HIV HEALTH & HUMAN SERVICES
PLANNING COUNCIL OF NEW YORK
A Mayoral Council established by the Ryan White C.A.R.E. Act of 1990

CONSUMERS COMMITTEE

Thursday, January 16, 2013, 1-3 PM
NYCDOHMH, 2 Gotham Center, Room 19-27, Long Island City, NY

Planning Council Members Present: Victor Benadava (Co-Chair), Gregory Cruz (Co-Chair), Randall Bruce (Consumer-At-Large), Felicia Carroll, Rev. Keith Holder, Muying Hunt, Deborah Marcano, David Martin, Tracy Neil

Planning Council Members Absent: Victor Alvarez (Tri-County), Lotus Blackman, Gerald DeYounge, Pastor Jerome Payne

Appointed Community Members Present: Jose Colon-Berdecia**,** Billy Fields

DOHMH: Marie-Antoinette Bernard, M.D., Rafael Molina, Jan Park, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- December 19, 2012 Draft Meeting Minutes;
- NY HIV Planning Council 2013 Committee Application;
- 2011 regional Listening Forums, New York State Department of Health;
- Obtaining In-Depth Consumer Input for a Comprehensive Plan and/or PSRA Process, EGM Consulting, November 2012;
- 2013 HIV Planning Council Borough-Based Consumer Listening Sessions – Issues for Consumer Input, January 2013;
- Follow-up on Using the Treatment Cascade for Special Populations, January 10, 2013, HIV Epidemiology & Field Services Program;
- Medical Monitoring Project (MMP) 2010 Local Questionnaire – English version;
- Announcement of January 17, 2013 HASA presentation, Federation of Protestant Welfare Agencies;
- Announcement of LTI PSRA Planning Council February 12, 2012 Training; and
- NY HIV Planning Council January & February 2013 Meeting Calendars.

WELCOME & INTRODUCTIONS:

Victor Benadava and Gregory Cruz, Co-Chairs, opened the meeting beginning with the review of the Rules of Respectful Engagement, followed by the review of the agenda and meeting materials by Darryl Wong. In particular, the 2011 NYSDOH report of the Listening Forums was included for reference. The minutes of the December 2012 meeting were approved by acclimation. Tracy Neil led the committee in a moment of silence.

PUBLIC COMMENT:

There was no public comment.

MEDICAL MONITORING PROJECT UPDATE (MMP)

The Consumers Committee has been designated as the local CAB for NYC's participation in this national surveillance project and on a cyclical basis is given the opportunity to provide input on questions in the survey of a more local, culturally sensitive and appropriate nature, in contrast to the fixed set of core questions which is distributed nationally to all participating sites. In order for consumers to provide input into the 2013 cycle of local questions, the 2010 English version was distributed to committee members for review in advance of a more in-depth discussion. Dr. Marie-Antoinette Bernard, the MMP Data manager for

the project, introduced the local survey. A summary of the following comments *(in light blue italics)* were elicited as the Committee reviewed each question individually:

- *I*
  s the survey anonymous or confidential?
- Q
  6 forward:
  Why is *refused to answer* listed as an answer option, as opposed to *declined to answer*?
  The former term implies that the respondent has something to hide and connotes a more aggressive stance than a more neutral declination and could imply that a respondent's not answering indicates there is something to hide or deny.
- *I*
  s knowledge of HIV/AIDS assessed?
- Q
  6: In what NYC borough do you live?
  What if the respondent is homeless? How does he/she answer this question.
- *W*
  hy is there no question asking "When did you get diagnosed with HIV?"
- Q
  8: Has a doctor or health care provider ever told you that your HIV infection has progressed to AIDS?
- *C*
  an the interviewer utilize "teachable moments" during the interview in order to heighten the level of HIV/AIDS knowledge or must they adhere to the script? Are there questions assessing level of HIV/AIDS knowledge? Are they in the core questionnaire?
- *W*
  hat about concurrent diagnosis (given an AIDS diagnosis when testing positive for HIV)?
- Q
  10: Now I'd like to ask you about your understanding of certain aspects of the HIV virus and medications. The next questions are about Drug resistance"
  Why didn't they ask if the survey respondent is aware of what drug resistance is?
  Is it clear that this is addressing viral resistance and not psychological resistance?
- *Q*
  12: Need to clarify term "resistant" for respondent?
- *W*
  hy is there no question asking when and where you first diagnosed?
- A
  s a follow-up to Q13 "When you were first told you tested positive for HIV, did anyone try to help you get into HIV medical care?"
  What about other types of care?
  Why do the response options not include "There was no HIV medical care when I was diagnosed"? For example, in 1986, there was no HIV medical care. What does HIV medical care mean? Any medical care? This question demonstrates a lack of understanding on behalf of those conducting the survey?
- Q
  14: *Among response choices: "A person from your church" assumes respondent is Christian.*
  Replace church with religious institution/faith-based institution.
  Specify NYSDOH or NYCDOH?
- Q
  16: Have you done anything in the past 12 months to reduce the chances of giving HIV to other people*?*
  This question puts an individual at risk of criminalization if they answer no.
  What is the purpose of this question?

- Q 17: What have you done in the past 12 months to reduce the chances of giving HIV to other people
  "Warned" is a poor word choice that is stigmatizing and casts blame.
- Q *18: Replace "doctor" with "health care provider". What if a person doesn't have a doctor?*
- Q *18d/e: What is the importance of the "number of partners/how many new sex partners" What does this mean? Why is this important?*
- Q *20 (NYC Condom): what is the relevance of this question in the context of HIV care?*
- Q *22: Other responses can include "size is not appropriate". What about female condoms?*
- Q 25: Have you or your sexual partner(s) used an NYC condom in the last 6 months?
  How would your sexual partner know that it's a NYC condom?
- Q *27: Why only one choice, even if question asks the main reason?*
- Q *29: Why vaginal or anal sex, and not both?*
- Q 30: In the past 12 months, how many men did you have vaginal or anal sex with?
  Why not both? Is this seeking to ascertain if a male has had sex with a transgender male?
- Q 33: Of all your male sex partners in the past 12 months, how many did you know were HIV+?
  How would you know if they were HIV positive? How do you quantify "some"
- Q 34: Of all of your male sex partners in the past 12 months that you knew were HIV positive, with how many did you have sex without a condom? None, some or all? When I say without a condom, I meant that you either didn't use a condom at all or that you only used a condom for part of the time during sex.
  How do you define "sex"? How do you know if they are HIV positive?
- Q 35: Now I'd like you to think about the first time you had sex with these HIV positive male partners after you tested positive for HIV. Did you discuss your HIV status with none, some or all of these men before you had sex without a condom?
  There are numerous concerns about self-incrimination and the use of confidential data that can be linked to an individual's identity re: HIV criminalization.
- Q 36: Of all your male sex partners in the past 12 months, how many did you know were HIV negative?
  How would one know if their sex partner is HIV negative? Were you told (the truth), did you ask, did you assume or was an at-home HIV test performed in the presence of both partners?
- Q *37/Q38: Similar concerns as Q35, 36*
- Q *39: How do you not know?*
- Q *40: Not all sex involves a condom*
- Q *41: Question seems redundant, with similar concerns as Q36-38*
- Q *43-48: Same questions and issues as Q30-35:*

- *Q 49/50: How do you know someone's status?*
- *Q 52: Confusing: Choose one: none, some or all. Are choices limited to none, some or all? What about don't know or refuse to answer?*
- *Q 54: Inclusion of "relationship", as in sexual relationship, may be a reflection of individual or personal cultural values and/or mores. What about anonymous sexual encounters, where a relationship may not be implied.*
- *Q 56: Why is oral sex included in the range of sexual activities comprising group sex, when it is not included when referring to sexual activities between two partners (only vaginal or anal)?*

BOROUGH-BASED CONSUMER LISTENING SESSIONS

The NYC treatment cascade and continuum will be used as the framework for the borough-based listening sessions to be conducted in the Spring 2013. The cascade begins with the number of estimated HIV-infected, HIV diagnosed, those ever linked to care, those retained in care, those presumed ever started on ART and those with suppressed viral load (< 400 copies/mL). It was noted that the NYC model uses surveillance data throughout because NYC has an alternative to MMP (but CDC does not, as not all jurisdictions have reporting of all HIV related laboratory tests).

Utilizing the NYC Treatment Cascade to frame questions regarding *current barriers and necessary actions to remove or minimize these barriers* will be useful in articulating and describing the *disparities in engagement and retention in care* that prevent PLWHAs from moving along the continuum of engagement in HIV care. In particular,

- W hat are the most important barriers to *testing* for the estimated 18,000+ persons who are infected but not diagnosed?
- O nce people are diagnosed, what are the most important barriers for the estimated 15,300 persons who are diagnosed but not linked to care?
- W hat are the barriers to *obtaining needed services/being linked to care* for the estimated 24,000+ linked to care but NOT retained in care?
- W hat are the barriers to *being retained in care* for the estimated 7,000+ persons retained in care, but not started on ART?
- W hat are the barriers to *treatment adherence to help the estimated 12,000+ PLWHAs who have started ART therapy but have not reached not viral suppression.*

BOROUGH UPDATES: HIV NETWORKING ACTIVITIES/PUBLIC COMMENT/ANNOUNCEMENTS: ADJOURNMENT:

There being no further business, the meeting was adjourned at 3:00PM.