

2009 DRAFT CONSUMER FOCUS GROUP GUIDE

(adapted from 2008 Consumer Focus Group guide and Planning Council Consumer Committee input)

Pre-focus group activities: participants will complete the quantitative survey and eat lunch/dinner.

Notes to facilitator: An examination of consumer perspectives on Health Resources and Services Administration (HRSA) Ryan White service categories represents an opportunity to assess and improve HIV/AIDS care, treatment, and housing services in the New York City (NYC) Eligible Metropolitan Area (EMA). The purpose of the focus group is to elicit consumer opinions regarding the utility, priority, impact, accessibility, and quality of Ryan White Part A services.

Food/Nutrition, Outreach Services, Home Care, and Housing Services will be re-bid shortly. NYCDOHMH is interested in consumer feedback on these services, in particular, since there is the opportunity to alter deliverables/service models for these categories.

Intro: Re-state purpose of the focus group, how/why these participants were invited, the understanding that participants speak from their personal experiences, the protection of privacy of participants, and the structure of the focus group interview guide and the similarities/differences between discussion groups and focus groups. Remind all present that the group is being audio-taped for transcription and later review/analysis of responses. The facilitators should define terms. For example, “services” refer here to Care, Treatment, and Housing services (funded under Ryan White Part A, formerly called Title I), and *discussion will be focused on New York City* or specific areas within New York City.

This is also a time to lay out some ground rules or expectations – for example, participants should:

1. Use their first name only or use a nickname/pseudonym if they feel at all uncomfortable using their first name and having it on tape;
2. Refer to other participants *without* mentioning names *or* using only the first names or nicknames those others have chosen to use for the group (rather than forgetfully calling out someone else’s real or full name);
3. Respect all other participants and allow everyone his/her own perspective and voice;
4. Respect the moderator if he/she says it is time for the group to move to the next question;
5. Be clear when they are speaking for anyone other than themselves (e.g., people they know or the larger NYC PLWHA population);
6. Ask questions whenever something is unclear.

Icebreaker: Go around the room and everyone state their first name (or what they would like to be called during the group) and their favorite type of candy.

Section 1: Assessment of Services on Relevance to HIV Primary Care Utilization and Consumer Needs

1. Thinking about the services you have used in New York City, how helpful/useful/important is a particular service for you to *access* HIV-related primary care? Why?

Instructions: Go through each service category. Identify the different criteria participants are using to determine usefulness or importance for access to care, draw out places where (and reasons why) participants see the actual service as delivered as different from the intent of that service category.

Probing questions: 1) Which service categories were most important for you to access care? 2) What motivated you to seek out HIV medical care? 3) Were there any barriers for you to access HIV-related primary care? (If so, what got in the way?) 4) Are there any services that are not covered under Ryan White Part A that you think would better enable you to access HIV primary care?

2. Thinking about the services you have used in New York City, how helpful/useful/important is a particular service for you to *remain in* HIV-related primary care? Why?

Instructions: Go through each service category. Identify the different criteria participants are using to determine usefulness or importance for retention in care, draw out places where (and reasons why) participants see the actual service as delivered as different from the intent of that service category.

Probing questions: 1) Since you started care, what has been your biggest challenge in keeping it up? 2) What services have you needed or used to maintain your medical care regimen? 3) If you stopped going for HIV care in the past, what caused you to stop? 4) What helped you get re-connected to care? 5) Are there any services that are not covered under Ryan White Part A that you think would better enable you to stay connected to HIV primary care?

3. Which services did you want to use in New York City but couldn't? Why?

Instructions: Refer to the list of all services. Determine which services participants think are rarely available or hard to access. Determine if any services are becoming harder to get and why. If services are not accessed, but are needed, which of these gaps should be prioritized in the planning of Ryan White Part A spending? Determine which gaps may have more to do with accessibility or quality, and could be addressed in some other way (e.g., selection of funded contractors, quality improvement activities, provider training requirements or other requirements that the NYC DOHMH could set to make sure that services are delivered according to the levels and intent of their funding and according to specific standards of care).

Probing questions: 1) Which services would you use if you had the opportunity? 2) Have you tried to access a particular service and been unable to use that service? Which ones? What happened? 3) What about HIV-related services that you do not see on this list –

were there any that you wanted to use but couldn't find or couldn't access in New York? Why and which ones?

4. How well do these Ryan White Part A services meet your needs?

Instructions: Go through each service category. Identify criteria for “meeting needs” and ways in which meeting needs overall may differ from serving primarily to increase access to or engagement in HIV-related primary care. Ask participants to clarify what they think of as “need,” and whether need is based on expected health outcomes/benefits of the service and their importance to survival, uniqueness of the service in addressing issues that are not addressed by other services, and/or client expectations for and interest in the service.]

Probing questions: 1) What is your biggest service need that has been met? 2) What is your biggest service need that has not been met? 3) Which services do you think have the most lasting effect on HIV-related care and health outcomes? Why?

Section 2: Satisfaction with and Quality of Part A (Title I) Services

Instructions: Facilitator to determine what participants think determines their satisfaction with care – what are the factors behind satisfaction or dissatisfaction? What are the providers doing right or wrong, or is it partly just in the nature of the service or the expectations surrounding it (e.g., meals are a generally positive experience, but dental visits are not)? What aspects of HIV services can be made more satisfying, or at least agreeable, to clients? How? Also, discuss what is affected **by** satisfaction with care (utilization, outcomes?), and how.

Are there opinions in the group as to where satisfaction should count more, and where it should count less (in planning for how to divide Ryan White funding between service types), or should it be weighed equally for all types of services? Where in particular (if it varies by service type) do participants think that increased satisfaction would cause consumers to use more of the services they need? Where in particular would increased client satisfaction improve the impact/outcomes of those services, not just through utilization rates (any examples)?

Housing has been suggested repeatedly by NYC consumers as a key topic. Consider probing about HIV-related housing services, where they are failing, and how they could be improved.

1. What services in New York City are you most satisfied with? Why?

Probing questions: 1) What has been your best or most encouraging experience with HIV-related services? 2) Which services do you think have made the most positive impact on your HIV related care and health outcomes? Why?

2. What services in New York City are you least satisfied with? Why?

Probing questions: 1) What has been your most frustrating or disappointing experience with your HIV-related services? Why? 2) Does (dis)satisfaction sometimes have to do with an experience of stigma and/or providers (consciously or not) making you feel stigmatized? 3) Which services (in terms of how they were actually delivered) have made the most negative impact on your HIV related care and health outcomes? Why?

3. Are there other ways in which the quality of HIV-related services can be improved in New York City? How?

Probing questions: 1) What factors should be considered in judging the quality of a service? 2) Do you consider stigma to be a service quality issue? (If yes, how?) Is this true for some types of services or some types of providers more than for others?

Section 3: Geography and Specific Populations

1. In your experiences with seeking and using HIV-related services in New York, do you feel like you are treated differently because of some aspect of yourself (for example, being a member or being *seen* as a member of a particular group? Please describe your experience and how you explain it.

Instructions: Facilitator to determine if there are any specific populations that are underrepresented in the available/funded HIV related services.

Probing questions: 1) Do you represent a particular population or group that you think may not be getting adequate levels of service? 2) How can these gaps best be addressed? 3) What are the barriers to access that might remain even with increased funding targeting those under-served groups or populations?

2. What HIV services do you receive in your neighborhood? What HIV services are needed in your neighborhood? Why?

Instructions: Facilitator to determine if participants receive care in their neighborhood or if participants are unsatisfied with the services in their neighborhood and have to travel to receive adequate care. Do any participants indicate that they travel out of neighborhood for HIV services for other reasons (e.g., privacy and lower chance of running into neighbors/acquaintances)?

Probing questions: 1) What improvements are needed to improve services in your neighborhood? Why? 2) Are there any other factors that affect your ease or comfort in accessing services in your own neighborhood?

Section 4: Other Health Concerns (i.e., “It’s Not All Just About Living with HIV!”)

1. What is your most important health concern other than HIV?

Instructions: Consider mental health and emotional health as well as physical health. Consider social functioning as well as basic physical functioning.

Probing questions: 1) What are some of your other health related challenges? 2) Are the other health concerns related to the HIV in some way? How? 3) Do you think the other health concerns relate to other factors such as age or gender? 4) Are these other health concerns more serious or important to you at times, compared to the HIV?

2. How do you deal with that concern at the same time as managing your HIV?

Probing questions: 1) How do non-HIV conditions make it more or less difficult to cope with HIV? 2) Does care for these other conditions tend to get in the way of care for HIV, or vice-versa? 3) How do you prioritize these different needs and the different parts of your health care?

3. How satisfied are you with the medical care you are receiving for your other health concern(s)?

Probing questions: 1) What is/was your experience accessing care for other health concerns? 2) Do you have any challenges remaining in care for your other health concerns?

4. Do your health care providers work at coordinating the care for your different needs? If so, how?

Probing questions: 1) Do you have a health care provider who you are working with for other chronic or serious conditions aside from HIV? Is it the same provider as your HIV care provider? If it is a different provider, do you think your other health care provider and your HIV care provider coordinate your care in any way? How well is this working? 2) Are there communication gaps or other gaps? If so, where are the gaps?

Section 5: Participating in Improvement and Planning

1. When you have a concern about the delivery of HIV/AIDS care and supportive services in New York City, what do you think of as your options for making that concern known/heard (what actions do you think you could take)?

Probing questions: 1) Before now, have you ever made your voice heard about the delivery of HIV/AIDS care and support services? 2) What was that experience like? What happened as a result? Were there repercussions, or did you feel things changed for the better? 3) Would you do it again? If not (or for those participants who haven't taken such an action before), what would you think of doing now, in a situation where you had

a problem with your services or with the larger picture of HIV services in New York City?

2. Have you ever had the experience of serving on a consumer advisory board (“CAB”) or consumer advisory group (“CAG”) of an HIV-services-providing agency in New York City?

Probing questions: 1) *Can you talk about that experience?* 2) *Do you feel like you have been able to improve services at that agency, through your CAB /CAG participation?* 3) *Has your experience been disappointing or frustrating? Why?* 4) *How could CABs or CAGs work better in NYC?*

3. What do you know about the HIV Health and Human Services Planning Council of New York (which we can call “the Planning Council” for short)? Is there anything in particular you would want the Planning Council to be doing to improve HIV services and care for you?

Probing questions: 1) *Do you know about the Planning Council and its role in deciding priorities for Care, Treatment, and Housing (Ryan White Part A) service delivery?* 2) *What do people think the Planning Council does now, and what do they think it should do, to ensure that PLWHA in NYC can get the kinds of care/services they need?*

Conclusion

1. Are there other things you would like to discuss?

Instruction: *Facilitator to thank the participants for their thoughts and time, encourage people to take home any leftover food, etc.*