volunteer) 2. CQM committee member (as employee or consultant)
Co-Design and Leadership	<ol style="list-style-type: none"> 1. Patient (consumer) advisory committee member 2. Board of Directors 3. Experienced-based co-design of activities, services, programs, systems

Domain: Empathic Listening

This patient involvement domain helps to ensure that there is a welcoming and accepting environment for all patients by actively paying attention to gain patient perspectives, insights, and information on their lived experience, including their experiences in healthcare. These activities help to cultivate empathy among staff members, create ways to collect and listen to patient experiences and stories, and to weave these qualities into the organizational culture. Staff and patients work together to collect information, package it, and disseminate it in a way that is accessible to staff, patients, and possibly the broader community. Many of these activities can be carried out by people with HIV since other people with HIV may feel more comfortable sharing with a peer. Peer volunteers may be appropriate for some of these activities. If this work is conducted on an ongoing basis, hiring a person with HIV, as staff or a consultant with a formal agreement, may be the best approach. This ensures that the work is consistently done and that the person doing the work is compensated for their expertise and time.

Qualities/Capacities	Building Skills/Training
<ol style="list-style-type: none"> 1. Active listening skills 2. Interviewing skills 3. Ability to develop rapport with patients 4. Respect of boundaries 5. Ability to capture patients’ stories 	<ol style="list-style-type: none"> 1. Training to address personal attitudes and beliefs (which may already be part of organization’s training program) 2. Possible training topics include stigma and bias, social determinants of health, intersectionality 3. Training to ensure compliance with privacy/confidentiality requirements (e.g., HIPAA) 4. Skills training (dependent on activity). Examples of possible training include effective interviewing, how to capture patient stories via short videos, gaining permissions (e.g., waivers), etc. 5. Quality improvement patient-oriented guides (e.g., self-care) for staff and patients to become familiar with this concept and self-care strategies

SECTION 2. Patient Involvement Spectrum: What Does Patient Involvement Look Like?

Activity	Level of Commitment/Deliverables	Resources Required
<p>Empathy Mapping <i>Collaborative tool to help staff gain a deeper insight into their patients. Mapping usually involves developing a persona (i.e., a fictional patient) and then considering various domains (e.g., what they think, what they feel, what they need). This process could include staff only or both staff and patients. Learn more about empathy mapping.</i></p>	<ol style="list-style-type: none"> 1. Dependent on number of personas/ maps to be developed 2. Lead staff develop personas and facilitate meeting 3. Staff participation in meetings 4. Patient participation in the meetings 5. Review and comment on empathy maps by staff and patients 	<ol style="list-style-type: none"> 1. Staff time 2. Community engagement support for patients (e.g., transportation, childcare, patient incentives) 3. Meeting expenses
<p>Patient Stories <i>Collecting and sharing patient stories to staff and other patients via multiple media. The article Health Care User Perspectives on Constructing, Contextualizing, and Co-Producing “Quality of Care” provides more information on this activity.</i></p>	<ol style="list-style-type: none"> 1. Training for staff, peers, or volunteers on how to collect and present patient stories 2. Identification and recruitment of patients for stories 3. Development of stories by staff and patients 4. Packaging of stories (videos, story boards, posters, newsletter articles, etc.) 	<ol style="list-style-type: none"> 1. Development of interview protocol for stories 2. Training for staff on how to conduct interviews and compile stories 3. Time to compile/package stories 4. Promotion of stories
<p>Language of Caring <i>This intervention focuses on elevating compassion, collaboration, and effectiveness with patients and coworkers; and creating and sustaining a distinctive culture of caring in an organization.</i></p>	<ol style="list-style-type: none"> 1. Engagement with Language of Caring for training 2. Training for staff (all staff or specific team members) 	<ol style="list-style-type: none"> 1. Partnering with Language of Caring 2. Staff time



Patient Involvement in Practice: Healthcare Stories Project

The Healthcare Stories Project (HCSP) is an initiative of the NYSDOH AIDS Institute. HCSP was developed in consultation with Dr. Baim-Lance based on findings from her *Consumer Lens Study*.⁹ The intervention is designed to provide concrete tools for health care organizations to include patients as meaningful, integral participants in the delivery of quality HIV care and its improvement. The HCSP consists of three interactive activities designed to learn from patients about their health care experiences. The first two activities focus on gaining information from patients. The final activity includes both patients and staff, with the goal of co-designing responses to improve the quality of care and the patient experience.

Evergreen Health, a federally qualified health center (FQHC), serves the communities of Buffalo and Jamestown, New York. Formerly AIDS Community Services, which was founded in 1983 by volunteers, Evergreen now provides comprehensive health care services across multiple sites. Several years ago, Evergreen participated in HCSP. A key part of the process of soliciting patient feedback on their health care experience was Dawn Trotter, who at the time was a peer navigator, but has since become a patient care specialist, focusing on engagement in care and adherence. Dawn has also served on the New York State consumer advisory board and as a consultant for quality improvement. She is a committed advocate of elevating the patient voice to improve care.

Patients were given survey cards where they could document their experience from the minute they entered the clinic—their interaction with the receptionist and every other staff person. Three days a week, for one month, Dawn was in the waiting room to tell patients about the process and distribute the survey cards. Since the goal of the process was to improve the patient experience in general, cards were offered to all patients, regardless of their HIV status. However, as a peer navigator, Dawn knew most of the patients with HIV and could reach out specifically to them. Patients could write comments about the experience at each stage or the encounter, or they could simply enter a smiley face or a frown.

To share back with patients, Evergreen created a poster with the findings from the survey featuring an evergreen tree. The framed poster is still in the waiting room for patients to see, along with cards patients can fill out to provide ongoing input on their experience and suggestions for changes.

⁹Baim-Lance, A., Tietz, D., Schlefer, M., & Agins, B. (2016). Health Care User Perspectives on Constructing, Contextualizing, and Co-Producing “Quality of Care.” *Qualitative health research*, 26(2), 252–263. <https://doi.org/10.1177/1049732315569736>



What was learned from the initial survey? Patients provided feedback about how to make their time in the clinic better—they didn't like that Jerry Springer was always on the TV in the waiting room. They also provided more important feedback about significant issues that could result in negative experiences that might make a patient not want to come back. Patients shared that the windows in the reception area were too close together so that there was no privacy during the check in process. The patient at the next window could hear the entire conversation.

When Evergreen built new facilities, privacy was a consideration in designing the check in area.

Dawn felt that as a peer, she had the trust of the patients, and this helped her to encourage their participation. If peer involvement is not an option, she recommends educating all staff about the process so that they can answer questions from patients about the survey and encourage their participation.



Patient Satisfaction in Practice: Language of Caring

Sun River Health is a federally qualified health center (FQHC) with over 40 locations, serving more than 245,000 patients throughout the Hudson Valley, New York City, and Long Island. Sixteen sites offer integrated HIV/HCV care. Sun River has a long-time focus on patient-centered care and is the only FQHC that is Planetree certified.

Sun River selected Language of Caring after seeing data from other community health centers that the intervention had improved patient satisfaction and was positively received by staff, with reports that it improved communication across providers and teamwork. An important aspect was the emphasis on empathy and the promotion of caring vs. just communicating. The decision to select the intervention also included patients.

Over the course of two years, Sun River provided training to staff, with patients sometimes serving as facilitators. There is an initial, one-hour foundational training followed by six, 45-minute modules selected by clinicians. All other staff participated in seven other Language of Caring modules, based on the same themes but targeting all non-provider staff. Habit builders, short reminders built into gatherings such as staff meetings, are provided between modules. New employees will view recordings of the original trainings. Sun River plans to evaluate the intervention by using a survey specific to Language of Caring with staff and through quarterly patient satisfaction surveys.

The initial plan was to conduct in-person training, but due to COVID-19, the trainings were virtual. This had some advantages, such as allowing staff to come together across sites and share best practices that could be useful at other sites.

“In community health centers, communication between staff and with patients can be an issue, especially as organizations grow,” states Katherine Brieger, Executive Director of Planetree at Sun River. “We’ve seen staff communicate more effectively and work better as a team, which in turn impacts the care patients receive.”

Domain: Gathering Perspectives and Insights

This domain focuses on actively soliciting information from patients about their current lives, individual needs, expectations, aspirations, and experiences receiving care with the goal to improve their lives, health outcomes, and health care experiences. Depending on the circumstances, anonymity may be required. While staff, including peers, can carry out many of these activities, it is also an area where patients can be recruited, as volunteers, or hired as employees or consultants to collect this information from other patients. For some of these activities, such as the data analysis and writing of reports, hiring people with additional expertise in these areas may be the best option.

Qualities/ Capacities	Building Skills/Training
<ol style="list-style-type: none"> 1. Listening skills 2. Interviewing skills 3. Ability to develop rapport with patients 4. Respect of boundaries 5. Ability to capture patients' stories 6. Development of survey questions and tools 7. Adherence to survey protocols 8. Focus group facilitation 9. Analyzing/coding findings 10. Report writing 11. Presenting data effectively to staff and patients 12. Effective presentation of stories, including visuals 	<ol style="list-style-type: none"> 1. Training to address personal attitudes and beliefs (which may already be part of organization's training program). Possible training topics include stigma and bias, social determinants of health, and intersectionality 2. Training to ensure compliance with privacy/ confidentiality requirements (e.g., HIPAA) 3. Training on interviewing, survey administration, data analysis, report writing; focus group administration, and report writing <ul style="list-style-type: none"> • Quality Academy (online training tutorials) to learn about quality improvement and performance measurement concepts

SECTION 2. Patient Involvement Spectrum: What Does Patient Involvement Look Like?

Activity	Level of Commitment/Deliverables	Resources Required
<p>Surveys <i>Surveys can take many forms. They can be administered by a person (conducted in person), paper, or completed online. They can vary in length from 1-2 questions on a single topic to many questions covering multiple topics and issues. Longitudinal surveys (same questions asked multiple times over a specific period) track change over time. One-time surveys may be used to identify needs, measure satisfaction with services, etc.</i></p>	<ol style="list-style-type: none"> 1. Development of survey 2. Administration of survey (online, on site, person to person) 3. Analysis of survey data 4. Reporting findings to patients 	<ol style="list-style-type: none"> 1. Staff time 2. Possible use of consultants (including people with HIV) 3. Compensation of participants (e.g., gift cards)
<p>Focus Groups <i>Small groups bring together participants to take part in a guided discussion about a specific topic. Participants can either be recruited at random (i.e., a diverse group) or meet specific criteria (e.g., gender, race/ethnicity). Because it is a discussion, participants may be more engaged, and their views may evolve over the course of the discussion.</i></p>	<ol style="list-style-type: none"> 1. Development of protocol 2. Logistics planning for group meeting 3. Recruitment of participants 4. Conducting group meeting 5. Compiling report 	<ol style="list-style-type: none"> 1. Staff time 2. Possible use of consultants (including people with HIV) 3. Compensation of participants (e.g., gift cards)
<p>Interviews <i>Interviews can be conducted with random interviewees (i.e., individuals in the waiting room) or with specific people who may have perspectives or knowledge that are important to capture (key informant interviews). The interview format (i.e., open ended questions) allows interviewees to elaborate, as opposed to providing simple yes or no answers.</i></p>	<ol style="list-style-type: none"> 1. Development of interview protocol 2. Identification of interviewees 3. Scheduling interviews 4. Conducting interviews 5. Compiling report 	<ol style="list-style-type: none"> 1. Staff time 2. Possible use of consultants (including people with HIV) 3. Compensation of interviewees (e.g., gift cards)



Patient Involvement in Practice: Gathering Patient Perspectives and Insights

The Maricopa County RWHAP Part A Program has historically gathered input from patients, as required in planning activities and by subrecipients. In the last few years, it has taken patient engagement to a new level, which has not always been the role for administrative agencies.

In 2020, the Program conducted a survey of young adult patients (18–30 years of age). Program staff set up tables at subrecipient agencies and offered incentives (small gift cards) for completing the survey. The survey identified that patients needed and wanted specific services but didn't know where the services could be accessed (and that they were available). Based on the results, the Program has launched activities focused on young adults.

Now, a monthly electronic newsletter is produced by the Young Adult Support Squad (YASS), made up of subrecipient staff who are in the same age group as the priority population (and some are people with HIV). The newsletter has a 50 percent open rate—showing that young people still use email and, more importantly, that they are interested in the content.

“Providing engaging and relevant information makes it successful,” states Jeremy Hyvärinen, Quality Manager for the RWHAP Part A Program and a CQII consultant with lived experience

During the COVID-19 pandemic, the Program hosted monthly virtual chats for the same population, with specific topics, such as dating and disclosure. Time would also be reserved for participants to provide information on issues they were confronting, needs, or what was working in terms of their HIV care and treatment. The Program is hoping to add live events, in addition to the virtual ones, as live events tend to have higher turnout.

Feedback from the newsletter and the chats was used to develop a web-based campaign focused on young people with HIV, **Positively You**. While the site provides general information about accessing RWHAP services, it also features Positively You ambassadors—young people with HIV recruited by the Program to tell their stories of using RWHAP services. As a result of the campaign, the Program is now participating in more community events,



such as Pride and the AIDS Walk. At these events they can engage one-on-one with people, ask some questions, and gather feedback through informal conversations and using short surveys.

The Program has a Community Engagement Coordinator who has had success in “warm” calling young gay, bisexual, and other men who have sex with men of color. Over 100 patients were called to ask about access to services, needs, and other issues impacting them. The calls helped to introduce the engagement coordinator to the community. It also showed that young people still will answer the phone. Many said they preferred a short phone call to showing up at a focus group or town hall. The coordinator was also able to identify patients who were willing to further engage and provide input on service delivery to the program.

While it has only been a couple years that the Program has engaged patients at this level, it has provided invaluable information.

“When we did the first survey, we asked what services they needed most,” states Jeremy. “What we identified was that this population was largely unaware of the Ryan White services that were available. We quickly pivoted our approach and developed engaging, community-driven methods to informing them about the services that are out there to meet their needs. And, most importantly, we included people with lived experience in this process.”

Domain: Engagement in Quality Improvement Activities

Going beyond collecting patients’ perspectives and observations, this domain involves them as equal members in various aspects of local quality improvement and CQM activities (i.e., as a member of the quality improvement team, member of the agency’s CQM committee). Patients can be involved in identifying issues, planning for improvement activities, collecting data, and developing solutions to improve patient care processes and experiences. To fully participate, patients may need training in quality improvement processes, data collection, analysis, and developing solutions to identified issues.

For example, patients have long participated in CQII collaboratives along with providers. It is also incumbent on the organization to create a process where patient voices are heard and there is a feedback loop to inform the broader patient population.

Qualities/ Capacities	Building Skills/Training
<ol style="list-style-type: none"> 1. Regularly attend meetings (either virtual or in person) 2. Comfortable contributing during discussions 3. Understand basic concepts of quality improvement and performance measurement 4. Understand basic elements of project planning 5. Understand qualitative and quantitative data 6. Use data to develop PDSA cycles or other quality improvement response 7. Ability to engage in program planning to respond to needed changes 	<ol style="list-style-type: none"> 1. Review existing resources, including the <u><i>Guide to Consumer Involvement: Improving the Quality of Ambulatory HIV Programs</i></u> to gain their insight into the factors that contributed to meaningful and effective patient involvement. 2. Quality Academy (online training tutorials) to learn about quality improvement and performance measurement concepts. 3. Technical Assistance Call Series with routine webinars for patients to build their capacity for quality improvement. 4. Learning Lab to learn more about quality improvement concepts and their application in HIV care. 5. Experience-based Co-Design (EBCD) Learning Lab to build capacity among people with HIV and providers to utilize a co-design methodology to understand and improve the experience of HIV care and services, by both those who provide care and receive care. 6. Training for Consumers on Quality Plus (TCQPlus) to further build the skills of consumers to participate in quality improvement activities. 7. ELEVATE, conducted by NMAC, prepares people with HIV to meaningfully engage and take on leadership roles in planning bodies, advocacy actions, and the HIV workforce.

SECTION 2. Patient Involvement Spectrum: What Does Patient Involvement Look Like?

Activity	Level of Commitment/Deliverables	Resources Required
<p>Participant in Improvement Activities (as employee, consultant, volunteer) <i>The development of specific improvement activities needs the expressed input of patient voices [i.e., development of cause-and-effect diagrams, flow charts, prioritization of improvement interventions]. The time commitment is activity-driven, at times participation in a single meeting versus a series of inputs to refine quality improvement tools.</i></p>	<ol style="list-style-type: none"> 1. Review of documents to share insights and priorities 2. Meetings to participate in project-specific quality improvement activities 3. Recruitment of additional staff/patients as appropriate 4. Collection of data (e.g., surveys, interviews, focus groups) 5. Processing and analysis of data 	<ol style="list-style-type: none"> 1. Resources for patient members who have a formal consultancy or employment agreement in place 2. Incentives for patients who share their experiences (e.g., gift cards) 3. Resources/staff time to develop quality-related activities 4. Resources required to implement strategies and track their success
<p>Member of Quality Improvement Team (as employee, consultant, volunteer) <i>Quality improvement teams are usually assembled to address a specific issue (projects may take several months to complete). Composition of teams may vary depending on the project but typically involve 5–10 people. Ideally teams involve staff [i.e., quality management, clinical, and other staff as appropriate] and patients.</i></p>	<ol style="list-style-type: none"> 1. Regular meetings 2. Identification of quality issues (through various processes) 3. Design of project 4. Recruitment of additional staff/patients as appropriate 5. Collection of data (e.g., surveys, interviews, focus groups) 6. Processing and analysis of data 7. Summarizing findings (in report or another format) 8. Developing strategies (e.g., PDSA cycles) 9. Integrating successful strategies into clinic flow 10. Tracking effectiveness of strategy over time 	<ol style="list-style-type: none"> 1. Staff time (IT, clinical, and other staff on team) 2. Possible use of consultants (including people with HIV) 3. Community engagement support for patient members (e.g., transportation, childcare) 4. Incentives for patients who share their experiences (e.g., gift cards) 5. Resources/staff time to develop reports 6. Resources required to implement strategies and track their success
<p>CQM Committee Member <i>The clinical quality management committee monitors the quality of clinical care and patient satisfaction. It is focused on the big picture (as opposed to quality improvement teams looking at a single issue). Serving on the CQM committee is a long-term commitment. It also requires a certain level of expertise to be an effective member. Depending on the nature of the organization (AIDS service organization vs. community health center), the work of the quality management committee may not be HIV specific.</i></p>	<ol style="list-style-type: none"> 1. Regular meetings 2. Regular review of data on key indicators 3. Regular reporting to organization on the activities of the CQM committee 4. Administer patient satisfaction surveys, review/analyze data, respond to findings 5. Review patient data (e.g., viral suppression reports), identify concerns/potential patterns, consult with clinical and other staff of appropriate responses 6. Maintain transparency with patients during the process 7. Develop and implement strategies to address deficiencies/issues 8. Track success of efforts to address issues 	<ol style="list-style-type: none"> 1. Staff time (IT, clinical, and other staff on committee) 2. Possible use of consultants 3. Community engagement support for patient members (e.g., transportation, childcare) 4. Incentives for patients who share their experiences (e.g., gift cards) 5. Resources required to implement strategies and track their success



Patient Involvement in Practice: Engagement in Quality Improvement Activities

Life takes us in unexpected directions. When she started volunteering for service providers where she was receiving HIV-related services 21 years ago, Reachelian Ellison's main motivation was to give back to the organizations that were providing her so much help and support. But as she got more involved, becoming a member of a consumer advisory board (CAB), she realized that no one was representing her. There was talk of involving mothers with children. There was talk of involving women with a history of drug use. Because neither of these represented Reachelian's life experience, she felt a need to speak up.

"I felt left out," stated Reachelian. "If I was going to have a voice, I needed to open my mouth."

This advocacy led to her current position, Consumer Relations Coordinator at the Houston Regional HIV/AIDS Resource Group, where she has been able to bring about significant change in terms of patient involvement and is also an excellent example of co-producing (See [Domain: Co-Producing](#)). Reachelian strengthened the jurisdiction's Consumer Engagement Program, which trains and supports people with HIV to become more actively involved in CABs and in achieving their personal goals. The program gave patients the platform, resources, and support to become more empowered in seeking care, and as advocates. The Healthy U Initiative helps patients (in collaboration with clinicians) to design educational materials for peers. These resources helped improve adherence and accessibility. Reachelian's "Education First" approach ensures patients are equal partners in addressing HIV by informing them about the advocacy process—making sure they know every meeting's purpose, what their role is, and how they can prepare.

Reachelian also worked to revamp CABs in the jurisdiction. When she started, only one CAB was active. Reachelian initiated the formation of a CAB in every subrecipient as well as four regional CABs (across the jurisdictions' 51 counties) that serve to address regional issues.

In carrying out this work over the years, Reachelian has not only been committed to elevating patient voices, but also the patients themselves. Reachelian promoted involvement in these activities as an opportunity to learn skills



and build a resume—both of which could be leveraged into employment opportunities; patient involvement was professionalized. The goal is to move patients beyond the CAB to employment opportunities, if that is what they want.

“In the beginning we had lots of engagement, but people were showing up for the pizza,” states Reachelian. “We established membership committees. People had to submit applications, bios, and be interviewed. We asked people why they wanted to be on the CAB. We also conducted a skills assessment to determine training needs.”

What is next for Reachelian? While she loves her “dream” job, she admits that there is always a need to promote diversity—would another voice be a better fit for her job? Her goal is to bring in more people (one by one), even if it is on a temporary basis, and provide them the skills they need to obtain other jobs. She feels it is especially important to engage the younger generation.

Reachelian’s advice for others who want to engage in this work: 1) Figure out what you want to do; 2) Acknowledge that there is room at the table for everyone; 3) Focus on the future (e.g., building your resume); and 4) Pick your priorities. For her, she wants to focus on mental health, trauma-informed care, and change management. But also, going back to her early days in this work, she just wants to bring voices to the table—especially new ones that need to be heard.

Domain: Co-Producing and Leading

This domain requires the recruitment of people with HIV for leadership roles. Given the expertise and responsibilities required for this work, we recommend that they be hired as staff or have formal consulting agreements in place. The domain focuses on the involvement of patients in decision making in the organization as equal partners in design and implementation, including the development of policies/ programs and the decisions of the organization. Patients can be actively involved in co-producing and leading organizational activities to improve patient care, health outcomes, and health care experiences.

Qualities/ Capacities	Building Skills/Training
<ol style="list-style-type: none"> 1. Regularly attend meetings (either virtual or in person) 2. Strong advocacy skills, for own needs and others 3. Ability to quickly process information, whether in written form or presentations 4. Understand community priorities related to health and needs of subpopulations 5. Understand basics of health care service delivery 6. Understand various funding streams and requirements related to this funding 7. Understand basic concepts of quality improvement and performance measurement 8. Understand basics of data collection and analysis 9. Understand program planning and implementation 	<ol style="list-style-type: none"> 1. Review existing resources, including the <i>Guide to Consumer Involvement: Improving the Quality of Ambulatory HIV Programs</i> to gain their insight into the factors that contributed to meaningful and effective patient involvement. 2. Quality Academy (online training tutorials) to learn about quality improvement and performance measurement concepts. 3. Technical Assistance Call Series with routine webinars for consumers to build their capacity for quality improvement. 4. Learning Lab to learn more about concepts and their application in HIV care. 5. Experience-based Co-Design (EBCD) Quality Improvement Learning Lab to build capacity among people with HIV and providers to utilize a co-design methodology to understand and improve the experience of HIV care and services, by both those who provide care and receive care. 6. Training for Consumers on Quality Plus (TCQPlus) to further build the skills of consumers to participate in quality-related activities. 7. ELEVATE, conducted by NMAC, prepares people with HIV to meaningfully engage and take on leadership roles in planning bodies, advocacy actions, and the HIV workforce.

SECTION 2. Patient Involvement Spectrum: What Does Patient Involvement Look Like?

Activity	Level of Commitment	Resources Required
<p>Patient/Consumer Advisory Board Member <i>Some health care providers, such as FQHCs, have specific requirements. For FQHCs, the majority (at least 51%) of the health center board members must be patients served by the health center. For other providers, it is part of their effort to be more patient-centered and transparent.</i></p>	<ol style="list-style-type: none"> 1. Attend regular meetings 2. Identification of issues for consideration 3. Prepare for meetings, review of materials 4. Participate in task groups, as assigned 5. Participate in report writing and review 	<ol style="list-style-type: none"> 1. Staff time to convene and coordinate the committee 2. Resources for patient members who have a formal consultancy or employment agreement in place 3. Community engagement support for patient members (e.g., transportation, childcare)
<p>Board of Directors <i>The board is legally responsible for a health care organization and the activities that are conducted. They are responsible for overseeing the activities of the chief executive officer and other leaders in the organization. In addition to oversight, the board builds relationships within the community and are active in fundraising activities. A patient serving on the board may not share all these responsibilities (e.g., fundraising) but has the same legal requirements as other members.</i></p>	<ol style="list-style-type: none"> 1. Attend regular meetings 2. Identification of issues for consideration 3. Prepare for meetings, review of materials 4. Participate in task groups, as assigned 5. Participate in report writing and review 6. As appropriate, participate in fundraising 	<ol style="list-style-type: none"> 1. Resources for patient members who have a formal consultancy or employment agreement in place 2. Community engagement support for patient members (e.g., transportation, childcare) 3. Recognition of contribution at live events and in media
<p>Experienced-Based Co-Production of Activities, Services <i>Patients participate as a full partner, from beginning to end, in the design and implementation of care services. Their voice is equally heard and valued in all decisions. They play a role in monitoring, implementation, and the evaluation of the services.</i></p>	<ol style="list-style-type: none"> 1. Participate in regular meetings 2. Effective in advocating for the needs of people with HIV and other marginalized communities 3. Research/review of effective interventions 4. Participate in discussions related to service design and how to improve care 5. Comfortable discussing stigma, bias, trauma, and how they impact care 	<ol style="list-style-type: none"> 1. Resources for patients who are employees or consultants 2. Recognition of patient members 3. Coordination, guidance, and assistance for patient members wishing to build their careers or access non-RWHAP employment services



Patient Involvement in Practice: Co-Producing

In co-producing, the patient experience matters. Given this, a patient who has received care from multiple providers, in multiple jurisdictions, with different experiences, might be the ideal co-producer. The patient has seen various approaches to service delivery, and how the approach can make a difference in the care and services provided.

Before he moved to Waco, Toby Kurosky received care in two other jurisdictions in Texas. In Waco, he developed a close relationship with his case manager at the Waco-McLennan County Public Health District. She suggested he become more involved in the health district's response to HIV. He became a member of the newly revitalized consumer advisory board (CAB). At the same time Laurel Churchman, program manager for HIV services, was participating in CQI's create+equity Collaborative and reached out to Toby to participate along with her. In Toby's own words, he is a RWHAP success story, having accessed many of the services the program has to offer—health care, case management, dental care, and more. He has also received housing assistance through HUD's Housing Opportunities for People with AIDS program. He knows the importance of effectively navigating the system to optimize care.

Toby and Laurel were equal partners in the create+equity Collaborative. When it came time to pick an intervention, they were convinced that they should address transportation—such as arranging Uber rides for patients. But when they looked at the data, they saw that transportation was not an issue for most patients. Instead, they selected peer navigation to help patients improve patient access to services, with a focus on those who were not engaged in care or who had not achieved viral suppression.

“I know how to access services,” states Toby. “I have accessed many parts of the system in various jurisdictions. I also survived cancer twice. I can ‘navigate’ and I can help others by sharing my experiences.”

Laurel and Toby are taking a methodical approach to implementing the peer navigation intervention. Together they reached out to programs across the country to identify what works. This has mostly been by peer sharing through the create+equity Collaborative. They also reached out through their networks. They visited AIDS Outreach Center in Ft. Worth, where Toby had previously been a patient, and spent a day with both supervisors and navigators to see the process in action.



Next up in the process is for both Laurel and Toby to be trained in all aspects of patient navigation through KC CARE, as well as the health district's case management team. This will give Laurel and Toby an in depth understanding of what is required of peer navigators so that they can design a pilot. It will also ensure that they can inform case managers about the intervention so that they understand it and can answer their patients' questions.

Due to limited resources for the pilot, Toby is volunteering to be the first navigator. He will learn first-hand what works, what doesn't, and gain insight into why patients want to access peer navigation services. Toby acknowledges that having one peer navigator for a diverse population is an issue. There could be some patients that do not want to engage with him. Beyond the pilot phase, the health district would like to hire additional peer navigators. Toby and Laurel anticipate that there will be lots of lessons learned from the pilot that will inform what the peer navigator program eventually looks like.

“Toby’s knowledge and enthusiasm have really shaped what we are doing,” states Laurel. “He has been critical to our progress to date.”



Patient Involvement Journey: Checklist for Providers and Patients

Initiating or Expanding Your Patient Involvement Journey: Checklist

(Note: This is not a step-by-step checklist. It is a list of suggested activities that patients and organizations can use to further their patient involvement journey.)

1. Advocate for greater patient involvement (patients, staff, leaderships, stakeholders)
2. Engage patients in the patient involvement planning process
 - Members of consumer advisory boards
 - Employees who are also patients (e.g., peer navigators)
 - Get informal input—talk with some patients, use an existing peer or staff meeting for additional input
 - Develop a process to recruit additional people with HIV (e.g., both formal and informal—encourage patients already involved to recruit others)
3. Review existing sources of relevant patient feedback
 - Findings from patient focus groups, annual meetings, town halls, patient surveys
4. Form a planning committee with staff and people with HIV as equal members
 - Invite specific individuals or extend an open invitation (to staff and patients)
 - Conduct regularly scheduled meetings
 - Designate a member to lead the process (communicate with members, set agenda, etc.); consider an individual with lived experience to lead this effort
 - Establish the milestones that you want to accomplish and an implementation timeline
 - Document the process (e.g., meeting notes)
5. Address any training needs for staff and patients
 - Identify already existing training tools and resources
 - Develop training strategies for new patients as they engage in the process
 - Consider having a patient oversee this training



Initiating or Expanding Your Patient Involvement Journey: Checklist

6. Consider ways to support the meaningful involvement of people with HIV in the planning process (and subsequent activities) as staff, paid consultants, or by providing incentives for their time and effort. *For more information review PCN 16-02 and the 2023 community engagement program letter, both issued by HRSA.*
 - Consider other support needs (e.g., transportation, childcare)
 - Explore other forms of recognition/acknowledgement (e.g., awards, volunteer of the month features in monthly newsletter)
7. Conduct research on what patient involvement should look like in the organization (patients, staff, other stakeholders)
 - Set up focus groups, key informant interviews, or surveys
 - Participate in CQII activities related to patient involvement (e.g., EBCD Learning Lab)
 - Conduct a site visit with another HIV program (in-person or virtual) that made documented progress in this field
8. Develop a plan with specific goals and objectives and a strategy to track progress in achieving the goals (i.e., evaluation)
9. Develop a way to report back to patients and staff about patient involvement activities and their outcomes (e.g., new services added, changes made to existing services)
 - Share your local success stories and changes that were made in response to input by people with HIV
 - Select a wide variety of communication channels such as newsletters, consumer advisory committee meetings, staff meetings, posters in waiting or staff rooms
10. Develop a process to regularly recruit people with HIV in this process and support them in their work
 - Consider having a person with lived experience oversee recruitment
 - Establish a standard onboarding process
 - Standardize training

SECTION 3.

Key Elements of Effective Patient Involvement





In this Section...

Before you start planning the steps to implement effective strategies for patient involvement consider the following variables:

- | | |
|-------------------------------------|-------------------------|
| Agency/Organization: Size Matters | Recognize Differences |
| Integration is Key: Value the Voice | Acknowledge Limitations |
| Equal Partners: Patients are Peers | Manage Expectations |

The following steps address many of the issues—the nuts and bolts—both providers and patients face as they engage in this process. It will not only give you insight into the issues confronting patients, but also provide you with an understanding of why providers have policies and procedures in place.

- | | |
|---------------------------|--------------------------------|
| Recruitment and retention | Patient self-care |
| Setting boundaries | Documentation and evaluation |
| Training | Sharing findings with patients |
| Incentives/Support | |

The following activities focus on strategies for facilitating patient involvement and how organizations can take steps to support their patients.

- | | |
|---|---|
| Set Goals for Patient Involvement in Quality Improvement Activities | Power Dynamics |
| Identify Appropriate Activities to Initiate Patient Involvement | Timely Engagement |
| Avoid Tokenism, Ensure Multiple Voices | Ensure the Necessary Skills to Partner in Quality Improvement |

Check List: Patient Action Steps

- ➔ Take advantage of the various quality improvement training opportunities.
- ➔ Ensure that your skills and experiences match the proposed activity.
- ➔ Ensure self-care and maintain a high quality of health and wellbeing.

Things to Consider Before You Start

Before you start planning the steps to implement effective strategies for patient involvement, consider the following variables.

Agency/Organization: Size Matters. It is important to recognize that there are different realities across organizations. A small organization may have very flexible policies regarding onboarding a staff person. Given a smaller caseload, staff may have more interaction with patients and know who would be a great addition to a quality improvement team. Larger organizations, such as academic hospitals, may have very strict processes for hiring staff and consultants, and for defining the roles of staff, consultants, and volunteers. For example, the process for onboarding a consultant in a large organization, with requirements for resumes, proof of hourly rate, and references, may constitute a barrier for a person with HIV who has not previously served as a consultant. The process for invoicing may be complicated and cumbersome, and there may be a long delay between invoicing and payment. When integrating patients into quality and other activities, carefully consider potential barriers within the organization.

Integration is Key: Value the Voice. As organizations seek to involve patients and value their voices, some patients

may perceive these efforts as tokenism—there are too few voices, and the voices are marginalized. Patients have complained of always being asked for “feedback,” which implies they are reacting to something after the important decisions are made. Thoroughly integrating multiple patients throughout all quality-related activities (e.g., as members of quality management committee and quality improvement project teams) so that they are involved in both planning and execution of activities ensures that their perspectives and expertise are meaningfully included in the decision-making process.

Equal Partners: Patients are Peers. Emphasize to staff that patients who are engaged in quality improvement and other activities are equal participants in these processes. Their perspectives and expertise matter as much as those of the staff members participating in these activities.

Recognize Differences. While they should be treated as equals in terms of the contributions they can make to quality improvement and other activities, it is important to recognize that people with HIV may need some accommodations to facilitate their participation. For example, patients may have jobs outside the clinic or other demands on their time, such as caring for children. These obligations should be taken into consideration when

Variables to Consider for Patient Involvement



scheduling meetings. Patients' health realities must also be respected. For example, people with HIV are more likely to face co-morbidities than those who do not live with HIV. While it may be tempting to load the agenda and “power through,” some participants (both with and without HIV) may need breaks.

Acknowledge Limitations. Even with the best intentions, quality-related activities cannot always result in the desired changes—policies, resources, or other reasons can limit the ability to make change. For any organization, managing expectations across funders, staff, patients, and other stakeholders is critical. Clearly identifying expected outcomes at the beginning of an activity or project and then clearly communicating these expectations to all stakeholders can help to address expectations about intended outcomes. Transparency throughout the process

keeps stakeholders informed, especially when anticipated outcomes are not achieved.

Manage Expectations. Both for the general patient population and for those patients involved in quality improvement activities, it is important to manage expectations. For patients in general, be clear about the degree to which changes are possible. Any quality projects undertaken should be actionable—a problem that the organization has the capacity to address. For patients engaged in quality and other activities, it is important to clearly communicate what will be expected of them (and staff too) throughout the process before they agree to participate. This is especially important when patients are volunteering their time. If expectations are not met, they have little motivation to continue to participate.



Patient Involvement in Practice: Getting Started

As a peer navigator at Little River Medical Center, Robert Pierce shares his lived experience as he helps patients initiate or re-engage in their own health care journey. Little River has six sites in Horry County, South Carolina. With a caseload of about 250 patients with HIV and given that the South is the current epicenter of the HIV epidemic, Robert relates that there is high demand for the services of the two peer navigators.

Keeping up with the needs of patients is important but the navigators also want to support increased patient involvement in care. There was an effort to form a CAB in 2021 as the pandemic was winding down but patients were too busy getting back to regular life and the peer navigators were focused on other projects. Still seeing a need to engage with patients, Robert and his colleague initiated a support group for patients in summer 2022. The group will focus on education and sharing of experiences. Robert is hopeful that this will be a step towards further engaging patients in their own care and the delivery of care at the clinic level.

Integrating Patient Involvement

Effective patient involvement should be integrated throughout all programmatic aspects of an organization to generate the necessary commitment.

1. **Policies.** Organizational policies should either include patients involved at various levels (volunteers, consultants, staff) or there should be specific policies focused on patients involved in quality improvement and other activities.
2. **Program Planning.** Program planning should involve patient representatives, as appropriate, to ensure their voices are included.
3. **Orientation.** Both staff and patients need to know the importance of patient involvement and the role patients can contribute. During onboarding, staff should receive information about the organization's commitment to patient involvement and the roles patients provide across the organization. Patient representatives also need an orientation as well. The orientation should be tailored to their unique role within the organization but also cover much of the information received by staff (e.g., organizational policies, priorities, expectations).
4. **Training.** The role of patients participating in quality improvement and other activities should be thoroughly covered in training activities, whether trainings are specific to staff, for staff/patients, or just patients. Patients participating in quality improvement and other activities should receive the training necessary to effectively carry out their role in these activities.
5. **Quality Improvement.** Quality improvement activities benefit significantly from patient involvement. Whether it is involvement in planning for quality improvement or as members of a quality improvement project team, patient voices help to keep the focus on what matters to patients.
6. **Evaluation.** Patient involvement should be integrated into an organization's evaluation activities. Not just whether patients are involved (i.e., quantitative

evaluation) but qualitative assessments of their contributions and how patient representatives viewed their experiences (e.g., I felt heard, staff treated me as an equal, etc.).

Patient Involvement Implementation Steps

Key steps for engaging patients in quality-related activities:

1. Recruitment and retention
2. Setting boundaries
3. Training
4. Support
5. Patient self-care
6. Documentation and evaluation
7. Sharing findings with patients

Recruiting and Retaining Patients in Quality Improvement and Other Activities

Just as an organization spends significant time and resources in identifying, hiring, and retaining employees—after all they are their most important asset—organizations should have standard processes in place that support the recruitment and retention of patients in their quality improvement (and other) activities.

For both recruitment and retention, having a clear “ask” is essential. Recruit people for a specific, time-defined task—do not ask them to make a life-long commitment. For example, have terms of service (e.g., two years) for CABs and other advisory bodies, board of directors, and quality committees. For improvement projects or specific tasks, be clear about the length of the commitment and the expected amount of time (e.g., two hours per week).

Clearly define roles (for both staff and patients) and responsibilities. This ensures that patients are aware of expectations and the type of contributions they will be asked to make before they commit.

Recruitment

1. **Get the Word Out.** It is hard to recruit if no one knows you are recruiting. Use multiple methods to reach as wide an audience as possible—newsletters, announcement boards, social media postings, flyers, signs in the waiting room, patient forums, or even letters to all patients. By casting a wide net, you may be more likely to reach a diverse group of patients. Don't forget the importance of the "personal ask." Staff can ask patients directly to participate. This may be particularly effective with patients who are not highly engaged (e.g., do not read the newsletter or attend patient forums). These patients may bring different insights than those of highly engaged and motivated patients.
2. **Encourage Staff Referrals.** Staff interact with patients on a regular basis and can encourage patients to participate. They can let the staff person in charge of recruiting know of patients who would be strong contributors—so they can be invited to apply. Peers (either on staff or volunteers) can be especially effective as recruiters. They may spend more time interacting with patients and have a stronger rapport. They also may be more trusted, and their suggestions taken more seriously by patients.
3. **Make it Easy.** If a patient is interested in becoming involved, how do they go about it? Make information about patient involvement activities easy to access (e.g., specific webpage on organization's website). Make it clear who patients should contact and what information is required. Do they simply fill out an application? Do they need to submit a resume or references? Centralizing this information and the application process online can greatly streamline the recruitment of patients. However, it is important to note that some patients may not have access to a computer so other application options and outreach methods should still be in place.

Retention

1. **Welcoming Work Environment.** Providing a supportive work environment begins with the organization's culture—one that is welcoming, supportive, and free of discrimination, stigma, and bias. Patients involved in improvement activities should be treated with the same respect as staff and their contributions equally valued. Policies should be in place to ensure this happens and both staff/patients should be informed of these policies (e.g., during orientation, regular training, staff manuals).
2. **Say Thank You!** Throughout their involvement, and not just at the end, patients' contributions should be acknowledged.
3. **Train for Success.** Training and other skill building techniques (e.g., mentoring) can help patients fully participate with confidence and effectively share their experiences and expertise.
4. **Value Their Time.** Any activity should be conducted as efficiently as possible and assigned tasks should be integral to the activity—not busy work. Just because patients may be volunteering doesn't mean that their time is not as valuable as staff members.
5. **Treat as a Colleague.** Whatever the activity, patients should be considered as equals in the process. Those overseeing the activities should make sure that patients are thoroughly integrated on the team and allowed to contribute fully. Their contributions and opinions should be valued and considered, just as any other member of the team.
6. **Support.** Make participation easy. Provide travel support and childcare if possible. This can also help to increase the diversity of patients participating since barriers are removed.
7. **Recognition.** Beyond saying thank you, recognize the contribution of patients. Consider having an annual recognition event. Also, feature patients participating in quality-related activities in newsletters, or in other ways, such as on the organization's website or in social media.
8. **Client Incentives.** If possible, provide incentives (e.g., gift cards) for patients involved in improvement activities.



Patient Involvement in Practice: Recruitment and Retention

Recruitment and retention can be hard, regardless of the activity. Ensuring that a person is well prepared for the role they step up for, is provided incentives (as appropriate and allowable), and has opportunities for advancement can make a difference.

David Moody knows how to engage patients in HIV-related activities beyond their care. He is the former director of outreach for Metro Health in Washington, DC. His work relied heavily on social networking—using current patients to recruit others from their social network that might be at risk, with the goal of getting people tested and quickly engaged in HIV care if positive.

David encouraged patients to get involved, which turned out to be easy. People wanted to help, especially others in their social network. Those who said yes were provided training in HIV 101, HIPAA/confidentiality, how to do HIV testing, and computer skills (if necessary). Once trained, the volunteers worked within their social networks to encourage HIV testing. For each test, the tester and the person being tested received a \$10 gift card for groceries. This proved a very effective strategy.

“The best people to reach the focus population is the focus population,” states David.

While wanting to help their friends was a key motivator for keeping people involved, offering incentives was also a factor. Another important factor was the possibility of employment. Some volunteers who had the necessary skill set received additional training in cultural humility, motivational interviewing, and trauma informed care. This led to paid positions. For others, there was skills building such as resume development and employment support. Working toward a paid position in the field was the goal for many of the volunteers and acknowledging and supporting this goal helped to retain them as volunteers and was key to their ongoing participation.

Setting Boundaries for Patients and Staff

Boundaries in the workplace are important for everyone. Without them, people can feel that they are being taken advantage of, are not being heard (i.e., their needs are not being met), are under appreciated, or that people are asking too much. Setting physical, emotional, and mental limits helps to create a safe and supportive environment for everyone.

When patients are engaged in the day-to-day activities of a clinic (i.e., quality improvement), there needs to be close attention to boundaries, especially on the part of staff. Perhaps the most important of these is observing confidentiality and privacy. While organizations have processes in place for clinical interactions, it is easy for a staff person to mention that they have a “patient member” on their quality improvement team and then give their name or breach privacy in some other way.

Another area is questioning a patient’s lived experience. If someone discloses personal information in relation to improving services, and then are questioned on it, it devalues their experience. While it is not necessary to incorporate every suggestion made by patients, it is important to be respectful and acknowledge their experience and their contribution to quality-related activities.

When considering boundaries, it is important to acknowledge trauma. It is estimated that at least one-third of people with HIV have experienced trauma.¹⁰ Any staff working with people with HIV should be trauma informed and processes should be in place to support patients in the event they experience triggers.

Like with any staff and volunteer working in a clinic, it is also important to help people with lived experience engaged in this work to understand boundaries and how they adhere to organizational policies. Clear boundaries need to be set in terms of what can and cannot be done as a staff person or volunteer.

¹⁰ McLean, C. P., & Fitzgerald, H. (2016). Treating Posttraumatic Stress Symptoms Among People Living with HIV: a Critical Review of Intervention Trials. *Current psychiatry reports*, 18(9), 83. <https://doi.org/10.1007/s11920-016-0724-z>



Patient Involvement in Practice: Setting Boundaries

Any one of the many positions Dottie Rains-Dowdell holds can easily result in over work or burnout. She is program director of New Jersey's HIV Planning Group, which involves working on the state's integrated HIV/AIDS plan. She is a part-time lecturer at the Rutgers, School of Social Work. She has traveled to South Africa, West Africa, and Haiti on missions to help increase awareness of HIV/AIDS, child sexual abuse prevention, and economic development. She is pursuing a doctorate in health science. And is also a wife and a mother.

One of the key elements to her approach to self-care is setting boundaries, especially in positions with direct patient contact.

“I've worked as a case manager, and it can be overwhelming,” states Dottie. “You can identify with a patient, but you don't always have to disclose your HIV status. You need to set boundaries so there are limits on how much you take in.”

Given the demands on her time, Dottie takes steps to ensure a work/life balance—taking time for family and friends and finding the joy in life. She also stresses identifying and relying on personal supports.

While people often associate setting boundaries with self-care, they also apply to other aspects of working with patients. Since her diagnosis 25 years ago, Kneeshe Parkinson has held several positions focused on helping patients overcome their barriers to health care—as a family advocate, case manager, CAB member, and more recently, as a trainer, motivational speaker, and life coach.

“Every time an opportunity presented itself, I made sure that I was at the table,” states Kneeshe.

Given her close interaction with patients in much of her work she knows the importance of establishing clear boundaries—making sure patients do not ask too much of her or ask for something that is not allowed by the organization. This helps to ensure both integrity and balance.

*“You need to protect the mission and the reputation of the organization,” states Kneeshe.
“Boundaries keep us in check and make us more accountable about the work that we do. We must set a very high standard. If a policy or a rule is in place, it is there for a reason and should be respected.”*

Training and Capacity Building

Quality improvement has its own language and processes—these can seem to be a barrier to participation for anyone who is not familiar with the application of quality improvement methodologies and tools. Basic training in quality improvement can lay the foundation for all participants. There are many resources to assist in training. CQII has a robust collection of resources on a wide variety of quality improvement topics that are designed to support members of quality improvement teams. Training opportunities are outlined in a previous section of this Guide (Existing Training Resources).

Depending on the project, more specific quality improvement training can help to ensure that all team members, including patients, are:

1. Engaged in the process and have the understanding and skills to fully participate in all aspects of the improvement activity or project; and
2. Have the confidence to express their views and are supported in an environment where their views are valued.

The previous section identifies the skills that patients should possess or develop to participate effectively in quality-related activities (for each domain). While the specific content of training may vary, the process is still the same for training activities.

1. Assess the knowledge/skills necessary to participate in a specific activity (not only for patients but for all participants).
2. Identify appropriate training materials and activities.
3. Conduct training, whether in person, virtual, or online.
4. Monitor that training takes place and the content is well received.
5. Provide additional training support (e.g., a brief one-on-one tutorial) or more in-depth training follow-up if necessary (e.g., mentorship).
6. Evaluate training, both for effectiveness and whether participants found it valuable.



Patient Involvement in Practice: Training

CQII has long utilized the train the trainer model. In theory, trainees go on to train others in their community. But does this really take place in practice? The answer is yes.

New Jersey held a five-day Training of Consumers on Quality in 2017, which was offered statewide as part of New Jersey Cross-Part Collaborative Team's efforts to meaningfully engage communities of people with HIV in clinical quality management activities. The training was funded by the New Jersey RWHAP Part B Recipient, the New Jersey Department of Health, and implemented by the South Jersey Regional Partner of the Northeast-Caribbean AIDS Education and Training Center (NECA AETC). The program was led by CQII's Training for Consumers on Quality (TCQ) co-developers Deloris Dockrey and Adam Thompson. People with HIV from communities throughout New Jersey who had attended CQII's TCQPlus supported the training during planning and implementation, serving as co-facilitators. Many of the community members who took part in the training went on to become staff at HIV service providers.

“Local TCQPlus graduates were effective in training others in their community, which was the purpose of the program,” states Adam Thompson. “The result is more people with HIV engaged in improving care for our own community.”

Support, Incentives, and Other Recognitions

As stated above under recruitment and retention, providing support, incentives, and other recognitions is an important aspect of engaging patients in quality improvement and other activities—as volunteers, consultants, or staff. Depending on their roles, the support and recognition will vary.

Patients are sharing their skills, knowledge, and lived experience. This knowledge should be valued, appreciated, and recognized. There are various ways to make sure that patients are recognized for their input. As noted before, RWHAP funds may not be used to make cash payments or provide cash equivalents as per Policy Clarification Notice 16-02 and the subsequent HRSA Consumer Engagement letter from February 2023. Patients could be formally contracted as a consultant or hired as staff if they are to receive cash paid for their time and effort.

Consultants. When a patient is making a significant and ongoing contribution of time and expertise, consider contracting with that individual as a consultant. Most organizations have mechanisms in place to hire consultants. Be sure to advise patients about the implications of receiving this income (e.g., tax implications, RWHAP eligibility, benefits such as SSI/SSDI). Also, being a “consultant” may be different from their previous work experiences. They may need help understanding their role and related processes like invoicing. This is also one of those areas where size matters. Smaller organizations may have more flexibility in terms of the organizational process while larger organizations might be more bureaucratic in their contracting processes.

Staff. Consider hiring patients to fill certain roles that can support patient involvement. These positions can focus on recruitment and training of patient participants, surveying and other forms of data collection, or as ongoing members of CQM committees.

For one-time or less intensive patient involvement activities, such as participating in a survey or focus group or attending a CAB meeting, other forms of recognition may be more appropriate.

Patient Incentives. RWHAP funds may be used to provide incentives (e.g., gift cards for completing a survey) for patients as discussed in PCN 16-02., given some limitations.

1. Gift cards are participant incentives and are allowable when reasonable, allocable, and necessary to meet program objectives.
2. Store gift cards that can be redeemed at one merchant or an affiliated group of merchants for specific goods or services that further the goals and objectives of the RWHAP are allowable as incentives.
3. Ensure that the gift cards cannot be used to purchase unallowable items (e.g., tobacco, alcohol, or firearms).
4. RWHAP funds may not be used to make cash payments or provide cash equivalents.
5. General-use prepaid cards are considered “cash equivalent” and are therefore unallowable.

RWHAP recipients and subrecipients should develop a tracking system for the purchase and disbursement of incentives, and establish policies and procedures that outline the criteria for offering incentives that include, but are not limited to, the:

1. type and amount of the incentive;
2. criteria for determining who receives the incentive; and
3. frequency of distributing the incentives.

RWHAP recipients and subrecipients should note that they do not need to seek prior approval from HRSA before purchasing incentives. They also do not need to submit a budget revision as long as there is not a significant change in scope of their program.

Community Engagement Support. Per PCN 16-02 and the 2023 HRSA HAB Community Engagement Program Letter, community engagement support, including transportation or childcare during activities, are allowable costs under the HRSA HAB Outreach Services Support Category and can also indicate that patients' contributions are appreciated. If you have questions about community engagement, contact your HRSA program officer.

Appreciation. There are many ways to say thank you and acknowledge efforts. Volunteers can be featured in newsletters or on social media (e.g., volunteer of the month). Make sure to gain permission from patients before you promote their work. Events or regular casual gatherings that provide an opportunity for patient participants and staff to socialize and share experiences can serve to support ongoing engagement and provide an opportunity for peer support. Regardless of how you do it, showing appreciation and saying thank you can go a long way to keeping current patient participants involved and recruiting new patients.



Patient Involvement in Practice: Compensation

CQII is committed to elevating the patient voice in all aspects of its work. To this end, it contracts with multiple people with lived experience to participate in the planning and implementation of its projects. People with HIV serve as faculty on collaboratives and pilot projects, presenters on webinars and other training tools, and contribute to and review materials under development (like this Guide). They are compensated for all these activities—they are no different than any other consultants engaged by CQII. The process includes drawing up a contract with a scope of work and a negotiated hourly rate based on expertise. The number of consultants with lived experience varies but usually around 10 have contracts at any given time. Some of these consultants work with CQII in addition to their full-time work with other organizations. Others may be engaged on a part-time to almost full-time level.

Based on her long-time work as an advocate, volunteer engaged in various activities such as planning councils, and as an employee in HIV-related organizations, Martha Cameron emphasizes the importance of compensation at various levels.

“There should be no need for patients to ask for what they need, whether it is transportation or childcare support, or lunch during day-long meetings.” states Martha. “This is something that should be a standard provision for anyone volunteering their time.”

Patient Self-Care

While patient involvement is important, patient participants must not put their involvement in these activities above their health and wellbeing—and organizations need to take steps to support them as they engage in these activities. For example, simple strategies on the part of organizations include being mindful about meeting logistics (e.g., no marathons, schedule breaks).

Patient participants should be made aware of the importance of self-care during patient involvement orientation and training activities. Many resources are available to help them learn about self-care and support their efforts.

Burnout. Burnout can occur for multiple reasons—the length of the commitment, intensity of the effort, or lack of training resulting in the feeling of ineffectiveness. For example, relying on a small number of patient participants in quality improvement can result in participants feeling overwhelmed by the commitment or burned out after serving for a long period. Both can result in participants dropping out. As stated above, define and limit the level of commitment required of patients—don't ask for a lifetime commitment.

Preventing Burnout

1. Involve as many patients as possible. Don't rely on a small group who are constantly asked to participate in quality improvement activities.
2. Provide ongoing training to address evolving needs so that patients have the necessary information and skills to fully participate (and avoid feeling frustrated or marginalized).
3. Provide mentors and other support to help patient participants be successful in their efforts.
4. Acknowledge that patients may need to take a break from activities—let them know that it is okay and understood.
5. Encourage and support patients in self-care.

Stigma. Whether on the part of staff or internalized by patients, stigma can create an atmosphere where patients engaged in improvement activities are unable to effectively take part in them. Unfortunately, the impact of stigma may not be readily apparent. Ideally, organizations are already carrying out stigma reduction activities. Evaluation activities can help to identify to what extent stigma is impacting patients participating and quality-related activities. For general resources on stigma, visit [TargetHIV](#), the RWHAP technical assistance website, or ESCALATE (Ending Stigma through Collaboration and Lifting All To Empowerment), an innovative training and capacity-building initiative specifically designed to address HIV-related stigma, at [TargetHIV/escalate](#) or the NMAC [escalate](#) website.

Trauma. As with stigma, experience with trauma may not be readily apparent and therefore, not identified as an issue for patients participating in improvement efforts. Quality improvement and other activities that patients may engage in can focus on sensitive issues that can be triggers. Many organizations strive to provide trauma-informed services, and this sensitivity will extend to their patient involvement efforts. For resources on trauma visit [TargetHIV](#), the RWHAP technical assistance website.



Patient Involvement in Practice: Self-Care

You might want to hear that key to self-care is mental health days, frequent massages, and of course, lots of chocolate. But based on her long experience as an advocate and working within HIV-related organizations and service providers, Martha Cameron thinks that a more holistic approach to self-care is necessary—an approach that supports everyone, both staff and patients, as they participate in activities.

The key to creating a healthy workspace is making sure the right people are on the team, whether they are staff or patients. If a team member has the necessary capabilities and skills, they are well prepared to do the work. Otherwise, it can be challenging and frustrating—for everyone involved. Having the right people at the table is more likely to result in a productive effort where everyone feels that their contributions are valued.

“Everyone on the team should be thinking about self-care,” states Martha. “They should be looking out for each other.”

According to Martha, the ideal team member is the “activated” patient. They are stable, managing their care, and already practicing many forms of self-care in their daily life. They bring this understanding of how to effectively manage HIV to the quality-related and other activities they participate in.

Once the right people are on the team, they need to be supported. It can be difficult to perform these demanding roles without support. Sometimes asking for help requires creativity. Martha relates how when she served on a planning group, many of the women members faced challenges with childcare. To make the point, they all brought their children to a meeting. Childcare support was soon provided.

“Asking for what you need, whether it is transportation, childcare support, or lunch during day-long meetings is a skill that anyone doing this work needs to develop,” states Martha.

While asking for support is essential to these activities, Martha has some additional advice for patients doing this work.

“You need to learn to say ‘no,’” she states. “We are all passionate about being in these spaces and you feel you are representing everyone else who isn’t at the table. Self-care can be as simple as saying no.”

Documenting and Evaluating Patient Involvement

Documenting and evaluating patient involvement activities serve multiple purposes. It allows the organization to be transparent in their efforts around patient involvement and report these efforts to staff, patients, other stakeholders, and the larger community. It documents and quantifies activities and level effort. It can also identify areas where patient involvement can be improved—not all efforts to involve patients are effective and successful.

The evaluation methods are basically the same as those for any other program within a clinical organization.

Process Evaluation. Documenting efforts to implement patient involvement. This can include recruitment, training, and retention efforts (e.g., monthly progress reports, number of meetings, meeting participation).

Quantitative Evaluation. Collecting data to measure efforts (i.e., how many patients were recruited, how many patients are participating on quality improvement project teams and as board members, etc.).

Qualitative Evaluation. Qualitative data can be used to document experiences and perceived impact. For example, patients involved in improvement activities can be asked about their experience with recruitment, training, participation in quality improvement efforts, and whether they perceived their work (and the work of their colleagues) as effective in bringing about positive changes in the organization. Methods include surveys with open ended questions, interviews, and focus groups.

Sharing Data/Outcomes with Patients

Hopefully, you are already sharing information through various methods about your quality-related activities with staff and patients. Sharing information about patient involvement activities can build on these efforts. Existing communication vehicles (e.g., newsletters, bulletin boards, social media, website, patient forums) can include additional information about patient involvement—how patient participants are involved and the outcome of their efforts.

Additionally, it is important to share when efforts do not turn out as expected. For example, if a quality improvement project team does not include patient participants, explain why (e.g., unsuccessful recruitment, patient participants dropped out). Such transparency can build staff and patient confidence in the process.

In addition, sharing information about patient involvement activities can aid in recruitment of more patients. Seeing the role patients can play and that their voices are valued and have an impact can inspire other patients to get involved.



Patient Involvement in Practice: Sharing Data/Outcomes with Patients

For CQII's PROMS/PREMS Pilot Project, sites used various methods to share findings with patients. This was especially important since they were interviewing large numbers of patients about the outcomes and experiences of the project had resulted in some "buzz" at several of the sites. They 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.

Plans to communicate findings back to patients included: working with CABs for suggestions to reach the broader patient population; using the organization's patient newsletters or listserv; announcements via social media; 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.

Facilitating Effective Patient Involvement Activities

The following section focuses on strategies for facilitating patient involvement. While many of these strategies have been mentioned in previous sections, given their importance, it is worth taking a closer look at how organizations can take these steps to support their patients.

Set Goals for Patient Involvement in Quality Improvement Activities

Patient involvement should be thoroughly integrated and detailed throughout the quality management plan. During planning processes, specific goals and objectives should be included that outline how patients are meaningfully engaged. For evaluation metrics related to assessing goals and objectives, build in a process for assessing patient involvement activities. This level of accountability shows patients, staff, and stakeholders the commitment to patient involvement and ensures that patient involvement is intentional and not an afterthought.

Identify Appropriate Activities to Initiate Patient Involvement

For an organization that wants to increase patient involvement, it is necessary to take a systematic approach and make a plan. There are many activities where patient involvement is appropriate and can be a valuable contribution. Taking time to identify these activities can help to ensure the effective involvement of patients across these efforts and that patients are matched to the activities that are the best fit for their skill set.

While this is not a comprehensive list, possible patient involvement activities include:

1. Participation in strategic planning for the CQM program (co-design)
2. Member of a quality improvement project team (involved in planning and other activities)
3. Development of survey/focus group questions
4. Administering surveys/conducting focus groups
5. Analyzing performance data results
6. Participating in quality-related activities such as PDSA cycles to identify potential changes
7. Participation in process of implementing changes
8. Recruiting patients to participate in quality improvement and other activities (e.g., quality improvement projects, and CQM committee members, CAB, board of directors)

Avoid Tokenism, Ensure Multiple Voices

Patient involvement is all about elevating patient voices, and that means involving more than a small group of patients. Tokenism is defined as making a symbolic effort, one that will probably have no meaningful impact. Tokenism can take the form of involving too few participants to effectively represent a population. For example, one patient as a member of a quality improvement team cannot possibly represent the diversity of the patient population. Tokenism can also be reflected in “how” people are involved—is their participation recognized, meaningful, and acted upon? Are they provided the information and skills to effectively participate? Is the process respectful? Are patients’ input and opinions valued and acted upon? An effective feedback loop can help to ensure patient participants have an opportunity to express concerns related to possible tokenism so that these concerns can be addressed.

Fostering Diversity of Voices. A small number of patients cannot represent the diversity of the patient population. Effective patient involvement involves a diversity of patients that represent a wide variety of patient populations. Providing support to reduce barriers to participation—whether it is transportation support, childcare, language interpreters, or another form of accommodation—can allow for more diversity among participants.

Create Space for Patients to Participate. Recruiting patients is not enough. Creating a welcoming space that values and acts on their input is necessary. People who oversee your CQM committee and quality improvement projects must be good managers—they need to have a vision of quality improvement, put together effective teams, and be able to carry out projects. They also need to acknowledge, value, and act upon patient input.

Power Dynamics

In groups, such as project teams or consumer/patient advisory boards, ideally all voices are equal. Unfortunately, unequal power dynamics can impact the effectiveness of patient participants. Power dynamics can be addressed in multiple ways.

Leadership. Leaders set the tone for any activity. Leaders must make it clear from the beginning that all participants are treated with respect and every opinion matters. Throughout the process, leaders must ensure that these expectations continue to be met.

Training/Capacity Building. Supporting patients to gain the skills and obtain the information they need to fully participate serves to allow them to take part in activities as equals.

Timely Engagement

No one wants to be brought in on a project after all the decisions have been made. As co-production emphasizes, involving patient participants in initial planning for projects not only makes them feel invested in the team but it also ensures that their valuable observations and input are incorporated into the design of activities.

Ensure the Necessary Skills to Partner in Shared Quality Improvement Efforts

Patients need specific skills and knowledge to contribute effectively to quality-related activities. Attention should be given when recruiting team members to determine if they already possess the necessary skills and knowledge or if they will need support to develop these. Once both staff and patients have been identified and engaged, key steps include:

1. Assess any gaps in skills and/or knowledge;
2. Make a plan to address any gaps; and
3. Provide support (e.g., training, mentoring).

It is important to note that staff may need training on how to work effectively with patients involved in quality improvement and other activities—they need to understand the valuable contributions patients can make to the process. They also have to understand the limitations of patient involvement (e.g., a small number of patients cannot represent the entire patient population).

Supporting Participation: Key Skills for Staff/Patients

1. Project planning
2. Communication
3. Facilitation
4. Conducting meetings
5. Quality-related terminology
6. Understanding data/graphics

Appendices



Appendix 1: Quality Improvement Terms

Name	Definition
Algorithm	Description of an ordered sequence of steps in patient care under specified circumstances. Algorithms can be used to display a decision tree for certain care conditions (e.g., linkage to care).
Baseline Data	Data collected at the beginning of an improvement project or initiative. It is compared with future data collected on the same system to measure improvement.
Benchmark, Benchmarking	A benchmark is a comparative measure for a particular indicator or performance goal; within the health care or non-health care field. The benchmarking process identifies the best performance in the industry (health care or non-health care) for a particular process or outcome, determines how that performance is achieved, and applies the lessons learned to improve performance.
Brainstorming	Brainstorming is a technique to freely and uninhibitedly generate ideas, problems, or opportunities using a group approach.
Cause-and-Effect Diagram	A Cause-and-Effect Diagram is a picture of various system elements and is used to identify possible variables influencing a problem, outcome, or effect. The diagram is sometimes called an Ishikawa diagram or a fishbone diagram because its resemblance to the skeleton of a fish.
Consumers/Clients	Anyone who receives health care services and/or products. Customers can be internal (e.g., patients) and external (e.g., other departments within organization) to the organization.
Flow Chart	A Flow Chart is a picture of any process, such as sequence of events, steps, activities, or tasks. Flow Charts are drawn with standard symbols that represent different types of activities or tasks.
Gantt Chart	A Gantt Chart is a list of all activities (including the roles and responsibilities) to accomplish a specific goal. It helps to highlight key components of a problem and sequence of tasks to be completed.
Guideline	Statements or standardized specifications for care to assist providers and clients with appropriate health care decisions for specific clinical circumstances. Guidelines are developed through a formal process and are based on authoritative sources, including clinical literature and expert consensus. Guidelines can also be referred to as “clinical or practice guidelines.”
Indicator	A measurement tool or operational definition of one specific quality characteristic that can be measured (e.g., viral suppression) conforming to guidelines or standards of care. They are often categorized as either outcome or process indicator. It can also be called measure.
Mean	The arithmetic average of a set of numbers.
Median	The median is the value that divides an ordered series of numbers so that there is an equal number of values on either side of the center (or median).
Mode	The mode is the most frequently occurring number in a group of values.
Model for Improvement	An approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the pace of change; the Model includes use of “rapid-cycle improvement;” successive cycles of planning, doing, studying, and acting (PDSA Cycles).

Appendices

Name	Definition
Outcome	The results achieved through the performance of a process or function.
Pareto Chart	A Pareto Chart or Diagram is a simple bar chart, which ranks related categories (e.g., viral suppression) in decreasing order of occurrence. It can be used to analyze causes, study results, or plan for improvements.
Plan-Do-Study-Act (PDSA)/ Plan-Do-Check-Act (PDCA) Cycle	A process to describe a quality improvement cycle using four-steps: Plan, Do, Study, and Act. It is sometimes referred to as the Shewart Cycle (Walter A. Shewart) or as the Deming Cycle (W. Edwards Deming). Also called Plan-Do-Check-Act (PDCA) Cycle.
Process	An action, or series of actions, that transform inputs into outputs.
Provider	The professional who provides health care services Practitioners are usually required to be licensed as defined by law and include MD, NP, PA. An institution, organization, or person that provides health care services.
Quality Assurance (QA)	A formal set of activities to review and to safeguard the quality of services provided, QA includes quality assessment and implementation of corrective actions to address deficiencies. It is focused on identifying problems, ensuring that standards are adhered to and solving single quality issues with problem resolution focused on the responsible individual. QA is used more in a regulatory environment.
Quality Improvement (QI)	An organizational approach to improving quality of care and services using a specified set of principles and methodologies, including, but not limited to, leadership commitment, staff involvement, cross-functional team approach, consumer orientation, routine performance measurement, and a continuing cycle of improvement activities.
Quality Improvement Team	A cross-functional, specially constituted working group that addresses one specific opportunity for improvement (e.g., quality improvement team to improve the viral suppression). A quality improvement team consists of those people who have regular involvement in the process, a leader, and sometimes a facilitator. A quality improvement team is also called a “project improvement team.”
Quality Management (QM) Plan	A written plan outlining the agency’s quality management infrastructure (including clear responsibilities and accountability for activities) and process for ongoing evaluation and assessment to identify and improve the quality of care.
Quality Management (QM) or Clinical Quality Management (CQM) Program	An umbrella term encompassing all agency-specific quality activities, including organizational quality infrastructure (e.g., CQM committee, QM plan) and quality improvement-related activities (e.g., performance measurement, quality improvement projects).
Quality of Care	The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.
Sampling	A statistical process for selecting the size and frequency of populations under study.
Standard of Care	Performed and agreed upon principles and practices for the delivery of services that are accepted by recognized authorities. The standard of care is based on research (when available) and the collective opinion of experts.
Step Measure	The goal of quality improvement is to improve the outcome of care. If a valid correlation between the process and an improved outcome can be proven, step measures can sometimes be called process indicators or intermediate outcome indicators.

Appendix 2: Quality Improvement Acronyms and Abbreviations

Abbreviation	Definition
AIDS	Acquired Immune Deficiency Syndrome
ART/ARV	Antiretroviral Therapy
CAB	Consumer/Community/Patient Advisory Board
CAC	Consumer/Community/Patient Advisory Committee
CBO	Community Based Organization
CQII	Center for Quality Improvement and Innovation
CQM	Clinical Quality Management
EMA	Eligible Metropolitan Area
EMR	Electronic Medical Record
FQHC	Federally Qualified Health Center
HAB	HIV/AIDS Bureau
HHS	Health & Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
HRSA	Health Resources Service Administration
NYSDOH	New York State Department of Health
PDSA	Plan-Do-Study-Act
PREMS	Patient-Reported Experience Measures
PROMS	Patient-Reported Outcome Measures
QA	Quality Assurance
QI	Quality Improvement
QM	Quality Management
RWHAP	Ryan White HIV/AIDS Program
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
VL	Viral Load
VS	Viral Suppression

Appendix 3: Consumer Involvement Quality Award Winners and Acknowledgements



Consumer Involvement Quality Award Winners

Through the [CQII Quality Award Program](#), CQII has recognized people with HIV and agencies that have made a difference in their organizations through their participation in quality improvement activities. Recent awardees are listed below. To learn more about those award winners and others, visit our [CQII Quality Award Program](#) website.

- **2021 Quality Award Winner—Reachelian Ellison, Houston Regional HIV/AIDS Resource Group, Inc., Houston, Texas**
 - As the consumer relations coordinator at the Houston Regional HIV/AIDS Resource Group (TRG), Reachelian Ellison has significantly enhanced TRG’s ability to deliver quality care and services for people with HIV in and around Houston by implementing a Consumer Engagement Program, the Healthy U Initiative, and an “Education First” approach.
- **2019 Quality Award Winner—Neighborhood Health Services Corporation, Plainfield, New Jersey**
 - To address suboptimal medical appointment adherence, the Neighborhood Health Services Corporation designed and carried out a quality improvement project to address the rates of low adherence to appointments. The group committed to develop an improvement project to increase the adherence rate to 80 percent. They developed a tool to assess reasons for non-adherence, analyzed the results, and then used Plan-Do-Study-Act (PDSA) cycles to test their interventions.
- **2017 Quality Award Winner—Dawn Trotter, Evergreen Health Services**
 - There is no job title for Peer Extraordinaire, yet Dawn Trotter of Buffalo’s Evergreen Health Services (her actual job title: Peer Retention Support Assistant) delivers peer services in her agency and somehow participates in numerous advisory boards focused on patient involvement and quality improvement. While doing all of this, she also got 30 HIV patients back in care over a 6-month period.
- **2017 Quality Award Winner—Randall Furrow, Maricopa County, Phoenix EMA**
 - Randall Furrow has worn, as they say, many hats during his time working on the Phoenix RWHAP Planning Council. He started as a member in 2004 and later became Chair, while simultaneously working on enhancing patient involvement in planning and quality improvement as well as more robust patient self-management.

Acknowledgements

For the development of this Guide, CQII convened an advisory group to provide their knowledge, expertise, and experience. This support included the development of the outline, advice on content, providing real-world examples, and reviewing draft documents. CQII is thankful for their invaluable contributions. CQII also wants to thank Melissa Curry for contributing her powerful poem to be included in this Guide.

Advisory Group:

Martha Cameron, Melissa Curry, Dottie Dowdell, Jeremy Hyvarinen, David Moody, Amanda Norton, Adam Thompson, Dawn Trotter

In addition, we relied on HRSA HIV/AIDS Bureau staff and CQII staff to provide critical information.

HRSA HIV/AIDS Bureau Staff:

Marlene Matosky; Ronald (Chris) Redwood

CQII Staff:

Shaymey Gonzalez, Andrea Mayer, Dennis Pearson, Michelle Pendill, Kehmisha Reid, Clemens Steinbock



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

www.cqii.org