

July 29, 2011

Deputy Assistant Secretary Garth Graham  
United States Department of Health and Human Services  
Office of Minority Health Resource Center, P.O. Box 37337  
Washington, DC 20013

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**Headquarters:**  
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Main 202-466-7772  
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*National Advocates for  
Asian American,  
Native Hawaiian &  
Pacific Islander Health*

Re: Affordable Care Act Section 4302 Data Standard Comments (HHS-OMH-2011-0013)

Dear Deputy Assistant Secretary Graham:

The undersigned members of the National Council of Asian Pacific Americans (NCAPA) Health Committee and community partner organizations thank the Department of Health and Human Services (HHS) and the Office of Minority Health (OMH) for the opportunity to comment on the proposed data collection standards under Section 4302 of the Patient Protection and Affordable Care Act (ACA). We strongly support the efforts of HHS in implementing this provision, as standardized data collection is an essential component of fulfilling the goals of the ACA and understanding and addressing health and health care disparities.

NCAPA is a coalition of 29 national organizations dedicated to representing the interests of Asian Americans, Native Hawaiians and Pacific Islanders (AA and NHPIs) across our nation. The member organizations also work in partnership with a network of community-based organizations in various states. While HHS has made tremendous strides in developing policies, providing investments and promoting research to reduce health disparities, people of color and other vulnerable populations continue to experience differences in health and health care outcomes when compared to their white counterparts. AAs and NHPIs in particular suffer disproportionately high rates of cervical cancer, stomach cancer, hepatitis B, mental health issues, and many other serious health impairments. In addition, high rates of uninsurance, affecting over one in six Asian Americans and one in four Native Hawaiian and Pacific Islanders, and limited English proficiency compound the obstacles these communities face in preventing illness and achieving good health.

Asian American and Pacific Islander communities are overwhelmingly immigrant; over 60 percent of Asian Americans and 30 percent of Pacific Islanders living in the U.S. are foreign-born, representing the full spectrum of immigration status categories. Asian Americans, Native Hawaiians and Pacific Islanders trace their heritage to more than 50 countries and speak more than 100 different languages. Data from the Census Bureau's American Community Survey reveal that more than 8 million people in the United States speak Asian and Pacific Island languages at home, and more than 4 million of them are considered "limited English proficient," meaning they speak English less than "very well" or not at all.<sup>1</sup>

The proposed data collection standards will play an essential role in understanding and addressing health and health care related disparities among groups that are traditionally underrepresented in federal surveys, including AAs and NHPIs. For these reasons, we strongly support implementation of Section 4302 of the ACA and the development of data collection standards for race, ethnicity, primary language,

sex and disability status. In addition, we urge HHS to consider the following general comments and modifications and additions to the proposed standards:

## **General Comments**

### **Implement Section 4302 to the Fullest Extent Possible**

As recognized by the ACA, consistent, accurate and standardized data collection and reporting is an essential aspect of identifying racial and ethnic health and health care disparities. The proposed standards present an opportunity to standardize HHS data collection activities, contribute to a more uniform and accurate collection and reporting system and help to understand how multiple demographic variables affect one's health status.

While we understand that this is an unfunded mandate, we hope HHS can provide clarity about when and how they plan to apply the new draft standards to other federal data collection efforts, beyond the major federal surveys. ACA requires these data collection standards be used for measuring quality and reporting in any federally conducted or supported health care or public health program, activity or survey. Given this requirement, we urge HHS to meet this intended purpose to the fullest extent possible, and extend the data standards to federally supported health programs, including Medicaid and Medicare. Implementation of Section 4302's data collection requirements will help ensure HHS' compliance with 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. Moreover, expanded implementation of Section 4302, beyond the major federal surveys, aligns with Healthy People 2020's and the National Prevention Strategy's emphasis on understanding the social and physical determinants of health.

### **Ensure Continued Community Stakeholder Involvement**

We request that HHS continue to ensure community stakeholders are included in the decision-making process and testing of the Secretary's data collection, reporting and analysis protocol under Section 4302. The inclusion of community stakeholders will help address privacy concerns and the unique cultural, linguistic, and social barriers that prevent our populations from participating in surveys. Moreover, the inclusion of community representation will help to build partnerships with local community organizations and trusted groups within these hard-to-count communities and develop data collection protocols that are culturally respectful, and ensure confidentiality for the survey participants.

## **Modifications and Additions to the Proposed Standards**

### **Race and Ethnicity**

We commend HHS for their leadership in addressing the need for granular race and ethnicity data in the proposed standards and aligning some of the standards with the recommendations of the 2009 Institute of Medicine (IOM) Report on Race, Ethnicity and Language Data (IOM Report). Specifically, we enthusiastically support HHS'

proposal to collect and report more granular Asian, Native Hawaiian and Pacific Islander ethnicity categories, aggregating to the broader OMB race categories. These improvements will help HHS to better understand and address the health disparities affecting Asian American, Native Hawaiian, Pacific Islander populations. To that end, we also encourage HHS to further align the standards with the remaining recommendations of the IOM Report to ensure that data for smaller population subgroups are more accurately collected, analyzed and reported.

In addition, while we understand the seven proposed granular Asian ethnicity categories and four proposed Native Hawaiian and Pacific Islander categories were selected based on a careful balancing of current census data and projected costs, we strongly recommend HHS include an open-ended option for persons whose granular ethnicity is not listed as a response option. Specifically, we recommend HHS include, in option “j” an open-ended option of “Other Asian, please specify: \_\_\_” and in option “n” an open-ended option of “Other Pacific Islander, please specify: \_\_\_.” The addition of an open-ended option, similar to that proposed in the spoken language standard, will balance the need for accurate collection of self-reported data in smaller populations with the financial burden of adding additional granular categories to the national list.

#### Primary Language

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. For those reasons, we commend HHS for taking the important step of including a set of questions assessing the respondent’s ability to speak English, whether another language is spoken at home and the language spoken, if other than Spanish.

However, the proposed draft standards for primary language place an emphasis on collecting information about a respondent’s English fluency, and to a lesser extent, information about Spanish speakers. We urge HHS to expand the collection and reporting of data in this category by implementing the 2009 IOM recommendations regarding language need to assess primary language, in addition to English literacy and proficiency. Consistent with the IOM Report, we recommend HHS provide a list of locally relevant response categories from a national standard list, including sign language. This option should be provided in addition to the open-ended response of “Other language (identify).”

Additionally, while there is evidence that supports a high correlation between English-language proficiency in speaking, reading, and writing ability, differences in education level, literacy, and health literacy can have an impact on an individual’s reading comprehension. As such, HHS should support the recommendations of the 2009 IOM Report and encourage the collection and reporting of written language preference including Braille.

#### Sexual Orientation and Gender Identity

We commend HHS’ commitment to addressing the data collection needs of lesbian, gay, bisexual and transgender (LGBT) communities. Accurate and standardized data collection of both sexual orientation and gender identity are essential to

understanding and addressing health and health care related challenges facing these communities and their families, as well as understanding how sex, gender identity and sexual orientation intersect with one's health. We support HHS' work in testing ways to reduce bias in sexual orientation estimates, as well as researching data collection strategies on gender identity, as this work aligns with the goals of Healthy People 2020 and implementation of the ACA.

In summary, we appreciate the opportunity to comment on the proposed data collection standards for race, ethnicity, primary language, sex and disability status required by Section 4302 of the ACA. We welcome future opportunities to work together.

Respectfully,

Asian & Pacific Islander American Health Forum (APIAHF)  
Asian & Pacific Islander Coalition on HIV/AIDS (APICHA)  
Asian Pacific Community in Action (APCA)  
Asian Pacific Partners for Empowerment, Advocacy & Leadership (APPEAL)  
Association of Asian Pacific Community Health Organizations (AAPCHO)  
Asian Services in Action (ASIA)  
Coalition for Asian American Children & Families and Project CHARGE  
Empowering Pacific Islander Communities (EPIC)  
Healthy Asian Americans Project  
Hmong National Development, Inc. (HND)  
Japanese American Citizens League (JACL)  
Korean Resource Center  
Laotian American National Alliance (LANA)  
Mary Queen of Vietnam Community Development Corporation (MQVN)  
National Asian Pacific American Families Against Substance Abuse (NAPAFASA)  
National Asian Pacific American Women's Forum (NAPAWF)  
National Asian Pacific Center on Aging (NAPCA)  
National Council on Asian Pacific Islander Physicians (NCAPIP)  
National Korean American Service & Education Consortium (NAKASEC)  
National Tongan-American Society  
Samoan National Nurses Association (SNNA)  
Southeast Asia Resource Action Center (SEARAC)  
South Asian Americans Leading Together (SAALT)  
Vietnamese American Young Leaders Association of New Orleans (VAYLA)

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<sup>i</sup> "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>.