The Consumer-led QI Project: Integrating the Lived Experiences of People Living with HIV into Recommendations for HIV Care Quality Improvement

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Disclosures

Presenter(s) has no financial interest to disclose.

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From Current Practice to Participatory Practice

- QI is now a major focus of health-related organizations and yet it is usually done as an internal process with minimal input from the end user (consumers)
  - If services are to be "client centered" they must involve the meaningful and sustained input of consumers
- Participatory research methods can be adapted for QI initiatives
- Participatory research is an approach to research or evaluation activities where the research is conducted directly with the immediately affected persons

Theoretical Framework of Participatory Research
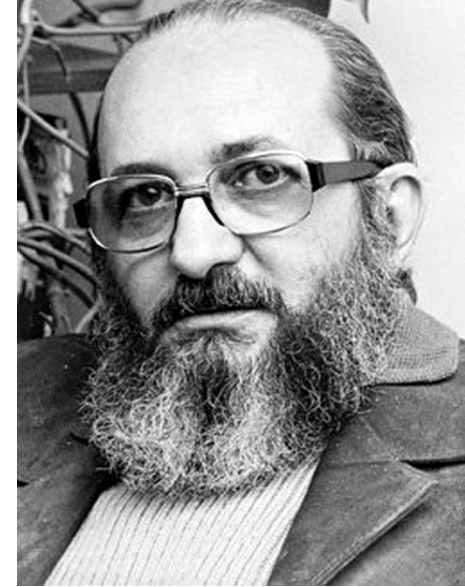
- Participatory research has many names and forms - it is an orientation rather than a specific method

- Participatory research derives its approach from Brazilian educator Paulo Freire (*Pedagogy of the Oppressed* 1968)[1]
  - Work directly in the community and disrupt existing binaries (provider vs. consumer)
  - True knowledge and expertise already exists within people
  - Co-creation of knowledge where the teacher becomes a student-teacher
  - Dialogue in groups to name your world by reflecting on your conditions, imagining a better world, and then taking action to create it

Examples of Participatory Methods

- **Photovoice**: Community members take pictures of some aspect of their lives, reflecting their community's strengths and concerns, and photos are then used to promote critical dialogue with researchers[2]

- **Participatory theatre**: Community members and actors co-develop a play/skits based on the lived experience of community members to be performed publically. In the process the audience is educated as are the actors who can then disseminate what they have learned[3,4]

- **Participatory Analysis**: Community members form part of the analysis team and are fully engaged in data preparation, coding, and making sense of the data in transcripts of interviews/focus groups[5]

How Participatory Practices are Different

- Treats community members not as objects of research but as co-researchers and knowledgeable subjects with the same rights as researchers[6]

- Co-researchers are often from marginalized groups whose views are seldom sought

- Co-researchers must be involved in decision-making regarding the research and the extent to which control over the process is shared and knowledge is co-created determines the extent to which it is participatory

- Be clear about the co-decision-making process

Strengths of Participatory Processes

- Relatively inexpensive (e.g. may not need software)

- Works for lower-literacy populations or individuals unfamiliar with research processes
  - Analysis steps broken down into manageable steps, visual aids used, manual methods utilized

- Flexible and can be made to be culturally appropriate

- Utilizes strengths of researchers (analytic skills) and strengths of community (lived experience)

- Co-learning process is empowering for both sides, fosters trust, and builds authentic relationships

Strengths of Participatory Processes

- Results can be used to make recommendations and for advocacy

- Gives an opportunity for consumers to tell their stories and be heard

- Community members feel empowered, improves self-confidence and a sense of belonging; Results have more community buy-in

- Community members may receive tangible skills and/or employment

- Helps to humanize and engender empathy, breaking down false binaries

- May produce unexpected and helpful findings

- Can utilize strengths of existing community groups/organizations (e.g. support groups)

Things to Consider Before Beginning

- Generally relies on qualitative methods and strategies are less clear for quantitative methods

- May still be time intensive (face-time), relationship-building doesn't happen quickly

- Researcher/professional needs to listen more and talk less
  - Letting go of control can be harder than it seems

- Instructions for process need to be very easy to understand; Avoid jargon
  - Can't assume a common knowledge base

- Community members may still not be able to do the work themselves in the future and need researcher assistance

Things to Consider Before Beginning

- Putting findings into practice not an easy thing to do
  - There may not be clear existing policies for implementing consumer input
- Findings may be taken less seriously than other methods such as quantitative analyses
  - Strong bias against qualitative methods or consumer "opinion"
- Some amount of conflict may arise requiring continual self-reflection, dialogue, and joint resolution
- Need to consider sustainability and long-term impact of the project
- May present unique ethical challenges (e.g. visibility of stigmatized populations)

Discussion Questions

1. To what extent have QI activities that you have participated in been participatory?

2. What are some barriers to getting more community engagement in the work that you do, whether it is QI-related or not QI? Or, what are some barriers to being more engaged in QI efforts at agencies where you are a consumer?

QI Project Process

The Consumers Committee is central to the Planning Council process
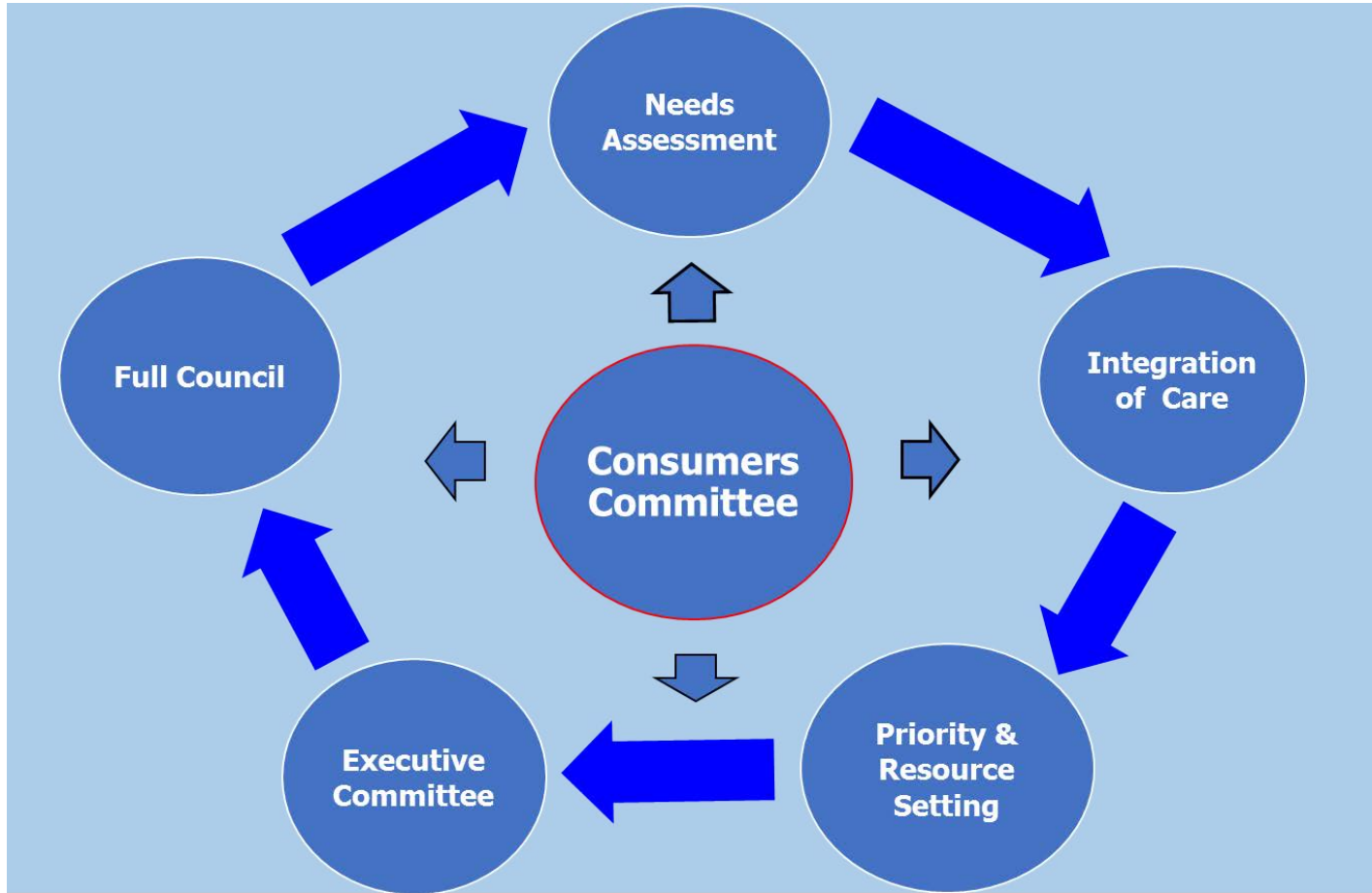
Nothing About Us Without Us

Background

- While great progress in viral suppression has been achieved in NYC (74% in 2017), it remains lower than in some other jurisdictions[7]

- Innovative, client-centered approaches are needed to close the gap

- Positive interpersonal interactions between consumers and providers are important at each step of the HIV Care Continuum

- Poor consumer/provider relationships and communication accounted for 62% of dissatisfied consumers in NYC and 53% of consumers in the Tri County region[8]

Project Goal and Objectives

Goal:

- To evaluate how to establish positive consumer-provider relationships from the perspectives of people living with HIV (PLWH)

Objectives:

- To assess barriers and enablers to receiving HIV care among PLWH at their HIV health provider
- To assess how the consumer-provider relationship either supports or hinders adherence and maintenance of viral suppression

Project Design was Participatory From Start to Finish

- Consumers Committee (CC) formed a QI workgroup that met from July-November 2017 with DOHMH staff

- They designed the evaluation goal, objectives, and 6 primary discussion questions

- Discussions were conducted with the CC and the Tri-County-based Living Together Support Group (LTSG) and were facilitated by a DOHMH employee unknown to the group to increase comfort

- Facilitated discussions were audio recorded and transcribed

Facilitated Discussion Questions

**Adapted from AIDS Institute's Living Cascade worksheet**:[9]

1. Can you describe your first HIV health care visit after you were diagnosed?
   Does anything stand out in your memory about the conversations you had, things you saw in the clinic, or how you felt?

2. How did this experience impact your willingness to go for continued HIV care?

3. Now thinking to the present, what motivates you to go to your HIV appointments?

4. If you've ever missed an appointment, what made you miss it?

5. What has been the hardest part about staying on your HIV meds?

6. What specifically does your HIV provider do that helps you take your HIV meds?

Participatory Analysis Process

We worked together to analyze data, adapting a participatory process in Jackson et al. 2008[5]

- Transcripts were divided by question and given to teams of 2-3
- Small teams pulled out themes and quotes and put them on poster boards
- Small teams presented poster boards and discussed these with the entire group so everyone could give input
- DOHMH staff used poster boards and meeting notes to develop workshop content and write a report with help from consumers

Example Poster Boards
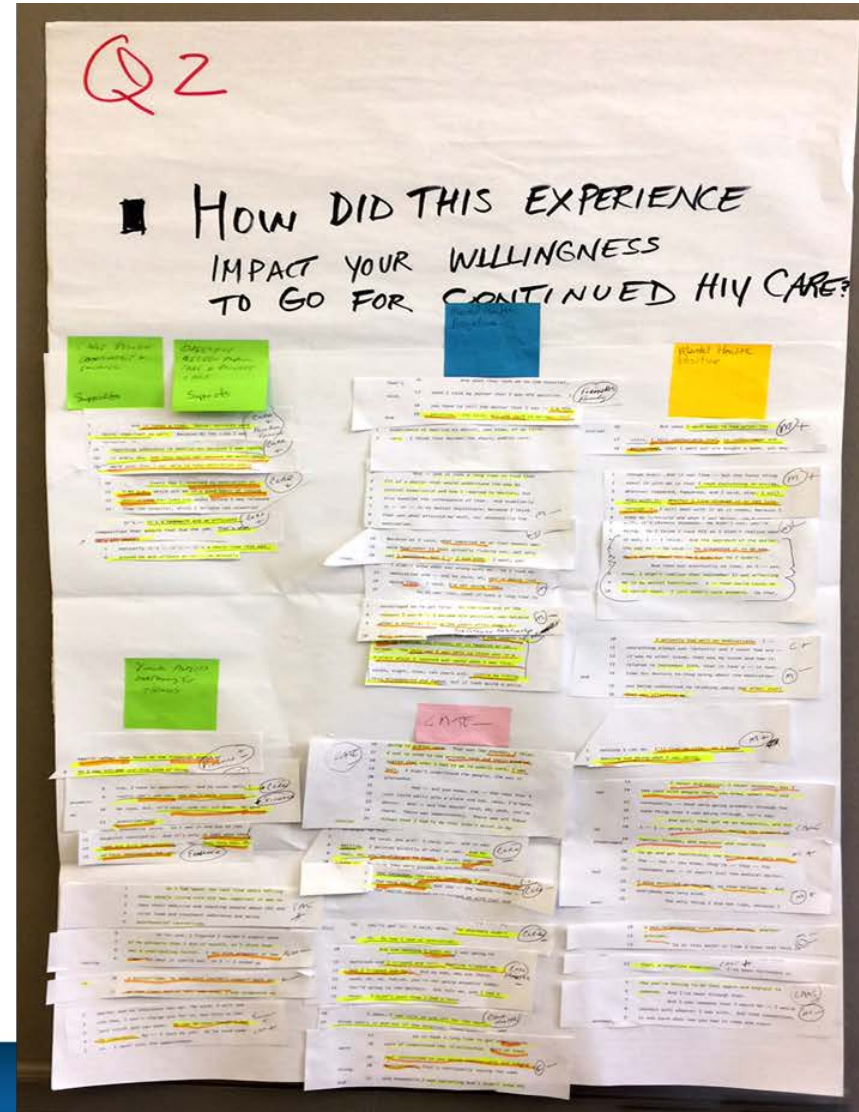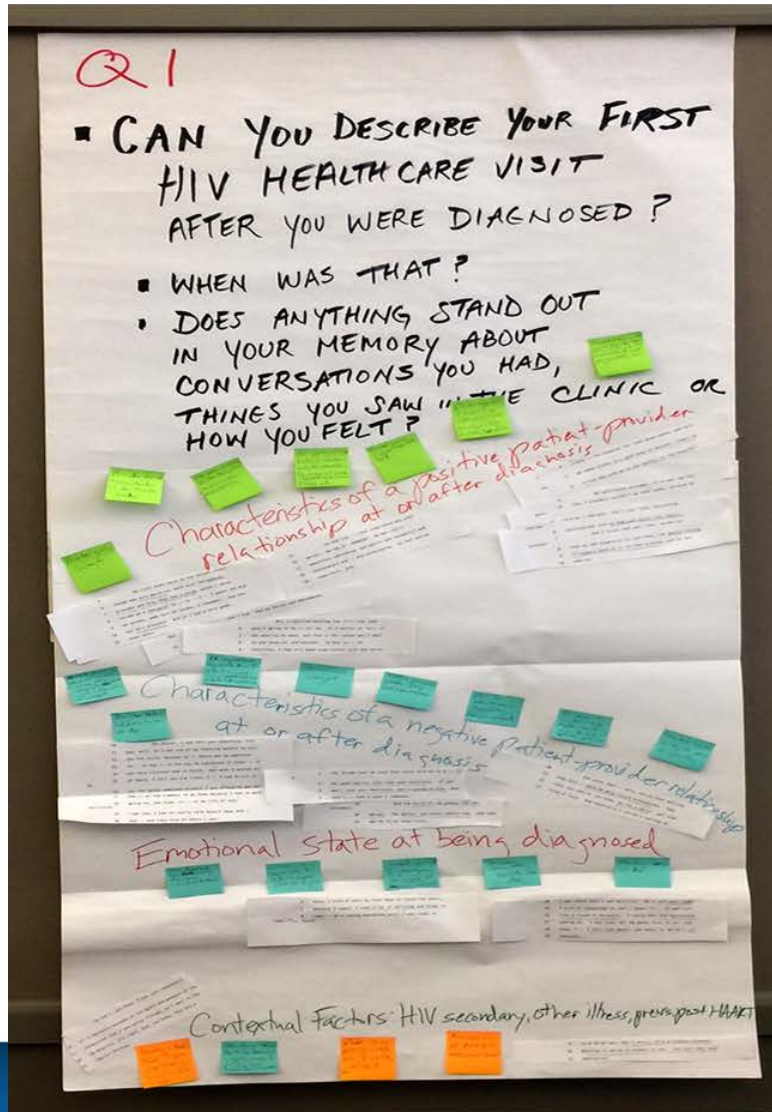
Results & Recommendations

Participant Characteristics

Participants were reflective of broader NY PLWH population

- 27 consumers participated (14 NYC, 13 Tri County)

- 63% were male and 85% were Black or Latino

- Median year of diagnosis was 1995

- Median year of initiation of HIV medications was 1997

- 100% were currently taking HIV medications, but 52% had stopped taking their medication at some point since starting medication

Broad Qualitative Thematic Analysis

We assessed how frequently each theme came up across questions

We were surprised to see that the most common theme was mental health since we did not directly ask about mental health

Theme	Facilitated Discussion Question					
	1	2	3	4	5	6
Individual Level						
Psychological						
Emotional state at diagnosis	X					
Mental health	X	X		X	X	X
Will to survive/positive outlook		X	X			
Health literacy and empowerment			X			X
Treatment fatigue				X	X	
Non-Psychological						
Substance use	X			X	X	
Side effects	X				X	
Aging and co-morbidities					X	

Broad Qualitative Thematic Analysis

Provider characteristics, peer support, family support, and substance use were next most common themes

Themes highlighted the considerable importance of emotional health and interpersonal relationships to HIV diagnosis and care

		Facilitated Discussion Question					
Theme		1	2	3	4	5	6
Interpersonal Level							
Provider characteristics		X		X			X
Peer support			X	X			X
Family support			X	X			X
Stigma and disclosure				X		X	
Societal Level							
Financial difficulty affording HIV care			X			X	
Continuity of care					X		
Doctors vs Nurses/Physician Assistants							
Public vs private health care			X				
Holistic/team approach			X				
Therapists				X			

Characteristics of a <u>Positive</u> Patient-Provider Relationship

Positive relationships: Supportive, welcoming, caring, gentle, thoughtful, encouraging, honest, good communicator, listens, shares up-to-date info, instills patient self-management skills and self-esteem, motivates patient to stay hopeful and is responsive to patient concerns

"Anything that I need to know, anything that I want checked, anything that I'm thinking about, we do what we have to do. I'm grateful for the structure that I have now surrounding my HIV care"

"I really spiraled downhill. And he knew. He knew enough about me to tell me that if I didn't do it for myself, that the drugs were going to kill me before the virus did and I needed to set my priorities straight – he knew my kids. He said, Don't you want to see your kids graduate high school? I didn't think that was possible"

Consumers Want to be Partners in Their Health Care

"I have actually gone over six months a couple of times. I just get tired of it, you know. I just want to feel like a normal human being again without having doctors probing or sticking me all the time and pulling out 12 vials of blood. I'm just tired of it. I'm coming in twice a year and I'm done. If I have a problem, I'll come to you. I'm tired of feeling like a human experiment. I just got off an eight month stint without seeing a doctor because she wasn't listening to me. She was not participating with me as part of it. And I said, thank you, but I'm not coming back"

Consumers Need Continuity in These Relationships

"The only time I've ever gone without seeing my provider for six months is when my doctor, who I've known from the time I got sick in the hospital, left. I didn't know where to go to find a doctor. I didn't want to walk into a doctor's office and say, I need a doctor, can you be my doctor? When my doctor left, someone took over his practice who I did not like at all and she knew it. I said I don't like the way you deal with me. She said Okay, but she continued to give me my medication even though I didn't see her anymore. She continued to give me my medication even though I didn't see her"

Mental Health illness and Substance Use Addiction Make Adherence Very Difficult

"I went six months without because my mind would not respond to my will to live. It didn't matter that I had family, children. Anything, it didn't matter. So stopping was easier than start, stop, start, stop"

"I was getting high and I just stopped. Just stopped. And I didn't go see a doctor. I didn't do anything. I don't know how long it went on. You know, I lost track of time. But I know when I did go back [to the doctor] I went from HIV positive to AIDS. Drugs have a way of just taking your memory away. It's been a whole chunk of my life that I just don't remember"

Family Support Critical to Remaining Hopeful, Informed, and Engaged

"Great grandma, grandkids. I love them with all my heart. I'd do anything for them and that's what's keeping me here. Sometimes when I get depressed, I call my youngest and she says, Mom, we need you; You can't leave us. You have to keep going on. My family has been very supportive from day one"

"If I'm drinking something, they come over and grab it. They drink out of my cup and eat off of my fork. They treat me as if nothing is wrong with me. When you're family, you're family. You're supposed to hold each other up no matter what. I am so thankful"

Peer Support Also Critical to Remaining Hopeful, Informed, and Engaged

"Everything that I've learned from being in this group Living Together, it's become my family. My family knows about this family. My family knows I call this family before I call them. The facilitator of the group brought us so close together, because he made it personal for each and every one of us to be together and share our stories"

"And because of their stories and because of the being able to ask questions I didn't know how to ask made me reluctantly go back to the doctor that didn't have a good bed-side manner, didn't know how to talk to people, wouldn't explain anything. So no, if -- if -- if I had to rely on the doctor, I probably may not be here right now"

Education on HIV, Self-advocacy, and Consumer Integration Lead to Empowerment

"I took a self-management leadership training on being your own healthcare advocate. What I learned from that was so much more than I ever would have learned from a doctor. I wanted to know as much as I could about this virus so I educated myself. I went to places that educated consumers"

"If I've made it through all that hell, this right here is a cake walk. I get mad at myself, I fight with myself. I fight with my disease. Even though I don't want to get up, I make myself do it. When you're dealing with HIV, it's like carrying an unseen passenger – you've got to find out if the seat belt is secure, you've got to make sure that it's not falling out of the car. And who's driving, you or the passenger? So, I'm in the driver's seat"

Recommendations in Provider Domain

Diagnosis visits: During these visits provide emotional support and begin educating the consumer on HIV as this visit impacts future engagement in care

Holistic provider communication: During medical visits, take the time to talk to consumers about a comprehensive set of concerns as this fosters trust, a will to survive, and positive outlook towards health care

Comorbidities and continuity of care: Comorbidities are common requiring better integration of care. Plans need to be in place for when consumers switch providers to provide continuity of care

Recommendations in Mental Health and Substance Use Domain

Mental health illness and substance use addiction: Consumers with mental health illness or substance use addictions need more intensive and integrated services to remain engaged

Expanded mental health support for all consumers: Expanded mental health support is needed for all consumers and should be explicitly addressed at diagnosis and care visits

Recommendations in Family and Peers Domain

Family and peer support: Facilitate access to the support of family and peers as they are key for consumers' emotional health and their outlook on the importance of treatment and adherence

Stigma and disclosure: Disclosure may not happen if consumers fear stigma. Although whether to disclose is the consumer's decision, providers can start the conversation on disclosure in order to facilitate consumer's access to more support from family and peers

Recommendations in Consumer Empowerment and Engagement Domain

HIV education and self-advocacy: Connecting consumers to support groups and self-advocacy activities contributes to consumer empowerment and a greater desire to take care of oneself and other consumers

Consumer involvement in QI: Provider-centric perspectives or client satisfaction surveys as QI initiatives may be inadequate without involving consumers in these QI activities in a client-centered and meaningful way

Empowering Consumers Improves Planning Processes

- With the support of DOHMH staff, consumers learned qualitative research methods and analyzed their own data using **rigorous** and **replicable** methods that other committees can use

- Consumers felt empowered by the process, addressing a desire to tell their own stories. Compelling quotes and concrete recommendations can guide action
  - Highlighted how qualitative data can address gaps in what quantitative data can show

- The process gave consumers a greater appreciation for their role on the Planning Council and they are seeking new ways to be more integrated into the work of other committees
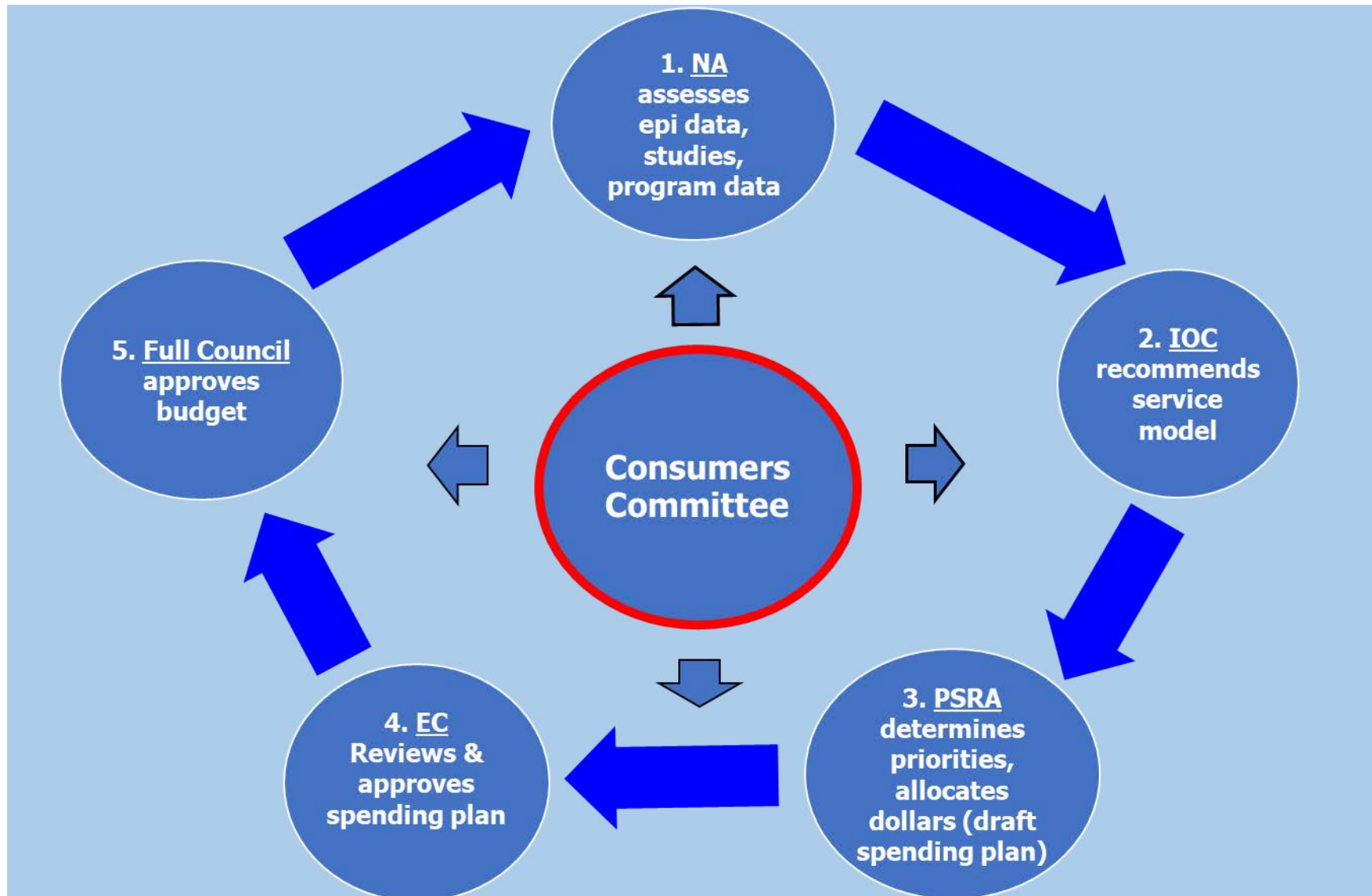
Next Steps: 2018-2019 year

- The 9 QI Project recommendations will be posted on the Planning Council website and the consumers are working to integrate them into Ryan White Part A service delivery

- The CC will lead a community consultative process to flesh out the 9 recommendations similar to the Integration of Care subcommittee's process of creating/revising Ryan White service directives

- Building on the momentum of the QI Project, the CC presented at DOHMH's 2018 Power of Quality Improvement Conference on structuring and sustaining community advisory boards (CABs)

Discussion Question

1. What are your impressions of the QI Project?
2. Would this be feasible to do in your agency?

References

1. Freire P. Pedagogy of the Oppressed. Retrieved at https://selforganizedseminar.files.wordpress.com/2011/08/freire_pedagogy_oppresed1.pdf

2. Bugos E. et al. Practical Guidance and Ethical Considerations for Studies Using Photo-Elicitation Interviews. Prev Chronic Dis 2014;11:140216.

3. Logie C. et al. Exploring the Potential of Participatory Theatre to Reduce Stigma and Promote Health Equity for Lesbian, Gay, Bisexual, and Transgender (LGBT) People in Swaziland and Lesotho. Health Education & Behavior 2018;[Epub ahead of print].

4. Jaganath D. et al. This is My Story: Participatory Performance for HIV and AIDS education at the University of Malawi. Health Education Research 2013;29(4):554-565.

5. Jackson S. A Participatory Group Process to Analyze Quantitative Data. Progress in Community Health Partnerships: Research, Education, and Action 2008;2(2):161-70.

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References

6. Bergold J. and Thomas S. Participatory Research Methods: A Methodological Approach in Motion. Forum: Qualitative Social Research 2012;13(1).

7. HIV Epidemiology and Field Services Program. HIV Surveillance Annual Report, 2016. New York City Department of Health and Mental Hygiene: New York, NY. December 2017.

8. Aidala A. et al. CHAIN Report 2007-2a,, Satisfaction & Dissatisfaction with Medical Services & Primary Medical Care Provider, Columbia Univ. Mailman School of Public Health. 2017.

9. Belanger D. and Tietz D. The Living Cascade: Consumer Cascade Journeys. AIDS Institute. 2017.