

March 15, 2016

Marcie Cynamon, Director Division of Health Interview Statistics National Center for Health Statistics 331 Toledo Rd, Room 2217 Hyattsville, MD 20782-2064

RE: National Health Interview Survey 2018 Questionnaire Redesign

Dear Director Marcie Cynamon:

We appreciate the opportunity to offer comments on the proposed questionnaire redesign of the National Health Interview Survey (NHIS). 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 14 states and 24 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 2<sup>nd</sup> deadliest cancer and remains the only cancer that continues to rise rising 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 up to 13 times higher than Caucasian populations in the U.S. In fact, HCC has recently become the #1 cause of cancer death in Vietnamese men in the U.S.

Limited access to culturally and linguistically competent health care adds additional barriers in accessing health care. Collection of health data of AAPI communities is important to identify and address health disparities, and for surveillance efforts. As such, Hep B United would like to provide comments on sections of the proposed questionnaire:

## 1. Discontinuation of the family questionnaire

We are concerned that the discontinued use of the family questionnaire, and the use of one sampled adult and one sampled child per household, will eliminate the use of NHIS to study the effects of the family context on health. This change will also be less likely to capture a large enough sample of special populations such as immigrant families and children, people with disabilities, or persons in same-sex relationships. The current system of collecting individual information for the entire

household works because it is flexible, allowing researchers and consumers of the data to select the family characteristics most relevant to their studies, and providing a better context of family and immigrant health issues among different socioeconomic groups and races/ethnicities. Removing the measurement of family characteristics will leave a gap in public health surveillance and population datasets, where it cannot be filled by other datasets that lack similar infrastructure.

## 2. Disaggregation of race/ethnicity

We encourage the collection of demographic characteristics under race be disaggregated to include the major race and ethnicity categories in the Institute of Medicine's 2009 report on Race, Ethnicity, and Language Data and aggregated to the broader Office of Management and Budget race categories. Collection of disaggregated data is important to improve understanding of and addressing the health disparities that affect diverse AAPI populations and the critical family and immigrant factors that adversely impact their health.

## 3. Emphasis on hepatitis B

We are encouraged by the inclusion of hepatitis as a chronic condition ever diagnosed by a doctor or other health professional. Chronic HBV and liver cancer disproportionately affects Asian American and Pacific Islander populations and populations from sub-Saharan Africa. AAPIs account for over half of the HBV infections in the United States, and suffer from liver cancer rates that are up to 13 times higher than Caucasian populations in the United States. Data collected by NHIS is used by the CDC Division of Viral Hepatitis (DVH), which supports programs for screening, testing, and surveillance of hepatitis. The CDC's DVH will continue to use the NHIS for data, as a national surveillance system for hepatitis is not in place.

## 4. Continue to oversample AA and NHPIs

We commend NCHS for oversampling certain underrepresented populations to ensure that they have adequate representation in NHIS data. We encourage NCHS to continue the oversampling of NHPIs, as was done once during the 2014 NHIS, so that this small, but rapidly growing population is accurately represented in NHIS data.

Thank you for the opportunity to provide feedback on the proposed changes to NHIS. We believe the continued survey of all individuals in the household, the disaggregation of race data, and the collection of hepatitis B data are important to be able to correctly assess the impact of health inequities in AAPI populations.

Sincerely,

Kate Moraras, MPH

Director, Hep B United