



CONSUMERS COMMITTEE

Thursday, November 14, 2012, 1:00-3:00 PM
NYCDOHMH, 2 Gotham Center, Room 20-38, Long Island City, NY

Planning Council Members Present: Victor Benadava (Co-Chair), Lotus Blackman, Randall Bruce, Deborah Marcano, David Martin, Tracy Neil,

Planning Council Members Absent: Gregory Cruz (Co-Chair), Victor Alvarez, Felicia Carroll, Gerald DeYounge, Muying Hunt, Pastor Jerome Payne

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;
- July 16, 2012 Draft Meeting Minutes;
- Announcement of 2012-13 Consumer At Large Nomination;
- NY HIV Planning Council 2012-13 Consumer Committee Contact Sheet;
- The Medical Monitoring Project, American Academy of HIV Medicine, June 2012
- Medical Monitoring Project (MMP) Powerpoint presentation, Marie Antoinette Bernard, HIV Epidemiology & Field Services Program, NYCDOHM;
- MMP: Links to Recent Publications & Presentations;
- 2011-12 Consumers Committee Year in Review;
- 2012-13 HIV Planning Council Work Plan & Timeline;
- Consumer Advisory Board Survey NYCDOHMH Powerpoint presentation, 8/3/11;
- Getting It Right, A Self-Assessment Tool for Consumer Advisory Boards, AIDS Alliance, 2008;
- Invasive Meningococcal Disease in MSM, Health Alert # 27, NYCDOHMH;
- Meningococcal Vaccine Recommendations for HIV-Infected MSM, Health Alert # 28, NYCDOHMH;
- Update: Invasive Meningococcal Disease in MSM, Health Alert #30, NYCDOHMH;
- Weathering the Storm: Living with HIV During Times of Natural Disaster, 10/31/12, Housing Works;
- Emergency Preparedness & HIV/AIDS, www.aids.gov, 11/13/12;
- Positive Voice, Series 2, Vol. 3, Issue 15, November 2012, National Association of People with AIDS;
- POZ Magazine, October/November 2012;
- NY HIV Planning Council November 2012 Meeting Calendar, NYCDOHMH

INTRODUCTIONS:

Victor Benadava, Co-Chair opened the meeting. Jan Park, Governmental Co-Chair of the Planning Council welcomed 2012-13 newly-appointed Planning Council Members David Martin and Lotus Blackman and community members Jose Colon Berdecia and Tracy Neil, who introduced themselves. The Rules of Respectful Engagement were reviewed and Darryl Wong reviewed the agenda and meeting materials. Meeting participants were asked to review the Committee's current contact sheet. Noting no changes, the minutes of the July meeting were approved by acclamation.

PUBLIC COMMENT:

There was no public comment.

ANNOUNCEMENT OF NOMINATIONS FOR 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, was described. This position also affords the elected individual the opportunity to attend the yearly CDC Medical Monitoring Project (MMP) update at CDC headquarters in Atlanta, GA. Nominations will be accepted at the December 12 meeting and candidates will furnish statements of interest, at which time the election will take place. Deb Marcano asked whether candidates could nominate themselves; members were informed that candidates must be present, physically or through conference call, in order to answer possible questions from committee members.

CDC MEDICAL MONITORING PROJECT (MMP)

Marie Antoinette Bernard, MD, HIV Epidemiology & Field Services Medical Liaison & MMP Data collection Team Leader provided a review of the CDC-funded MMP project, describing the two major goals of the project: 1) to develop greater understanding of the health-related experiences and needs of people living with HIV/ AIDS (PLWHA) who are in care in the US, by providing locally and nationally representative estimates of behaviors and clinical outcomes, determining accessibility and use of prevention and support services and by increasing knowledge of the care and treatment provided and 2) to inform the development and planning of policy and programs for PLWHA.

The multi-stage sampling methodology was reviewed, with Stage 1 focusing on local areas; in total 23 areas were selected (16 states, 6 cities and Puerto Rico), which includes >80% of US AIDS cases. It was noted that the probability of selection is proportional to size. Stage 2 focuses on the selection of health care facilities/providers who deliver out-patient HIV medical care, collecting metrics on monitoring CD4 count and viral load and antiretroviral treatment. Stage 3 focuses on patients seen by a selected provider and are randomly-sampled. Eligibility criteria include HIV+ status, age \geq 18 years, having received HIV medical care at facility 1/1 – 4/30 in a given cycle year. Participation is voluntary and in NYC requires informed consent. Patients are provided with a \$40 Metrocard incentive for participation. Participants in the project are interviewed by DOHMH staff, after which their medical records are abstracted. Data is collected using two sources: computer-based structured interview, face-to-face by trained interviewers, conducted in private and medical record abstractions (in certain states telephone interviews are also conducted). The data that is collected include clinical status, treatment adherence history, service utilization, info on the client's HIV-related service needs and health behaviors (health care utilization, sexual, drug use, risk reduction/prevention activities).

Victor Benadava, Co-Chair and local NYC CAB representative to the MMP, solicited input on barriers to engaging and remaining in care; factors such as stigmatization, history (GRID), staff insensitivity, long waiting times to see providers and lifelong treatment horizons with unknown toxicities were cited.

2012-13 PLANNING COUNCIL & COMMITTEE/WORKPLAN TIMELINE

The Committee's work during the last planning session was reviewed in order to provide context for the current 2012-13 planning year. This year's work will include ongoing implementation of an outreach and recruitment plan, the five (5) Borough-based listening sessions and subsequent analysis of the qualitative and quantitative data derived from this input and the final development of recommendations for consumer advisory boards with respect to engagement, retention, input and feedback processes at CABs convened by Ryan White-funded CBOs and ASOs in NYC.

With respect to consumers' roles in the planning process, there will be increased focus in utilizing Committee members' various perspectives and participation in the other committees of the Planning Council, so that they may bring back information and knowledge gleaned from other committee work and

achieve a better understanding of the planning process as a whole. In fact, the EMA's application for funding received a high grade (97/100) for many reasons, including the degree of consumer involvement in the EMA's planning activities.

The SPNS (Special Projects of National Significance) initiative on client engagement and retention in care has been launched in Upper Manhattan, but will be expanding to other geographic areas, including Queens and the Bronx. Agencies share their best practices with other ASOs from a quality improvement perspective, by identifying one metric for which they have tracked and successfully implemented a plan to improve patient outcomes.

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

Project Hospitality of Staten Island will be hosting a dinner on November 31. NYCDOHMH will be conducting the two-day Positive Life Workshop on December 6/7 at AIDS Center of Queens County. The Positive Life Workshop will also be conducted at GMHC. One committee member advised other members to insure that their supply of medications remains intact, especially in emergency situations, such as Hurricane Sandy.

ADJOURNMENT:

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

DRAFT