WRITTEN RESPONSE TO REQUEST FOR INFORMATION
RACE IN CLINICAL CARE

UNITED STATES HOUSE OF REPRESENTATIVES

COMMITTEE ON WAYS AND MEANS

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BY THE

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The Asian & Pacific Islander American Health Forum (APIAHF) submits this written statement responding to the Request for Information related to race in clinical care, dated September 17, 2020.

APIAHF is the nation's oldest and leading health policy organization working to advance the health and well-being of over 20 million Asian Americans, Native Hawaiians and Pacific Islanders (AA and NHPI) across the U.S. and territories. APIAHF works to improve access to and the quality of care for communities who are predominantly immigrant, many of whom are limited English proficient, and may be new to the U.S. healthcare system or unfamiliar with private or public coverage. We have longstanding relationships with over 150 community-based organizations across 35 states and the Pacific, to whom we provide capacity building, advocacy and technical assistance.

For 35 years, we have focused our policy efforts on: 1) improving access to health insurance and care for AA and NHPI and immigrant communities; 2) ensuring the collection, analysis and reporting of detailed demographic health data; and 3) protecting and advancing the language rights of the 1 in 3 AAs and NHPIs who are limited English proficient.

As such, we have a strong understanding of the needs and barriers to good health that are experienced by communities of color including AAs and NHPIs. We deeply appreciate the opportunity to provide information about barriers facing these communities within clinical care and thank the Committee for raising awareness through recent hearings including the *Disproportionate Impact of COVID019 on*

Communities of Color. Overall, we emphasize that it is racism and not race that results in inequities in care and health care outcomes.

Policy Makers and Medical Community Must Understand that Detailed Data Collection, Analysis and Reporting is Critical

As the nation continues to diversify and the population approaches majority minority in 2044, accurate and standardized data collection and reporting of race and ethnicity is critical to ensuring that federal departments and agencies and the broader medical establishment understand the needs of diverse communities and are able to effectively meet their obligations to serve the American people. Detailed data collection, analysis and reporting is particularly salient for Asian American, Native Hawaiian and Pacific Islanders (AAs and NHPIs) who comprise over 22 million people, trace their heritage to more than 50 different countries and speak over 100 different languages.[1]

AAs and NHPIs can differ dramatically across key social and economic indicators. For example, recent data shows that income inequality is greatest amongst Asians in the United States due to a number of factors including immigration patterns.[2] An estimated only 9% of Bhutanese adults had a bachelor's degree, compared to 72% amongst Indians in 2015.[3] Similarly, an estimated 35% of Burmese and 33% of Bhutanese were living in poverty.[4] An estimated 49% of Marshallese live below the poverty rate.[5] An estimated 18% of NHPI adults have a bachelor's degree. These data points underscore the importance of the type of detailed race and ethnicity that is required.

For over 35 years, APIAHF has worked with federal, state and local policymakers and advocates to raise awareness about the continued dearth of data that is collected, analyzed and reported on AAs and NHPIs.

Since our founding 1986, APIAHF has been a leader in advocating for health data equity, serving as a national convener and working with state and local community-based organizations to advance the issue. This focus, and the major impetus for the creation of APIAHF, originated with the 1985 Report of the Secretary's Task Force on Black and Minority Health ("Heckler Report"). This foundational report, by then U.S. Department of Health and Human Services Secretary Margaret Heckler, was one of the first comprehensive government reviews of minority health disparities, but incorrectly concluded that AAs and NHPIs were healthier than other minorities, despite only analyzing aggregated data. Since then, APIAHF has successfully led advocacy for the collection, analysis, and reporting of AA and NHPI data through successful legislative and administrative strategies, nationally funded partnerships, and as a thought leader on data equity.

Data Continues to Not be Collected, Analyzed or Reported in Sufficient Detail for AAs and NHPIs

For AA and NHPI populations, the biggest challenge when it comes to understanding and addressing health and health care disparities is the lack of consistent collection, analysis and reporting of detailed

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[1] 2020 Policy Platform, *National Council of Asian Pacific Americans (NCAPA)*. Available at: https://www.ncapaonline.org/wp-content/uploads/2020/05/NCAPA_PolicyPlatform_2020.pdf.
[2] Income Inequality in the U.S. is Rising Most Rapidly Among Asians, *PEW Research Center*. (July 12, 2018). Available at: https://www.pewsocialtrends.org/2018/07/12/income-inequality-in-the-u-s-is-rising-most-rapidly-among-asians/.
[3] *Id.*
[4] *Id.*
[5] Letter to Office of Management and Budget, *Asian & Pacific Islander American Health Forum*. (April 5, 2017). Available at: https://www.apiahf.org/wp-content/uploads/2017/05/April-2017_AANHPI-Response-to-OMB-Interagency-Working-Group-Notice_CommentLetter-1.pdf.

data. Often data is collected but not reported or aggregated with other groups.[6] This challenge remains despite decades of efforts by policymakers and advocates to address this barrier. For example, the federal standard for data collection that applies government wide, known as 1997 OMB Standards for Maintaining, Collecting and Presenting Federal Data on Race and Ethnicity, has not been updated for 23 years, despite detailed recommendations from the U.S. Census Bureau 2015 National Content Test.[7] While the Affordable Care Act included critical improvements for detailed collection of race and ethnicity data within U.S. Department of Health and Human Services surveys under Section 4302, to date those standards have not been consistently adopted.

Similarly, detailed data collection varies across federal agencies. For example, U.S. Food and Drug Administration Drug Trials Snapshots provide important transparency in the racial and ethnic make-up of clinical trials for drugs, and yet aggregate Native Hawaiians and Pacific Islanders with American Indians and Alaska Natives. As such, this publicly available data set does not comply with 1997 OMB data collection standards.

COVID-19

The case for detailed data collection and glaring gaps has been highlighted by APIAHF and data equity advocates during the current COVID-19 national crisis.[8]

To date, there have been more than 184,000 COVID-19 deaths and over 6,000,000 COVID-19 cases.[9] Communities of color make up less than 40 percent of the US population, but make up 52 percent of the excess deaths, compared to the average over the last five years.[10]

As of the end of August, the CDC reported that AAs accounted for 3.5 percent (n=78,203) of COVID-19 cases and 5.0 percent (n=5,614) of COVID-19 deaths, while NHPIs accounted for 0.3 percent (n=7,171) of cases and 0.2 percent (n=153) of deaths.[11] However, CDC data on race/ethnicity were missing for 51 percent of COVID-19 cases and 18 percent of COVID-19 deaths. The limited data on AAs and NHPIs demonstrate:

- The current available data are undercounting the impact of COVID-19 among AA and NHPI communities.[12]
- Recent estimates indicate a high burden of COVID-19 deaths among AAs, with almost 14,000 excess deaths, and AAs have the second-highest increase in deaths following Hispanic

[6] Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health, Policy Link. (2018). Available at: https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf.
[7] See Letter to Office of Management and Budget, *Asian & Pacific Islander American Health Forum*.
[8] COVID-19 Demographic Data Sign-on Letter to congressional Leaders, *Asian & Pacific Islander American Health Forum*. (May 4, 2020). Available at: https://www.apiahf.org/resource/covid-19-demographic-data-sign-on-letter-to-congressional-leaders/.
[9] Centers for Disease Control and Prevention. Demographic Trends of COVID-19 cases and deaths in the US reported to CDC. CDC COVID Data Tracker. Accessed August 31, 2020. https://www.cdc.gov/covid-data-tracker.
[10] Flagg A, Sharma D, Fenn L, Stobbe M. COVID-19's Toll on People of Color Is Worse Than We Knew. *The Marshall Project*. Published August 21, 2020. Accessed August 31, 2020. https://www.themarshallproject.org/2020/08/21/covid-19-s-toll-on-people-of-color-is-worse-than-we-knew.
[11] Centers for Disease Control and Prevention. Demographic Trends of COVID-19 cases and deaths in the US reported to CDC. CDC COVID Data Tracker.
[12] Moore JT. Disparities in Incidence of COVID-19 Among Underrepresented Racial/Ethnic Groups in Counties Identified as Hotspots During June 5–18, 2020 — 22 States, February–June 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69. doi:10.15585/mmwr.mm6933e1. Goldfarb A, Rivera JM. COVID-19 Race and Ethnicity Data: What's Changed, and What Still Needs Improvement. The COVID Tracking Project. Accessed August 31, 2020. https://covidtracking.com/blog/covid-19-race-and-ethnicity-data-whats-changed-and-what-still-needs.

Americans.[13] The rapid increase in COVID-19 cases and deaths among this population make future prevention critical with mounting evidence of waning immunity from natural infection and preliminary reports of re-infection.[14]

- Regional data have reported greater COVID-19 cumulative incidence and case fatality rates (proportion of deaths to cases) among AAs[15] and NHPIs (see Figure 1). In contrast to CDC reports, data from the NHPI COVID-19 Data Policy Lab Dashboard reported 12,992 COVID-19 NHPI cases and 211 COVID-19 NHPI deaths as of August 26, 2020.[16]
- Initial research suggests there may be lower testing among AA populations.[17]
- In at least 10 states, AAs have a case fatality rate that is disproportionately higher than the general population, while the same is true for NHPIs in 8 states.[18] For example, in South Dakota, the case rate for AAs is 6 times higher as a proportion of their population in the state.[19] These numbers may be larger, but many states are not reporting out data in sufficient enough detail to evaluate disparities, while the CDC has not reported out any data about AA or NHPI subpopulations, many of whom often face distinct health disparities.[20]
- In some localities, like King County, Washington, and San Francisco County, California, NHPIs have rates 3 times or more their proportion in the population.[21] In Spokane County, Washington, Marshall Islanders make up less than 1% of the county's population, but make up 30% of confirmed COVID-19 cases.[22]
- Across the country, Pacific Islanders are being hospitalized with COVID-19 at up to 10 times the rate of other racial groups. In Washington, the rate of confirmed cases for NHPIs are 9 times higher than those of whites. In Oregon, Pacific Islanders make up .4% of the population, but represent nearly 3% of all COVID-19 infections. Summarily, in Arkansas, Pacific Islanders

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[13] Flagg A, Sharma D, Fenn L, Stobbe M. COVID-19's Toll on People of Color Is Worse Than We Knew. *The Marshall Project.*

[14] Young K. COVID-19: Waning Antibodies / Seroprevalence of Antibodies / Thromboses. *NEJM Journal Watch*. 2020;2020. doi:10.1056/nejm-jw.FW116855. *See also* Ibarrondo FJ, Fulcher JA, Goodman-Meza D, et al. Rapid Decay of Anti–SARS-CoV-2 Antibodies in Persons with Mild Covid-19. *New England Journal of Medicine*. Published online July 21, 2020:null. doi:10.1056/NEJMc2025179.

[15] Yan B, Ng F, Nguyen TT. *High Mortality from COVID-19 among Asian Americans in San Francisco and California*. UCSF School of Medicine and Asian American Research Center on Health (ARCH); 2020. https://asianarch.org/press_releases/Asian%20COVID-19%20Mortality%20Final.pdf. *See also* Yan B, Ng F, Chu J, Tsoh J, Nguyen T. Asian Americans Facing High COVID-19 Case Fatality. *Health Affairs Blog*. doi:10.1377/hblog20200708.894552.

[16] UCLA Center for Health Policy Research. NHPI COVID-19 Data Policy Lab Dashboard. Accessed August 31, 2020. https://public.tableau.com/views/NHPI_CDPL_Dashboard_with_extract/NHPICDPLDashboard?:embed=y&:showVizHome=no&:host_url=https%3A%2F%2Fpublic.tableau.com%2F&:embed_code_version=3&:tabs=no&:toolbar=yes&:animate_transition=yes&:display_static_image=no&:display_spinner=no&:display_overlay=yes&:display_count=yes&:language=en&publish=yes&:loadOrderID=0.

[17] Kandula N, Shah N. Asian Americans invisible in COVID-19 data and in public health response. *Chicago Reporter.* Published June 16, 2020. Accessed August 31, 2020. https://www.chicagoreporter.com/asian-americans-invisible-in-covid-19-data-and-in-public-health-response/. See also Quach T, Đoàn LN, Liou J, Ponce N. Simultaneously Blamed and Ignored: Barriers, Behaviors, and Impact of COVID-19 on Asian Americans. *JMIR Preprints*. Published online August 30, 2020. doi:10.2196/preprints.23976.

[18] Testimony from the National Council of Asian Pacific Islander Physicians to the Committee on Ways and Means (June 9, 2020). Available at: https://mcusercontent.com/d7f02dd24377959c916d14de6/files/5ebe9b24-21f8-4d67-93d2-4f218db2e323/NCAPIP_Statement_to_House_Ways_and_Means_Committee_on_COVID_19_Disparities.pdf.

[19] Wen, Leana and Nakisa Sadeghi, Addressing Racial Health Disparities In The COVID-19 Pandemic: Immediate And Long-Term Policy Solutions, *Health* Affairs. Published July 20, 2020. Available at: https://www.healthaffairs.org/do/10.1377/hblog20200716.620294/full/.

[20] For example, APIAHF analysis of 2018 American Community Survey data shows that while the overall uninsured rate for Asian Americans is 6.2%, the uninsured rate for Nepalese is 13.4% and 9.4% for Pakistanis.

[21] "Devastating COVID-19 Rate Disparities Ripping Through Pacific Islander Communities in the U.S.," *Pacific Islander Center on Primary Care* Excellence. Published April 27, 2020. Available at: https://mk0picopce2kx432grq5.kinstacdn.com/wp-content/uploads/2020_0424-PICOPCE-COVID19-Press-Release.pdf.

[22] Jackson, Lagipoiva, "Pacific Islanders in US Hospitalized with COVID-19 at up to 10 Times the Rate of Other Groups," *The Guardian*. Published July 26, 2020. Available at: https://www.theguardian.com/world/2020/jul/27/system-is-so-broken-covid-19-devastates-pacific-islander-communities-in-us?CMP=share_btn_link.

make up .3% of the population, but account for 8% of COVID-19 cases. In Hawaii, Pacific Islanders make up 4% of the population, but 25% of COVID-19 cases.[23]

- Initial research from San Francisco suggests that AAs had the highest proportion of deaths due to COVID-19 across all other racial groups.[24] While AAs make up one-third of the city's population, they make up half of its COVID-19 deaths.[25]
- In California, the NHPI community makes up .3% of the state's population, but accounts for .6% of cases, while AAs represent 11.8% of COVID-19 deaths and 15% of the state population.
- AAs represent 16% of COVID-19 deaths and 15% of the state population, while NHPIs make up 1.6% of cases but .3% of the state's population.[26]
- Using what limited information is available, researchers have found that Filipino-Americans are dying of the virus at very high rates, accounting for 35% of COVID-19 deaths amongst California's AA population.[27]

Given these alarming and documented disparities, there is a critical need for better understanding that these data are important to control the spread and reduce the impact of COVID-19 among racial and ethnic communities. The social determinants of health that underlie these disparities in COVID-19 deaths include increased incidence of xenophobic hate and violence. AA and NHPI organizations have documented at least 1,900 hate incidents in 46 states.[28] In addition, AA and NHPIs have increased risk of adverse COVID-19 outcomes (e.g., burden of chronic conditions and multigenerational homes), and a large proportion of AA and NHPI frontline essential workers.[29]

As such, it is critical that detailed data collection, analysis and reporting be made available to ensure that differences are not masked and subpopulations are not rendered invisible. We thank the Committee for its attention to this matter.

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[23] *Id.*

[24] Constance, Agnes, Asian American Death Rate in San Francisco Concerning, Researchers Say, *NBC* News. Published May 20, 2020. Available at: https://www.nbcnews.com/news/asian-america/asian-american-covid-19-death-rate-san-francisco-concerning-researchers-n1211491.

[25] Palomino, Joaquin, Why has coronavirus taken such a toll on SF's Asian American community? Experts perplexed over high death rate, *San Francisco Chronicle*. Published May 2020, 2020. Available at: https://www.sfchronicle.com/health/article/Why-has-coronavirus-taken-such-a-toll-on-SF-s-15282096.php.

[26] COVID-19 Updates, *California Department of Public Health COVID-19 Cases and Deaths by Race/Ethnicity*. Accessed September 3, 2020. Available at https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/COVID-19/Race-Ethnicity.aspx.

[27] Wong, Tiffany, Little noticed, Filipino Americans are dying of COVID-19 at an alarming rate, *Los Angeles Times*. Published July 21, 2020. Available at: https://www.latimes.com/california/story/2020-07-21/filipino-americans-dying-covid.

[28] Ko JY, Danielson ML, Town M, et al. Risk Factors for COVID-19-associated hospitalization: COVID-19-Associated Hospitalization Surveillance Network and Behavioral Risk Factor Surveillance System. *medRxiv*. Published online July 27, 2020:2020.07.27.20161810. doi:10.1101/2020.07.27.20161810.

[29] Kaholokula JK, Samoa RA, Miyamoto RES, Palafox N, Daniels S-A. COVID-19 Special Column: COVID-19 Hits Native Hawaiian and Pacific Islander Communities the Hardest. *Hawaii J Health Soc Welf.* 2020;79(5):144-146. See also Krisberg K. Essential workers facing higher risks during COVID-19 outbreak: Meat packers, retail workers sickened. *The Nation's Health*. 2020;50(6):1-16. See also Jurado L-FM, Saria MG. Filipino nurses in the United States. *Nursing Management*. 2018;49(3):36–41. doi:10.1097/01.NUMA.0000530423.71453.58.