



hepbunited.org

October 31, 2016

Katherine K. Wallman,
Chief Statistician
Office of Management and Budget
1800 G St., 9th Floor
Washington, DC 20503

Re: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

Dear Ms. Wallman,

On behalf of Hep B United, we thank the White House Office of Management and Budget for reviewing the current Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity and the opportunity to offer comments. Hep B United is a national coalition comprised of over 30 community-based multi-sectoral coalitions and national partner organizations with a reach of over 4 million---working across 15 states and 25 cities to address and eliminate hepatitis B. Our collective goals are to raise the profile of hepatitis B and liver cancer as an urgent public health priority, increase hepatitis B testing and vaccination, and improve access to care and treatment for individuals living with hepatitis B.

Up to 2 million Americans have chronic hepatitis B (HBV) infection; unfortunately, 67% are unaware of their infection, placing them at significant risk for advanced liver disease, liver cancer, and/or in need of a liver transplant. HBV is the leading cause of primary liver cancer (hepatocellular carcinoma, HCC), which is the 2nd deadliest cancer and remains the only cancer that continues to rise in both incidence and mortality among men and women in the U.S.

HBV is associated with significant health disparities in the U.S. Both chronic HBV and HCC disproportionately affect Asian Americans and Pacific Islanders (AAPI), who make up 50% of the HBV infection burden in the U.S., and have liver cancer rates that are 13 times higher than Caucasian populations. In fact, HCC has recently become the #1 cause of cancer death in Vietnamese men in the U.S.

There is a continued need to collect data that is representative of our entire population so we can work towards reducing disparities and address health needs. In Philadelphia, PA, *Hep B United-Philadelphia* was able to collect disaggregated data by ethnic groups, which serves as a valuable tool for identification of gaps and implementing targeted public health interventions for specific populations. Among 3,500 AAPI and African immigrants tested in Philadelphia in 2012, 8.2% were found to be chronically infected with HBV. High rates have been found among the Philadelphia Korean (4%), Cambodian and Vietnamese (6%), and Chinese (12%) communities. Among 115 African immigrants tested, 11% were infected. It is essential to be able to distinguish

individual population data to work towards reducing these numbers with population-specific approaches. Each community has unique characteristics that should be approached differently when planning community outreach and interventions. We encourage this type of data to be expanded on a national level through OMB guidance and standards.

Hep B United asks that OMB:

- 1) Continue to count Asian Americans, Native Hawaiians, and Pacific Islanders (AAs & NHPs) among the minimum reporting categories;
- 2) Count each detailed group (e.g. Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, Native Hawaiian, Chamorro, Samoan, Tongan, etc.) to represent the 50 different ethnic groups that speak 100 different languages and dialects. AAPI communities have unique histories, cultures, resiliencies, and challenges that differently impact their health, housing, education, and economic experiences, or at a minimum, use the standards set in Census 2010 or the Affordable Care Act's Section 4302;
- 3) Encourage oversampling Asian Americans and NHPs by ethnic group in future testing protocols to ensure an adequate sample of both large and small groups;
- 4) Add the classification of a Middle Eastern and North African group and a distinct reporting category; and
- 5) Disaggregate the reporting category of "Black or African American" in order to count each detailed group to accurately reflect the diversity and unique cultures and histories of African immigrant populations in the U.S. from Sub-Saharan Africa.

In regards to the *Intent of Minimum Categories*, we recommend that OMB strengthen its language and guidance to encourage federal agencies to collect and present race and ethnicity data with more granularity so as not to allow misinterpretation of the minimum reporting categories as the only permissible reporting categories.

Disaggregation of data is essential to improve understanding of disparities that affect diverse AAs & NHPs and African immigrant populations and the critical family and immigrant factors that adversely impact their health. Having the ability to have this detailed data allows our coalition to better understand, serve, and reduce health disparities within our populations. OMB will help contribute to a better understanding of the diverse realities that exist across our communities, which will result in stronger policies and programs for all.

Thank you for the opportunity to provide feedback on the proposed changes to the current Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity. We believe that the disaggregation of race and ethnicity data is essential to effectively serving our communities and will have a positive impact towards reducing health disparities.

Sincerely,

Hep B United

Hepatitis B Foundation (Co-Chair)
Association of Asian Pacific Community Health Organizations (Co-Chair)
Asian & Pacific Islander American Health Forum
Immunization Action Coalition
National Center for Reducing Asian American Cancer Health Disparities
National Task Force on Hepatitis B
National Viral Hepatitis Roundtable
Asian American Health Coalition (HOPE Clinic), Houston, TX
Asian American Community Services, Upper Arlington, OH
Asian Health Coalition, Chicago, IL
Asian Pacific Community in Action, Phoenix, AZ
Asian Pacific Health Foundation, San Diego, CA
Asian Pacific Liver Center at St. Vincent Medical Center, Los Angeles, CA
Asian Services in Action, Inc., Cleveland, OH
Center for Asian Health, St. Barnabas Medical Center, Livingston, NJ
Center for Pan Asian Community Services, Atlanta, GA
Charles B. Wang Community Health Center, New York, NY
Dallas-Fort Worth Hepatitis B Free Project, Dallas, TX
Hepatitis B Coalition of Washington State (International Community Health Services), Seattle, WA
Hepatitis Education Project, Seattle, WA
Hep B Project, Oakland, CA
Hep B United Philadelphia, Philadelphia, PA
Hep B United - Twin Cities (Lao Assistance Center of MN), Minneapolis, MN
Hep Free Hawaii, Honolulu, HI
Hep B Free Las Vegas, Las Vegas, NV
Hep B Free Los Angeles, Los Angeles, CA
Hepatitis B Initiative of Washington DC, Washington, DC
Midwest Asian Health Association, Chicago, IL
North East Medical Services, San Francisco, CA
New York City Hepatitis B Coalition, New York, NY
New Jersey Hepatitis B Coalition, Trenton, NJ
NYU Center for the Study of Asian American Health, New York, NY
Ohio Asian American Health Coalition, Columbus, OH
Project Prevention, Merced, CA
San Francisco Hep B Free, San Francisco, CA