# Data Disaggregation Resource Guide

## Advancing Equity for Asian American, Native Hawaiian, and Pacific Islander (AA and NH/PI) Communities in COVID-19 Response Efforts

OMH®
U.S. Department of
Health and Human Services
Office of Minority Health

# Purpose

The purpose of the Data Disaggregation Resource Guide is to provide guidance on best practices, strategies, and actions to improve the collection, use, and reporting of disaggregated data on Asian American, Native Hawaiian, and Pacific Islander (AA and NH/PI) populations related to COVID-19. The AA and NH/PI population is diverse, and disaggregated data will support improved identification and understanding of disparities experienced by specific groups within the population.

This guide is part of a set of resource guides developed by the U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH) to provide guidance on best practices to advance cultural competency, language access, and sensitivity toward AAs and NH/PIs in the context of the Federal COVID-19 response, in accordance with the Presidential Memorandum Condemning and Combating Racism, Xenophobia and Intolerance Against Asian Americans and Pacific Islanders in the United States. For more information on the resource guides, please visit the OMH website at https://minorityhealth.hhs.gov.

# Audience

This guide is designed for the government (i.e., Federal, State, and local departments and agencies), community-based organizations, and health care settings (e.g., health departments, hospitals, care providers, etc.) to support the collection, use, and reporting of AA and NH/PI population-specific, disaggregated data related to COVID-19.

For those entities subject to the requirements of the Health Insurance Portability and Accountability Act (HIPAA), when reporting Personal Health Information that has not been fully anonymized, please bear in mind your obligations under HIPAA.

# How to Use the Guide

Begin by referring to the Roadmap on page 3 that outlines the content of the resource guide, which is divided into sections that describe the best practices, strategies, and actions related to data disaggregation.

- Section 1 focuses on the collection of disaggregated data.
- Section 2 focuses on disaggregated data reporting.
- Section 3 focuses on the use of data to engage AA and NH/PI communities and to improve COVID-19 response efforts.

Each section includes examples and resources to assist in the implementation of the best practices, strategies, and actions outlined within the guide.

# Roadmap

**This resource guide is divided into three sections, each of which includes relevant best practices, strategies, and actions; and examples and resources to support implementation.**

## Data Collection

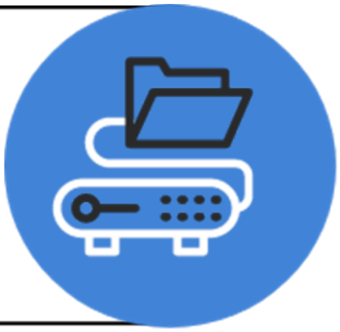
1

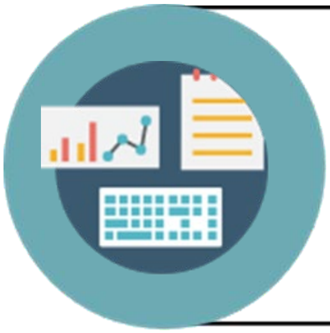
How to collect disaggregated AA and NH/PI population-specific data related to the COVID-19 pandemic.

2

## Data Reporting

How to report COVID-19 data that is inclusive of AA and NH/PI subpopulations.





## Data Use

How to use available disaggregated data to engage AA and NH/PI communities and elevate and respond to disproportionate COVID-19 impacts.

3

# Data Collection

1

How to collect disaggregated AA and NH/PI population-specific data related to the COVID-19 pandemic.

Data provides a window into the health and wellbeing of communities. When data is collected in general categories such as "Asian" or "Pacific Islander" without consideration for ethnic and cultural diversity, specific communities become invisible and subgroup disparities can be masked. During the COVID-19 pandemic, insufficient data collection and reporting for AA and NH/PIs in the U.S. resulted in a dangerous misrepresentation of the needs, health, and safety of these communities. To advance the availability of disaggregated data for AA and NH/PI communities, it is necessary to both increase data collection efforts and capture the subpopulation data that comprise these community groups.

Using appropriate and sufficient data collection methods, including identifying sample size, ethnic groups, and data tools (e.g., focus group, interview, questionnaire, etc.) can support the meaningful and accurate representation of the health status and outcomes for AA and NH/PI communities during the COVID-19 pandemic. Moreover, it is important to understand that stories of lived experiences shared about COVID-19 by specific AA and NH/PI communities also provide valuable information to support or complement quantitative data.

## Strategies and Actions

### Use data collection methods like oversampling for smaller AA and NH/PI populations to help increase representation in data samples.

Sampling is the process of choosing participants for a research study. Sampling involves choosing a small group of participants that will represent a larger group (HHS, ORI). Oversampling is deliberately sampling a portion of the population at a higher rate than the remainder of the population (NCED). Oversampling of certain population subgroups is also done to increase the reliability and precision of estimates for these particular subgroups (CDC, 2022).

## Resources

**Best Practices for the Disaggregation of Federal Data on Asian Americans and Pacific Islanders**

This guide from the White House Initiative on AsianAmericans and Pacific Islanders provides an overview of best practices for providing disaggregated AAPI data, including those addressing data collection challenges.

**Improving Health Research on Small Populations**

This publication from the National Academies of Sciences, Engineering and Medicine summarizes workshop discussion about ways of addressing the challenges of conducting epidemiological studies or intervention research with small population groups, including innovative methodologies for data collection.

**Collect data using granular categories (e.g., AA and NH/PI subgroups, AA and NH/PI subpopulation languages).**

## Example

Granular Categories for AA and NH/PI Populations

Below are examples of Federal data standards or collections that include some granular categories for AA and NH/PI populations. These examples use categories that specify ethnic groups and/or provide the option to write in responses. Please note that the examples do not reflect a comprehensive list of AA and NH/PI ethnicities.

| Source | Asian Categories | Native Hawaiian and Pacific Islander Categories |
|---|---|---|
| HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status | Asian Indian<br>Chinese<br>Filipino<br>Japanese<br>Korean<br>Vietnamese<br>Other Asian* | Native Hawaiian<br>Guamanian or Chamorro<br>Samoan<br>Other Pacific Islander* |

|  |  |  |
|---|---|---|
| 2020 Census | Asian Indian<br>Chinese<br>Filipino<br>Japanese<br>Korean<br>Vietnamese<br>Other Asian† | Native Hawaiian<br>Samoan<br>Chamorro<br>Other Pacific Islander† |
| American Community Survey | Afghan, Asian Indian, Bangladeshi, Bengali, Bhutanese, Bruneian, Burmese, Buryat, Cambodian, Central Asian, Cham, Chinese, East Asian, Filipino, Hakka, Han, Hmong, Hong Kong, Indo, Indo-Chinese, Indonesian, Iwo Jiman, Japanese, Kalmyk, Kazakh, Khmer, Korean, Kuki, Kyrgyz, Lahu, Laotian, Macanese, Malay, Malaysian, Maldivian, Mien, Mili, Mizo, Mongolian, Montagnard, Nepalese, Okinawan, Pakistani, Pashtun, Punjabi, Sikh, Sindhi, Singaporean, South Asian, Southeast Asian, Sri Lankan, Tai Dam, Taiwanese, Tajik, Thai, Tibetan, Timorese, Turkmen, Urdu, Uzbek, Vietnamese | Bikinian, Carolinian, Chuukese, Cook Islander, Easter Islander, Ebeye, Ejit, Enewetak Islander, Fijian, French Polynesian, Guamanian or Chamorro, Hawaiian, I-Kiribati, Indo Fijian, Kili, Kosraean, Kwajalein Islander, Maori, Marshallese, Melanesian, Micronesian, Native Hawaiian, Nauruan, New Caledonian, Niuean, Ni-Vanuatu, Northern Mariana Islander, Pacific Islander, Palauan, Papua New Guinean, Part Hawaiian, Pohnpeian, Polynesian, Rotuman, Saipanese, Samoan, Solomon Islander, Tahitian, Tokelauan, Tongan, Tuvaluan, Ujelang, Wallisian and Futunan, Yapese |

* HHS agencies may request permission from OMB during the Paperwork Reduction Act clearance process to add a write-in option of "other" to interviewer-administered surveys.
† Write-in response areas and examples are included.

**Identify the AA and NH/PI subpopulations within a geographic location or community to determine minimum data disaggregation standards.**

**Collect data on acculturation indicators, such as the cultural behaviors, knowledge, attitudes, and values of communities.**

### Example

**“Asian Americans, Native Hawaiians, and Pacific Islanders on COVID-19 and Getting Vaccinated” Survey**

This national survey conducted by Hart Research Associates, COVID-19 Collaborative, and Asian & Pacific Islander Health Forum (APIAHF) collected AA and NH/PI data related to COVID-19 vaccination attitudes. Survey questions included those related to the perception of COVID-19 as a serious problem, concerns about getting vaccinated, and important reasons to get vaccinated.

**Collect race, ethnicity, language, and disability (REALD) data**

### Example

**Oregon Health Authority COVID-19 REALD Report**

The Oregon Health Authority COVID-19 Race, Ethnicity, Language and Disability (REALD) Report demonstrates the collection and reporting of REALD as a way to gather more information about self-identified racial and ethnic identity, language, and disability and to identify health inequities. REALD variables included primary race or ethnicity, preferred language, English proficiency, interpreter need, and disability status and type. The report includes data on COVID-19 cases and encounters, describes data methods used, and makes recommendations for improvement and further investigation.

2

# Data Reporting

How to report COVID-19 data that is inclusive of AA and NH/PI subpopulations.

It is important to report disaggregated COVID-19 data for AA and NH/PI populations, when reliable estimates are available, to maximize the usefulness of the data. During the COVID-19 pandemic, data reports often presented AA and NH/PI communities as a homogenous group or excluded the communities altogether. With aggregated data, it is more difficult to identify, raise awareness of, and account for community-specific COVID-19 impacts.

## Strategies and Actions

**Report disaggregated data at the most granular level possible.**

### Example

**State of Hawaiʻi COVID-19 Data Dashboards**

The State of Hawaiʻi's Department of Health website offers data dashboards which report disaggregated data on COVID-19 cases, outcomes, mortality, hospitalizations, and vaccination rates by demographic or other characteristics like county, island, zip code, travel history, age, and race and ethnicity. The dashboards report data for Native Hawaiians separately from Pacific Islanders and also include available data for Asian ethnic groups.

**When conducting secondary data analyses, identify and use data sources that include granular data on AA and NH/PI populations whenever possible.**

**Make available, in a timely manner, all disaggregated AA and NH/PI data collected. Keep in mind that insufficient data (e.g., small numbers) can inaccurately convey public health needs.**

**Provide details about missing data when reporting disaggregated data, such as data not being available because it does not meet the criteria for statistical reliability, data quality, or confidentiality.**

## Example

Healthy People 2030 Data

The Healthy People 2030 website includes available data on each Healthy People 2030 objective. The data charts and tables use the following abbreviations to provide specific details on data that is not available.

- DSU: Data do not meet the criteria for statistical reliability, data quality, or confidentiality.
- DNA: Data have not been analyzed.
- DNC: Data for specific population not collected.

**At a minimum, report data related to COVID-19 testing, vaccination, and treatment in accordance with the Office of Management and Budget (OMB) race and ethnicity standards, reporting data on Native Hawaiians and Pacific Islanders separately from data on Asian Americans.**

## Resource

OMB Standards for the Classification of Federal Data on Race and Ethnicity

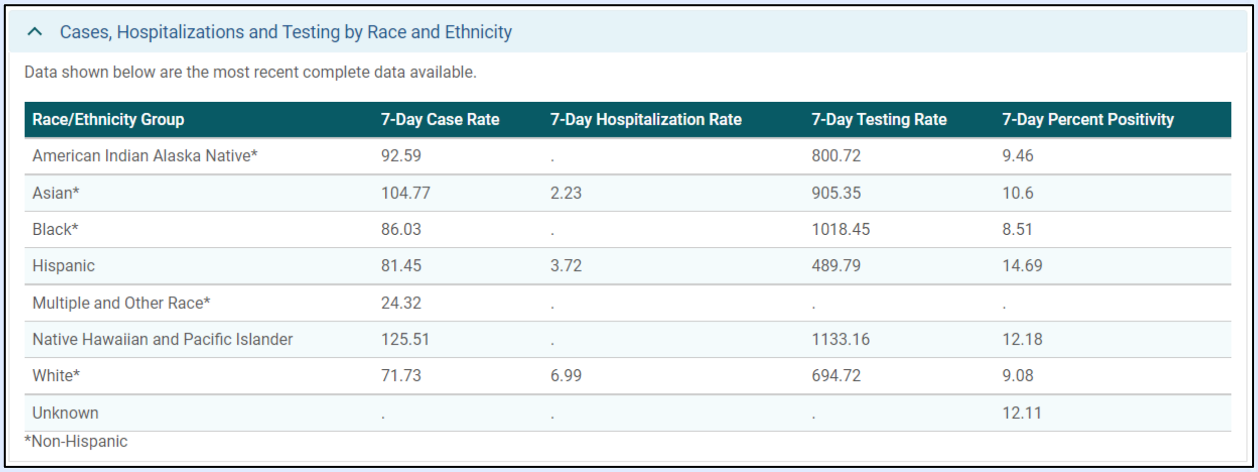
The 1997 revision of OMB’s Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting, included separation of the Asian or Pacific Islander category into two categories—"Asian” and “Native Hawaiian or Other Pacific Islander.” The revised standards have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White; and two categories for data on ethnicity: “Hispanic or Latino” and “Not Hispanic or Latino.”

**Report disaggregated data inclusive of AA and NH/PI populations on the impact of COVID-19. Include information about disparities identified for indicators such as: COVID-19 cases, COVID-19 outcomes, mortality and morbidity, risk of exposure, pre-existing or co-morbid conditions, barriers to care, unemployment, and food insecurity.**

## Examples

### Washington State COVID-19 Data Dashboard

The state of Washington's Department of Health website offers an interactive COVID- 19 dashboard that includes charts and tables with the latest available and trend data showing current status, disease activity and testing, vaccinations, and hospital use. Data is available by county, region, age, sex, and race and ethnicity.



^ Cases, Hospitalizations and Testing by Race and Ethnicity

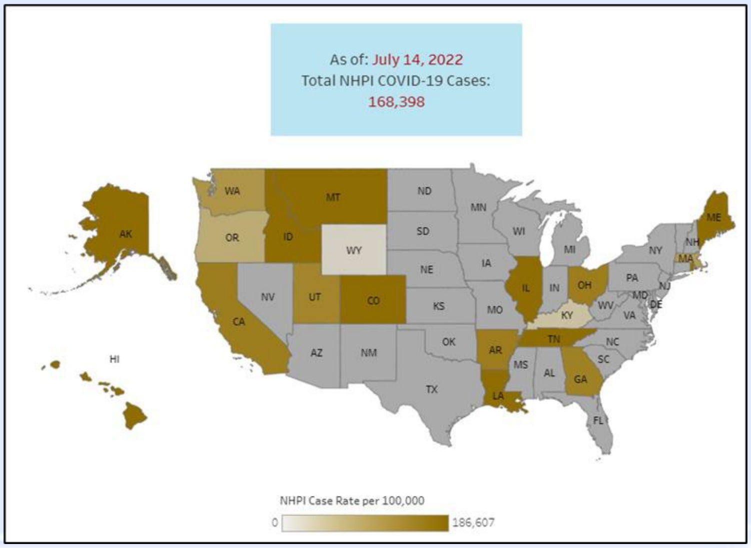
Data shown below are the most recent complete data available.

| Race/Ethnicity Group | 7-Day Case Rate | 7-Day Hospitalization Rate | 7-Day Testing Rate | 7-Day Percent Positivity |
|---|---|---|---|---|
| American Indian Alaska Native* | 92.59 | . | 800.72 | 9.46 |
| Asian* | 104.77 | 2.23 | 905.35 | 10.6 |
| Black* | 86.03 | . | 1018.45 | 8.51 |
| Hispanic | 81.45 | 3.72 | 489.79 | 14.69 |
| Multiple and Other Race* | 24.32 | . | . | . |
| Native Hawaiian and Pacific Islander | 125.51 | . | 1133.16 | 12.18 |
| White* | 71.73 | 6.99 | 694.72 | 9.08 |
| Unknown | . | . | . | 12.11 |

*Non-Hispanic

### UCLA Center for Health Policy Research NHPI COVID-19 Data Policy Lab Dashboard

The UCLA Center for Health Policy Research hosts an online dashboard with national and state-level COVID-19 case and mortality data specifically on the NH/PI population.

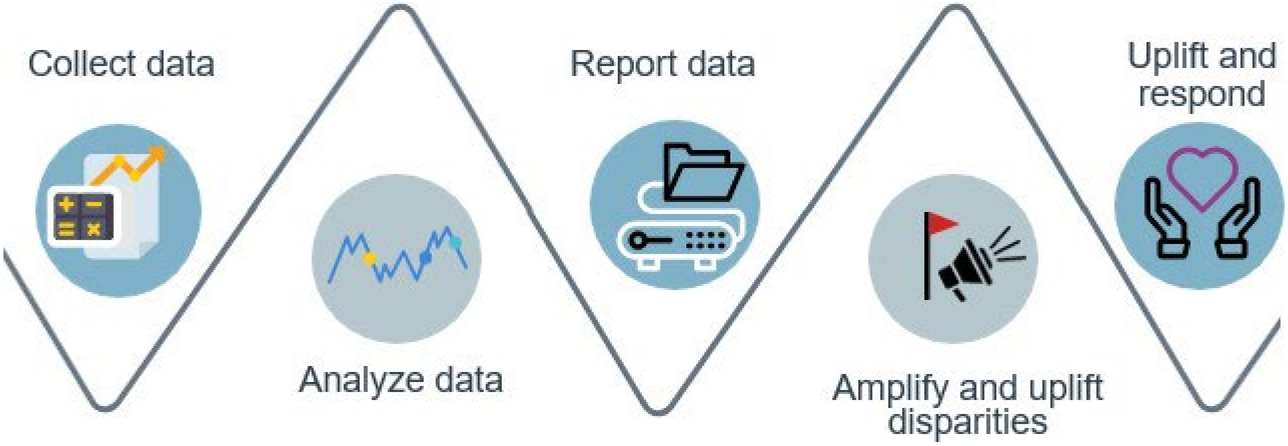


As of: July 14, 2022
Total NHPI COVID-19 Cases:
168,398

# Data Use

## 3

How to use available disaggregated data to engage AA and NH/PI communities and elevate and respond to disproportionate COVID-19 impacts.



Increased and improved data collection can enable more qualitative and quantitative data analysis, leading to a better understanding of community health and potential inequities. Reporting disaggregated COVID-19 data for AA and NH/PI populations allows the affected AA and NH/PI communities' experiences and disparities to be seen. The use of data to better understand these experiences and disparities can inform planning and action to uplift and respond to the community's needs.

The following strategies and actions guide how to use data to support response to disproportionate COVID-19 impacts and engage AA and NH/PI communities in the process.

## Strategies and Actions

**Promote awareness of the importance of making the health needs and disparities experienced AA and NH/PI populations visible through data disaggregation and how data findings can be used to promote health equity.**

**Provide the context for why minoritized and marginalized communities experience disparities because of systemic inequities. This is important as it helps communicate how failing to disaggregate data can contribute to health care inequalities that exacerbate health disparities among AA and NH/PI populations.**

## Resource

**[Advocating for Data Disaggregation by Race and Ethnicity]**

This report from the Robert Wood Johnson Foundation (RWJF) explains how incomplete data acts as a barrier to health equity and describes the importance of disaggregating data by race and ethnicity. It includes information and messages to support advocacy for policies that ensure disaggregated data on race and ethnicity are collected, analyzed, and reported.

## Example

**Dr. Ray Samoa Testimony Before the House Ways & Means Committee**

On Wednesday, May 27, 2020, the U.S. House of Representatives Ways & Means Committee hosted a virtual hearing on "The Disproportionate Impact Of COVID-19 On Communities Of Color." Dr. Raynald Samoa of the Pacific Islander COVID-19 Response Team provided witness testimony which included an overview of social determinants of health and other systems-related disparities experienced by Pacific Islander communities that provided a context for the disproportionate impact of COVID-19 on Pacific Islander communities.

**Engage the community through community events and other avenues to share and collaborate around AA and NH/PI data and trends related to COVID-19.**

**Present available data in a manner relevant to each community's needs via community-specific platforms (e.g., community podcasts, etc.) using preferred languages.**

## Example

[Koviki Talk Podcast - Data Disaggregation Episode]

Koviki Talk is a 21-episode podcast series on COVID-19 from Native Hawaiian & Pacific Islander perspectives. It is a platform for sharing insights on COVID-19 experiences, impacts, and community data, etc. The episode below includes a discussion of the importance of data disaggregation with experts from the NHPI COVID-19 Data Policy Lab at the UCLA Center for Health Policy Research and the Pacific Basin Development Council.

# Resources

Below is a list of all resources and examples referenced in this guide.

**Data Collection**

- U.S. Department of Health and Human Services, Office of Research Integrity. (2022). *Elements of Research: Sampling.* Available from: https://ori.hhs.gov/education/products/sdsu/sampling.htm
- U.S. Department of Education, National Center for Education Statistics. (n.d.). *NCES DLDT Glossary.* Retrieved from https://nces.ed.gov/training/datauser/NCESGlossary.pdf
- Centers for Disease Control and Prevention. (2022). *NHANES Tutorials – Module 2 - Sample Design*. Retrieved September 20, 2022, from https://wwwn.cdc.gov/nchs/nhanes/tutorials/SampleDesign.aspx
- White House Initiative on Asian Americans and Pacific Islanders, Interagency Working Group – Data and Research Subcommittee. (2016). *Best Practices for the Disaggregation of Federal Data on Asian Americans and Pacific Islanders*. Retrieved from https://www.hhs.gov/sites/default/files/mar2016-whiaanhpi-data-disaggregation-report.pdf
- National Academies of Sciences, Engineering, and Medicine. (2018). *Improving Health Research on Small Populations: Proceedings of a Workshop*. Washington, DC: The National Academies Press. https://doi.org/10.17226/25112.
- U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. (n.d.). *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Dtatus.* Retrieved from https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability
- Marks, R., & Rios-Vargas, M. (2021). *Improvements to the 2020 Census Race and Hispanic Origin Question Designs, Data Processing, and Coding Procedures*. The United States Census Bureau. Retrieved from https://www.census.gov/newsroom/blogs/random-samplings/2021/08/improvements-to-2020-census-race-hispanic-origin-question-designs.html

- Federal Committee on Statistical Methodology. (n.d.). *American Community Survey (ACS).* (n.d.). Retrieved from https://nces.ed.gov/fCSM/acs.asp

## Data Reporting

- State of Hawaiʻi, Department of Health. (n.d.). *Race/Ethnicity Data*. Disease Outbreak Control Division COVID19. Retrieved from https://health.hawaii.gov/coronavirusdisease2019/tableau_dashboard/race-ethnicity-data/
- U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (n.d.). *Objectives and Data*. Objectives and Data - Healthy People 2030. Retrieved from https://health.gov/healthypeople/objectives-and-data
- Office of Management and Budget. (1997). *58782 Federal Register Vol. 62, No. 210 Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity.* Retrieved from https://www.govinfo.gov/content/pkg/FR- 1997-10-30/pdf/97-28653.pdf
- Washington State Department of Health. (n.d.). COVID-19 Data Dashboard. Retrieved from https://doh.wa.gov/emergencies/covid-19/data-dashboard
- UCLA Center for Health Policy Research (n.d.). NHPI COVID-19 Data Policy Lab Dashboard. Retrieved from https://healthpolicy.ucla.edu/health- profiles/Pages/NHPI-COVID-19-Dashboard.aspx

## Data Use

- Robert Wood Johnson Foundation. (2020). *Advocating for Data Disaggregation by Race and Ethnicity*. Retrieved from https://www.apiahf.org/wp-content/uploads/2021/05/FINAL-REL-DataDisaggregationMessage-Guide-December-2020.pdf
- Association of Asian Pacific Community Health Organizations. (2020, May 27). *Dr. Ray Samoa Testimony Before the House Ways & Means Committee (excerpt)*. YouTube. Retrieved from https://www.youtube.com/watch?v=0fM6YIf1Kzg
- PasificaByDesign. (2020, December 3). *Koviki Talk Episode 11 Data Disaggregation*. Retrieved from https://www.youtube.com/watch?v=PnmXBYoaacA

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To find other resource guides and for more information about OMH, visit:
[minorityhealth.hhs.gov](minorityhealth.hhs.gov)

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The HHS Office of Minority Health does not intend, in sharing these resources, to provide legal advice. The sole purpose of the resource list is to provide information that may help users to advance data disaggregation for AA and NH/PI communities in COVID-19 response efforts. The resources and examples included are not intended to be comprehensive.

**SUGGESTED CITATION**

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