APIAHF
ASIAN & PACIFIC ISLANDER AMERICAN HEALTH FORUM

Headquarters:
450 Sutter Street
Suite 600
San Francisco CA 94108
Main 415-954-9988
Fax 415-954-9999
www.apiahf.org

Washington D.C. Office:
1828 L Street N.W.
Suite 802
Washington, D.C. 20036
Main 202-466-7772
Fax 202-466-6444

National Advocates for Asian American, Native Hawaiian & Pacific Islander Health

August 29, 2011

Daniel L. Holcomb
CDC Reports Clearance Officer
Centers for Disease Control and Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
1600 Clifton Rd, MS-D74
Atlanta, GA 30333

Re: Comment on Web-Based HIV Behavioral Survey among Men who have Sex with Men

Dear Mr. Holcomb:

The Asian & Pacific Islander American Health Forum (APIAHF) thanks the Centers for Disease Control and Prevention (CDC) for the opportunity to comment on the Web-Based HIV Behavioral Survey among Men who have Sex with Men (MSM) (MSM Survey). We strongly support CDC's efforts in developing surveys to monitor the MSM community to adequately determine risk behaviors, trends in HIV testing and service needs. Moreover, we offer recommendations intended to help generate credible and valid data, especially as they concern the Asian American (AA), Native Hawaiian, and Pacific Islander (NHPI) MSM community.

General Comments

Asian Americans and Pacific Islanders represent one of the fastest growing ethnic groups in the United States, with the Asian American population alone in the U.S. growing 43% between 2000 and 2010 and the NHPI population alone growing 35% in the same time frame.[i] The Census Bureau projects that by the year 2050, the number of Asian Americans will exceed 16 million, or more than 9% of the population, and the number of Native Hawaiians and Pacific Islanders will be 2.6 million or .06% of the population.[ii]

While AA and NHPI HIV/AIDS cases account for approximately 1% of cases nationally,[iii] the rate of new AIDS cases increased by fifteen percent from 2002 to 2005 in Asian Americans and Pacific Islanders.[iv] In addition, recent analysis of CDC data shows that Asian Americans and Pacific Islanders were the only racial/ethnic group with a statistically significant increase in new HIV diagnoses (4.4%) between 2001 and 2008.[v] AAs and NHPIs have some of the lowest rates of testing for HIV, compared to other ethnic groups, in which over two-thirds of Asian Americans and over one half of Pacific Islanders have never been tested.[vi] Moreover, preliminary analysis of CDC data shows that AA and NHPI HIV rates will exceed those of Latinos in five years and African Americans in ten years, if left unchecked. In addition, recent CDC data shows that Asian Americans and Pacific Islander men who have sex with men ages 13-24 experienced the largest proportionate increase, 255.6% (EAPC 30.8), among the overall MSM population. [vii]

AAs and NHPIs experience a variety of barriers preventing these populations from testing for HIV, attaining quality care, achieving positive health outcomes and maintaining continuous care. The diversity of languages spoken by AAs creates significant barriers in the health care setting, in which 73% of AAs speak a language other than English in their homes.[viii] Additional barriers include large populations with limited English proficiency (LEP), high immigrant populations with varying degrees of health literacy amongst AAs, economic factors and lack of culturally appropriate care and services.

In addition, one unique barrier facing AAs and NHPIs and other communities of color is HIV-related stigma. Nearly 70% of Asian Americans and Pacific Islanders infected with HIV are men who have sex with men (MSM).[ix] AA and NHPI MSM populations face strong cultural barriers, including homophobia and presumed heterosexuality. Taboos over questions of sexual orientation and gender identity place unique burdens on transgender AAs and NHPIs. HIV-related stigma and cultural taboos directly affect the health of AA and NHPI MSM and transgender persons by preventing them from seeking HIV testing, accessing care and developing family support systems.

MSM Survey findings will improve our understanding of the risks and barriers facing the MSM community as they relate to HIV testing, infection and prevention services. The data collected from this survey will be central to moving our nation forward in addressing the HIV/AIDS epidemic given the high numbers of infections in the MSM community and the historical lack of data collected on this community. As such, the Survey is consistent with the goals of Healthy People 2020 in understanding and promoting healthy behaviors and environments, preventing HIV infection and understanding the social determinants of health. For these reasons, APIAHF strongly supports the collection of individual behavioral data in the MSM Survey.

Specific Data Collection Strategies and Methodologies

As recognized by the Affordable Care Act (ACA), consistent, accurate and standardized data collection and reporting is an essential aspect of identifying racial and ethnic health and health care disparities, as well as those related to gender, gender identity and sexual orientation. The following recommendations align with implementation of the Section 4302 data collection requirements of the ACA, Title VI of the Civil Rights Act of 1964 and Section 1557 of the ACA, which reinforces the prohibition against discrimination by any federally conducted program or entity, that receives funding or assistance on the grounds of race, color, national origin, gender and disability.

For these reasons, we strongly recommend CDC consider the following data collection strategies and methodologies in regards to the collection of demographic data as part of the MSM Survey.

Adopt the Proposed HHS Section 4302 Data Collection Standards for Collection of Race and Ethnicity

On June 29, 2011, HHS released proposed data collection standards ("draft standards") implementing Section 4302 of the ACA. The standards address the need to collect more granular race and ethnicity data and align more closely with the recommendations of the 2009 Institute of Medicine (IOM) Report on Race, Ethnicity and Language Data (IOM Report). Importantly for AA and NHPI communities, the standards propose the use of more granular Asian, Native Hawaiian and Pacific Islander ethnicity categories, aggregating to the broader OMB race categories.[x] Given the ethnic, linguistic, and socioeconomic diversity among AA and NHPI subpopulations and varying degree of health related disparities, granular level data is essential to accurately accessing these factors. Therefore, we commend HHS for addressing the need for granular race and ethnicity data in the proposed standards and strongly encourage CDC to adopt the same standards in the MSM Survey. In addition, we recommend CDC expand the number of Asian ethnic subgroups provided as response options, to better identify disparities in smaller populations.

Oversample AAs and NHPIs

We urge CDC to oversample AAs and NHPIs in the MSM Survey. Because AAs and NHPIs make up a small proportion of the overall U.S. population, nationally representative samples tend to include small numbers of AAs and NHPIs, in particular, making it difficult to generate stable health estimates.

AA and NHPI ethnic subgroups are incredibly diverse, differ in access to health care coverage, are affected by different community conditions and reside in geographically diverse areas. For example, in areas where disaggregated AA and NHPI HIV data is available (California, Hawaii, Los Angeles, San Francisco), data indicates that cumulative HIV incidence is higher among certain ethnic groups such as Filipino, Chinese, Japanese, Vietnamese, and Thai. Given this diversity, it is critical to understand the prevalence of and trends in risk behaviors, trends in HIV testing, use of prevention services and unmet HIV prevention needs that influence specific AA and NHPI subgroups differently.

There have been several recently released reports on HIV across racial/ethnic communities by CDC's Division of HIV/AIDS Prevention where data for AA and NHPIs were not analyzed due to insufficient sample size. Oversampling of AAs and NHPIs is critical to allow for a large enough sample size of AA and NHPIs to draw generalizable findings. Oversampling of AAs is consistent with other CDC efforts, such as data collection by the National Center for Health Statistics (NCHS), which has been oversampling Asians in National Health Interview Survey data since 2006 and, more recently, in the 2011-2014 National Health and Nutrition Examination Survey (NHANES). Therefore, we urge CDC to follow the important precedent set by NCHS in designing and conducting the MSM Survey.

Primary Language

We urge CDC to administer the on-line survey in Asian ethnic languages, particularly those used by the ethnic groups with high HIV rates, in addition to English. According to the 2007-2009 American Community Survey, 70.5% of Asian Americans speak a language other than English at home. In addition, of the 8 million people in the United States that speak Asian and Pacific languages at home,

more than 4 million are considered "limited English proficient," meaning they speak English less than "very well" or not at all.[xi]

Language barriers are widely known to reduce rates in enrollment and lower the quality and effectiveness of prevention, treatment and patient education programs. Members of these communities are often linguistically isolated and continue to encounter significant health and health care disparities. Section 4302 of the ACA requires that any federally conducted or supported health care or public health program, activity or survey collects and reports data on a number of demographic factors, including primary language. HHS' release of its draft Section 4302 data standards take the important step of including a set of questions assessing the respondent's ability to speak English.

To ensure limited English proficient (LEP) persons are able to meaningful participate in the MSM survey, we strongly recommend the survey be administered in-language for LEP participants. Population-based surveys conducted only in English capture a fraction of the eligible individuals from Asian ethnic groups. Recent research has found that those who respond to surveys in English are significantly different from those who do so in Asian languages, with the latter being of lower socioeconomic status and experiencing potentially greater barriers in accessing health care and information, including that disseminated by community interventions.[xii] Findings from an English-only survey may thus lead to a vastly skewed sample of Asian Americans and gross underestimation of the health disparities affecting those with limited English proficiency.

In summary, we appreciate the opportunity to comment on the proposed HIV Behavioral Survey among MSM. As CDC moves forward with implementing this survey, we welcome future opportunities to work together to ensure the meaningful inclusion of AA and NHPI participants.

Respectfully,

Kathy Lim Ko
President & CEO
Asian & Pacific Islander American Health Forum

---

[i] Overview of Race and Hispanic Origin: 2010, The US Census Bureau (March 2011) available at http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf.

[ii] American Community Survey 2007-2009, U.S. Census Bureau.

[iii] HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States and Dependent Areas in 2007 vol. 19, The Centers for Disease Control and Prevention (2009) available at http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf.

[iv] Asian/Pacific Islanders and HIV/AIDS, The RYA HIV/AIDS Program (August 2008) available at ftp://ftp.hrsa.gov/hab/Asian.Pacific.pdf.

[v] W. Adih, M. Campsmith, C. Williams, F. Hardnett, D. Hughes, *Epidemiology of HIV among Asians and Pacific Islanders in the United States, 2001-2008*. Journal of the International Association of Physicians in AIDS Care, April 20, 2011. Available at http://jia.sagepub.com/content/early/2011/04/19/1545109711399805.

[vi] Stigma, HIV/AIDS and Asians & Pacific Islanders," Banyan Tree Project, available at http://www.banyantreeproject.org/extras/factsheets/btp_stigma_fs_FINAL.pdf.

[vii] CDC Morbidity and Mortality Weekly Report, 06/27/08.

[viii] We the People: Asians in the United States, Census 2000 Special Report, The US Census Bureau (December 2004) available at http://www.census.gov/prod/2004pubs/censr-17.pdf.

[ix] HIV/AIDS among Asians and Pacific Islanders, CDC HIV/AIDS Fact Sheet (Revised August 2008) available at http://www.cdc.gov/hiv/resources/factsheets/API.htm.

[x] The Section 4302 Draft Standards go beyond the 1997 Office of Management and Budget (OMB) standards for the classification of federal data on race and ethnicity categories that separated the "Asian or Pacific Islander" category into two categories, "Asian" and "Native Hawaiian or Other Pacific Islander."

[xi] Language Use in the United States: 2007, U.S. Census Bureau, American Community Survey Reports, April 2010. Available at http://www.census.gov/prod/2010pubs/acs-12.pdf.

[xii] Importance of native language in a population-based health survey among ethnic Chinese in Australia, Kam Cheong Wong and Zhiqiang Wang. 2008. Australian and New Zealand Journal of Public Health 32(4):322-324.