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Including Island Areas in Federal Public Health Datasets

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Executive Summary

Public health datasets inform effective policymaking, guide intervention planning and resource distribution, and make the case for services and programs. As such, collecting and sharing data are crucially important to improving health equity. Federal public health datasets need accurate and relevant data to facilitate evidence-based policies and programs that improve health outcomes and reduce health disparities.

Despite having some of the most challenging population health outcomes, the U.S. island areas—Puerto Rico (PR), U.S. Virgin Islands (USVI), Guam, Commonwealth of the Northern Mariana Islands (CNMI), American Samoa, Palau, Republic of the Marshall Islands (RMI), and Federated States of Micronesia (FSM)—are often absent within federal public health datasets.

In a review of 32 commonly used federal public health datasets, only 18 (56%) include island jurisdiction data and only two (6%) include data from all eight island jurisdictions. Puerto Rico, the U.S. Virgin Islands, and Guam are best represented while Palau, the Marshall Islands, and the Federated States of Micronesia are least represented in these datasets. At least 11 (35%) datasets include no island representation. Island data collection and representation has facilitated improved island, regional, and federal public health policy and programming. The lack of island representation in key federal public health datasets obscures the pronounced health disparities and the need for programs and services throughout this region.

Federal, island, and nonprofit partners should prioritize efforts to increase T/FAS inclusion in federal datasets to promote improved public health policy, planning, and programming. Next steps center around efforts to understand barriers to island inclusion, to ensure island capacity for vital statistics, and to map federal and multilateral agency data collection efforts.

About the Report

Established in October 2021, ASTHO's Island Areas Workgroup (IAW) brings together representatives from island jurisdictions, federal agencies, and trusted partners to address key administrative challenges impacting health outcomes in island jurisdictions, including efforts to strengthen procedures and organizational policies affecting health financing, data capacity, and workforce development.

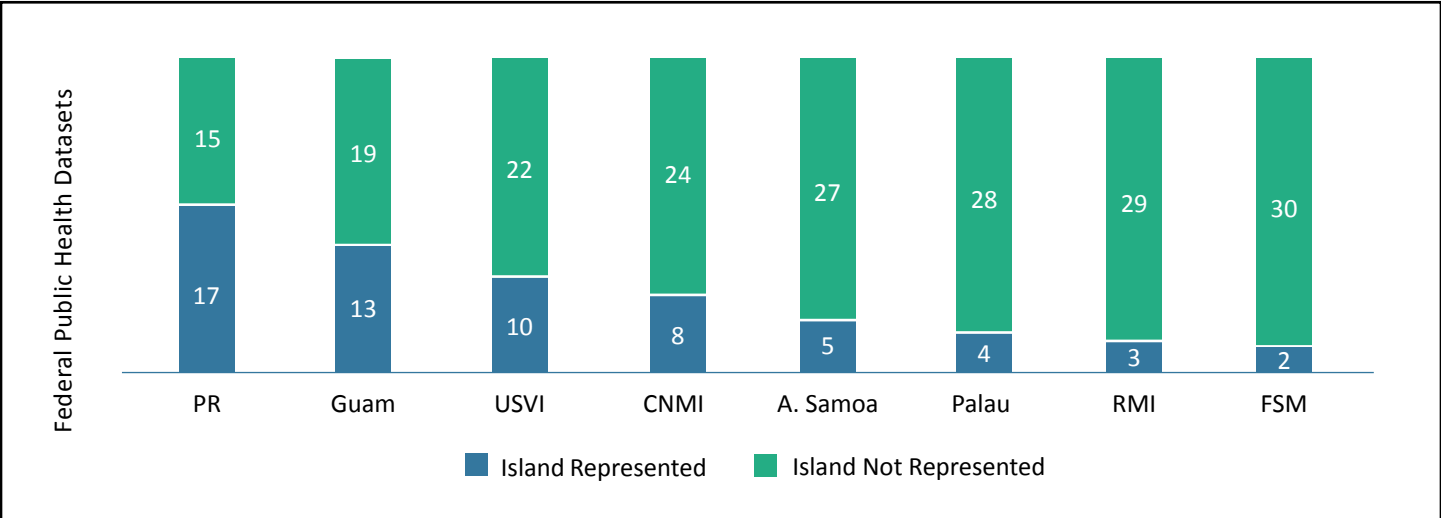
The Data Capacity Subgroup submits this report to the IAW as a tool to guide future efforts to improve territorial and freely associated state (T/FAS) representation within federal public health datasets.

The IAW Data Capacity Subgroup thanks Dr. Janis Valmond, Deputy Commissioner, U.S. Virgin Islands Department of Health for her leadership of the subgroup. Additional thanks go to all subgroup members for their time and input and ASTHO staff Alex Wheatley, Nicole Harris, and Corinne Gillenwater.

Summary

The United States outlying islands include five territories and three freely associated states.¹ In a review of 32 commonly used federal public health datasets (Appendix A), 18 (56%) contain at least one of these island jurisdictions. Inclusion in these datasets is not evenly distributed across the islands. PR (17), Guam (13), and USVI (10) are best represented, while Palau (4), RMI (3), and FSM (2) are least represented (Figure 1).

Figure 1. Island Areas Not Fully Represented in Federal Public Health Datasets



CDC’s National Program of Cancer Registries (NPCR) and COVID-19 Data Tracker include data from all eight island jurisdictions and are the most inclusive datasets considered in this report. These data sources align with regional success stories. For example, COVID-19 data has helped federal and regional partners address and champion island jurisdictions’ unique needs throughout the pandemic (during which many Pacific island jurisdictions avoided community spread until 2022). Comprehensive inclusion in the NPCR was achieved in 2007 when regional Pacific cancer control organizations applied for and received the NPCR cooperative agreement.^{2,3} NPCR funding and data has been used in each island jurisdiction to support systematic and data-driven cancer prevention and control.

Figure 2 shows island representation across the 18 datasets with at least one island represented. Table 1 shows the eleven federal public health datasets that do not include island jurisdictions—a substantial gap. For example, the National Survey on Drug Use and Health is used to define the extent of substance use and mental health issues in the United States. And, while behavioral health is an emerging priority in the island jurisdictions, there are no island jurisdictions included in this survey. Appendix A delineates island inclusion in key federal health datasets.

Island inclusion was not clearly defined in the methodology of three CDC datasets: the National Ambulatory Medical Care Survey, the National Electronic Health Records Survey, and the National Health Interview Survey. Additional research is needed to determine island inclusion in these datasets.

¹ Territories: Puerto Rico, the U.S. Virgin Islands, Guam, the Commonwealth of the Northern Mariana Islands, American Samoa Freely associated states: Palau, the Marshall Islands, and the Federated States of Micronesia.
² “NPCR Timeline.” National Program of Cancer Registries (NPCR), CDC. <https://www.cdc.gov/cancer/npcr/timeline.htm>
³ Palafox N, Given L, Hohman K, et al. “Comprehensive Cancer Control Planning in the Pacific: the Cancer Council of the Pacific Islands a multi-national regional coalition.” Cancer Causes Control. 2018 December ; 29(12): 1287–1295. doi:10.1007/s10552-018-1115-z. Available at <https://stacks.cdc.gov/view/cdc/61797>.

Figure 2. Island Representation Varies Across Federal Datasets*

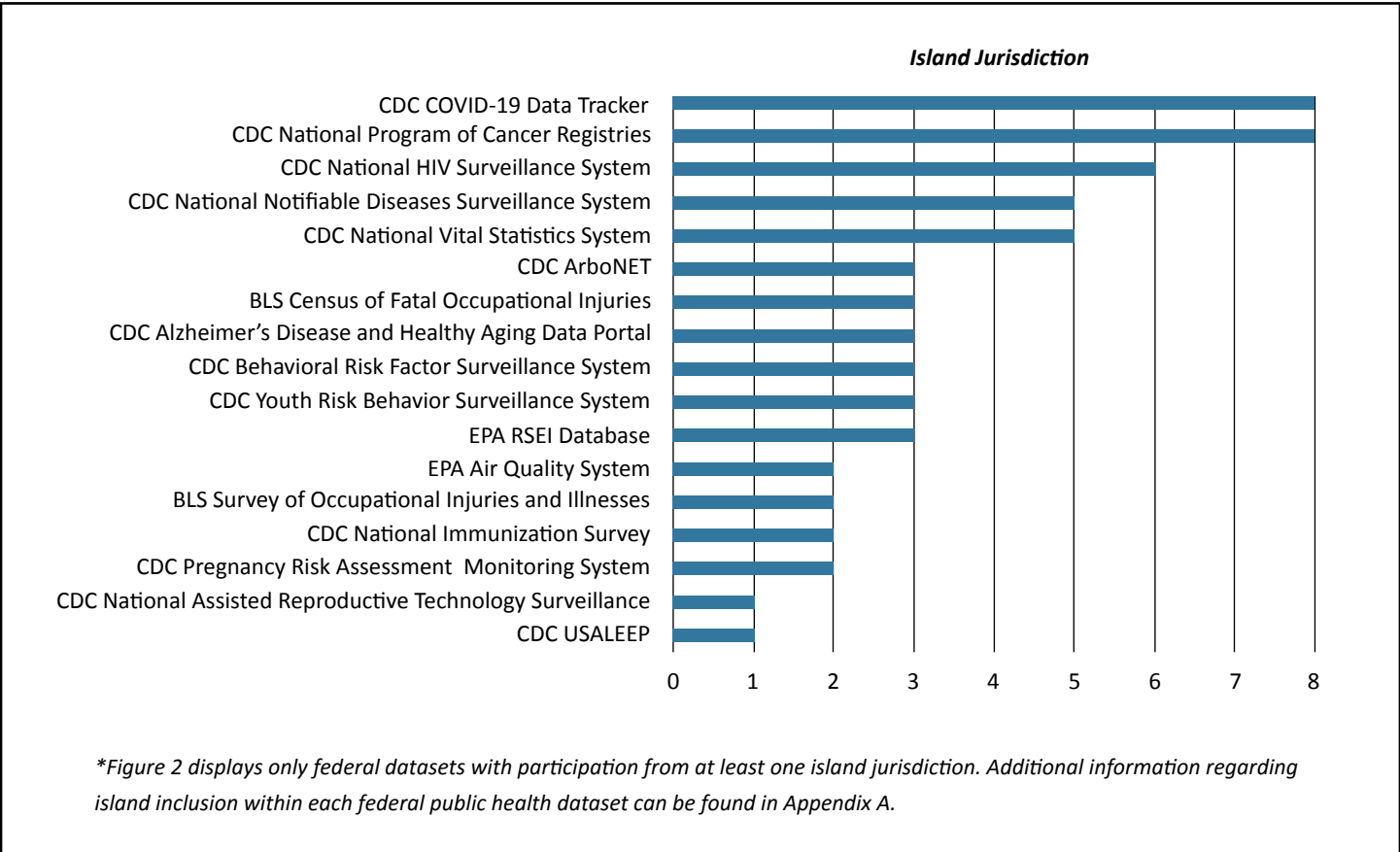


Table 1. Federal Public Health Datasets with No Island Representation

CDC National Health and Nutrition Examination Survey (NHANES)	CDC PLACES Database
CDC National Hospital Ambulatory Medical Survey	CDC Pregnancy Mortality Surveillance System
CDC National Hospital Care Survey	CMS National Health Expenditures Accounts
CDC National Post-Acute and Long-Term Care Study	NCI Surveillance, Epidemiology, and End Results Program
CDC National Survey of Family Growth	SAMHSA National Survey on Drug Use and Health
CDC National Youth Tobacco Survey	

States are significantly better represented than islands within these 32 federal public health datasets. Figure 3 shows state (excluding Washington, D.C.) and island representation in the 20 datasets that report jurisdiction-level data. Among these 20 datasets, 15 (75%) include data from all states while only two (10%) include data from all islands. On average, 49 states (98%) and three islands (36%) are represented in each of these datasets. Figure 4 shows state and island eligibility for inclusion among the 12 datasets that do not collect or report jurisdiction-level data (e.g., nationally representative surveys, regional registries, county monitors). Among these datasets, only two include some island jurisdictions (EPA Air Quality data includes PR and USVI. CDC ArboNET data includes Palau, PR, and Guam). Three datasets do not clearly define island eligibility and seven include only state-based data.

Figure 3. State vs. Island Inclusion: Jurisdiction-Level Federal Public Health Datasets

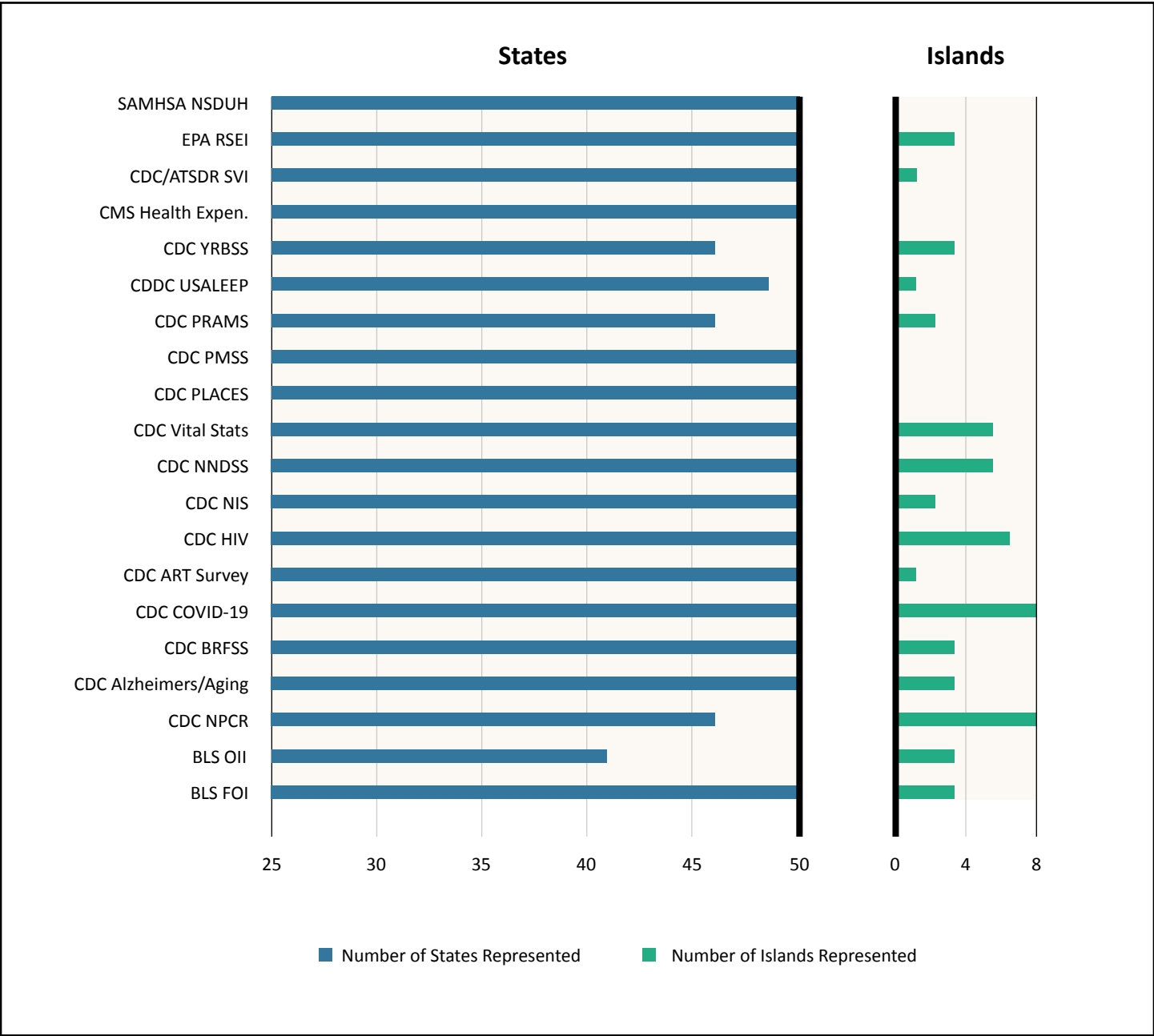
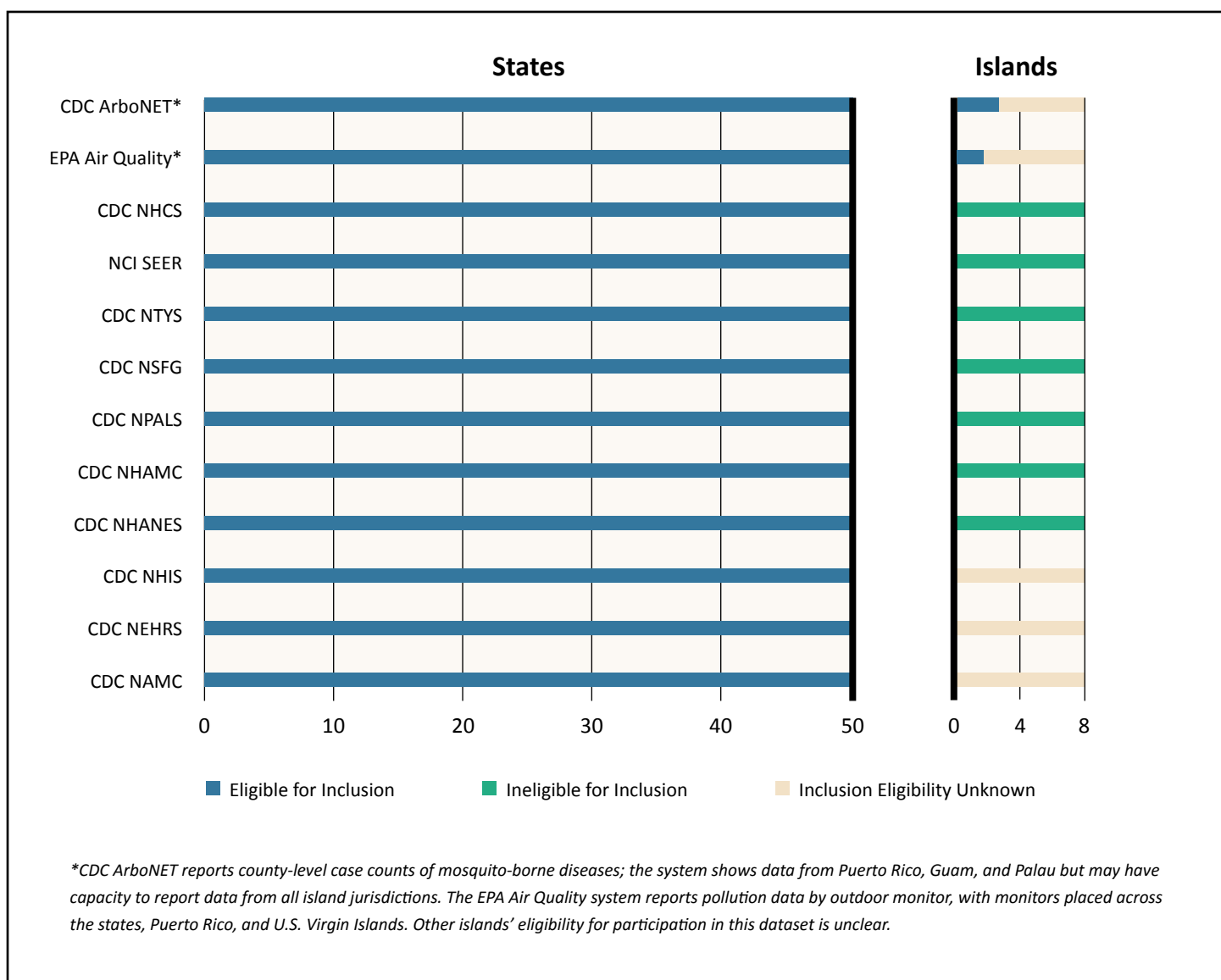


Figure 4. State vs. Island Inclusion: Other Federal Public Health Datasets



The lack of island representation within commonly used federal public health datasets is a significant health equity issue with repercussions for island health programming and outcomes. Reasons for T/FAS exclusion from federal public health datasets vary and are not clearly defined in public-facing resources.

Anecdotally, an island jurisdiction may not be represented because it is ineligible for the relevant data collection program (e.g., the Census Bureau's American Community Survey) or may not collect data of sufficient quality to meet database requirements. Where islands are eligible, populations may be too small for standard sampling protocols or island health measures may be perceived as too different from those of U.S. states to merit inclusion.

Regardless of reason, there is a critical need to address these barriers and increase island jurisdiction representation in federal public health datasets.

Recommendations

Datasets are catalysts for change. They are tools to inform effective policies, guide intervention planning, and support strategies to improve health outcomes and achieve health equity. Increasing island jurisdiction representation in federal public health datasets is a critical island health equity issue with significant ramifications for island population health outcomes.

This report illustrates the underrepresentation of U.S. territories and freely associated states in common federal public health datasets. Stakeholders—including federal and island policymakers, data scientists, public health agencies, and partners—must work collaboratively to improve T/FAS representation in key federal public health datasets.

The Data Capacity Subgroup submits this report—a tool to guide future efforts to improve T/FAS health data inclusion and visibility within federal public health datasets—to the Island Areas Workgroup with several recommendations and considerations.

1. The results of this study should be shared with the Government Accountability Office to inform their ongoing review of territorial representation in federal statistical agencies, as well as with other relevant partners.
2. The Island Areas Council—with support from island representatives and partners—should work collaboratively to understand and address the barriers to island inclusion for the datasets highlighted in this report and other priority datasets.
 - a. Island feedback could further inform which of the datasets are prioritized for immediate action. Island inclusion in the CDC Vital Statistics System, CDC BRFSS, and American Community Survey (not addressed in this report) may have an outsized impact on overall island inclusion, as many surveys are based on or draw from these three datasets. Partners could also target those datasets in which all states are represented but no islands are represented. The subgroup wants to prioritize ensuring jurisdiction capacity for vital statistics and inclusion in the National Vital Statistics System.
 - b. Solutions at the federal level may require changes to individual practices, federal agency internal procedures, or Congressional authorizing language. Solutions at the island level may require changes to local data infrastructure, funding streams, policy, or reporting practices.
 - c. An island data inclusion community of champions currently exists within the Data Capacity Subgroup. This group should be maintained and/or expanded to ensure progress on these efforts.
3. The subgroup should contact sub-regional multilateral partners—such as the WHO Western Pacific Regional Office, the Pan American Health Organization, and the Caribbean Public Health Agency—to understand T/FAS representation within these non-federal public health datasets. These datasets may be able to supplement or supplant data collected and reported within federal datasets.



Methods

The datasets featured in this report were compiled through three rounds of review. The initial set of datasets was pulled from the Aschengrau and Seage (2020) list of the most significant sources of descriptive public health data.⁴ From there, a “snowball” method—in which datasets were added if they were referenced by the original dataset—was used to gather a broader round of public health datasets.

Datasets entirely contained within other datasets were excluded (e.g., CDC Sudden Unexpected Infant Death Reporting is entirely captured within the CDC Vital Statistics System). Lastly, members of the IAW Data Capacity Subgroup provided feedback on additional datasets they would like to see included in the report.

All descriptive information about the datasets was pulled from the respective dataset’s website and public-facing informational materials. Datasets were included if they featured up-to-date jurisdiction-level population public health data, aligned with island perceptions of critical sources of public health data, and were hosted by U.S. government federal agencies. These criteria were developed to ensure the results of this report would add value to island jurisdiction data collection efforts and be actionable for federal partners engaged in the IAW. Further information regarding international dataset considerations is addressed in Appendix B.

This report is not intended as a comprehensive assessment of island inclusion in all federal public health datasets. Rather, it is intended as a small-scale review of island inclusion in a selection of important federal public health datasets in summer 2022.

In future years, the subgroup seeks to increase island participation in subgroup discussions to ensure subgroup activity aligns with and supports local data priorities.

⁴. Aschengrau, a., & Seage iii, g. r. (2020). “Sources of Public Health Data.” *Essentials of epidemiology in public health* (4th ed., pp. 77-97), Jones & Bartlett Learning.

Appendix A

Table A1. Island Inclusion in Federal Public Health Datasets

Dataset	PR	USVI	A. Samoa	CNMI	FSM	Guam	RMI	Palau
BLS Census of Fatal Occupational Injuries	Yes	Yes	No	No	No	Yes	No	No
BLS Survey of Occupational Injuries and Illnesses	Yes	Yes	No	No	No	Yes	No	No
CDDC Alzheimer's Disease and Healthy Aging Portal	Yes	Yes	No	No	No	Yes	No	No
CDC ArboNET	Yes	No	Yes	No	No	Yes	No	Yes
CDC Behavioral Risk Factor Surveillance System	Yes	Yes	No	No	No	Yes	No	No
CDC COVID-19 Data Tracker	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
CDC National Ambulatory Medical Care Survey	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown
CDC National Assisted Reproductive Technology Surveillance System	Yes	No	No	No	No	No	No	No
CDC National Electronic Health Records Survey	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown
CDC National Health and Nutrition Examination Survey	No	No	No	No	No	No	No	No
CDC National Health Interview Survey	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown
CDC National HIV Surveillance System	Yes	Yes	Yes	Yes	No	Yes	No	Yes
CDC National Hospital Ambulatory Medical Survey	No	No	No	No	No	No	No	No
CDC National Hospital Care Survey	No	No	No	No	No	No	No	No
CDC National Immunization Survey	Yes	No	No	No	No	Yes	No	No
CDC National Notifiable Disease Surveillance System	Yes	Yes	No	Yes	No	Yes	Yes	No

Appendix A (Continued)

Table A1. Island Inclusion in Federal Public Health Datasets

Dataset	PR	USVI	A. Samoa	CNMI	FSM	Guam	RMI	Palau
CDC National Post-Acute and Long-Term Care Study	No	No	No	No	No	No	No	No
CDC National Program of Cancer Registries	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
CDC National Survey of Family Growth	No	No	No	No	No	No	No	No
CDC National Vital Statistics System	Yes	Yes	Yes	Yes	No	Yes	No	No
CDC National Youth Tobacco Survey	No	No	No	No	No	No	No	No
CDC PLACES Database	No	No	No	No	No	No	No	No
CDC Pregnancy Mortality Surveillance System	No	No	No	No	No	No	No	No
CDC Pregnancy Risk Assessment Monitoring System	Yes	No	No	Yes	No	No	No	No
CDC USALEEP Database	Yes	No	No	No	No	No	No	No
CDC Youth Risk Behavior Surveillance System	Yes	No	No	Yes	No	Yes	No	No
CDC/ATSDR Social Vulnerability Index	Yes	No	No	No	No	No	No	No
CMS National Health Expenditure Accounts	No	No	No	No	No	No	No	No
EPA Air Quality System	Yes	Yes	No	No	No	No	No	No
EPA RSEI Database	No	No	Yes	Yes	No	Yes	No	No
NCI Surveillance, Epidemiology, and End Results	No	No	No	No	No	No	No	No
SAMHSA National Survey on Drug Use and Health	No	No	No	No	No	No	No	No

Appendix B

This report narrowly targets public health data hosted within domestic public health federal datasets (e.g., datasets hosted by HHS, EPA, DOI). It did not consider datasets hosted within internationally-oriented public health federal datasets (e.g., datasets hosted by USAID) or internationally-oriented public health datasets hosted by multilateral organizations (e.g., datasets hosted by WHO or the World Bank).

The report was narrowly targeted to ensure its findings would be most relevant and actionable for participants within the IAW. The goal of this workgroup is advance health equity for U.S. territories and freely associated states through local and federal departmental coordination and administrative change. The findings of this report are intended to encourage administrative change within federal agencies to increase the visibility of island health disparities in federal datasets and within island health agencies to increase submission of quality island health data. In turn, these changes may increase opportunities for tailored support to help island health leaders address local health disparities and improve health outcomes.

That said, it is important to recognize that international datasets are an important platform to promote global awareness of and multilateral technical assistance for island public health priorities. This is particularly true for the sovereign freely associated states, which are more likely to be include in these international datasets. In recognition of this fact, Table B1 summarizes the inclusion of U.S. territories and freely associated states in three sample international datasets, as recommended by members of the Island Areas Workgroup Data Capacity Subgroup.

Table B1. Island Areas Sometimes Represented in Commonly Used Global Health Datasets

Dataset	PR	USVI	A.Samoa	CNMI	FSM	Guam	RMI	Palau
WHO STEPS Survey	No	No	Yes	No	Yes	No	Yes	Yes
WHO Global Tobacco Survey: Adults	No	No	No	No	No	No	No	No
WHO Global Tobacco Survey: Youth	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes



Appendix C

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