



CONSUMERS COMMITTEE

Thursday, March 20, 2013, 1-3 PM
NYCDOHMH, 42-09 28th Street, Conf Rm 19-27
Long Island City, NY

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

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

Appointed Community Members Present: Jose Colon-Berdecia, Billy Fields, Delores Henley, Glen Phillip, Joey Lopez, Ron Joyner, Yves Gebhardt

Guests: Donna Classe, Mallory Lowenstein, Marcelo Soares

NYCDOHMH: Rafael Molina, Jan Carl Park, Darryl Wong

MEETING MATERIALS DISTRIBUTED:

- Meeting Agenda/Planning Council Ground Rules of Respectful Engagement;
- February 20, 2013 Draft Meeting Minutes;
- Consensus Statement on the Criminalization of HIV in the US, Positive Justice Project, February 2013
- Policy Committee Letter to Mayor Bloomberg re: HIV Criminalization;
- 2012 NYS HIV Testing Law: Highlights from a Multiple Component Evaluation;
- Community Letter to NYS Gov. Cuomo in support of the NYSDOH/AIDS Institute;
- Announcement of Housing Works' Second Life Job Training Program;
- Summary of Public Input from HIV/AIDS Ryan White Stakeholders, March 2013, HRSA;
- HRSA/HAB Website: Ryan White & the Affordable Care Act: What you need to know;
- HRSA Action: Accurate Data Collection & Submission Improve HIV Planning & Delivery;
- NYCDOHMH Health Alert #5: Update: Invasive Meningococcal Disease in MSM, Four New Cases in 2013, March 2013;
- HIV Epidemiology & Field Services Semiannual Report, Vol 78, No.2, October 2012;
- You & Your Pharmacist: Partnering with your Pharmacist, NYSDOH/AIDS Institute;
- NY HIV Planning Council March & April 2013 Meeting 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 February 2013 meeting were approved by acclamation.

PUBLIC COMMENT:

There was no public comment.

MEDICAL MONITORING PROJECT UPDATE (MMP) 2013 DRAFT SEXUAL BEHAVIOR QUESTIONS: CONSUMER FEEDBACK & DISCUSSION:

In general, The Committee expressed its concern that these questions, along with others in the standard questionnaire, could not be answered in the time allotted (45mins), given the complexity of some of the questions. There was concern that 12 months is too long of an interval for an individual to accurately recall information about their sexual partners and suggested shortening the time period to 6 months. There was the continuing recommendation to substitute "Refused to answer" with "Declined to answer". It was noted that there are no questions in this section that address substance use and abuse directly in connection with sexual behavior, although they may appear in other areas of the standard questionnaire. Questions addressing anal sex (defined as when a man puts his penis in the other person's anus or rectum) use anus or rectum interchangeably. There was discussion as to which is the more technically correct, given that the rectum is at the distal end of the anal canal and anal sex is the more commonly-used term? It was also noted that there were no questions addressing whether ejaculation occurred during vaginal, anal or oral sex, e.g., "Did you ejaculate inside ____?" Were there bodily fluids exchanged?

Specific comments to questions are noted below, in the order in which the question appeared in the survey:

Opening (Page 1):

- "Please remember that we will keep this information private"
- It is not clear who the "we" is – the local health Department or CDC?
- What does private mean? Anonymous? Confidential?
- Need for specification, especially since this is sensitive and personal information.

Q1 & 2: Since these questions ask if there are female or male partners, why is there no question asking how many transgender individuals one might have had sex with?

Q4: "What would you like me to call this partner?"

- Concern that the term "partner" may not be appropriate, especially in casual sex encounters and that the term "person" should be used
- There were concerns that regardless of the descriptives, initials, first names, nicknames, etc used to refer to individuals with whom one has had a sexual encounter, it would be difficult for many to recall specific information on that individual, particularly if the intent of the encounter was to "hook up".

Q6: "How old is ___"?

- Members understood the motivation to collect demographic information, but specific age, in years, is difficult to ascertain/judge and is often not known. Use of age range (20-30, 30-40, etc) is suggested.

Q7: "Is ___ Hispanic, Latino or Spanish origin"?

- Concern that this particular group is being targeted and that persons of this background might feel uncomfortable in further participating in the study.

Q8: "Which of the following racial group or groups best describes ___?"

- Concern that it is often difficult to determine racial group based on appearance
- Why is "mixed race" not included in answer options?

Page 2 (Interviewer Script)

"Now I'd like to ask how you...main or casual partner..... or don't know very well"

- Concern that use of terms "main" or "casual partner" does not uniformly reflect individuals' sexual histories/experiences and that it is subjective (even with supplied definitions).

- Response might vary according to age and stage of life, e.g., one may be committed to another above anyone else (as in long term partners) but no longer have a sexual relationship with that person.
- Similarly, many young people may refer to a person whom they have known for a brief period of time (and have had sex with) and call that person “boyfriend/girlfriend”.

- Q10: “During the past 12 months did you have vaginal or anal sex with ___?”
- Concern that strict definition of vaginal sex does not take into account range of sexual activities for lesbians, such as use of sex toys. If the respondent is female and has only female partners, there are no questions regarding oral sex (instructions say to skip to box 22), even if statistical risk for HIV infection is low. Some found this omission to be offensive and degrading.
- Q11 “Now, please tell me the **exact** number of times that you had vaginal or anal sex”
- Concern that **exact** recall is extremely difficult, especially given 12 month time frame. Also the questions asks vaginal or anal sex and does not address those who engage in both vaginal and anal sex in the same sexual encounter, making an accurate response even more difficult.
- Q12 “Over the past 12 months how many months did your sexual relationship last?”
- Concern that this question, frames the length of the sexual relationship in months, which may not reflect the reality of the sexual encounter(s). How would one answer if they had vaginal and/or anal sex 10 times in one, two or three days?
- Q16/Q19 Q16 asks “How often did you and ___ use a condom when you had vaginal sex?”
Q19 asks “ How often did you use a condom when you had receptive anal sex with _____”
- Concern about inconsistency:
Why does Q16 refer to “you and ___” when addressing vaginal sex, while Q19 states “you” only when addressing receptive anal sex? Is this a reference to the use of the female condom, which can be exclusively controlled by the receptive partner
- Q21 “How often did you use a condom when you had insertive anal sex?”
- Concern is the same as Q 19. How does one answer if the receptive partner uses a female condom?
- Q23 “What was ___’s HIV status the last time that you had sex?”
- Concern that a sex partner’s HIV status may not be known. If the respondent answers DK (don’t know) is it because he/she has not asked the other person, or because the person they had sex with does not know their status?
- Q26 “Of these X additional people that you had unprotected sex with during the last 12 months, how many were HIV negative?”
- How would one know if their sexual partner was HIV negative?
- Q28: “Did you have sex with any of these people in exchange for money, food, shelter, transportation”
- Does not recognize that some people will have sex in exchange for drugs

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

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