

# The Consumer Solar System: A Report From the Consumer QI Project

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HIV Health & Human Services Planning Council of New York  
Consumers Committee & Living Together of Tri-County  
February 15, 2018  
Presentation to the Planning Council Executive Committee



# The Consumer Solar System



# Background

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- While great progress in viral suppression has been achieved in NYC, quality improvement initiatives have long focused on providers' experiences with the clients they serve
- Less frequently are such initiatives directly informed by the clients' lived experiences as people living with HIV/AIDS (PLWHA) and as consumers of services
- Consumers' views and experiences are integral to efforts in quality improvement. Their experience is driven by the level of positive interpersonal interaction at every point during their encounter
- Poor consumer/provider relationships and communication accounts for 62% of dissatisfied consumers in NYC and 53% of consumers in the Tri County region (CHAIN Report, 2007-2a)



# Analysis Project Methodology

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- **Goal:**
  - To evaluate how to establish positive client-provider relationships from the perspectives of PLWHA
- **Objectives were to assess:**
  - Barriers and enablers to receiving HIV care among PLWHA at their HIV health provider
  - How the client-provider relationship either supports or hinders adherence to HIV medications and maintenance of viral suppression

# Community-Based Participatory Design (CBPR)

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## QI Project utilized CBPR methods from start to finish

- Consumer Committee formed a QI workgroup to develop content for the conference workshop that met 2-3 times/month from July-mid November with DOHMH staff
- QI workgroup designed evaluation goal, objectives, and 6 primary discussion questions in consultation with DOHMH staff
- Facilitated discussions were conducted with the NYC-based Consumer Committee (CC) (n=14) and the Tri-County-based Living Together Support Group (LTSG) (n=13) and were facilitated by a DOHMH employee unknown to the group to increase comfort
- Facilitated discussions were audio recorded and transcribed



# Facilitated Discussion Questions

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Adapted from AIDS Institute's Living Cascade worksheet:

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

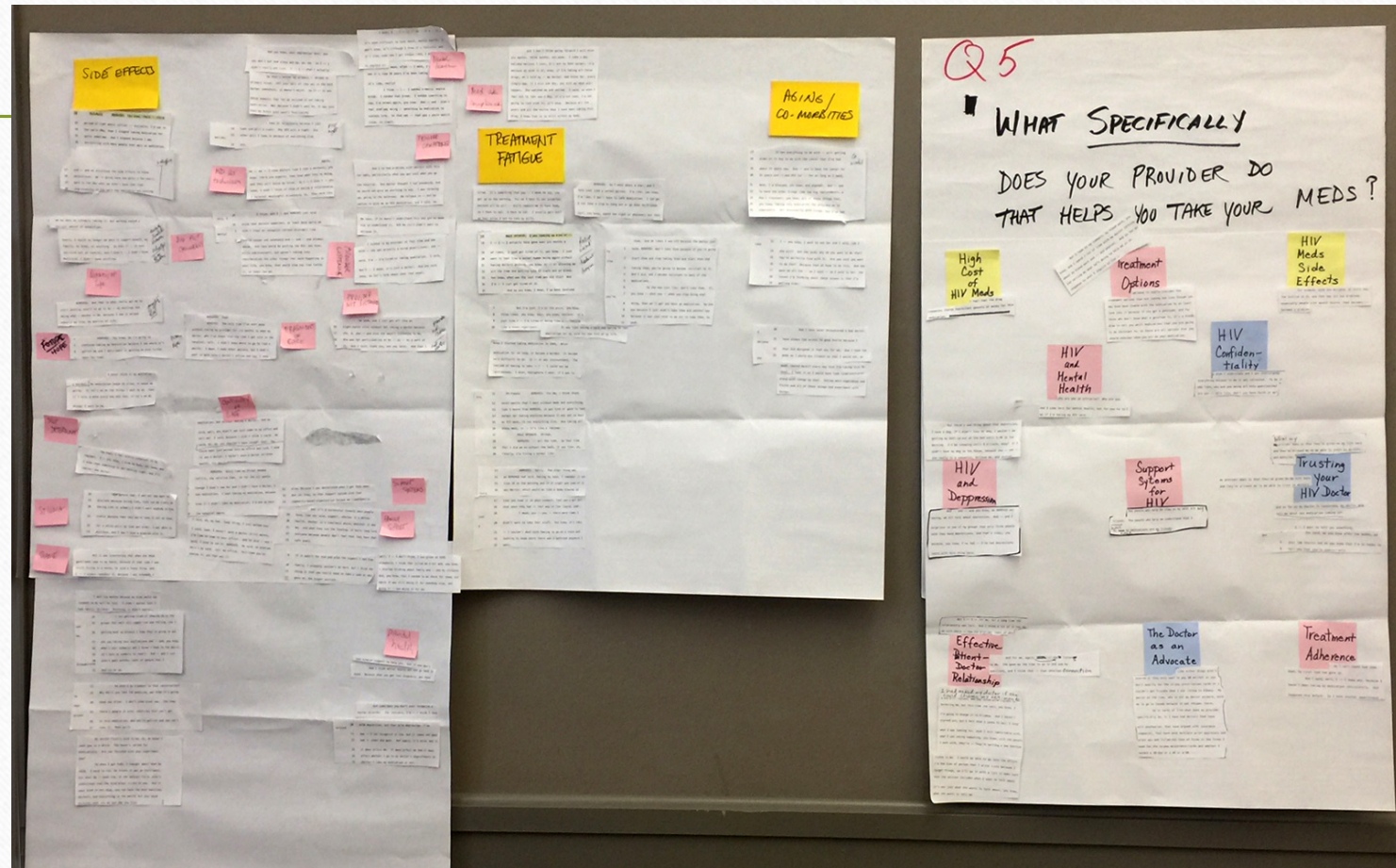
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QI workgroup modified participatory analysis process described in Jackson et al. 2008 in order to tell their own stories

- CC and the LTSG conducted analysis of their own data as a group along with DOHMH staff
  - Transcripts were divided by question and given to teams of 2-3 individuals who pulled out themes and quotes during one 4-hour meeting in NYC and one in Westchester
  - Small teams then presented poster boards or summary documents of themes and discussed these with the entire group so everyone could give input
- DOHMH staff used poster boards and meeting notes to write a report with help from consumers to disseminate to the Planning Council



# Example Poster Boards





# Participant characteristics

Participant Characteristics	Total		NYC		Tri-County	
	N	%	N	%	N	%
Total	27	100.0	14	100.0	13	100.0
Age Mean (Range)	59 (37-69)		56 (37-68)		62 (50-69)	
Gender						
Male	17	63.0	11	78.6	6	46.2
Female	10	37.0	3	21.4	7	53.9
Race/Ethnicity						
Black	17	63.0	7	50.0	10	76.9
Latino	6	22.2	3	21.4	3	23.1
White	4	14.8	4	28.6	0	0.0
Other	0	0.0	0	0.0	0	0.0
Sexual Orientation						
Heterosexual	13	48.2	4	28.6	9	69.2
Gay/Homosexual	10	37.0	8	57.1	2	15.4
Bisexual	2	7.4	2	14.3	0	
Other/Unknown	2	7.4	0	0.0	2	15.4
Area of Residence						
New York City	12	44.4	12	85.7	0	0.0
Tri-County Region	15	55.6	2	14.3	13	100.0

# Participant characteristics

Participant Characteristics	Total		NYC		Tri-County	
	N	%	N	%	N	%
Total	27	100.0	14	100.0	13	100.0
Year of Diagnoses Median (Range)	1995 (1986-2012)		1997 (1987-2012)		1992 (1986-1998)	
Area Where HIV Services Are Obtained						
New York City	15	55.6	14	100.0	1	7.7
Tri-County Region	12	44.4	0	0.0	12	92.3
Year Initiated Taking HIV Medications Median (Range)	1997 (1987-2014)		2000 (1987-2014)		1994 (1989-1999)	
Currently Taking HIV Medication						
No	0	0.0	0	0.0	0	0.0
Yes	27	100.0	14	100.0	13	100.0
Has Stopped Taking HIV Medications						
No	13	48.2	6	42.9	7	53.9
Yes, but for less than 6 months	8	29.6	4	28.6	4	30.8
Yes and it was at least for 6 months	6	22.2	4	28.6	2	15.4
For the Tri-County sample, there were missing answers for: 2 for sexual orientation, 2 for year of diagnosis, 2 for year initiated						



# Qualitative Thematic Analysis

When we compared themes across discussion questions we were surprised to see that the most common theme was mental/emotional health. Overall, it is notable that themes frequently clustered within a socio-psychological domain, highlighting the considerable importance of psychological aspects of HIV diagnosis and care as well as interpersonal relationships.

Theme	Facilitated Discussion Question					
	1	2	3	4	5	6
<b>Individual Level</b>						
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	

# Qualitative Thematic Analysis

After mental/emotional health, provider characteristics, peer support, family support, and substance use were the next most common themes across questions. Societal-level factors were mentioned but were not common.

Theme	Facilitated Discussion Question					
	1	2	3	4	5	6
<b>Interpersonal Level</b>						
Provider characteristics	X		X			X
Peer support		X	X			X
Family support		X	X			X
Stigma and disclosure			X		X	
<b>Societal Level</b>						
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			



# Lessons Learned From QI Process

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- With the support of DOHMH staff, the Consumer Committee 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

# Recommendations

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9 recommendations have resulted from the QI Project:

- 3 in the provider domain: diagnosis visits, holistic provider communication, comorbidities and continuity of care
- 2 in the mental health and substance use domain: mental health illness and substance use addiction, expanded mental health support for all consumers
- 2 in the family and peers domain: family and peer support, stigma and disclosure
- 2 in the consumer empowerment and engagement domain: HIV education and advocacy, consumer involvement in QI



# Characteristics of a positive patient-provider relationship at and after diagnosis

- **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

*"My doctor is my friend. She is my friend. There's nothing I can't say to her. There's nothing she won't do for me"*

*"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 and Need Continuity in These Relationships

*"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"*

*"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"*



# Recommendations in Provider Domain

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- **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

# Mental Health illness and Substance Use Addiction Make Adherence Very Difficult

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*"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"*



# Recommendations in Mental Health and Substance Use Domain

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- **Mental health illness and substance use addiction:** Consumers with mental health illness or substance use addictions need more intensive services to remain engaged
  - Example: Mental health professionals need to understand consumers' HIV care issues
- **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
  - Example: Create a holistic approach to mental health, "mental health universal precautions"

# Family and Peer Support Critical to Remaining Hopeful, Informed, and Engaged

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*"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"*

*"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"*



# Recommendations in Family and Peers Domain

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- **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

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

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*"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 Consumer Empowerment and Engagement Domain

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- **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

# Possible Next Steps?

- Disseminate QI report to increase awareness of cross-cutting themes & contextual factors involved in progression through the HIV prevention & care continuum
- Have discussions between providers and consumers regarding QI report recommendations
- Integrate recommendations into existing practice throughout the NY EMA (including Tri-County):
  - Ryan White master directive (client-centered care mentioned but not explained), standards of care, RFP evaluation criteria (e.g. scoring cultural competency)
  - DOHMH-provided trainings for providers
  - Create synergy with AIDS Institute/EtE consumer engagement activities
- Present findings to HRSA and other jurisdictions through conferences and a peer-reviewed article



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