



## **CONSUMERS COMMITTEE**

Thursday, April 17, 2013, 3 - 5 PM  
NYCDOHMH, 42-09 28<sup>th</sup> Street, Conf Rm 16-49  
Long Island City, NY

**Planning Council Members Present:** Victor Benadava (Co-Chair), Gregory Cruz (Co-Chair), Randall Bruce (Consumer-At-Large), Lotus Blackman, Muying Hunt, Deborah Marcano, David Martin, Tracy Neil

**Planning Council Members Absent:** Victor Alvarez (Tri-County), Felicia Carroll, Gerald DeYounge, Rev. Keith Holder, Pastor Jerome Payne

**Appointed Community Members Present:** Glen Phillip, Ron Joyner, Yves Gebhardt

Guests: Donna Classe, David Harris, Mallory Lowenstein, Marcelo Soares

**NYCDOHMH:** Rafael Molina, Darryl Wong

### **MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- March 20, 2013 Draft Meeting Minutes;
- Planning Council letter to Dr. Marie Bernard, Medical Liaison, HIV/AIDS Epi & Field Services;
- Obituary of Ilene Chung-Eddie, [Staten Island Sunday Advance](#), April 14, 2013;
- DHHD/CDC letter to Medical Monitoring Project (MMP) Stakeholders, 3/29/13;
- 2013 Standard Questionnaire for Medical Monitoring Project (For Stakeholder Review), Sections A, R, T, U, B, P, M, G, C;
- NYCDOHMH MMP outreach letter;
- NYCDOHMH STD Citywide Clinics flyer;
- Ryan White Program Re-Authorization Update, HIV Health Reform, April 16, 2013;
- US Department of Health & Human Services, Health Resources and Services Administration [Justification of Estimates for Appropriations Committees, FY 2014](#);
- ABAC/HRSA FY 14 Budget Justification;
- NY HIV Planning Council May 2013 calendars

### **WELCOME & INTRODUCTIONS:**

Gregory Cruz and Victor Benadava, Co-Chairs, opened the meeting. Joey Lopez led the group in a moment of silence, beginning with the group review of the Rules of Respectful Engagement and followed by the review of the agenda and meeting materials by Darryl Wong. The minutes from the March 2013 meeting were not reviewed for approval.

### **PUBLIC COMMENT:**

There was no public comment.

### **MEDICAL MONITORING PROJECT UPDATE (MMP) 2013 STANDARD QUESTIONNAIRE SURVEY (EXCLUDING SEXUAL BEHAVIOR QUESTIONS) - CONSUMER FEEDBACK & DISCUSSION:**

Over the past few months, the Consumers Committee of the NY HIV Planning Council has provided feedback on the MMP 2012 Local Questionnaire, as well as the Sexual Behavior questions in the 2013 Standard Questionnaire. The sexual behavior questions are now under revision at CDC and were not included in the review to be undertaken today, which will focus on reviewing and providing new input on .

the 2013 MMP Standard Questionnaire. Revisions to this survey instrument will be incorporated into the 2015-17 MMP data collection cycle.

In order to provide greater focus for the review and to meet the deadline for stakeholder input by May 10, a small group format was utilized to complete the review. Approximately (4) groups of 4 persons per group reviewed sections of the questionnaire, with each group containing 30-40 questions. The topic groupings addressed: Access to care (41 questions); Stigma & Discrimination, Transmission Risk Behaviors and Prevention Activities (32 questions); Sexual Behavior/Serosorting, Drug & Alcohol Use, Depression and Gynecological & Reproductive History (34 questions); and HIV Treatment & Adherence and Health Conditions & Preventive Therapy (40 questions). At the end of the review, all written comments were collected; comments were then submitted on electronic forms supplied by the CDC by mid-May.

A summary of topic-specific comments and revisions appears below:

**ACCESS TO CARE:**

- dd “Why did you feel that you needed to get tested for HIV?”(Modification to A1) A
- nclude “at home testing kit” to answer options as people will be testing at home more often (Modification to A3) I
- dd “Didn’t want to identify with having AIDS” due to stigma (Modification to A6a) A
- dd “HIV stigma” to answer options (Modification to A7a) A
- dd “HIV stigma” to answer options (Modification to A8a) A

**STIGMA & DISCRMINATION:**

- dd “Have you been in an intimate sexual relationship since your HIV diagnosis?” (Modification to R1) A
- dd “Has HIV prevented you from participating in a sexual relationship?”(Modification to R1) A
- dd “Did HIV stigma prevent you from dating, leading to isolation and depression?” (Modification to R1) A
- dd “Has any health care provider ever shown a negative or uncomfortable reaction once knowing your HIV status?” Body language is often more indicative of a person’s thoughts and feelings than spoken words (Modification to R2) A
- dd “Has any health care provider ever recoiled/backed away from you knowing your HIV status?” A
- he word dirty is derogatory and demeaning (Modification to R1b) T
- se the words “unclean” or”contaminated” instead of the word “dirty”, which seems to reflect he situation experienced or type of encounter engaged in as opposed to how the individual may view themselves with having HIV.” (Modification to R1b) U
- dd “Being HIV positive makes me feel unwanted” (Modification to R1) A

**HIV TREATMENT & ADHERENCE:**

- dd “Do you have a support system?” (Modification to T13b) A

**SEROSORTING:**

- dd “Did you choose your partner by his/her HIV status and/or viral load? (Modification to S26) A
- dd “I choose my partners by HIV status and/or viral load” (Modification to S26) A

**DRUG/ALCOHOL USE:**

- eliminate answer options “Refused to Answer” and “Don’t Know” because if individual refuses to answer questions regarding drug & alcohol use, the honesty of all answers is questionable. (Modification to U3) E
- dd “How many drinks did you have before or during sex?” (Modification to U6, U7) A
- rack is not purchased to be injected, as smoking gives it more potency (Modification to U9, U11) C
- dd “How many people have you shared needles with the last time you used injectable drugs?” (Modification to U16-U18) A
- define “mainlining, skin popping and muscling” as not everyone is familiar with these terms (Modification to U12, U12a) D

**TRANSMISSION & RISK BEHAVIOR:**

- dd “Have you ever worked in a professional capacity or medical field and assisted with or given injections or worked with needles?”(Modification to B10) A

**DEPRESSION:**

- dd “Have you ever used sex as a coping mechanism for depression?” (Modification to M1) A

**GYNECOLOGICAL & REPRODUCTIVE HISTORY:**

- keep answer options limited to yes or no; eliminate Don’t Know and Refused to answer (Modification to G3) K
- dd “Tell me if you or your partners have used ....” (Modification to G3) A

**HEALTH CONDITIONS & PREVENTIVE THERAPY**

- dd “Do you know what a CD4 test is”, although interviewer instructions defines CD4 test (Modification to C1) A
- dd “Don’t remember” as an answer option (Modification to C1b) A
- dd “Do you know what a viral load test is”, although interviewer instructions defines viral load test (Modification to C4) A
- dd Community-based organization, CBO or ASO as answer options (Modification to C12) A

**PLANNING COUNCIL UPDATES:**

- he PSRA committee met and approved a 5% scenario plan and the restoration of funds to three service categories. Randall Bruce, Consumer At Large, recently joined the PSRA Committee. T
- he Integration of Care Committee will be meeting to vote on the Health Education/Risk Reduction service directive. The Committee is also developing a non-medical case management service directive. T
- he Needs Assessment Committee is discussing timeframes for being “in care” and “out of care”. T
- he Policy Committee is examining how policy shifts will affect the NY EMA’s programming and portfolio. Issues of conflict of interest were cited as being problematic. T
- he Rules & Membership Committee is preparing the 2013-14 Planning Council Membership application for distribution. T

**PUBLIC COMMENT:**

Consumers should be empowered and have a voice in Community Advisory Board. The Committee was reminded that a best practices survey regarding recruitment, engagement, retention, feedback and input was conducted in early 2011. Results will be presented to the Committee and staff from Public Health Solutions at forthcoming Committee meetings.

**BOROUGH UPDATES: HIV NETWORKING ACTIVITIES/ /ANNOUNCEMENTS:  
ADJOURNMENT:**

Community Access, a provider of HIV/AIDS services, offers twice monthly HIV/AIDS support groups for HIV+ persons, as well as training in life skills, reading laboratory tests and healthy practices.

There being no further business, the meeting was adjourned at 3:30PM.