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, December 19, 2012, 1:30-3:30 PM
NYCDOHMH, 2 Gotham Center, Room 18-25, Long Island City, NY

Planning Council Members Present: Victor Benadava (Co-Chair), Gregory Cruz (Co-Chair), Randall Bruce, Felicia Carroll (Consumer-At- Large), Muying Hunt, David Martin

Planning Council Members Absent: Victor Alvarez, Lotus Blackman, Gerald DeYounge, Deborah Marcano, Tracy Neil, Pastor Jerome Payne

Community Members Present: Billy Fields, Glen Phillip

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

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- November 14, 2012 Draft Meeting Minutes;
- Announcement of 2012-13 Consumer At Large Nomination & Voting Ballot;
- NY HIV Planning Council 2013 Committee Application;
- CHAIN Report 2012-09: Tobacco Use, Cessation and Medical Provider Intervention, Messeri & Vardi, Columbia University Mailman School of Public Health;
- Syphillis and HIV: A Dangerous Duo Affecting Gay & Bisexual Men, Bolan, Centers for Disease Control & Prevention, December 13, 2012;
- Secretary Sebelius Approves Indicators for Monitoring HHS-Funded HIV Services, Forsyth & Yavkochenko, Office of HIV/AIDS and Infectious Disease Policy, USDHHS, August 8, 2012;
- Will Data Indicators Help Our AIDS Effort? An Update on HHS HIV/AIDS Indicators Activities, Powerpoint Presentation, Prevention Justice Alliance, Nov 28, 2012
- A Treatment Case for NYC Using HIV Surveillance, HIV Epidemiology & Field Services Program, Powerpoint Presentation, Bureau of HIV/AIDS Prevention & Control, NYCDOHMH, December 13, 2012;
- Obtaining In-Depth Consumer Input for a Comprehensive Plan and/or PSRA Process, EGM Consulting, November 2012;
- Driving the Story: Engaging the Media to Expand Health Access for People Living with HIV, Powerpoint Presentation, HIV Health Reform, December 2012;
- PEPFAR Blueprint: Creating an AIDS-free Generation, US Department of State, November 29, 2012;
- Medical Monitoring Project (MMP) Powerpoint presentation, Marie Antoinette Bernard, HIV Epidemiology & Field Services Program, NYCDOHM; and
- NY HIV Planning Council January 2013 Meeting Calendar.

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, allowable advocacy activities as defined by Federal legislation were discussed. The minutes of the November 2012 meeting were approved by acclimation. Muying Hunt led the committee in a moment of silence in honor of those we serve, as well as those who lives were taken in the Newtown, CT mass school shooting.

PUBLIC COMMENT:

There was some discussion about varying the venues for the Committee's meetings between Gotham Center in Long Island City and other community-based venues in the other four boroughs. Felicia Carroll shared an update of Myron Gold's health status and encouraged members to reach out to him. Mallory Lowenstein noted that an enhanced pneumovax vaccine, is available for PLWHAs.

NOMINATIONS FOR & ELECTION OF CONSUMER AT LARGE 2012-13

Darryl Wong announced the opening of the nomination process for the election of the Consumer At Large Position for the planning cycle of 2012-13. The unique role of the Consumer At Large, including a third vote at the Executive Committee when voting matters are considered and the overall voting process was described.

Nominees Felicia Carroll (currently the 2011-12 Consumer At Large), Randall Bruce and David Martin were asked to present their statements of interest, as well as to respond to individual questions from Committee members. Per Planning Council Bylaws, election of the member at large will be determined by plurality vote, with the At-Large member's term beginning in December 2012 and ending in December 2013. Ballots were distributed and the vote was tallied by Planning Council staff.

> ***ACTION***: Randall Bruce received the largest number of votes and was elected as the Consumer-At- Large for this current term.

CHAIN REPORT 2012 – TOBACCO USE, CESSATION & MEDICAL PROVIDER INTERVENTION

BACKGROUND:

- As PLWHAs live longer, tobacco use looms large as a major health problem.
- Smoking rates are high among PLWHA, undoubtedly a consequence that those at highest risk of HIV infection come from groups--substance users, gay men, and low income--with high smoking prevalence.
- Information remains limited on current smoking behavior and medical care provider support for cessation.

STUDY QUESTIONS: Among CHAIN participants,

- What is lifetime smoking prevalence and recent trends in current smoking, quit and relapse attempts?
- What are trends in medical provider advice and assistance?
- Are there significant group differences in current smoking, quit and relapse attempts and medical provider intervention?
- What is the evidence on the health consequences of smoking?

DATA:

Data was derived from six rounds of interviews conducted with NYC and Tri-County residents living with HIV/AIDS between 2001 and 2012 .

NYC cohort:

- 693 individuals recruited from 34 agencies during 2002 and 2003.
- An additional 319 individuals recruited from 18 agencies during 2009 and 2010.

Tri-County cohort:

- 398 individuals recruited from 28 agencies during 2001 and 2002.
- 58 individuals were added to refresh the Tri County cohort during the third round of interviews.
- Switched to a repeated cross section design, in which new individuals were recruited during a two-year survey cycle. In each cycle a small number of participants are linked to earlier CHAIN interviews.

SMOKING BEHAVIORS:

- At Baseline Interviews : "Have you smoked at least 100 cigarettes in your entire life?".
- At all interviews : "Do you smoke cigarettes now?"
- Starting in Round 3 (NYC) and Round 4 (Tri-County), current smokers were asked "In the past year has a doctor or medical provider talked to you about quitting?" [Advice] and "Has he or she prescribed anything to help you in stopping or referred you to someone who could help?"[Assistance]

STUDY OUTCOMES: Determine rates of the following:

- Current Smoking
- Former Smoking-Reported past at baseline or current smoking at an earlier interview
- Quit Rate: Among current smokers at previous interview, % not smoking at current interview
- Relapse Rate: Among former smokers at previous interview, % smoking at current interview
- Medical Care Provider Advice and Assistance

FINDINGS:

- No consistent group differences stand out with respect to medical provider advice and assistance in quitting.
- In New York City, medical provider advice is associated with increased quit rates; there is no further increase linked to extending assistance.
- Smoking was not related to utilization of medical care services and chronic health condition, but it was related to mortality:
  Mortality risk ratio for current smoking = 2.01
  Mortality risk ratio for former smoking = 1.17

SUMMARY:

- More than half the members of New York City and Tri County Cohorts continued to smoke at most recent interviews.
- Current smoking has declined as the cohort ages, but the high rates point to the difficulty of achieving permanent cessation.
- Substance use is perhaps the single most important obstacle to reducing smoking prevalence.
- It is encouraging that many medical care providers are providing smoking cessation advice and assistance.
- Advice encourages quit attempts, but assistance does not appear yield further reduction in quit rates
- While current smoking doubles mortality risk, those who have stopped smoking substantially lower mortality risk

CONCLUSIONS:

- Smoking continues to be widespread in the CHAIN cohort with consequent detriment to the cohort's life expectancy. Medical care providers are engaged in smoking cessation, but there is room wider and more effective provider advice and assistance. The written report will include a review of evidence based smoking cessation interventions in HIV+ populations.

DATA INDICATORS/ THE TREATMENT CASCADE FOR NYC USING HIV SURVEILLANCE DATA

In July 2012, Secretary Sebelius of the DHHS approved package of (7) common, core indicators for monitoring HHS-funded HIV prevention, treatment and care services. These common HIV indicators, which were informed by relevant treatment guidelines and empirical evidence, include the following:

1) H
IV Diagnosis; 2) Late HIV Diagnosis; 3) Linkage to Medical Care; 4) Retention in HIV Medical Care; 5) Antiretroviral Therapy (ART) among persons in HIV medical care; 6) Viral Load Suppression and 7) Housing Status.

Some of the challenges related to data collection involve a lack of common definitions, metrics and policies, multiple funding streams with different reporting requirements for similar activities, lack of a unified national electronic medical record, the non-interoperability of different data systems, the lack of integrated HIV surveillance, public health and clinical data, the disconnect between systems public and private care and legislative requirements.

The original US treatment cascade shows HIV-infected persons across the continuum of engagement in care. Originally presented by CDC in November 2011, it represents all persons with HIV in the US and is based on data from CDC HIV surveillance data, published literature on linkage to and retention in care and the Medical Monitoring Project (MMP).

NYC first attempted a NYC treatment cascade in December 2011 which has evolved into one that is consistent, transparent and easily reproducible. The NYC treatment cascade and continuum 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). There is a need to update the cascade annually, including future changes to the presumption of being on ART, as DHHS guidelines have already changed.

MEDICAL MONITORING PROJECT UPDATE (MMP)

Dr. Marie-Antoinette Bernard began the discussion with a brief overview of the CDC MMP Project. It was noted that the MMP project addresses (3) of the above (7) common indicators – Anti-retroviral use, Viral load suppression and housing status. In the past (2010), the Committee, acting as the local NYC CAB for the project, was given the opportunity to provide input on questions in the survey of a more local, culturally sensitive and appropriate nature, rather than one of a more general/national scope. There is once again an opportunity for consumer input into the 2013 local questionnaire; the 2010 version will be sent to Committee members for review in advance of a more in-depth discussion at the January 2013 meeting.

BOROUGH-BASED CONSUMER LISTENING SESSIONS

As we approach the timeframe (January/February 2013) for these listening sessions, a summary of approaches to gathering in-depth consumer input was distributed. Developed by our HRSA- funded technical assistance provider, EGM Consulting, a series of questions has been developed to elicit input in response to questions regarding gaps, barriers, disparities at each state of the continuum of engagement, roughly parallel to the above-discussed treatment cascade. Once venues have been identified and dates secured, the Planning Council will conduct broad-based outreach to ASOs and CBOs in each borough, in order to help assure a broad base of consumer input.

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

Members and staff who have attended the Planning Council committee meetings provided updates on each of the meetings they have attended. There were no updates on individual borough-based HIV networking activities.

ADJOURNMENT:

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