

**HIV Health and Human Services Planning Council of New York
2013 Listening Sessions
Summary Report of Key Findings**

**Prepared for the HIV Health and Human Services Planning Council of New York
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A total of six (6) listening sessions were held in the boroughs of Brooklyn, the Bronx, Manhattan, Queens, Staten Island, and Westchester County between May - June 2013. Five sessions were conducted in English, and one session was conducted in Spanish. All sessions were audiorecorded and transcribed. The following brief report summarizes key themes that emerged from analysis of listening session transcriptions. Data analysis was completed using Atlas.ti analytic software. Themes are presented as the most common responses to questions related to barriers and facilitators to accessing HIV testing and treatment services in New York. All quotes are italicized.

Barriers to HIV testing

A1. Lacking knowledge of HIV risks

The most commonly reported barrier to being tested for HIV was a general lack of knowledge of the risks of HIV transmission. Listening group participants indicated that despite education outreach efforts, many consumers are still unaware that they are at risk for HIV and therefore may not feel the need to get tested. Participants indicated that there is still a widespread misconception that HIV is transmitted only among men who have sex with men (MSM) and other at-risk groups, and that heterosexual men and women in long-term monogamous relationships are not at risk.

I think the prevalent understanding of HIV and AIDS at this time [is] that when people think about it and look at it, the first thing...you know, they think that MSMs [are] the only one that's getting this thing. People at high risk. Years ago, we always put the high risk categories and it was just thrown in everyone's face - high risk category, you know.... So some people... they're always thinking it's just a gay thing. They still think it's a gay thing. It's amazing that that is occurring right now when heterosexuals are passing this thing on very much.

-Brooklyn participant, male

You know somehow we've got to get that message out, you know and also there's still a lot of people that are so uneducated that they don't think they're at risk, you know so they don't think they need to be tested. We have to let everybody know that if you're having sex, period, you're at risk, you know? If you've ever had more than one partner, you know, if you go with somebody new. You know everybody is at risk, because when I found out I was positive I was shocked, because I never found myself in that category where I thought I was at risk, you know? Not promiscuous, didn't prostitute, never did intravenous drugs, did all the long term relationships, and yet I still wound up infected. If I had been a little more educated I might have seen the danger signs.

-Staten Island participant, female

A2. Sense of invulnerability

Another commonly reported barrier to testing was a perception of invulnerability, which participants associated with consumers (particularly younger consumers) not taking HIV "seriously." These related attitudes of invulnerability and dismissal of HIV can lead to consumers failing to prioritize testing, even if they suspect they have HIV.

A lot of the younger community don't care about the virus anymore. It's a common cold to them. They don't respect the virus as they used to when it was first discovered. They believe that 'now I can get the virus, I'm going to take care, I don't care'.... But the younger population, they don't respect the virus. [They think] 'I can get it, it's going to pass.' People are living longer. Before, people were looking like the virus. Now there's no face of the virus so they don't care.

-Brooklyn participant, male

Because each generation, the farther away they get from what AIDS was really like when it came on the scene, they don't know. They don't know about what we saw when it first hit. So they don't see those pictures and because everybody's so sensitive, we've kept those pictures away from people. And it's those kinds of things.... It becomes up to us to make sure the next generation understands, that they really comprehend the magnitude of the impact that HIV had but we don't do that. We continue to look pretty, we continue to look healthy, and we continue as we say, we're normalizing it. We're kind of repositioning it in a way that they don't see and understand the impact that it had in the early days.

-Brooklyn participant, male

A3. Not wanting to know status

Participants also noted that many people do not get tested because they do not want to know their status. This theme is related to theme **A5** – the continued stigma of being HIV positive and concomitant lack of social support for PLWHA.

Fear of the answer. People don't get tested because they don't want to know, they don't want to hear the answer they might get

-Staten Island participant, male

A4. Concerns regarding discretion and confidentiality

Related to themes **A3** and **A5**, participants explained that because of the stigma of HIV, many people may want to be very discrete about accessing testing services. People may be reluctant to even be seen near a facility known as an HIV treatment center. Additionally, participants noted that concerns regarding assurance of confidentiality of testing results may also prevent many people from being tested.

When I was tested, I was sent to an agency where in front of their building, it said AIDS Task Force. I drove past, I never stopped in. Unfortunately, years after, they painted it over. It's covered over. So not just stigma, it's like identification, information.

-Brooklyn participant, male

Nothing is secret, nothing. I don't care where you work. As long as you got people working, people do not hold water so they are not going to hold your information. That's just being real about it.

-Brooklyn participant, female

A5. Stigma of HIV and lack of social support

Many participants noted that people may not want to get tested due in large part to the continued stigma surrounding HIV. They explained that many people doubt whether their family and friends will support them if they disclose a positive status, and that to avoid rejection many people opt out of being tested altogether.

When - once you find that information, you do not know who is going to be supportive. A lot of the people have families that are not supportive, that reject them....And the confidentiality concerns that are there. So I - definitely, support systems are necessary or essential actually in somebody finding out this information.

-Manhattan participant, male

Other participants noted that the lack of social support could be compounded for **women** with abusive partners. The partners may be controlling of the woman, and prevent her from accessing testing or treatment services.

Depends on like well... women maybe... one have to come out to say where they are not allowed not, like in fear, which was when the domestic violence issue where she cannot even get out of the house, because he got so much control of her, and that is one of the other concerns.

-Westchester participant, female

A6. Lack of knowledge of where to get tested and what services are offered.

An additional barrier noted by participants was a general lack of knowledge on where to access testing services.

One of the things that I wanted to say is that, a lot of times we do get the information, but we do not know, we know what to do with it, but you just cannot pick up the phone and make that call.

-Westchester participant, female

Strategies/facilitators to testing**B1. More education outreach in multiple languages**

Participants emphasized the need for more education outreach in different venues – particularly schools and at community events– to continue to let people of all ages know about the importance of regular HIV testing, where to access services, and their rights as patients. Participants noted that this outreach should be conducted in multiple languages, particularly in metropolitan New York with a large population of non-English speaking residents.

I think with schools, the way to get information out, is to maybe make it mandatory to have an assembly in every high school, every middle school, where you have a packet with information built in, all languages you know, so that you can hand it to the student and have somebody speak on the issue.... But, it should be something that is mandatory, that the health department initiates and takes care of. And, once the information is there in the packet with everything you have all talked about, then they have and then they can take that information, the proper information and do with it what they will.... Schools now are great opportunity to not just inform the students, but to inform the teachers, to inform the administrative staffs, people who really do not have an understanding of what AIDS is, what HIV is. Give it to them, make it mandatory that they have this assembly once a year.

-Westchester participant, female

B2. Greater utilization of peers for pre/post-testing counseling

Participants agreed that greater utilization of peers to support pre- and post-test counseling could help to allay some of the fears/concerns that may prevent people from being tested.

And, I know that in my case, I got someone that was positive, that held my hand and showed me the ropes, so to speak. So, that it is like you have to learn to navigate the system of HIV. So, sometimes you need someone, especially when you are newly diagnosed and you go through that mourning period and everything and then it sets in. You need someone to guide you and to show you and help you.

-Westchester, female

Barriers to accessing HIV treatment services**C1. Concerns regarding confidentiality**

Beyond testing, concerns regarding confidential treatment and protection of status may impede consumers from regularly accessing treatment services.

And so people fear that [loss of confidentiality], particularly those who are in constructs where they're already living a double life. I deal with brothers on a regular basis who can't let, don't want to let their children know and don't want to let their significant other know. So it's not about other people, necessarily, but it's about those particular people because if they found out it could wreak havoc in their life.

-Brooklyn, male

Participants also noted that undocumented consumers face an additional barrier to accessing services, as they are afraid of being deported if their HIV status is disclosed.

I am from [a hospital in Queens]; we have a lot of undocumented [immigrants]. So they come in, maybe they get tested. They find out they are positive but there is no next step for them really because they are undocumented. So now what do we do? They are afraid, they do not come back. We reach out to them. We try to grab them. We try to explain to them. But if there is nobody behind the staff or the students say, we are here to help you. You have got to take that stigma away. You have to let the undocumented [immigrants] know that we are not going to put you in the truck and then ship you back home again because you have HIV or AIDS.

-Queens participant, male

C2. Inconvenient clinic hours/wait times

Participants explained that many people have difficulty accessing treatment if clinics are not open during the evenings or on weekends. Having clinics that are open during these times is particularly important for consumers who work full-time and are unable to take time off work to maintain their treatment schedule.

The convenience, if you have a full time job or if you have a family, it might send a flag to your supervisor that you're needing to go to the doctor more frequently than normal. I mean...if you're going every three months, that may send up a flag.... And then the convenience, again, the weekends, being able to go on the weekends or at night. Maybe there should be a night clinic of healthcare.

-Brooklyn participant, male

Many of the patients that I have met don't like to wait much time because some of them work, some have to pick up kids, and honestly the clinic doesn't work with them to give them appointments that are appropriate for their lives.... That's why many of the clients go through clinics and clinics, because truthfully they can't go to clinics that have different hours and are not open after 5. So, if the clinic doesn't work the clients won't go back.

-Bronx participant (Spanish speaking), female

Other participants noted that long wait times have discouraged them – and may discourage others – from regular visits to the clinic.

I have not had a doctor's appointment for the past year.... At one point I walked out of an office because I was technically there for three hours. I said this is enough. When you can see, call me. I will make an appointment to come in and see you. That is what I told the nurse. I said because I have waited up in here three hours...I said I am on my way home. [The nurse] said why? I said I have not seen a doctor... I said but it has been three hours. I said I am on my way home. I said I have to do stuff better than wait to see the doctor.

-Manhattan participant, male

C3. Inconvenient clinic location/lack of transportation

Several participants – particularly those in Westchester County and Staten Island – noted it can be difficult to access needed treatment services when these services are in locations not easily accessed by public transportation.

There's always an issue with transportation. It's either too difficult because of the fact that we are on Staten Island. We are on an island, we do have to take a boat to the train, you know and sometimes we have to take a bus to get to the boat and that's the only issue that I see that's really difficult.

-Staten Island participant, female

C4. Poor provider-consumer relationship

Participants explained that consumers may be deterred from continuing to access services if they do not perceive their provider to be caring. Participants cited a poor provider bedside manner as a common barrier to accessing treatment services.

[One doctor]... he's not good and we don't go into his doctor's office. Any time he's come into the program they just put you in any room that don't have a doctors table, a scale or -- you know? It ain't the proper medical equipment and then this doctor is like -- he don't even test you for nothing. He's just -- he get you in the room and say, "What you need" and then write a prescription. Come on now, that's not the care I want.
-Staten Island participant, male

C5. Lacking bilingual staff at clinics.

Participants noted the need for more bilingual (especially Spanish speaking) staff in HIV care clinics. Participants explained that the inability of non-English speaking consumers to communicate with providers may deter the consumers from regularly accessing needed services.

I think an important point of why some don't return, [is] because there are no people who speak Spanish. And, if they do speak it, they don't know, like, they don't quite understand it well.... That is also a very important factor of why people don't return.
-Bronx participant (Spanish-speaking), male

Strategies/ facilitators to accessing HIV treatment services

D1. Greater assurance for consumers regarding their rights to confidential care

Participants indicated that part of the education outreach to consumers (described in **B1**) should include education regarding their rights to confidential HIV care. This assurance of protection of their confidentiality may allay some of the concerns that prevent consumers from regularly accessing HIV treatment services.

D2. Caring providers

Participants explained that caring providers and clinic staff could also be great facilitators to consumers remaining retained in care. This was particularly true if partners were effective communicators, and took the time to listen to patient concerns and answer patient questions.

You made mention of the provider relationship and I think it's key in that it can't be overemphasized, the relationship between the provider and the patient, and the provider showing that level of concern or level of interpersonal connection. Because as a patient, you're looking for someone to take your situation seriously and maybe hold your hand through the situation, and give you the respect of asking you to think about levels of treatment or think about your behavior. I mean, not to reprimand you or anything like that but just be more listening and advising with options. And asking. I mean, "okay, your numbers are this and well, if your numbers reach this, then maybe we'll have to consider medication. But if your numbers do well...." So engage the patient in that process and understanding. Because you're educating them but you're also engaging them so that they know what to expect, not just wait until the numbers get to a point well, you've got to go on medication now. It's like whoa, whoa, whoa, whoa, you know. You want to slowly go into that. So take them through the whole process, you know.
-Brooklyn participant, male

D3. Having support of peer mentor

Participants indicated that HIV positive peers play a powerful role in facilitating consumer access to and navigation of the HIV care system.

I also think that the greatest asset we have are people living with AIDS.... To have someone that you feel can relate to where you are, to help guide you through, more so someone that's been in it longer than you, is just a plus. I don't care which way you go. And that is in every aspect.

-Brooklyn participant, male

D4. Improvement/oversight of transportation system

Participants emphasized the importance of considering transportation alternatives to facilitate easier access of clinic services for consumers living in the Staten Island and Westchester areas. Participants explained that the transportation barriers for consumers living in these areas were different from those living in other boroughs.

I only say this as a suggestion may be to consider looking at Staten Island as a different transportation issue as maybe a mid Hudson or an up state. The geographic area is very, very different and to ask people to rely on that over burdened transportation may be a barrier.... It's a very different borough. I just heard that it takes two hours to get [to a clinic] -- so someone is not going to go to their doctor or access care if it takes them two hours. I mean if I had to take a bus to a ferry, to a train when it's cold and it's windy and I'm not feeling good. So perhaps looking at Staten Island very different then you would look at Manhattan or Brooklyn; it's a suggestion.

-Staten Island participant, female

I would like to see change in transportation in regards to protocol. I have been in taxicabs that are filthy, I have been in taxicabs that have bedbugs, I have been in taxicabs that have vomit from the night before and it has not been cleaned up. And, I have also been recently, in the last couple months, cab companies do not pick you up when they are supposed to. I have felt stranded, and you know you get panicky when you know that you are waiting two hours and they still have not come to pick you up.... [So] I think there should be some kind of a monthly survey that we could fill out and send it to a committee that really looks over these things, and the protocol would be if a certain vendor gets five complaints, they should not be servicing Medicaid.

-Westchester participant, female

D5. Extended clinic hours

So my hospital, our clinic pretty well is a pretty good running oiled machine. Like every place else we have places where we get stuck. We work through them. And we started a night clinic for those patients that are working. So now we brought a lot of those people. What you are speaking about now here is unfortunately for us as a clinic we pretty much have a good relationship, a good machine.

-Queens participant, male

D6. More bilingual staff at clinics

The one thing maybe to emphasize is more of the help [and coordination] between providers in Spanish.... For Latin-American people like myself, who don't comprehend English very well, this would help.

-Bronx participant, male

Barriers to initiating ART

E1. Depression/Isolation

Some participants indicated that the initial depression and feeling of isolation that may follow the diagnosis may impede many consumers from initiating ART.

The isolation and the depression that comes with not being in the social scene because, I guess, you have to learn now 'how do I live with this illness?' And if you do not have the support from your family which a lot of times we do not, then just finding avenues to gain your confidence back to make you feel whole again and to be a part of the cause. It sometimes takes a long time to get there.

-Manhattan participant, female

E2. Fear of side effects

Participants explained that a concern regarding potential adverse side effects of ART may be a significant barrier to consumers initiating ART.

If anyone were to read all the side effects of all the medication that they are to take, nobody would be taking any of the medication. Because, when you here that this one causes diarrhea and that one causes this, and this one causes that, you are like, "Why am I taking this?" But, so that ties into the misinformation, because it is understanding that yes, you may experience those side effects, but it is still better than not taking the medication and it is still better that your body has to get adjusted to it. So, it is understanding that you may have to go through a period of six to eight weeks where you are having the crazy nightmare...or whatever the case may be. But, it is a matter of understanding that, and it is the education that that is what needs to happen more and more.

-Westchester participant, male

E3. Widespread misconceptions about medications

Related to theme **D2**, participants noted widespread misinformation and misconceptions about the severity of ART may prevent consumers from initiating therapy.

But, there is so much misinformation and old information that so many people are still operating from, and that that is a huge barrier to care. You think about whether the comments from AZT about how poisonous that drug was. Well, you know what, it was poisonous, but for a lot of people it possibly worked and possibly did do something....

-Westchester participant, male

E4. Being in denial of HIV progression.

Participants also indicated that it may be difficult for some consumers to initiate ART because to do so would mean acknowledging that their HIV was progressing – a reality that many may not want to recognize.

A lot of times you simply do not want to start ARV because it is like acknowledging that HIV is progressing.

-Westchester participant, female

I think that something keeps a person from starting the medication is like then that is saying that, "Yep. That's what it is, and I really have it." It is like, I think that when they start the medication, even though they already know they have it, and they are in programs where they are talking about it. But, once they start that medication, it is like, this is it. This is it. This is the real stuff.

-Westchester participant, female

Strategies/facilitators to initiating ART

F1. Greater education and communication regarding side effects

Participants emphasized the importance of educating consumers on the side effects of ART prior to beginning the therapy. This education is a key component of ensuring a well-informed, empowered consumer noted in theme **F2**.

I would say that one of the things about taking the meds is that you have to explain to the patient the contraindications and in the cases of the medicine. Let the patient know fully what are some of the side effects and how long they're going to last.... But let them know, explain to the patient fully what he's taking and how it's going to affect him. And then try to get the patient to understand how to take his medication.... So these things are very important. These are very important to understand that there's going to be a lot of discomfort. But the benefits outweigh the risk. Just one of the things [patients] need to know.

-Brooklyn participant, male

F2. Consumers feeling empowered to have input in their healthcare.

Participants highlighted the link between consumer education and empowerment, and noted that empowered consumers who are engaged in managing their healthcare are more likely to initiate and adhere to ART.

I am glad that I have an involvement in my health care. Another thing is, I go to the groups and I ask questions. ... I want to know, "what do you know about this medication?" I always want to be educated and I believe that that makes a hell of a difference.

-Westchester participant, female

F3. Good provider-consumer communication.

Related to themes **F1** and **F2**, participants indicated that good communication between an informed, engaged consumer and a caring provider was a powerful facilitator to initiation and adherence to ART.

I believe I have a great relationship with my doctor, and what makes the difference for me is being educated and I always want to know. I can recall a couple of months ago, I began a new medication, and my T-cells had dropped. My viral load went all the way up, and so I had a conversation with my doctor. I am like, "Okay, so what are we going to do?" But, I am involved. I am involved in my health care and I believe that that makes a lot of difference, because where she, we had a conversation. It is not her telling me, "Well, this is what I am going to do." It is, "This is what we're going to do," and I agreed or I disagreed.

-Westchester participant, female

Barriers to maintaining viral suppression

G1. Poorly coordinated system of HIV care

Participants noted that gaps in communication between providers of HIV services, as well as gaps in linkages and referrals within the HIV care system could impede consumer adherence to treatment and their ability to maintain a suppressed viral load. In particular, participants noted poor communication and coordination between HIV care specialists and providers of mental health, between providers and pharmacies, as well as between providers and insurance carriers.

My doctor, right, he may be good at telling me what pills to take, but then I am supposed to see the psychiatrist if I am having some sort of depression or dealing with isolation, but she had not a clue to me as a person and she might prescribe something, but if I am not sure how I am feeling and I am supposed to take something and tell her how it makes me feel, but I am not sure how I feeling, it seems that I am not being monitored properly.

-Manhattan participant, female

When you go to your doctor and you tell him that you're going to move, he should be able to link you to another doctor within your living area. You should -- they should be -- everybody should be -- there should be a communication between doctors.

-Staten Island participant, female

Well, one of the barriers can be that they [consumers] have other medical issues, multiple medical issues. And, if you are not addressing them also and keeping that on the same team with your HIV, then this is why sometimes your infectious disease doctor, they do not know why the medicine is not working and they keep changing your medication, because your numbers are not moving, but it is not that. It is that it is other things and stuff that is going on with you medically. And [the providers] are not on the same team and [are not] dealing with everything that you are dealing with at the same time.

-Westchester participant, female

G2. Feeling better and stopping treatment.

I would say [you stop treatment] when you feel better. I know that was one of my issues when I felt better I said, "Well I don't need medication, I feel better; I don't need it anymore". And you feel like you want to get normal and everything is fine. Like, "Well I'm okay" and that's it.... If you don't understand that you have to keep [taking] it everyday, even if you feel better, you know.

-Staten Island participant, male

G3. Having poor communication with providers

I do not feel that I get the support from even my healthcare provider regarding understanding more about the medications might - I can switch to. I find it very difficult to get information where I can understand it and not depend on the doctor to just say yeah, take this and we will see how it goes. I want to be more informed about that.

-Manhattan participant, female

G4. Having competing responsibilities

Participants explained that competing responsibilities – particularly caring for children or other dependents – may impede consumers' treatment regimen and their ability to maintain viral load suppression. Participants noted that this was particularly true for women, who often put others' needs before their own.

There are kids that one has to take care of, sometimes it's not the kids, sometimes it's one's partner that is sicker than oneself. Also, sometimes, it could be family members who are sick, not necessarily with HIV but the majority of women take care of others and forget about themselves, so sometimes they need someone to take care of them.

-Bronx participant (Spanish-speaking), female

G5. Not disclosing status

Participants explained that the failure to disclose one's status to family and friends can impede one's ability to remain adherent to a treatment regimen and maintain suppression of their viral load. This is due in large part to consumers being unable to take their medication in private and/or adhere to an appointment schedule when they are trying to avoid raising the suspicions of others.

[If people] are not at a certain place where they want to be in privacy or in terms of taking their medication.... Privacy is a big issue. Let us say you are out and some have to take medication with food. So let us say you go out to eat and then you are supposed to take your med at that point when you eat, but you are out and with friends or whatever. It is like what do you do, take it in your - How do you take it inconspicuously and with privacy? That concerns so many people....

-Manhattan participant, male

G6. Living in poverty/being transient

Participants acknowledged that transient consumers or consumers living in poverty faced considerable barriers to staying adherent and achieving viral load suppression. This was due in part to the considerable other difficulties faced by these consumers on a day-to-day basis –including lack of a stable job, lack of stable housing, and food insecurity – all of which also directly impact the health and well-being of these consumers and their families.

But I think sometimes people who are disabled or immune compromised, they're probably liable to have food insecurity in their lives. So not being able to get the proper nutrition or not having a consistent job, not being able to support their families, not being able to take their meds in private. Or they may find that they have no opportunity to take their meds at a particular time or the meds need to be taken with food or after food. So it's a combination of things that may cause [non-adherence].

Strategies/facilitators to maintaining viral suppression

H1. Developing integrated team of providers – with peers as integrated team members.

To address the barrier of a disconnected/uncoordinated team of providers, participants highlighted the need for developing integrated, interdisciplinary provider teams. Participants highlighted the importance of integrating HIV-positive peers on these teams to facilitate communication between consumers and providers, and who may also serve as advocates for consumers.

[More] interdisciplinary collaboration, meaning multiple task team, ID doctor, medical doctor, nurse practitioner, mental health provider, etc., etc., one-stop shopping. All that stuff has valid point to it. What I wanted to contribute to this part of the conversation is that, as long as, as well as having a multi-disciplinary team effort, there is a great need for peer involvement. Not just going to the clinic and getting your services, but being able to connect with the other consumers in the clinic and develop a support team.... And, I would like to see that model followed through at the actual clinics, at the hospital-based institutions, that they develop some kind of peer support teams for the consumers to get involved.
-Westchester participant, male

H2. Automated reminders to take medication

Seven o'clock my phone rings, my medication is in my mouth. But, what I am trying to say is, it is like you said, it is more of a mental issue. How the side effects, like I was on one medication and it was two pills and they made it now into one pill, and I was already telling them that, "I am not taking this." "Try it, Judy, try it." So, it is like it is more mental and you like, but once you get used to it and you make it a routine, it gets easier. Just for me, at seven o'clock, I do not care where I am, my medication is in my mouth.
-Westchester participant, female

H3. Caring providers

Participants emphasized the importance of having providers who demonstrate care and respect for consumers, and who actively communicate with and engage consumers in managing their health. Participants noted that providers with these characteristics served as powerful facilitators to consumers accessing and adhering to their treatment program.

I know it is very unfortunate that there are not medical groups quite like [ours] with these amazing doctors, who are well-informed and up-to-date and have these specialty doctors, the infectious disease doctors as part of their groups. But, getting people like that, if you could get them out in the public to educate and talk, that would be a phenomenal thing. And, it would break down the barriers for [consumers] to see these phenomenal doctors, who are willing to sit down and talk to you and go over it, and not just make decisions [for you].

-Westchester patient, female

H4. Continued education of consumers on importance of being adherent.

We need to get more education out there. Like I was saying, once you feel better you say, "Okay I don't need the medication anymore". It's like taking an antibiotic. You take it for seven days and you figure "Okay I feel better, I don't need the other three days worth", but you do. Continuing your care is how you're going to stay healthy and you need to know that if you don't take your medication you're going to get sick. If you get sick and you go to the wrong hospital you're going to die.

-Staten Island participant, female

H5. Greater integration of HIV care with other social support services – especially housing

Housing. I mean, people were getting housed but people were being put in housing that is in the worst neighborhoods. And if they're a substance user or if they're feeling bad about themselves, they're even feeling worse about themselves because they're in a negative supportive environment. I mean, it's not a supportive environment.

-Brooklyn participant, male

That is the basis of most people in this city who have HIV problems is with the housing. The housing is a big problem and no one seems to be addressing it.

-Brooklyn participant, male

Characteristics of an ideal system of HIV care

1. Better integration of HIV care with other social services (housing, food security, mental health services)

See themes **G1** and **H5**.

2. Improved transportation services

See themes **C3** and **D4**.

3. Wider availability of specialists in all boroughs and upstate – especially for provision of mental health services

[We need] not just more regular doctors, more of the specialists of the different types of doctors because there are so many different specializations now. If all these people - at least one somewhere - and they should be not just in one place. It should be scattered about so that if you can't get to this neighborhood, at least you can get to that neighborhood.

-Staten Island participant, female

4. Provision of bilingual services for both HIV education outreach and care

See themes **B1** and **C5**.

5. Engaging family/significant others in managing HIV

If nothing else, we were always a good team at defending each other. [Laughs] If I could change [the system] and make it a little different, I would change the exclusion to inclusion. And, the inclusion, being for the family. And, it is sad that I am just meeting all of you today when you were a big part of his life, and I would love to see in the future, that there would be more family involvement, because John had the disease, we lived with the disease. And, sometimes that is tougher. [Laughs] And, sometimes the feeling of the children and letting them have their say, and the wife or the husband, letting them have their say, is, could be very constructive and would make the family stronger, and not just the immediate family, but the family stronger.

-Westchester participant, female

6. Advocacy focus

The system of care is going to [change] with the rollout of the Affordable Care Act and Medicaid expansion. I think now we need to look at what our Ryan White dollar's going to look like. Because a lot of those programs and things that are funded under Ryan White, the different service categories might not exist if people are getting care now through the Medicaid program. And Ryan White is up for reauthorization this year and so I think we need to focus on what is that going to look like and what are the discrepancies going to be. Because for the Medicaid expansion, it's not going to be fully implemented right away. It's going to be a process. So people trying to navigate through the system is going to be difficult, too. They're not going to know where they're getting their services. So I think now, that should be really an advocacy focus here.

-Brooklyn participant, female

But, as far as what works, obviously what works is what is happening in this room. It is people who are living with the virus coming together and talking about the issues that they need and learning from each other. we have to do more to, I think really empower ourselves to make sure that we go back to the old days, where it was people living with HIV who spoke out. And, that is, so I think, that this group to have happen.

-Westchester participant, male

7. Developed with input from consumers and HIV care providers

[The care system] should include a voice for consumers, [and] maybe within each of the boroughs visit some of the clinics where a lot of people with HIV get care. Speak to case managers, doctors, to talk about inefficiencies that are happening within each of the primary care providers.... I think just going in and speaking to people so you can maybe write that down and bring that back to the larger group as an advocacy item.... But I think as a whole, when you're talking about a system of care, you can address those inefficiencies. I think you just really have to be on the ground and talking to people, both people living with HIV and the medical providers.

-Brooklyn participant, female