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CONFERENCE ON
HIV CARE & TREATMENT

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

Kneeshe Parkinson

Dawn Trotter

Dan Wakefield

Adam Thompson



Learning Objectives:



- At the end of this session, participants will:
 - Understand the importance of people with HIV participation in clinical quality management program activities
 - Learn effective strategies to overcome common barriers in engaging consumers in quality improvement activities
 - Know where to access resources to improve participation of people with HIV in quality improvement efforts
 - Develop hands-on strategies for receiving meaningful input by people with HIV to improve HIV care

Dedication



In loving memory of
Deloris Dockrey.

We continue this work
guided by your spirit, love,
and laughter.

You will be forever missed
and loved.

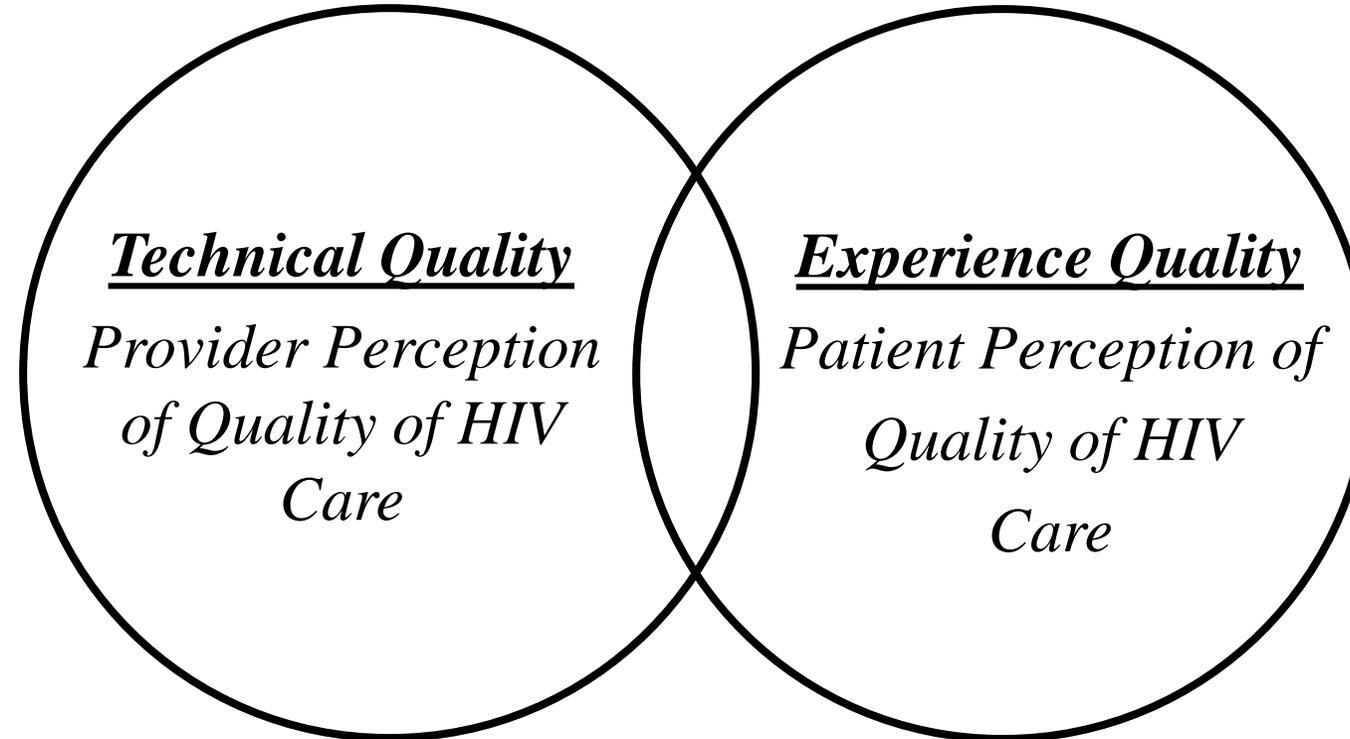


History of PWH Involvement & QI

Dimensions of Quality



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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

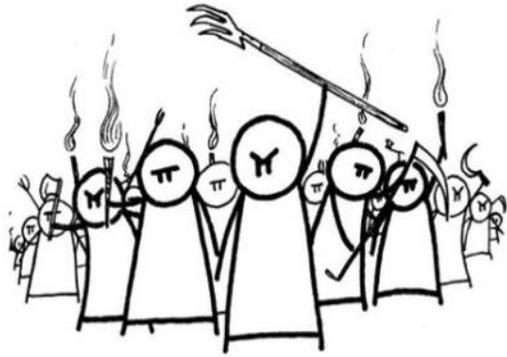


- Agitator – 1663
 - One who stirs up public feeling on controversial issues
 - Synonyms: exciter, incendiary, inciter, instigator, rabble-rouser
- Activism – 1915
 - A doctrine or practice that emphasizes direct vigorous action, especially in support of or opposition to one side of a controversial issue
- 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



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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



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National

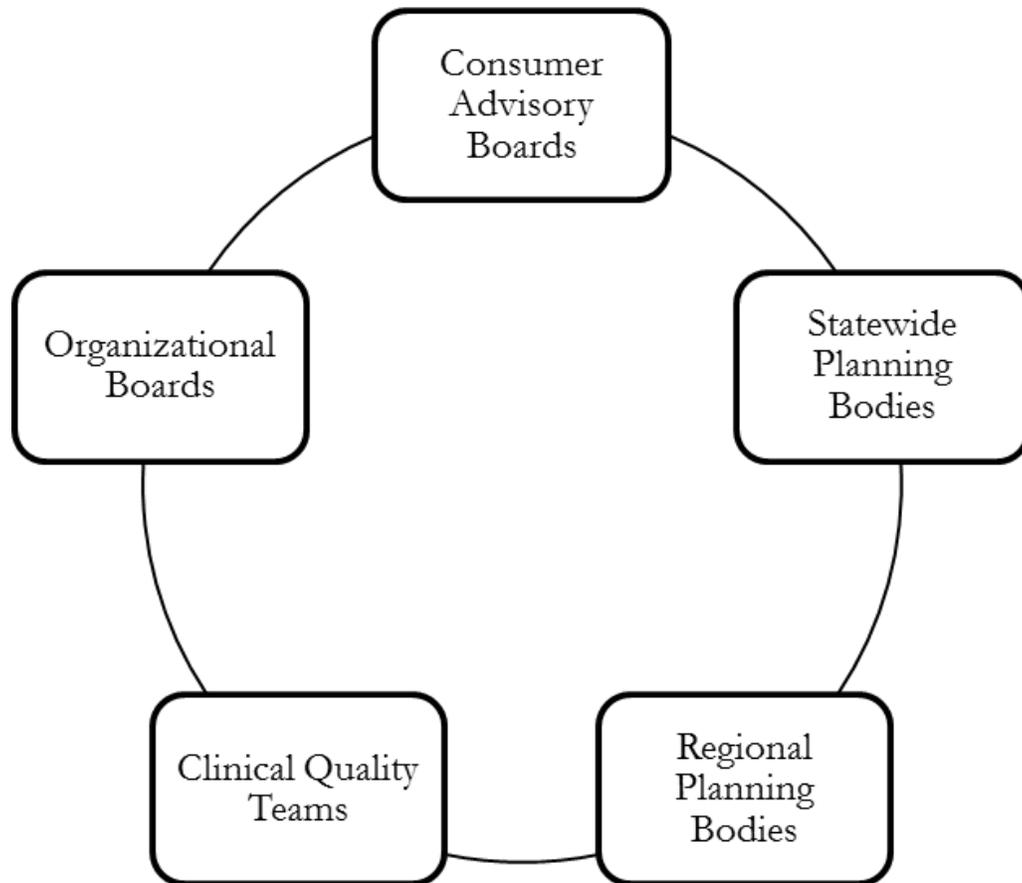
State and Territorial

Jurisdictional

Metropolitan

Clinic and Community-Based

Patient Involvement Structures

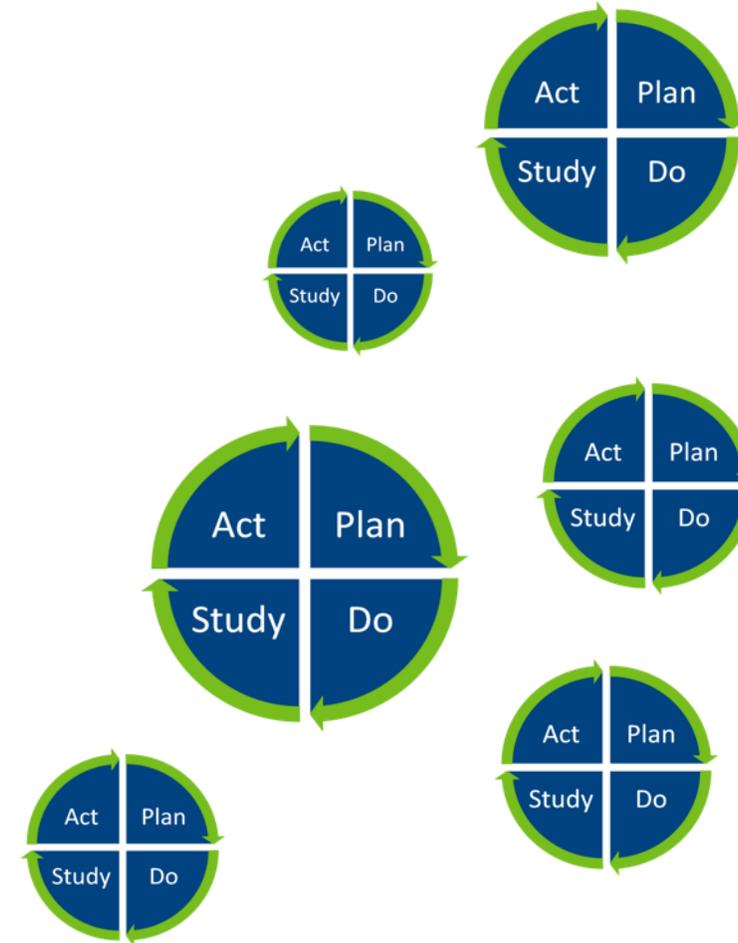


- Statewide, National, and International
 - Planning Groups
 - Advisory Groups
 - Technical Expert Panels
- Regional
 - Consortia
 - Planning Councils
- Local
 - Organizational Boards
 - Quality Teams
 - CABs

The goal is to incorporate
Patients and **Patient Experiences**
into quality improvement activities

Engagement of PWH with QI Tools

RWHAP Providers and Systems

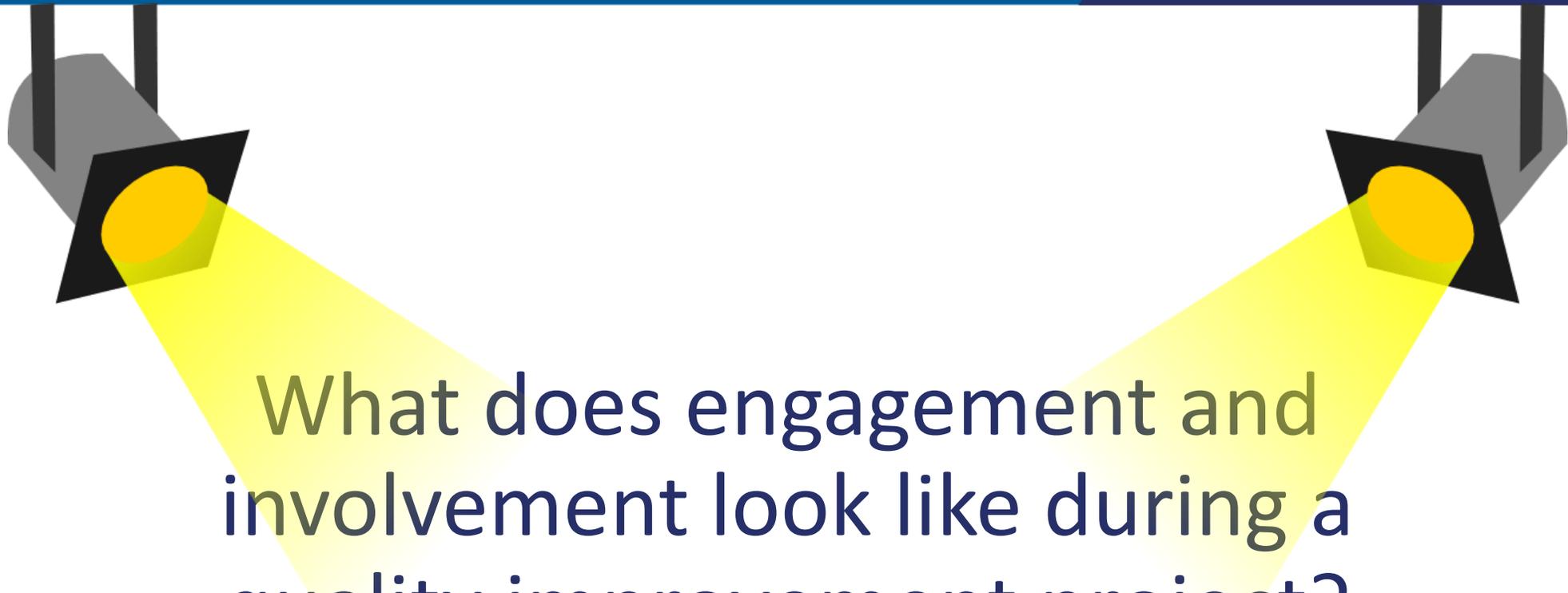


Quality Improvement Patient Engagement



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- Patient Representative on Clinical Quality Management Committee or Quality Improvement Team
- Participation on a Community/Patient/Consumer Advisory Boards
- Membership or Participation in Jurisdictional Planning Bodies
 - Integrated Planning Bodies, Planning Councils
- Participation in Focus Groups, Key Informant Interviews, Patient/Client Experience Surveys



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

Examples of PWH Involvement in QI Tools and Activities



- Cause and Effect Diagrams
- Brainstorming
- Case Conferencing
- Prioritization Matrix
- Tailoring and Adaptations
- Implementation

Cause and Effect Diagrams

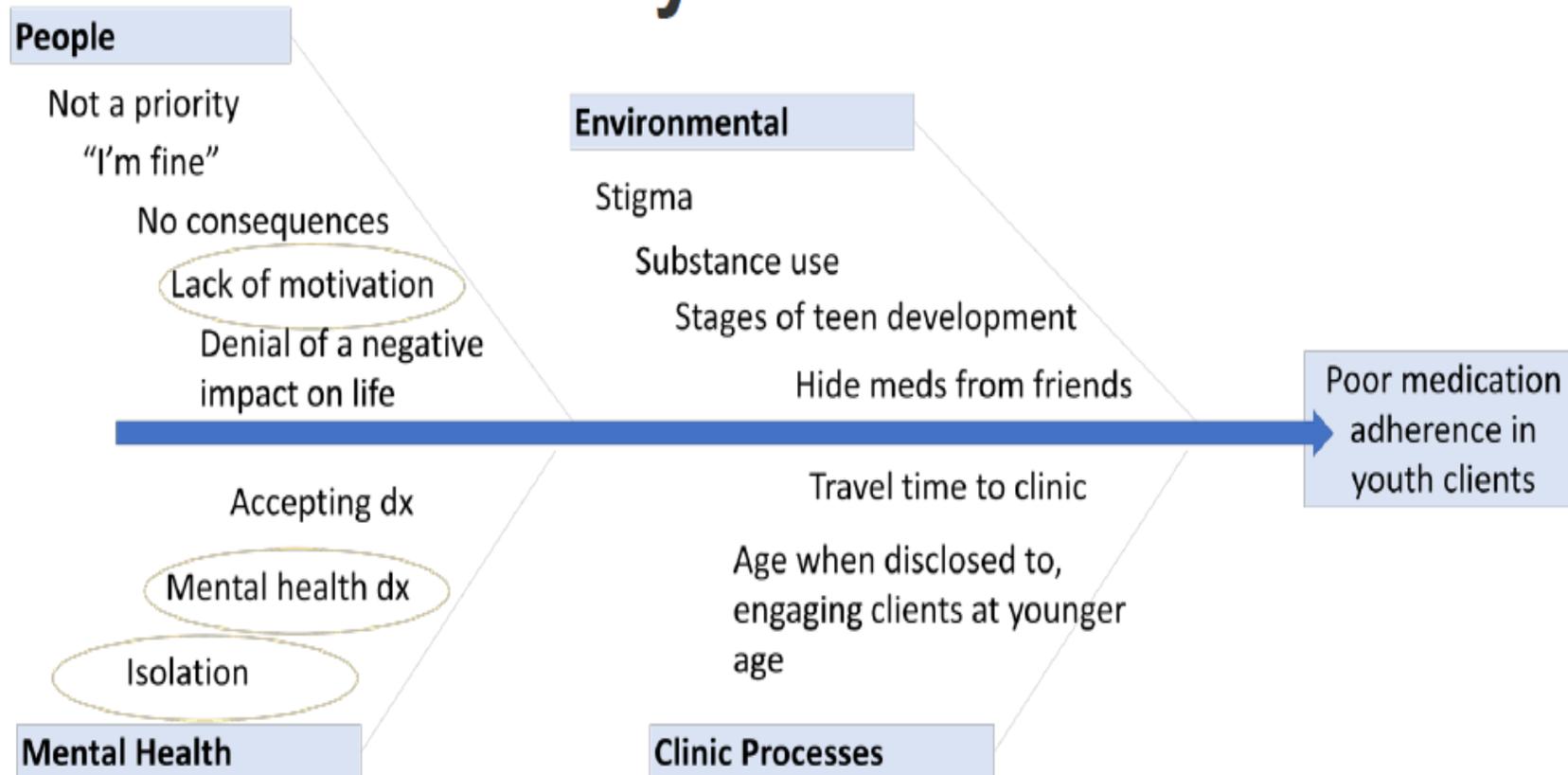


- A Root Cause Analysis (RCA) is a critical step in the quality improvement process helping a team refine and understand the problem(s) facing their systems
- A Root Cause Analysis can be conducted using a tool like a Fishbone Diagram
- PWH can be involved in the Root Cause Analysis by:
 - Participating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

Fishbone Diagram Example



Key Causes



Brainstorming



- Another step in the quality improvement process is ideation – producing changes or interventions which could drive improvement
- PWH 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
- PWH can participate in Drill-Down activities to support more creative brainstorming and solutions!

Case Conferencing



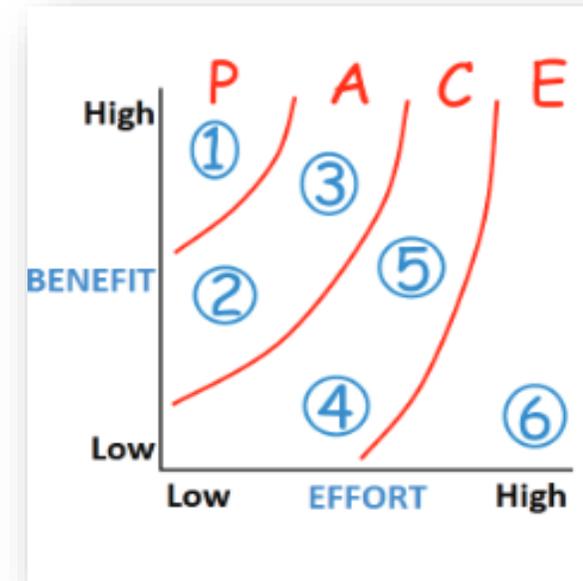
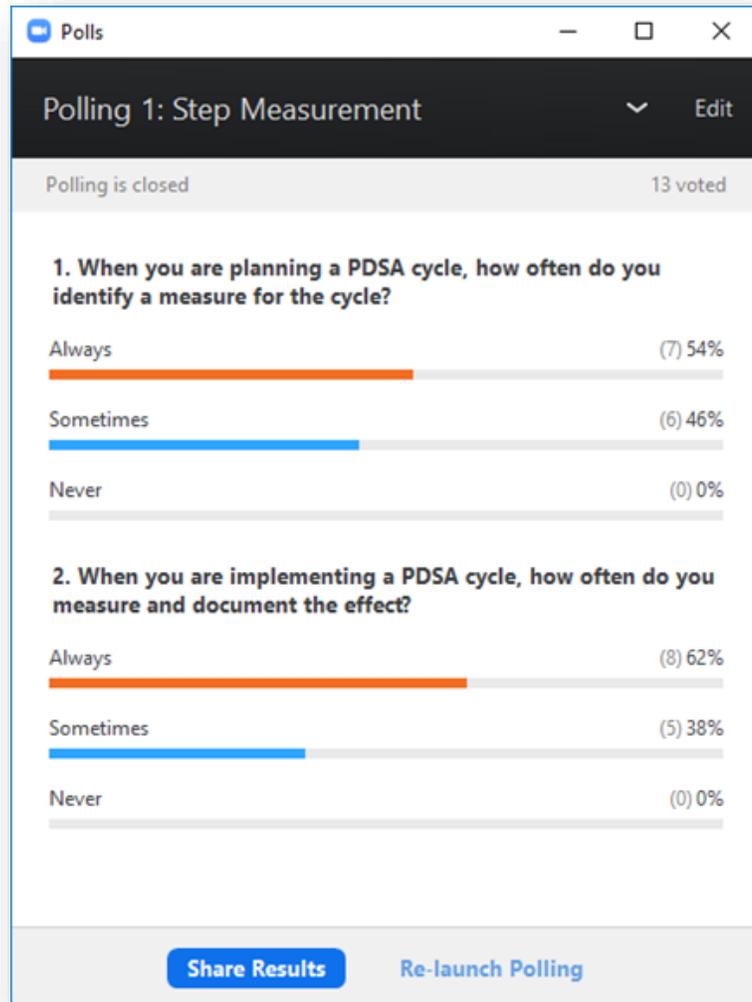
- A clinic using a case conference to conduct a drill-down reviewed a patient with HIV
- The woman is a long-term survivor with a history of intermittent adherence; she does not enjoy the medications and worries they are too toxic
- The care team has spoken to her many times about the importance of her 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 PWH
- PWH 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
- PWH 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
- PWH can serve in formal and informal roles supporting other PWH through navigation and emotional support
- The use of PWH in the delivery of health services is growing in the form of Peer Mentors, Peer Navigators, and Community Health Workers
- PWH can also support and inform the development of peer programs to ensure they are reflective of and acceptable to the community



Assessing PWH Involvement

The Missouri Ladder

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 consumer 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: <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> • 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							

Quality Advocates

Dawn Trotter

Dan Wakefield

Kneeshe Parkinson

Getting Support Giving Support

Dawn Trotter

Experience in HIV Groups

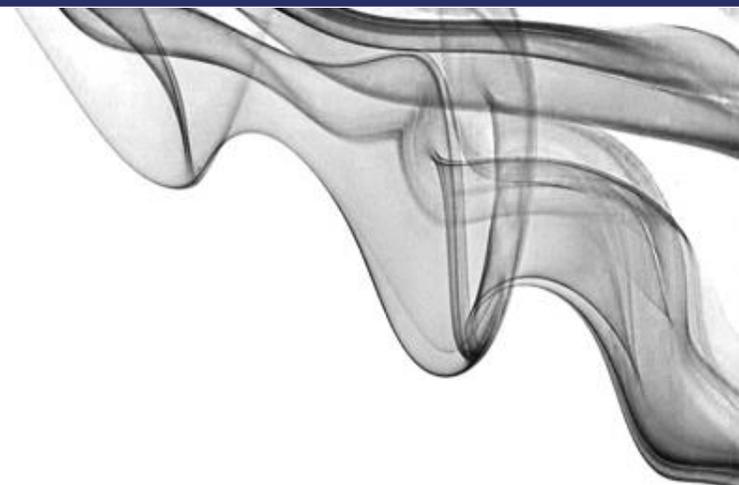


Dawn Trotter

Patient Adherence Specialist

Evergreen Health

Buffalo, New York



Overwhelmed: Before Getting Help



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FAMILY



psycholog
addiction. no
particular
habit-for



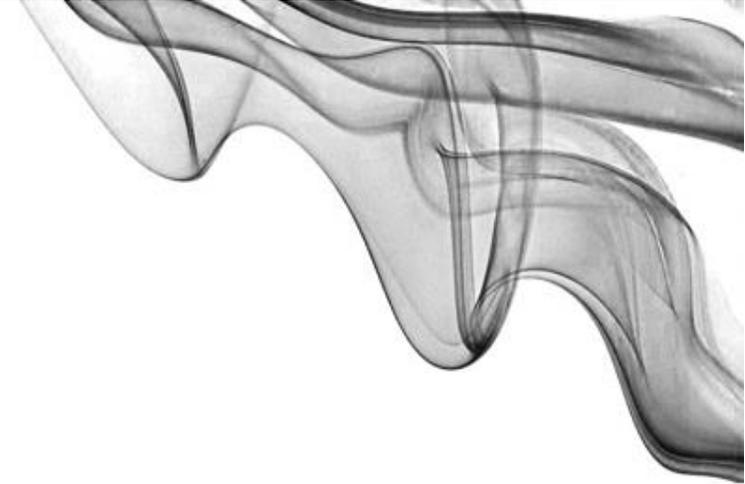
WORK



Diagnosis



Reaching Out: My First Support Group



Taking the Lead: Starting My First Group



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Sisterhood: Starting my Women's Group



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Support Groups Impact on Consumer Involvement & Engagement



- An effective strategy to engage community in QI or CQM activities
- Builds a sense of community and peer-sharing/learning
- Combat stigma by sharing our stories/experiences together
- An opportunity to share resources to improve participation among PWH in QI efforts



Overcoming Barriers for Consumer Involvement

Dan Wakefield – Ursuline Center in Youngstown, OH

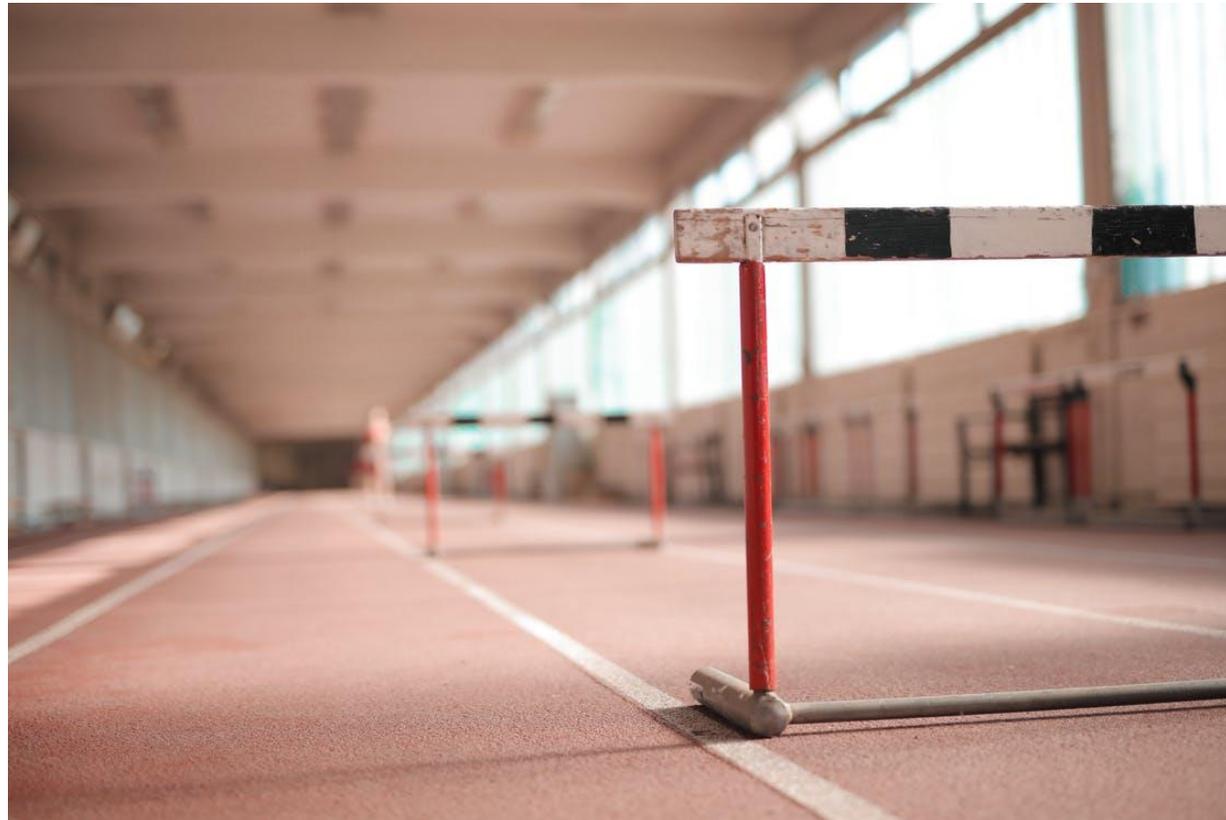
Objectives



- Objective #2: Learn effective strategies to overcome common barriers in engaging consumers in quality improvement activities
- Objective #4: Develop hands-on strategies for receiving meaningful input by people with HIV to improve HIV care

Barrier #1: Time

“Consumers don’t have the time to participate in activities”



Solution #1: Offer Levels of Commitment



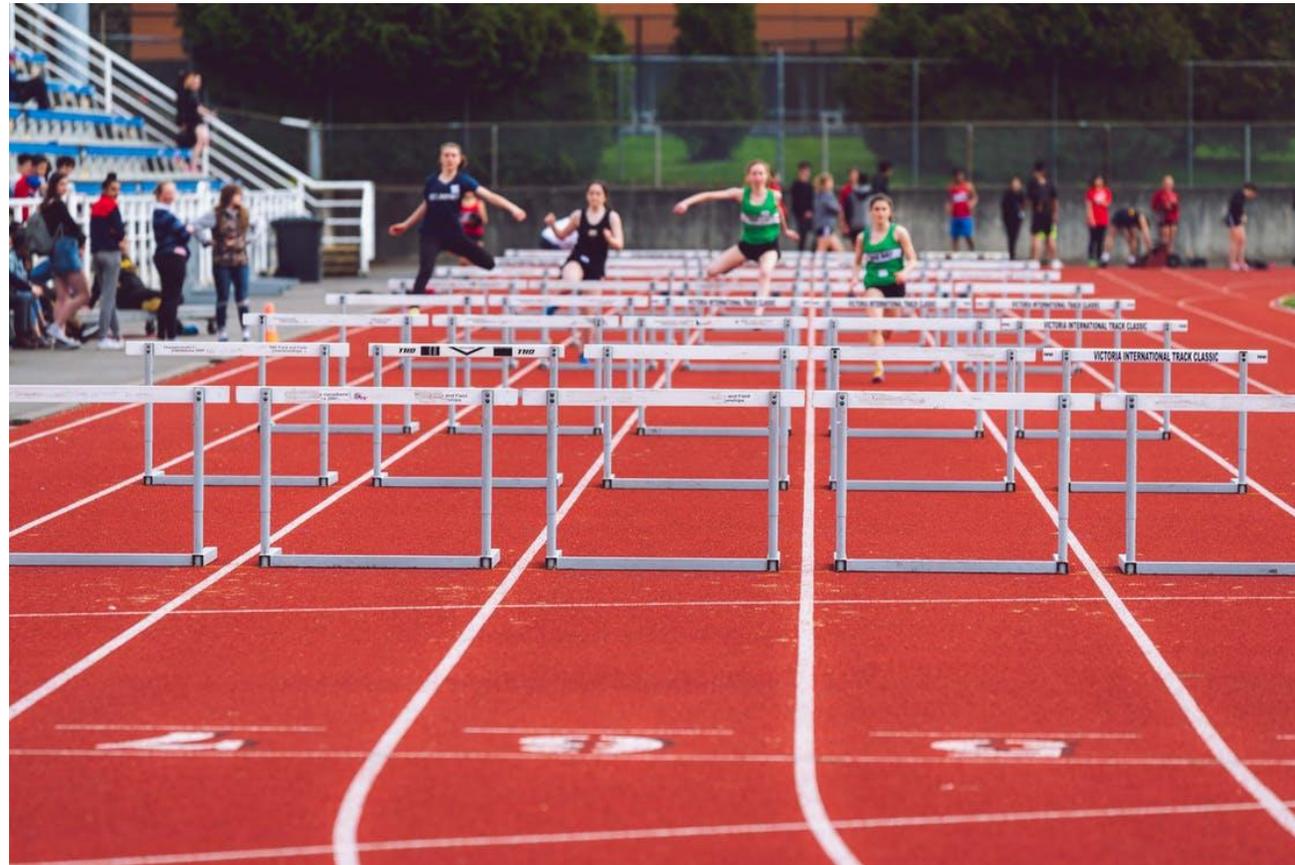
Level of Commitment	Examples of Activities
One time	Focus group Surveys Voting (i.e. encouragement token saying) Trauma-informed care environmental walk through
Short term/Medium range	Stories project (i.e. “Positive Voices”) QI Interventions
Long term/On-going	Consumer Advisory Board (CAB) QI Committee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

Barrier #2: No Interest



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“Consumers aren’t interested in QI activities”



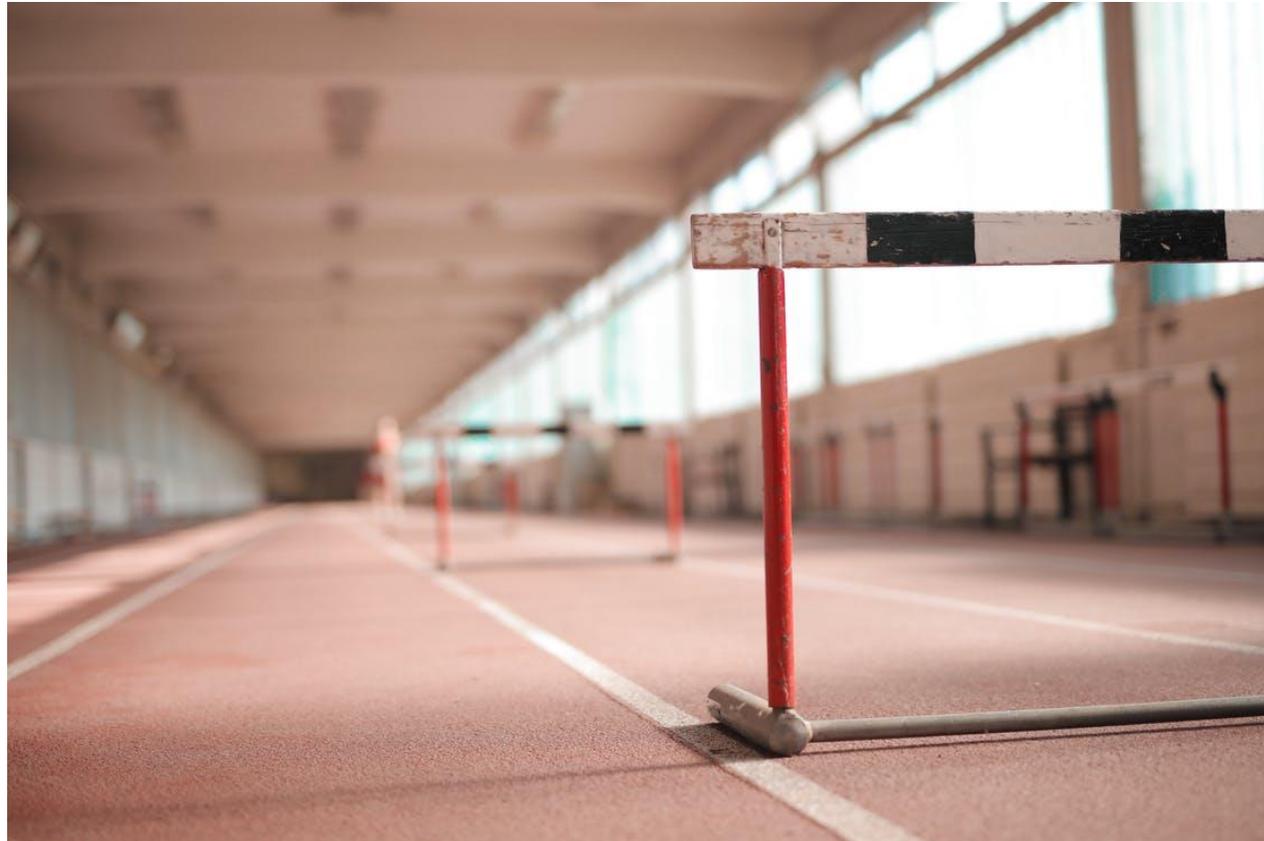
Solution #2: Vary the Activities



- Have realistic expectations: not all consumers 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 consumers at different stages

Barrier #3: Intimidation

“Consumers don’t feel qualified to help with QI activities”



Solution #3: Know Your Audience



Building Relationships

- Know your consumers and their interests, talents
- Listen to consumers
- 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 consumers how to promote it?

Encouragement Tokens

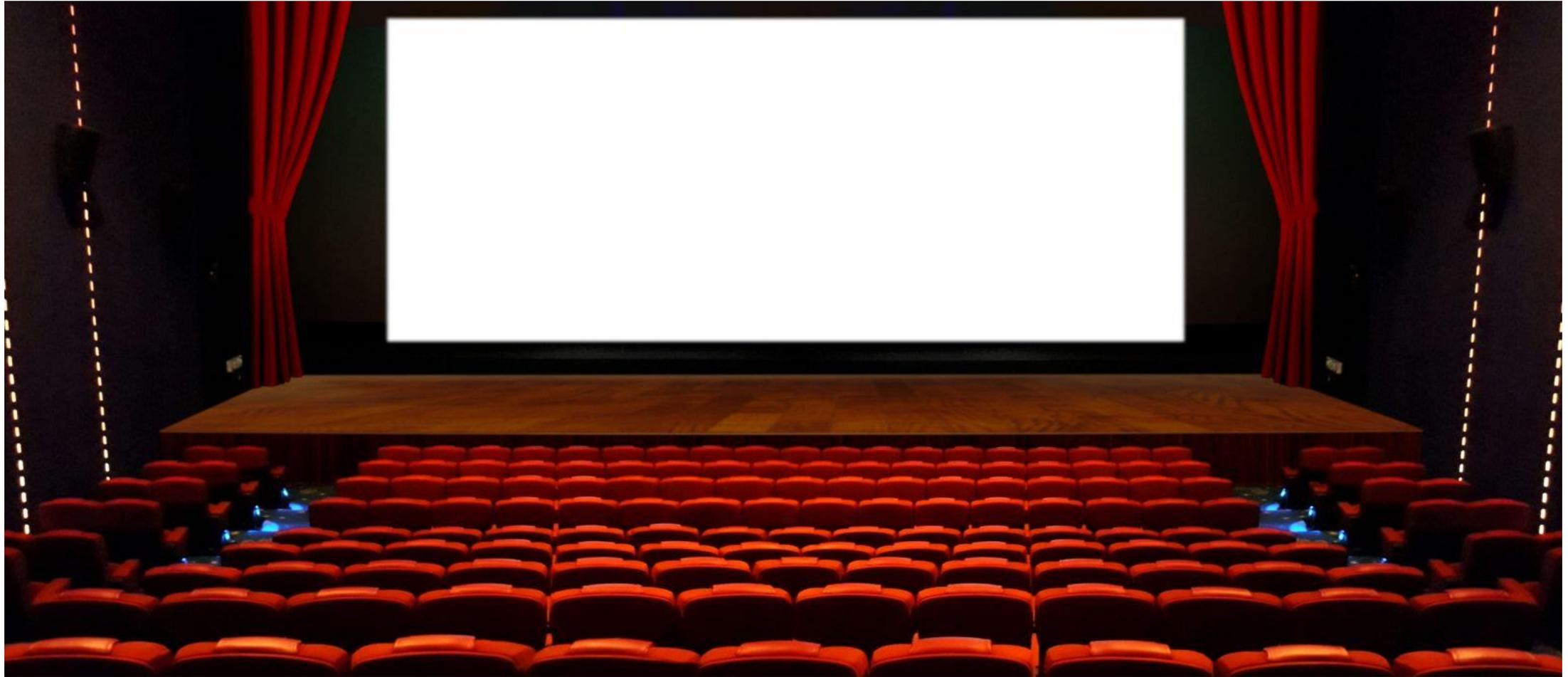


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Encouragement token
given to consumers at
our clinic



“Positive Voices” Video Example



Question



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



Quality Mapping

Take the Front Seat to Accessing Services
Engagement & Clinical Care



Kneeshe's Story

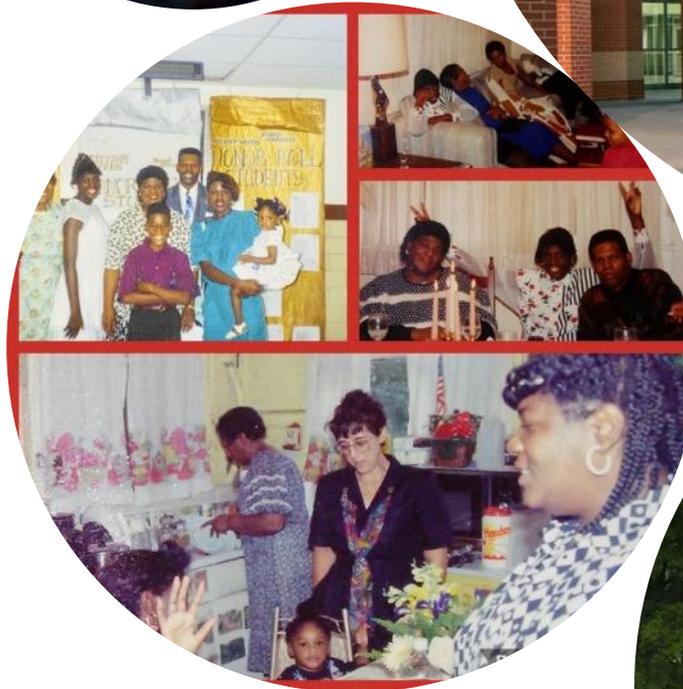


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Be
The
Rock



My Life : Before HIV





HIV Came into My Life



The Immediate Aftermath



My Best Friend, Krista



My Sister



Me and My Sister

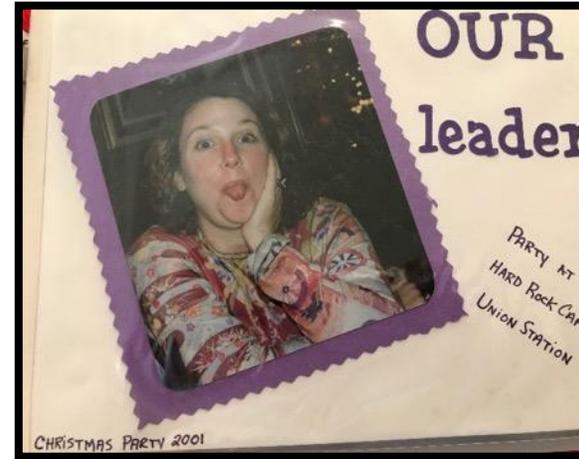
My Mood



Starting to Get Better



My Clinic



Jessica



Me

HIV+ Women -Strong ACTIVE Healthy





My Aunt

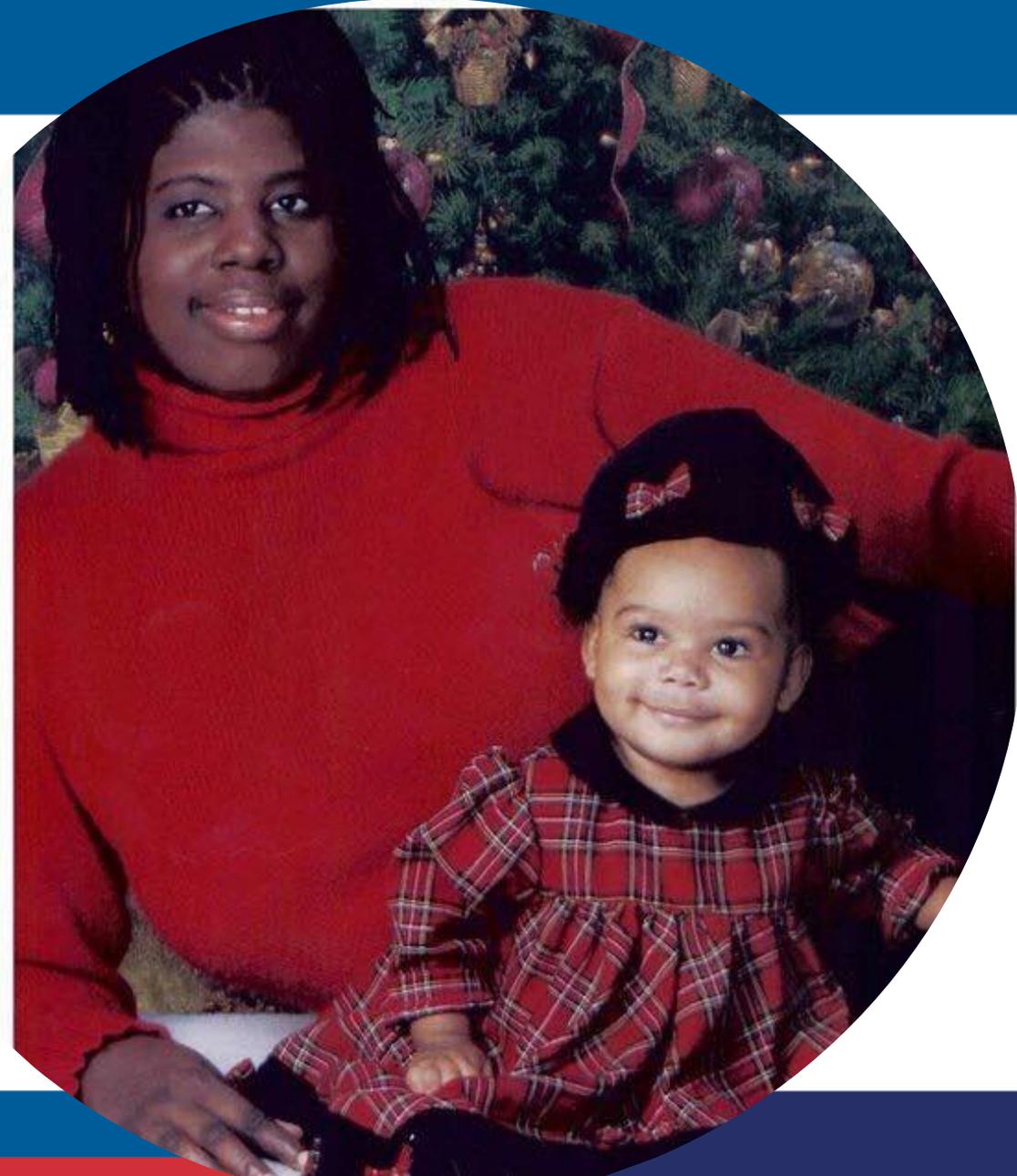
THE DENVER PRINCIPLES

(Statement from the advisory committee of the People with AIDS)

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

What HIV Showed Me About Myself

"I am not a victim. Working and walking in truth, integrity and service takes a lot of courage..."



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BELIEVE



CQII at the RW Conference

Other CQII Workshops



- QI 101 Institute: Clinical Quality Management
[Date]
- Advanced Quality Management: How to Best Track and Measure Your QI Project Using Intermediate Measures
[Date]
- Advanced Quality Management: Learn about QI Tools You Might Not Have Not Ever Used Before
[Date]
- Addressing Disparities Using Quality Improvement to Make Measurable Differences: Experiences from the end+disparities ECHO Collaborative
[Date]
- Engaging People with HIV in Quality Improvement: Best Practices to Meaningfully Engage and Involve Consumers
[Date]
- TargetHIV Panel: Resources and Technical Assistance by the CQII
[Date]



Contact Information



Contact Information

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Panel Discussion / Q&A