Engaging People with HIV in Quality Improvement: Best Practices to Meaningfully Engage and Involve Patients

Adam Thompson

Jeremy Hyvarinen

Kehmisha Reid, MPH

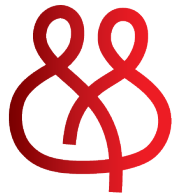2022

NATIONAL
RYAN WHITE
CONFERENCE
ON HIV CARE & TREATMENT

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Adam Thompson, Jeremy Hyvarinen and Kehmisha Reid have no relevant financial interests to disclose.

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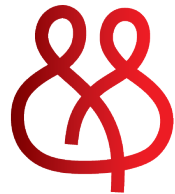
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Center for Quality Improvement & Innovation (CQII)

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  Center for Program Development, Implementation, Research and Evaluation (CPDIRE)

"Together, we continue to improve the lives of people with HIV across the United States. CQII provides state-of-the-art technical assistance and training to Ryan White-funded recipients and subrecipients that measurably strengthen local clinical quality management programs and improve patient care, health outcomes, and patient satisfaction."
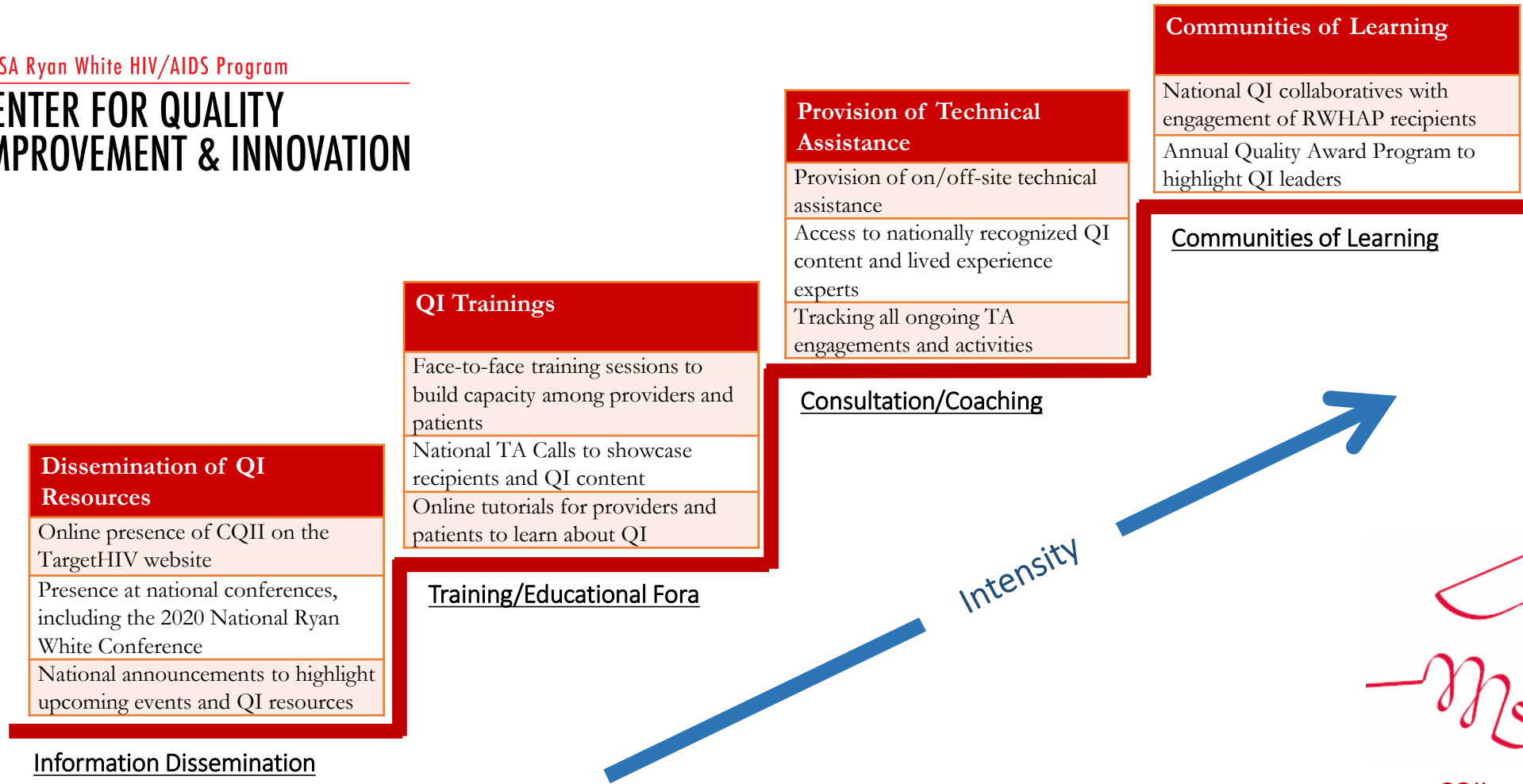
Technical Assistance Levels

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

Dissemination of QI Resources

Online presence of CQII on the TargetHIV website

Presence at national conferences, including the 2020 National Ryan White Conference

National announcements to highlight upcoming events and QI resources

Information Dissemination

QI Trainings

Face-to-face training sessions to build capacity among providers and patients

National TA Calls to showcase recipients and QI content

Online tutorials for providers and patients to learn about QI

Training/Educational Fora

Provision of Technical Assistance

Provision of on/off-site technical assistance

Access to nationally recognized QI content and lived experience experts

Tracking all ongoing TA engagements and activities

Consultation/Coaching

Communities of Learning

National QI collaboratives with engagement of RWHAP recipients

Annual Quality Award Program to highlight QI leaders

Communities of Learning

Intensity

CQII.org | 212-417-4730

Learning Objectives:

At the conclusion, participants will be able to:

1. Understand the importance of people with HIV participation in clinical quality management program activities

2. Learn effective strategies and resources to overcome common barriers in engaging people with lived experiences in quality improvement activities and improve their participation in HIV QI efforts

3. Develop hands-on strategies for receiving meaningful input from people with HIV to improve HIV care
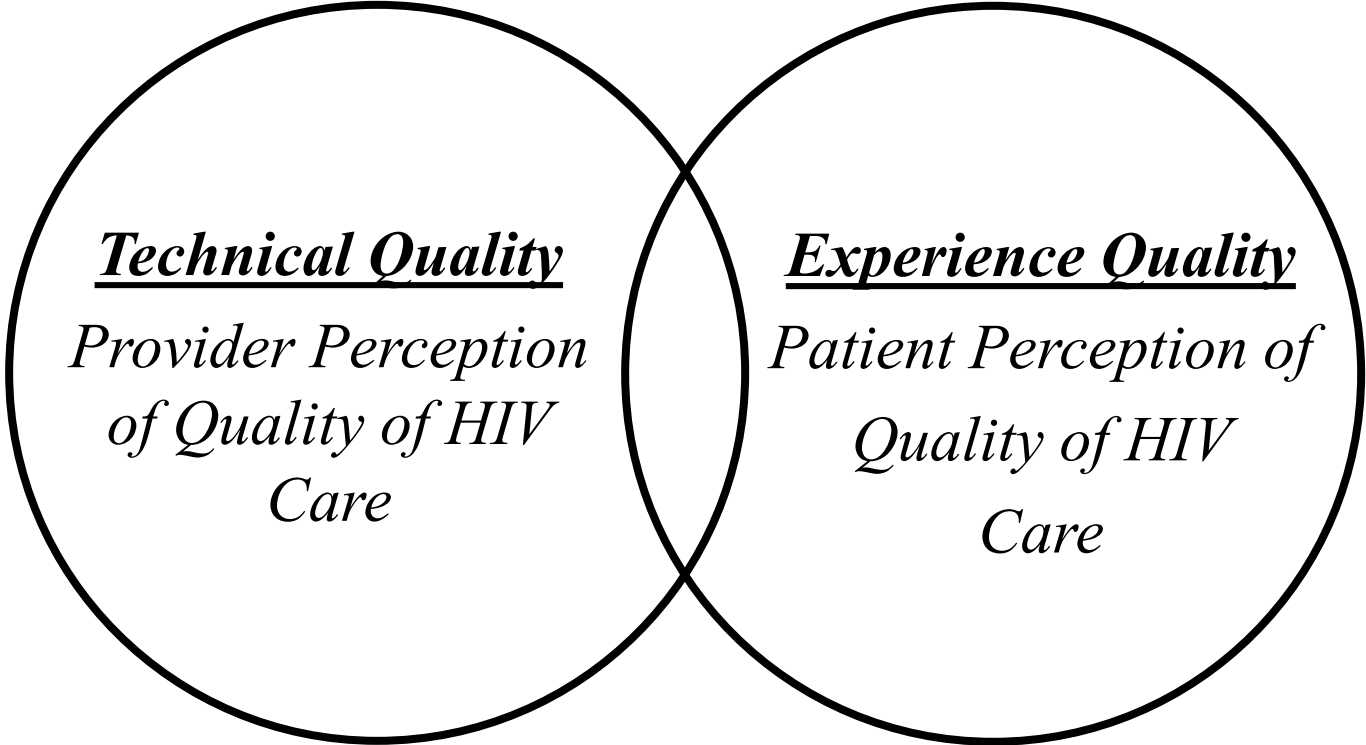
Introductions

Question

1. In your opinion, what impact does involving patients in QI activities have on patients themselves?

History of Involvement & QI

Dimensions of Quality

Technical Quality

Provider Perception of Quality of HIV Care

Experience Quality

Patient Perception of Quality of HIV Care

Leonard Berry, Texas A&M University, IHI conference 2001

History of Involvement

- Fingerprints – The Denver Principles; Authors and Souls

- Blueprints – RWHAP; Drafters and Supporters

- Nuts and Bolts – Community Planning Members

- Betterment – Quality Improvement Advocates, Meaningful Involvement of PLWH
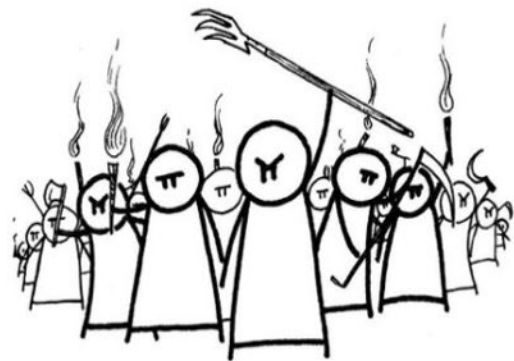
Methods of Involvement

- Agitation
- Activism
- Advocacy

Definitions

- Agitator – 1663
  - One who stirs up public feeling on controversial issues
  - Synonyms: exciter, incendiary, inciter, instigator, rabble-rouser

- Activism – 1915
  - A doctrine or practice that emphasizes direct vigorous action, especially in support of or opposition to one side of a controversial issue

- Advocate – 14th Century
  - One that pleads the cause of another; specifically: one that pleads the cause of another before a tribunal or judicial court
  - One that defends or maintains a cause or proposal
  - One that supports or promotes the interests of another

Then and Now

Patient Quality Advocates

Quality Advocates are …

- Activated patients
- Comfortable with data
- Effective communicators
- Comfortable with technology
- Effective and supportive team members
- Quality improvement literate
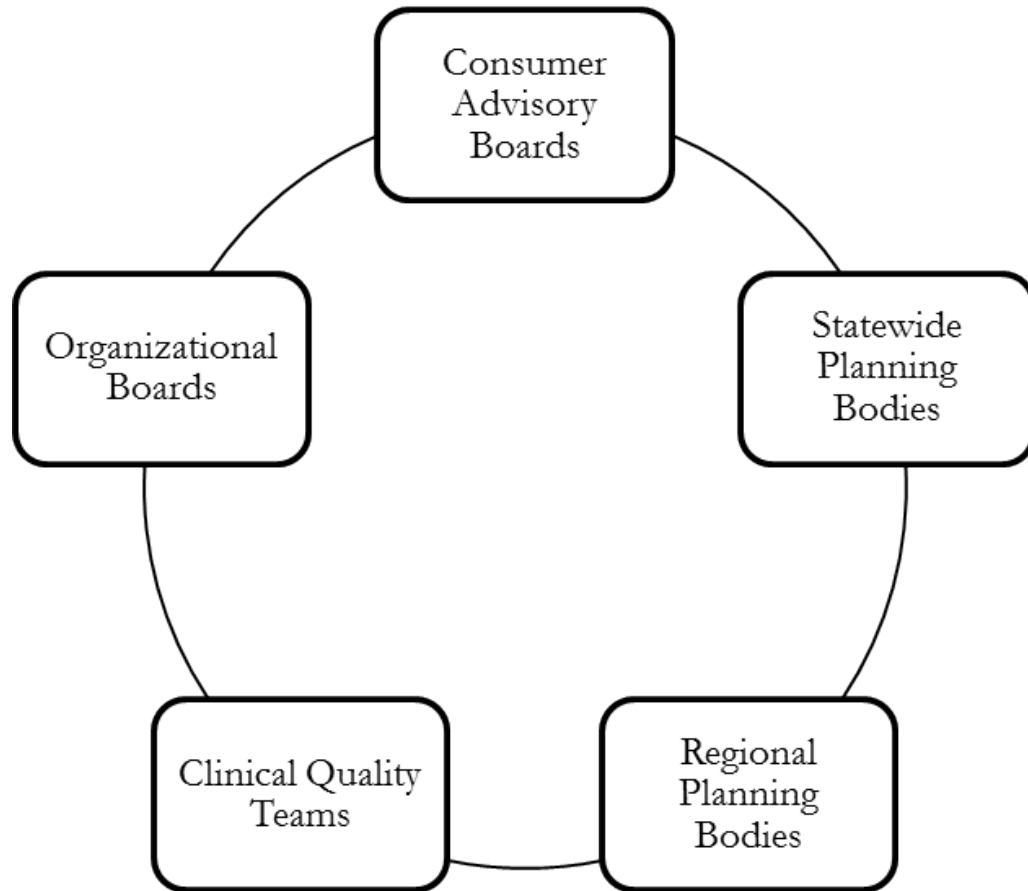
Levels of Involvement in Quality

National

State and Territorial

Jurisdictional

Metropolitan

Clinic and Community-Based

Patient Involvement Structures

- Statewide, National, and International
  - Planning Groups
  - Advisory Groups
  - Technical Expert Panels
- Regional
  - Consortia
  - Planning Councils
- Local
  - Organizational Boards
  - Quality Teams
  - CABs

CABs & QM/QI Teams

Client Advisory Board

- Qualifications
  - Meeting Participation
  - Person Living with HIV
- Expectations
  - Provide Input and Feedback
  - Share Personal Experience
- Make-up
  - Demographic Based

Quality Management Team

- Qualifications
  - Meeting Participation
  - People with HIV
  - Knowledge and Skills of QM
- Expectations
  - Provide Input and Feedback
  - Support QI Activities
  - Team Responsibilities
- Make-Up
  - Skills Based

Patient Involvement: The Body of Research

- The body of patient involvement goes back more than a decade and, while small, it is diverse and growing

- Many of these studies have found that involving patients supports engagement, increases satisfaction, and, in some cases, improves outcomes

Driver Diagram

Aim　　　　　**Primary Drivers**　　　　　**Secondary Drivers**

To improve HIV care and quality of life by increasing the meaningful and equitable involvement of people with HIV in quality improvement activities.

Organizational Design and Governance:
The agency has an environment for systems-level shared decision-making to assess and improve quality of care

- A culture of openness, inclusion, and support enables the input of individuals free of discrimination, stigma, and bias
- Leadership strategically prioritizes the inclusion of people with HIV in QI efforts at all levels
- Policies and procedures are in place to engage people with HIV
- All staff are provided training and tools to create an environment that supports and values patient contributions
- Boundaries are in place to assure patient confidentiality
- A mindful and healthy meeting culture promotes the importance of self-care and emotional wellness to prevent burnout

Culturally Responsive Training and QI Onboarding:
Systems are in place to actively engage and support people with HIV in QI efforts and staff are competent in community engagement skills and methods

- Knowledge/skills of people with HIV and staff are assessed to co-produce improved health outcomes and experiences
- Trainings on key QI topics and on community engagement skills and methods are provided
- All participants in QI efforts are actively onboarded
- Individualized support and coaching are provided to further develop QI capacities and content expertise
- People with HIV are prepared for employment opportunities

Compensation for Time and Effort:
The involvement of people with HIV with diverse backgrounds is equitably compensated

- Multiple methods are used to reach a diverse group of people with HIV for their input, guidance, and involvement
- Financial support, including travel, childcare, meals, and equal compensation is provided to people with HIV for their involvement in QI efforts, including stipends or gift cards
- People with HIV are hired as staff for roles that support patient involvement, including training, surveying, or data collection
- Patients are mentored in their role and opportunities for exchanges with others are provided to learn from each other

Measurement of Patient Involvement and Dissemination:
The impact of engaging people with HIV in QI efforts is measured and the results are widely shared with all stakeholders

- Efforts of patient involvement are well documented, and data are collected to indicate its impact
- Contributions of people with HIV are widely acknowledged and recognized in internal and external communications
- Successes of patient involvement activities are openly celebrated with patients and staff
- Past findings are utilized to make routine adjustments to processes of patient recruitment, onboarding, training

The Impact of Patient Involvement

- Patients provide input, suggest changes, and work with health care professionals/planners throughout the change process

- Patient involvement can put the focus on the patient experience – not just that the services were delivered but how the patient perceived them

- Focusing on patient experience, and not just the process or system, incorporates the subjective

- Collecting and analyzing patient experiences should be a formal process so that these data can be incorporated into subsequent changes processes.

- A focus on function will ensure that services are user friendly while the design of services retain their safety and functionality

Engagement of People with HIV
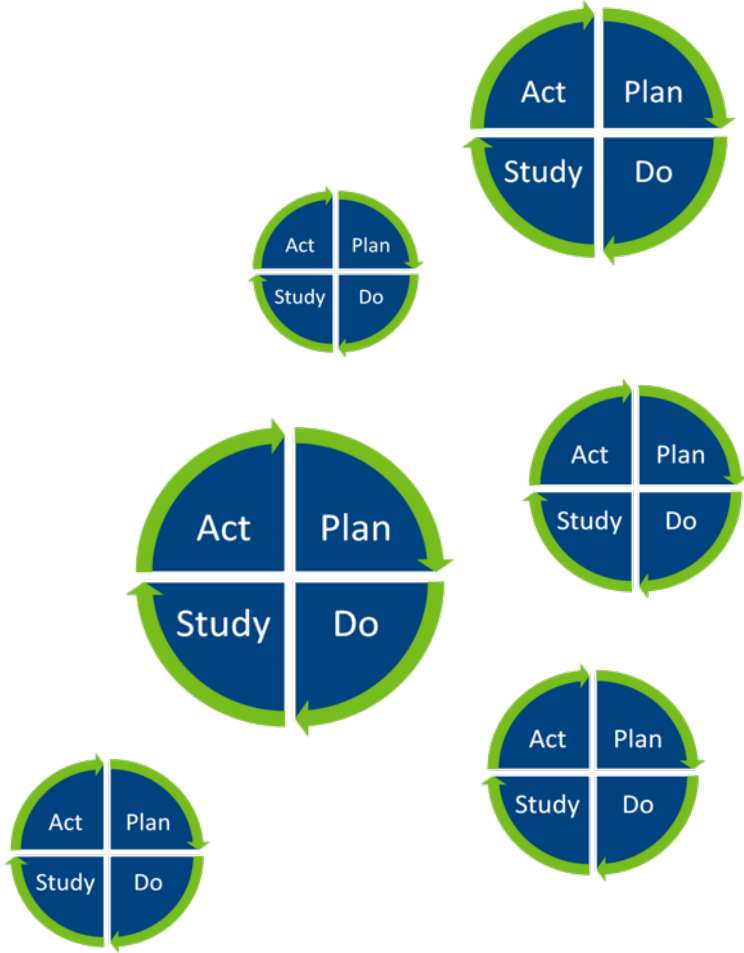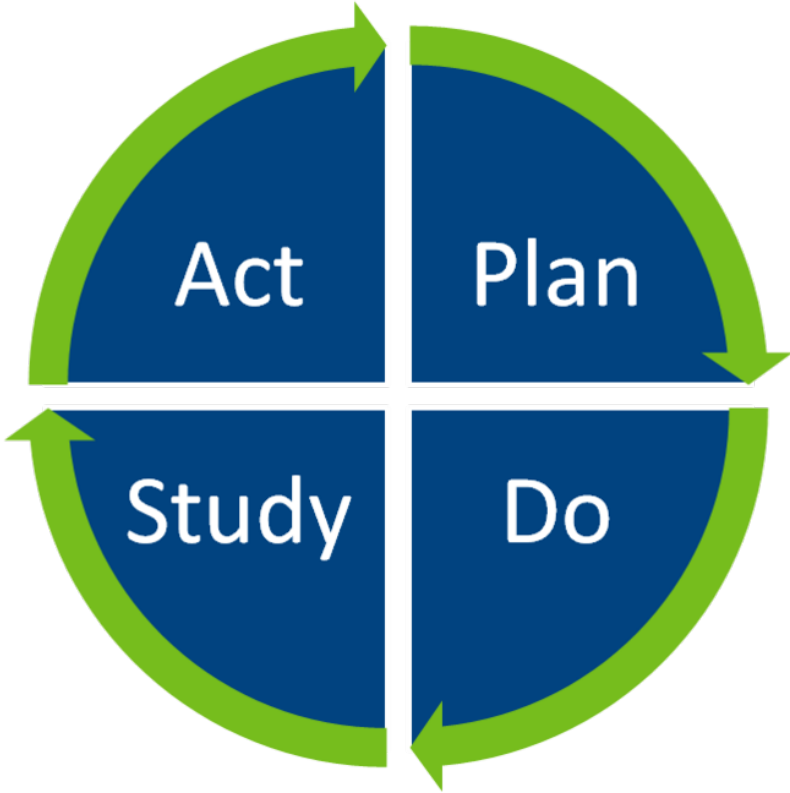
QI Patient Engagement

- Patient Representative on Clinical Quality Management Committee or Quality Improvement Team

- Participation on a Community/Patient/Client Advisory Board

- Membership or participation in jurisdictional planning bodies
  - Integrated Planning Bodies, Planning Councils

- Participation in focus groups, key informant interviews, patient/client experience surveys

Spotlight

National Ryan White Conference on HIV Care & Treatment

What does engagement and involvement look like during a quality improvement project?

# Examples of Involvement in QI Tools and Activities

- Cause and Effect Diagrams

- Brainstorming

- Case Conferencing

- Prioritization Matrix

- Tailoring and Adaptations

- Implementation

Cause and Effect Diagrams

- A Root Cause Analysis (RCA) is a critical step in the quality improvement process helping a team refine and understand the problem(s) facing their systems
- A Root Cause Analysis can be conducted using a tool like a Fishbone Diagram
- People with HIV can be involved in the Root Cause Analysis by:
  - Participating during the Fishbone Analysis with the QI Team
  - Participating as part of a Patient/Client Fishbone Analysis used for comparison

Fishbone Diagram Example
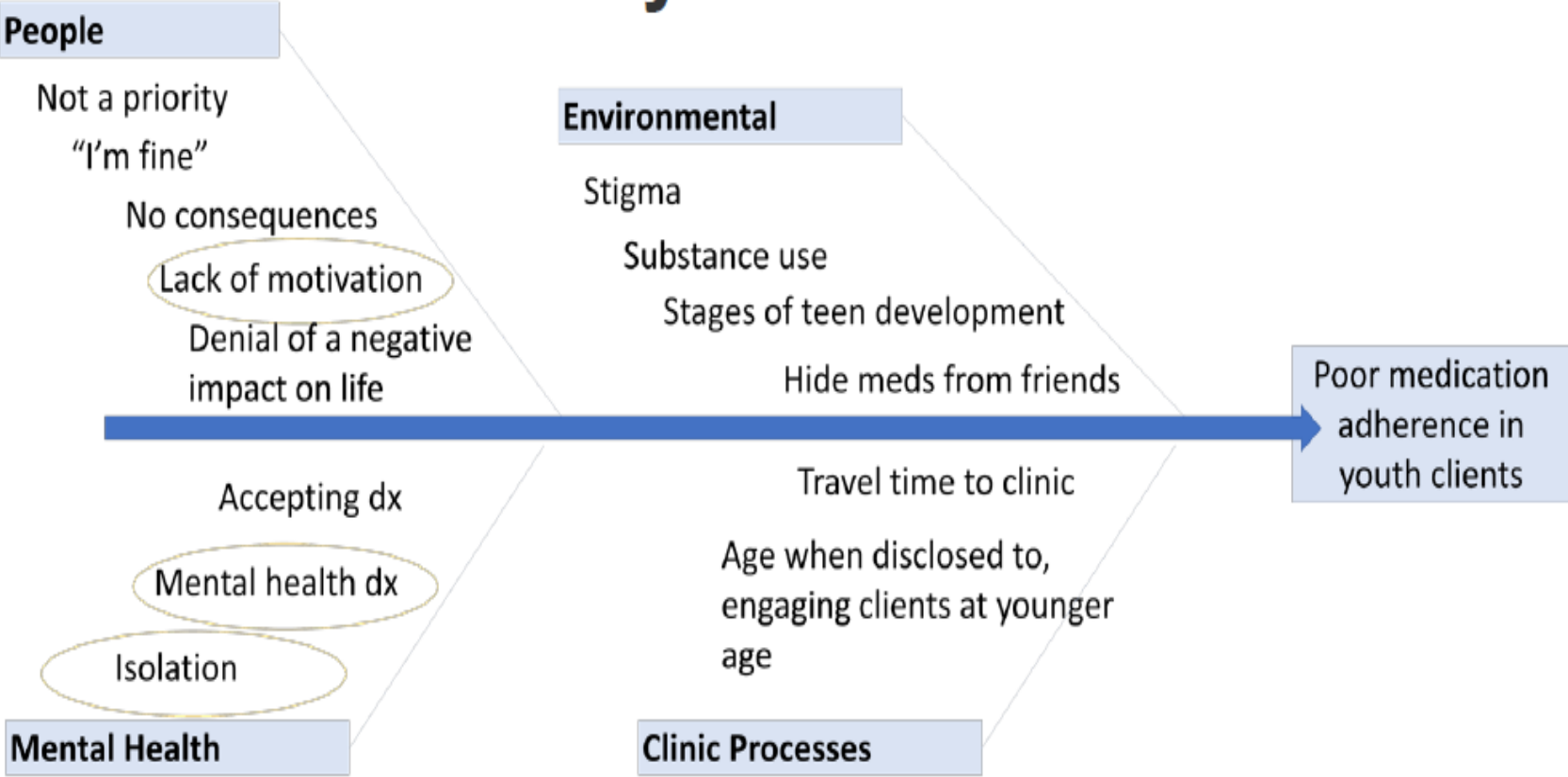
Brainstorming

- Another step in the quality improvement process is ideation – producing changes or interventions which could drive improvement

- People with HIV can be helpful during ideation because we are closest to the barriers and bring experiential knowledge of real-world challenges

- A "Drill-Down" is a process which a clinic goes through to identify barriers to care and solutions for overcoming them

- People with HIV can participate in Drill-Down activities to support more creative brainstorming and solutions!

Case Conferencing

- A clinic using a case conference to conduct a drill-down reviewed a patient with HIV

- The woman is a long-term survivor with a history of intermittent adherence; she does not enjoy the medications and worries they are too toxic

- The care team has spoken to her many times about the importance of her medication and now it's even more important with her CD4 count dropping as her viral load increases

- The care team is looking for ideas on how to approach the situation ... what would you do?

Prioritization Matrix

- After ideation, quality improvement teams must decide which idea or intervention will be the focus of the project
- Determining which idea will be tried first can be a collaboration opportunity for RWHAP programs and people with HIV
- People with HIV could be polled, surveyed, or participate in a process, which would help determine which idea to try
  - Polling and PACE Charts are different methods to drive prioritization

Polling & Pace Charts
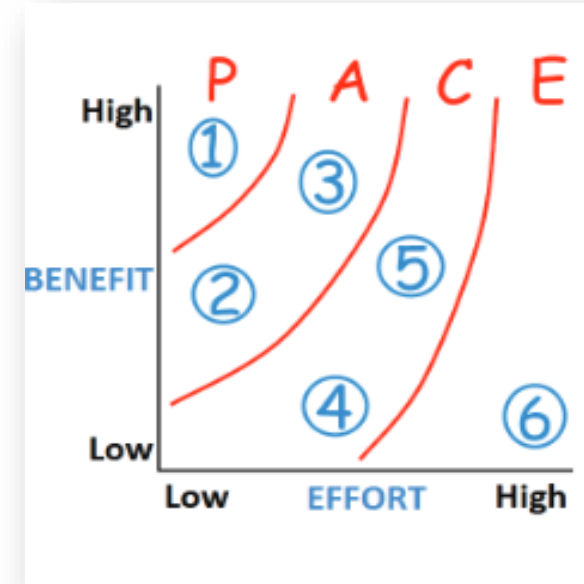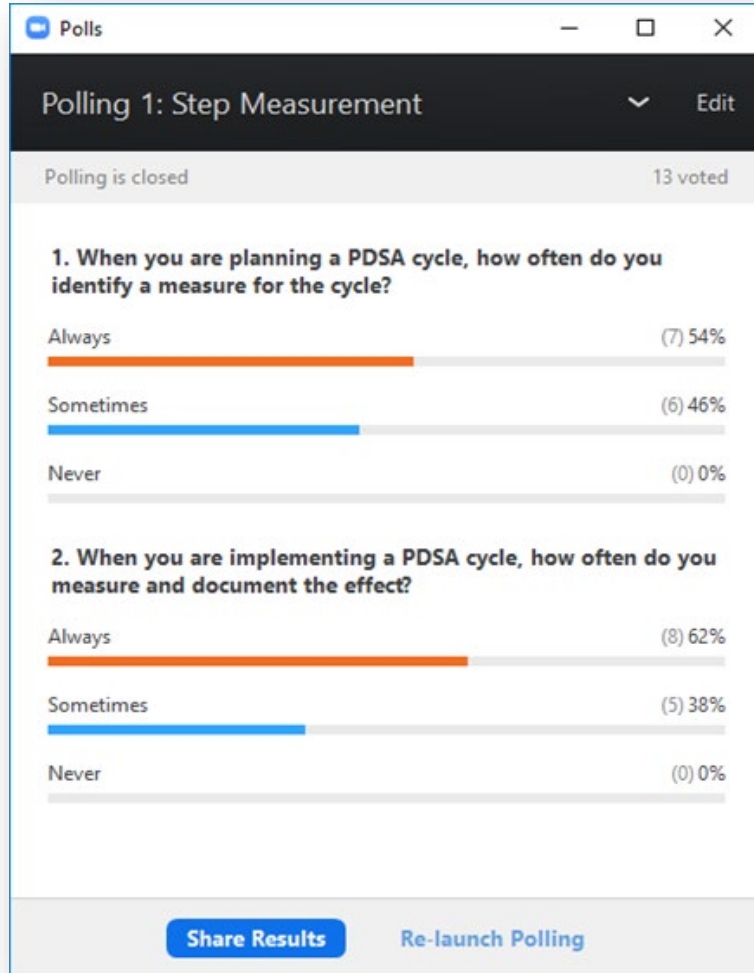
Key:

P	Prioritize; within 30-45 days
A	Action; act on these ideas as soon as the priority items have been implemented
C	Consider; keep these ideas on the radar for possible activity in the future
E	Eliminate; these ideas will not significantly benefit the organization and require too much effort to implement.

Tailoring and Adaptation

- Ensuring cultural responsiveness of services is a strategy to address HIV-related health disparities

- People with HIV serve as cultural brokers between systems and communities and can ensure that materials and interventions are acceptable to the community and appropriate to the real barriers facing patients

- Supporting projects that aim to increase communication – such as text-messaging – can help ensure the cultural responsiveness of the interventions and the messaging

Implementation

- The implementation of peer programs is one strategy being used to improve services in RWHAP

- People with HIV can serve in formal and informal roles supporting other people with HIV through navigation and emotional support

- The use of people with HIV in the delivery of health services is growing in the form of Peer Mentors, Peer Navigators, and Community Health Workers

- People with HIV can also support and inform the development of peer programs to ensure they are reflective of and acceptable to the community

The Patient Involvement Spectrum

Domains of the Patient Involvement Spectrum

- **Emphatic Listening**: Cultivating empathy among staff members and creating ways to collect and listen to patient experiences and stories helps to integrate these qualities into the organizational culture

- **Gathering Perspectives and Insights**: Actively soliciting information from patients about their current lives, individual needs, expectations and 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

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.

- 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, but it is recommended that they be compensated for their work.

- *Examples: empathy mapping, collecting and sharing patient stories, Language of Caring training*

Gathering Perspectives and Insights

- This domain focuses on actively soliciting information from patients about their current lives, individual needs, expectations and 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 in a paid capacity, to collect this information from patients. For some of these activities, such as the data analysis and writing of reports, hiring consultants may be the best option

- *Examples: surveys, focus groups, interviews*

Engaging in QI Activities

- Going beyond collecting patients' perspectives and observations, this domain involves them as equal members in various aspects of local quality improvement and clinical quality management

- To fully participate, patients may need training in quality improvement processes, data collection, and analysis, and developing solutions to identified issues

- 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

- *Examples: participant in improvement activities, member of QI team, clinical quality management committee member*

Co-Design and Leadership

- This domain focuses on the involvement of people with lived experience 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

- People with lived experience can be actively involved in co-producing and leading organizational activities to improve patient care, health outcomes, and health care experiences

- *Examples: Patient/Client Advisory Board member, Board of Directors, experience-based co-production of activities*

Assessing Patient Involvement

The Missouri Ladder

- Developed by Missouri during the HIV Cross-Part Care Continuum Collaborative (H4C)

- Missouri sought to answer the questions:
  - Where are persons with HIV in our state involved?
  - How are persons with HIV in our state involved?
  - How SHOULD people get involved, and in what order?

- Used as a guide to support patient decision-making in involvement structures as well as an assessment of current involvement for improvement activities

Beginner Involvement

Consumer Involvement Matrix of Statewide Activity							
Type of Involvement	**St Louis Region**	**KC Region**	**Southwest Region**	**Central Region**	**Northwest Region**	**Southeast Region**	**Statewide**
Beginner Involvement							
Talk to your health care team: • Provider • Nurse • Case Manager • Peer Educator • Pharmacy							
Review of Common Acronyms							
Provide your feedback through the client survey in clinic (quality driven)							
Read the literature: • Brochures • Newsletters • Magazines • Online resources							

Intermediate Involvement

Consumer Involvement Matrix of Statewide Activity

Type of Involvement	St Louis Region	KC Region	Southwest Region	Central Region	Northwest Region	Southeast Region	Statewide
Intermediate Involvement							
Attend CABs or PACs as an observer							
Attend Planning Council meetings as an observer							
Attend any advocacy boards							
Complete the National Quality Center's consumer-focused tutorial as part of our consumer track in the quality academy							
Attend chronic disease self–management classes							

Advanced Involvement

Consumer Involvement Matrix of Statewide Activity							
Type of Involvement	**St Louis Region**	**KC Region**	**Southwest Region**	**Central Region**	**Northwest Region**	**Southeast Region**	**Statewide**
Advanced Involvement							
Become a member of CABs, CACs and /or PABs at Provider or Clinical Level							
Become a member of CABs at Recipient (Grantee) Level							
Become a member of Planning Council and/or Sub-Committees							
Become a member of a Quality Advisory Group or QI Team							
Continued Training, QI Skill Building via Grantee and NQC (TCQ, Additional Quality Academy tutorials)							

Expert Involvement

Consumer Involvement Matrix of Statewide Activity

Type of Involvement	St Louis Region	KC Region	Southwest Region	Central Region	Northwest Region	Southeast Region	Statewide
Expert Involvement							
Lead and facilitate a Consumer Group							
Represent your jurisdiction Regionally							
Represent your jurisdiction on the MO Statewide QI team							
Public speaking on elements of QI or training other consumers on QI							
Represent your jurisdiction nationally							

Effective Patient Involvement

Recruitment and Retention

- Recruitment:
  - Get the word out
  - Encourage staff referrals
  - Make it easy

- Retention:
  - Welcoming work environment
  - Say "Thank you" and recognize their contribution
  - Train for success and provide compensation, if possible
  - Value their time and make participation easy
  - Treat as a colleague

Training and Capacity Building

- Basic training in quality improvement can lay the foundation for all participants

- Depending on the project, more specific quality improvement training can help to ensure that all team members, including patients, are:
  - Engaged in the process and have the understanding and skills to fully participate in all aspects of the improvement activity or project; and
  - Have the confidence to express their views and are supported in an environment where their views are valued.

Compensation and Recognition

- Patients are sharing their skills and life experience. This knowledge should be valued, appreciated, and compensated. There are various ways to make sure that patients are compensated for their input.
  - **Volunteers**: Incentives for volunteers could include gift cards, covering expenses related to participation, or providing snacks and/or meals
  - **Consultants**: When a patient is making a significant and ongoing contribution of time and expertise, consider contracting with that individual as a consultant. Patients may need help understanding their role and processes like invoicing
  - **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, and as ongoing members of CQM committees

Patient Self-Care

- 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

- Patient participants should be made aware of the importance of self-care during patient involvement orientation and training activities

- **Burnout**, **stigma**, and **trauma** can all affect patient participants, but can be mitigated

Documenting and Evaluating Patient Involvement

- Documenting and evaluating patient involvement activities 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
  - **Process Evaluation**
  - **Quantitative Evaluation**
  - **Qualitative Evaluation**
- Data and outcomes should always be shared with patients, even when efforts do not turn out as expected

Common Barriers and Solutions

Barrier #1: Time

"Patients don't have the time to participate in activities"
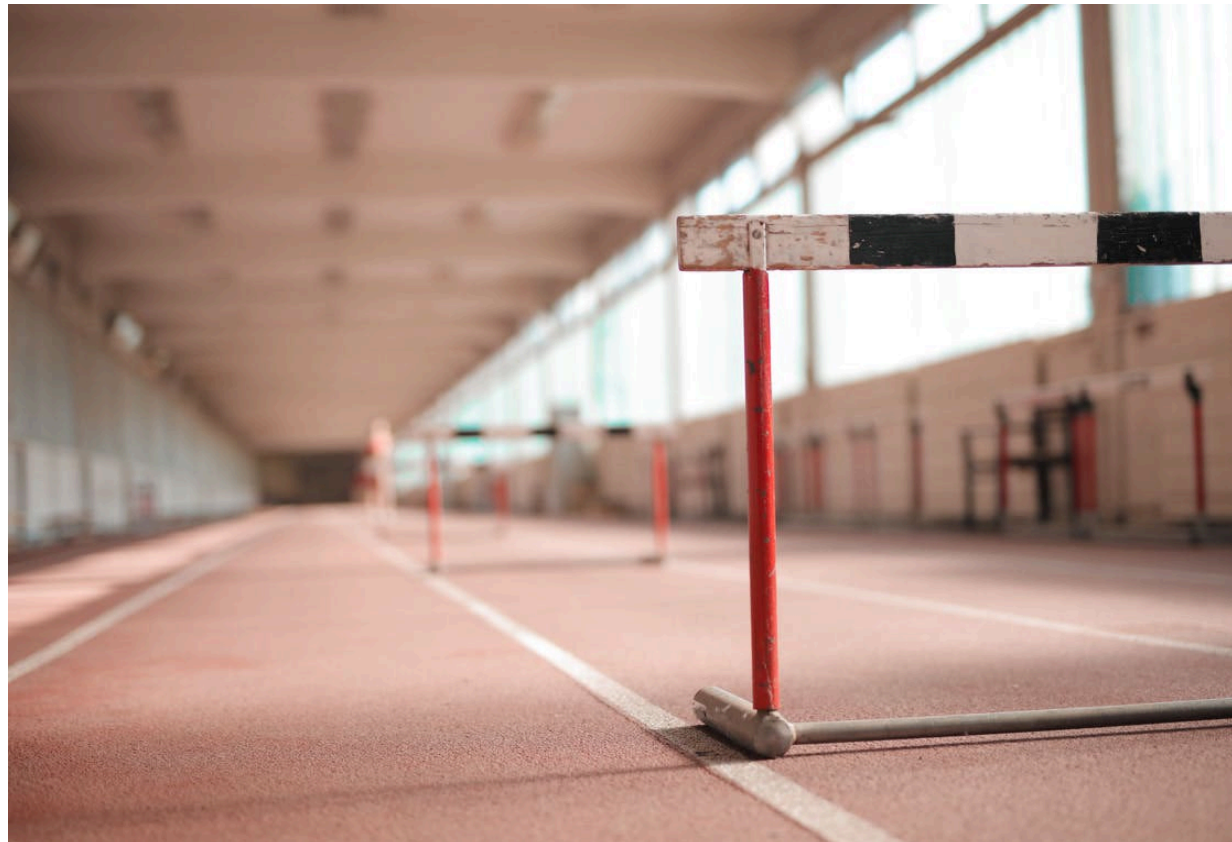
Solution #1: Offer Levels of Commitment

Level of Commitment	Examples of Activities
One time	Focus group Surveys Voting (i.e. encouragement token saying) Trauma-informed care environmental walk through
Short term/Medium range	Stories project (i.e. "Positive Voices") QI Interventions
Long term/On-going	Client Advisory Board (CAB) QI Committee Patient Advocates/Peer Navigators Program assistance (i.e. Pantry help)

Barrier #2: No Interest

"Patients aren't interested in QI activities"

Solution #2: Vary the Activities

- Have realistic expectations: not all patients can be involved for the duration of an entire project

- Different skills and talents can be used for different parts of QI activities
  - **Planning:** Those interested in identifying issues and offering their opinions/feedback
  - **Designing:** Those interested in developing solutions to the problems and who show creativity in brainstorming ideas
  - **Implementing:** Those interested in working with people directly to help improve health outcomes

- Stop looking for your QI soul mate; start looking for ways to involve multiple patients at different stages

Barrier #3: Intimidation

"Patients don't feel qualified to help with QI activities"

Solution #3: Know Your Audience

Building Relationships

- Know your patients and their interests, talents

- Listen to patients

- Provide opportunities and options for differing levels of comfort (in-person or anonymous)

Promoting Opportunities

- Do you promote opportunities?

- How is it being promoted?
  - Language used?
  - Personal invitation?

- Have you asked patients how to promote it?

Encouragement Tokens

Encouragement token given to patients at our clinic

"Positive Voices" Video Example

https://youtu.be/tsqIM1r6jAg

Q&A

CQII at the RW Conference

Other CQII Workshops

- Advanced QI: Advanced QI Tools to Improve Your Clinical Quality Management Program: Learn from Lean and Statistics [ID#: 20467]
  - ➢ August 25th, 3:30pm – 5:00pm ET

- Patient Involvement in QI: Engaging People with HIV in Quality Improvement: Best Practices to Meaningfully Engage and Involve Patients [ID#: 20468]
  - ➢ August 25th, 3:30pm – 5:00pm ET

- PROMS/PREMS: Incorporating the Patient Voices in Quality Improvement: PROMS and PREMS – An Emerging QI Topic [ID#: 20003]
  - ➢ August 25th, 3:30pm – 5:00pm ET

- Creating Equity Using Quality Improvement to Make a Measurable Difference: Interventions from the create+equity Collaborative [ID#: 20469]
  - ➢ August 25th, 11.15am – 12:45pm ET

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Contact Information

Contact Information

Kehmisha Reid, MPH
Sr. Program Coordinator, CQII
New York State Department of Health
AIDS Institute
90 Church Street, 13th Floor
New York, NY 10007-2919
212.417.4730 (main)
212. 417.4554 (direct)
Kehmisha.Reid@health.ny.gov

Jeremy Hyvarinen
Quality Manager
Ryan White Part A Program
4041 N. Central Ave, Suite 850 |
Phoenix, AZ 85012
C: (602) 647-2996
Jeremy.Hyvarinen@maricopa.gov