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Island Areas
Workgroup

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Addressing Island Participation in Six Priority Federal Public Health Datasets: Report Addendum

Contents

Executive Summary

In 2022, the Island Areas Workgroup (IAW) Data Capacity Subgroup created the "Including Island Areas in Federal Public Health Datasets" report, which summarizes island representation within 32 commonly used public health datasets. As of December 2022, 18 of these datasets (56%) included at least one island jurisdiction and two (6%) included data from all eight territories and freely associated states (T/FAS).

The goal of this addendum is to identify factors affecting island participation in and make recommendations to address identified barriers for the following six datasets originally included in the 2022 report: the National Vital Statistics System (NVSS), the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavioral Surveillance System (YRBSS), the National Notifiable Disease Surveillance System (NNDSS), the Pregnancy Mortality Surveillance System (PMSS), and the National Youth Tobacco Survey (NYTS).

The long-term goal of this research is to build island data capacity and to increase the availability of island public health data. Targeting island inclusion in federal datasets is one strategy of many that can support this goal. The federal datasets included in this report inform effective policymaking and guide local decisions around intervention, planning, and resource distribution. The Data Capacity Subgroup submits this addendum and its 23 recommendations (summarized in appendix A) to IAW as a tool to guide future efforts to improve T/FAS data capacity and evidence-based decision-making across island representatives, federal representatives, and partners.

Key themes from the recommendations include:

- **Future research:** Future research on island representation in federal statistics products would benefit from clear and public-facing documentation of island inclusion in each federal dataset, as well as greater clarity about how federal data systems feed into each other.

- **Vital statistics and the NVSS:** Island and federal leaders should collaborate to support island inclusion in platforms like CDC WONDER, strengthen available technical assistance, and address the "international issue" and the "privacy issue."

- **Health behaviors, BRFSS, and YRBSS:** Federal partners should consider supporting locally tailored adult chronic disease data collection in USAPI, while island leaders should seek sustainable funding to strengthen data collection on health behaviors and collaborate with their Department of Education on YRBSS-related efforts.

- **Disease surveillance and NNDSS:** There is a need for more clarity on how existing T/FAS data submissions can be represented in NNDSS weekly and annual case counts, as well as a need for additional resources to support data infrastructure, such as NNDSS-compatible electronic case record systems, in the T/FAS.

- Maternal mortality and PMSS: Island leaders should access technical assistance from CDC, National Association for Public Health Statistics and Information Systems (Naphsis), and partners to align death certificate standards with PMSS practices, as well as consider utilizing maternal mortality review committees to improve maternal mortality data collection and analysis.
- Youth tobacco and the NYTS: Additional research is needed to identify participation benefits for T/FAS as well as methodology alterations that would facilitate T/FAS participation.

The authors also recognize that this addendum aligns with recent momentum to address territorial data gaps through Congressional and Government Accountability Office (GAO) action (e.g., report GAO-24-106574). The IAW Data Capacity Subgroup offers this addendum as a tool and model for the Office of Management and Budget (OMB) and other federal partners looking to assess and improve island representation in federal statistical products.

Acknowledgements

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Introduction

Established in Oct. 2021, ASTHO's 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. In 2022, the IAW Data Capacity Subgroup created the "*Including Island Areas in Federal Public Health Datasets*" report, which summarizes island representation within 32 commonly used public health datasets. As of December 2022, 18 of these datasets (56%) included at least one island jurisdiction and two (6%) included data from all eight T/FAS. The report represents an important first step in defining the data gaps that impact island jurisdictions. The next step is to identify the barriers affecting island participation in each dataset in which islands are not fully represented.

The goal of this addendum is to identify factors affecting island participation in and make recommendations to address identified barriers for, the following six datasets: NVSS, the BRFSS, YRBS, NNDSS, PMSS, and NYTS. These datasets were included in the original cross-section of 32 datasets highlighted in the 2022 report and prioritized by the IAW Data Capacity via a subgroup vote in spring 2024. The six datasets vary in their population of focus, methodology, and scale. They were chosen by the subgroup due to their perceived importance for population health surveillance and/or the magnitude of island underrepresentation.

This report is divided into five sections. Each section is focused on a particular dataset (with BRFSS and YRBSS combined into one), and for each dataset, the report describes operational factors affecting island representation in that dataset. Each section also includes recommendations to help island leaders, federal agency representatives, and nonprofit partners address barriers and/or increase the quality and quantity of data available from each jurisdiction on these topics. The report also proposes several cross-cutting recommendations in the conclusion and summarizes all recommendations in Appendix A.

The work undertaken in this addendum aligns with recent momentum to address territorial data gaps through Congressional action and GAO activity. The May 2024 GAO report, "U.S. Territories: Coordinated Federal Approach Needed to Better Address Data Gaps," called on OMB to develop a coordinated, government-wide approach for federal statistical agencies to use, in consultation with territories and other stakeholders, to examine the costs, benefits, and feasibility of including territories (and freely associated states) in statistical products and, as appropriate, identify ways to address these gaps. The IAW Data Capacity Subgroup has spent the past year identifying barriers and potential solutions regarding island inclusion in these six prioritized datasets. The Subgroup offers this addendum as a tool and model for OMB and other federal partners looking to assess and improve island representation in federal statistical products.

It is important to emphasize that the long-term goal of this research is to build island data capacity and to increase the availability of island public health data. Targeting island inclusion in federal datasets is just one strategy through which to achieve this goal. The Data Capacity Subgroup submits this report to the IAW as a tool to guide future efforts to improve T/FAS data capacity and data for decision-making, including through improved representation in current federal public health dataset structures.

T/FAS in the National Vital Statistics System

Overview

Each state, territory, and freely associated state, as well as Washington, D.C. and New York City, is legally responsible for maintaining registries of the vital events that occur within its jurisdiction. These records—births, deaths, marriages, divorces, and fetal deaths—are critically important for legal, administrative, and statistical purposes.

Jurisdiction-level vital statistics data feeds into NVSS—which is hosted by the National Center for Health Statistics—through a series of contracts, standard forms, and uniform procedures, with some of the data collection funded through the Epidemiology and Laboratory Capacity (ELC) grant at CDC. This national system is a critical source of foundational public health data and guides public health decisions from Congress, federal agencies, research institutions, and more. NVSS data also feeds into other datasets hosted by NCHS and, as such, influences a broad swath of public health activities (e.g., NVSS demographic data shapes all population health estimates).

Factors Affecting Island Representation in NVSS

As of December 2022, public-facing NVSS datasets represented American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), Guam, Puerto Rico (PR), and the U.S. Virgin Islands (USVI), with some gaps in annual data. Public-facing NVSS datasets did not represent the three FAS: Palau, the Republic of the Marshall Islands (RMI), and the Federated States of Micronesia (FSM).

Through conversations with NCHS representatives and island vital statistics experts, the subgroup identified the following factors shaping island representation in NVSS:

- Though all territories are eligible to participate, in some years, territories have not submitted their data due to capacity challenges—resulting in gaps in available territorial NVSS data.

- At present, NVSS considers the FAS "international," which leaves these jurisdictions ineligible to participate in NVSS. If they became eligible, inclusion in the NVSS would require the FAS to use the U.S. standard certificate for birth and death data as well as establish contracts between FAS governments and NCHS to share vital statistics data. At present, Palau does not use the U.S. standard certificate, while FSM and RMI are in the process of deciding whether to update their certificate to the U.S. standard certificate.

- Public-facing territorial vital statistics data files include geographic markers, while public-facing state vital statistics data files do not. This difference was attributed to a desire to increase the availability of territorial vital statistics data, given the lack of territorial inclusion in many datasets. NCHS's immediate priority is to improve annual territorial NVSS data submission.

- Islands' immediate priority is to improve vital statistics capacity and visibility for local decisionmakers, funders, policymakers, and researchers.

Next Steps and Recommendations

- Improve capacity: Island health leaders can strengthen local capacity for high-quality, timely vital statistics collection, analysis, and reporting by leveraging technical assistance from non-profit partners and federal agencies, training staff, and addressing administrative bottlenecks that currently impede vital statistics processes within jurisdictions.
    - The subgroup recommends vital records staff from USAPI engage with the Pacific Island Health Officer's Association's (PIHOA) Civil Registration and Vital Statistics System Technical Work Group, and that partners offer equivalent support to vital records staff in PR and USVI as needed. The current momentum around data modernization provides an opportunity to target vital statistics capacity within Public Health Infrastructure Grant activities. This could include feasibility analyses and pilot work in collaboration with federal agencies.
- Improve visibility: CDC Wonder is a publicly available and powerful visualization tool for accessing vital statistics data (e.g., underlying and multiple causes of death). The subgroup recommends that island vital statistics leaders work collaboratively with NCHS and other partners (e.g., academic institutions, research programs, etc.) to ensure the platform includes data from all T/FAS.
- Address the "international" issue: FAS inclusion in NVSS will require various changes, beginning with FAS use of U.S. standard certificates for mortality and natality data. The IAW recommends FAS leaders first decide whether to use U.S. standard certificates. If FAS elect to use U.S. standard certificates and want inclusion in NVSS, island representatives and partners can collaborate with NCHS to analyze legislative authorities and agency policies to identify opportunities to include the FAS within NVSS's domestic portfolio, as is done with other HHS federal datasets. If they choose not to use U.S. standard certificates and/or do not value NVSS inclusion, partners can pursue alternative solutions to improve visibility into island vital statistics data (e.g., through WHO datasets). Ideally, alternate solutions would identify ways to support coding and storage of vital statistics data, as NVSS currently does for states and territories.
- Address the "privacy" issue: Island leaders must determine whether geographic markers in vital records data present a privacy concern and, if so, take steps to address this through partnership with NCHS. Stakeholders value the NCHS confidentiality guidelines as a means to address privacy concerns.

Summary

A lack of accessibility, visibility, and reporting drive territorial NVSS data gaps while a lack of eligibility drives FAS NVSS data gaps. A first step toward addressing these gaps could include technical assistance for territorial NVSS efforts, as well as follow up conversations with FAS vital statistics leaders to determine their interest in participating in NVSS or improving the visibility of FAS vital records through other platforms.

T/FAS in the Behavioral Risk Factor Surveillance System and Youth Risk Behavioral Surveillance System

Overview

BRFSS is the nation's premier system of health-related telephone surveys that collect data about U.S. adults' health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states as well as Washington, D.C. and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. YRBSS is a set of surveys that measures health-related behaviors and experiences that can lead to death and disability among students grades 9 through 12. Collectively, these two surveys are critical and prominent population health data sources for prevalence estimates, chronic disease, preventable injuries, and other emerging health threats across the life span.

Jurisdictions looking to participate in BRFSS and/or YRBSS are funded through a five-year cooperative agreement; the deadline to apply to the current BRFSS five-year grant was April 15, 2024, while the deadline to apply to the current YRBSS five-year grant (YRBSS is component three of a multicomponent grant) was April 1, 2024.

Factors Affecting Island Representation in BRFSS and YRBSS

As of December 2022, BRFSS represented Guam, PR, and USVI but not American Samoa, FSM, RMI, and Palau; however, IAW Data Capacity subgroup members identified that American Samoa and FSM have received BRFSS funding.

As of December 2022, YRBSS represented CNMI, Palau, and PR but not American Samoa, FSM, Guam, RMI, and USVI. In subgroup conversations, USVI indicated their intent to participate in the upcoming five-year project. Other jurisdictions' intent to participate is unknown.

Table 1: *Island representation in BRFSS and YRBSS as of December 2022.*

	American Samoa	CNMI	FSM	Guam	PR	Palau	RMI	USVI
Generating usable BRFSS data	No	No	No	Yes	Yes	No	No	Yes
Receiving BRFSS funding	Yes	No	Yes	Yes	Yes	No	No	Yes
Receiving YRBSS funding and producing usable YRBSS data	No	Yes	No	No	Yes	Yes	No	TBD

Through conversations with island vital statistics experts, the subgroup identified the following factors shaping island representation in BRFSS:

- BRFSS relies on two elements that do not translate well to most USAPI operating contexts: landline phones and locally based call centers. BRFSS recipients must use an approved call center to conduct the survey, and in the Pacific, the nearest call center is in Hawaii. This poses financial and logistical challenges, including different time zones, languages, and cultural norms. In addition, very few USAPI households maintain a landline, with many residents relying on traditional or pay-per-minute cell phone plans. These two things reduce the feasibility and utility of BRFSS in the USAPI.

- PIHOA hosts the NCD Hybrid survey, which merges questions from BRFSS, WHO's STEPwise approach to NCD risk factor surveillance (STEPS Survey), and in-person measurements (which BRFSS does not include). This survey better meets Pacific health leaders' needs around chronic disease data. Funding for this survey is not tied to BRFSS and relies on "opportunistic" funding from various federal and local sources.

- Atlantic territories reported more satisfaction with their participation in BRFSS.

- In both BRFSS and YRBSS, island representatives identified challenges associated with collecting and submitting data of sufficient quality and in the correct format to be included in the public-facing portions of these datasets. Federal partners have also recognized the extended timeline required to build island capacity to submit data that meets these standards.Through conversations with island vital statistics experts, the subgroup identified the following factors shaping island representation in YRBSS:

- YRBSS has a flexible structure that can be adapted to local needs. For example, YRBSS maintains a free, public-facing guide on how to conduct a youth survey, and YRBSS allows jurisdictions to create a version of the survey that makes sense locally while also offering technical assistance to support locally-tailored surveys.

- RMI and FSM do not participate in YRBSS but have conducted Rapid Youth Surveys in the past with PIHOA; the Rapid Youth Surveys include some questions captured through YRBSS but are not as comprehensive as YRBSS.

- One challenge for island health agencies looking to leverage YRBSS data is that, because the YRBSS is offered through schools, the funding to support this survey is intended for education agencies (not health agencies). Health agencies may not have control over whether their department of education chooses to apply.

Next Steps and Recommendations

- Federal partners should consider alternative methods to support locally tailored adult chronic disease data collection in the USAPI (e.g., regular funding for the PIHOA NCD Hybrid Survey).
- Island health leaders should secure additional sustainable funding opportunities through grants or health organizations to implement YRBSS or BRFSS in T/FAS if jurisdictions have missed the deadline for the five-year cooperative agreement to fund participation in BRFSS or YRBSS.
- Islands looking to leverage YRBSS to evaluate youth chronic disease risk factors should consider:
  - Engaging with their local departments of education to collaborate on the YRBSA grant application.
  - Leveraging CDC's free guide, "A Guide to Conducting Your Own Youth Risk Behavior Survey," to support creation of a locally-relevant tool for youth data collection and assessment.

Summary

Methodological challenges undermine the utility of BRFSS in many USAPI. YRBSS is more widespread in the islands and may have more long-term utility due to its flexible methodology. To improve adult chronic disease data availability and visibility in the T/FAS, partners should look to support and amplify NCD data collection tools that are complementary to BRFSS, such as PIHOA's NCD Hybrid Survey.

T/FAS in the National Notifiable Diseases Surveillance System

Overview

NNDSS collects de-identified case-level data on reportable diseases from state, local, and territorial health departments. CDC administers the surveillance system, in partnership with the Council of State and Territorial Epidemiologists (CSTE), to collect and share health information from each jurisdictional level of public health. All states and territories are eligible to voluntarily participate in NNDSS, but no federal laws, regulations, or CDC authority exists to require participation. Most participation in NNDSS is financially supported through CDC's ELC funding, which provides money to state, large local, and U.S. territory and affiliate health departments for laboratory and epidemiologic capacity to address infectious disease outbreaks. All USAPI are funded under the ELC.

Jurisdictions who submit data to NNDSS must do so through a system that is compatible with the National Electronic Disease Surveillance System (NEDSS) standards. Participating jurisdictions submit data to CDC using legacy HL7, NEDSS Base System (NBS) Master Message or the National Electronic Telecommunications System for Surveillance (NETSS) files. While NETSS is still currently in use, CDC plans to retire this system for reporting. To be compliant with NEDSS, jurisdictions' surveillance systems must meet strict requirements associated with data source, data entry platforms, integration, and messaging. After receiving the data, CDC uses the Message Validation, Processing, and Provisioning System, a software that receives and processes data from jurisdictions. This software allows jurisdictions to review the data they've submitted.

Relative to other datasets considered in this report, NNDSS has a massive scope; this system connects with many nested datasets, each focused on specific factors associated with one or more notifiable diseases. In this way, island representation in this dataset may have significant ramifications. Full participation in NNDSS by T/FAS may increase capacity for disease tracking, outbreak response, public health preparedness, and connection to federal resources.

Factors Affecting Island Representation in NNDSS

The laws determining reporting status and the surveillance systems in each jurisdiction vary, which creates the need for caution when comparing information between jurisdictions within the NNDSS. The publicly available NNDSS dataset includes data on reportable diseases from all 50 states, Washington, D.C., New York City, and all five U.S. territories.

Through conversations with island vital statistics experts, the subgroup identified the following factors shaping island representation in NNDSS:

- FAS are submitting some case-level reporting data to NNDSS through ELC and individual disease programs (e.g., through the National Tuberculosis Surveillance System, or NTSS), but these data are not included in the publicly available weekly or annual case counts. The cause of this omission is unknown, but the subgroup believes it may be tied to two components:
    - **Difficulties meeting infrastructure requirements:** Infrastructure requirements to participate in NNDSS continue to advance with improvements in electronic case reporting, and T/FAS have noted significant challenges meeting the technological requirements for participation in NNDSS. For example, FSM shared that their electronic health record system does not have the capabilities required for participation in NNDSS.
    - **Low case counts:** While this methodological consideration may prompt omission from weekly or annual case-count tables, the subgroup highlights that data notes and data characterizations can help to describe data limitations in a way that reflects T/FAS participation. For example, a table could note whether a jurisdiction submitted data to CDC that week or include a designation of whether there is sufficient data to support calculation of certain metrics.
- FAS are motivated to participate in NNDSS. For example, RMI submits some data to NNDSS through ELC electronic reporting and expressed an interest in expanding their participation in NNDSS to enhance local case surveillance, which would allow the agency to support timely outbreak detection and improved disease control efforts.

Next Steps and Recommendations

- Additional resources are needed to support the implementation and interoperability of electronic case record (ECR) systems in T/FAS. This could include technical assistance from CDC and CSTE, who are increasingly focused on improving electronic case reporting for NNDSS. Territories have had mixed success implementing ECR systems.
    - » Steps to improve ECR systems may include connection to other T/FAS that have successfully implemented or improved their ECR systems, partnerships with technology providers to address the costs of these systems, or training programs from national organizations or federal agencies for health agencies and officials.
- National and federal partners should clearly identify and monitor situations in which NNDSS system requirements are updated, understanding that while the change is intended to improve overall data quality and access, it also may cause integration challenges within island jurisdictions.
- Funding and in-kind support to strengthen the local data infrastructure, such as cloud services or improved internet capacity, will be necessary to make full NNDSS participation feasible in some island areas.
- Federal partners should explore opportunities to leverage nested datasets for NNDSS representation. For example, FAS submit tuberculosis (TB) data to CDC through NTSS—could CDC connect FAS TB data submissions with NNDSS to represent FAS TB data in NNDSS?

Summary

NNDSS is an important dataset for national, regional, and local disease surveillance, with many nested datasets impacting a wide swath of public health surveillance initiatives. At present, all five territories' data is visible in the public-facing NNDSS dataset. FAS are also submitting some data to NNDSS, but this information is not reflected in weekly or annual case counts. Expanding T/FAS participation in NNDSS will require additional resources to support island data infrastructure, especially electronic case records. In addition, the subgroup seeks creative workarounds to highlight currently submitted data within NNDSS (e.g., TB data through NTSS).

T/FAS in the Pregnancy Mortality Surveillance System

Overview

PMSS is CDC's mechanism for national surveillance on pregnancy-related deaths. It defines pregnancy-related deaths as a death during or up to one year postpartum from any cause related to or aggravated by the pregnancy. PMSS analyzes the clinical factors associated with deaths and publishes national information that supports the interpretation and uptake of information among clinical and public health practitioners. Participating in PMSS provides jurisdictional benefits such as improving tracking of maternal health issues and garnering support for addressing maternal health.

CDC requests that reporting jurisdictions voluntarily send death records and any additional linked birth records or fetal death records, for all women who died during or within one year of pregnancy. A CDC team of medical epidemiologists analyze the data, determine if the death was pregnancy-related, and code by cause of death. This surveillance data is periodically disseminated to report on the pregnancy-related mortality ratio and national trends and characteristics of pregnancy-related deaths.

In researching the PMSS, the IAW Data Capacity subgroup identified maternal mortality review committees (MMRCs) as an important and complementary mechanism through which jurisdictions can monitor maternal mortality in their communities. A comparison between PMSS and MMRCs is below.

- PMSS is oriented toward national-level data, while MMRCs are built for assessments of pregnancy-related death at the state, territory, and local levels.
- PMSS, MMRCs, and NVSS differ in their definitions of pregnancy-related deaths. PMSS and MMRCs include deaths during pregnancy and up to one year postpartum while NVSS includes deaths during pregnancy and only up to 42 days postpartum.
- PMSS, MMRCs, and NVSS rely on different data sources. PMSS relies on death records and any linked birth records or fetal death records while NVSS relies solely on death records. MMRCs use death records, any linked birth records or fetal death records, medical records, social service records, autopsies, and informant interviews to assess preventability and develop actionable prevention recommendations in addition to maternal mortality data. Utilizing MMRCs provides contextual data and contributing factor information to collect pregnancy-related death data through MMRCs, NVSS, and/or PMSS.

Factors Affecting Island Representation in PMSS

Participation in PMSS for states and territories is voluntary. PMSS currently includes data from all 50 states, Washington, D.C., New York City, and PR. Subgroup respondents highlighted that CNMI, American Samoa, Guam, Palau, and RMI also receive PMSS funding, but the federal dataset does not currently include their data. USVI and FSM do not participate in PMSS.

- The following factors influence T/FAS representation in PMSS:
- The FAS do not currently use the U.S. standard death certificates necessary for PMSS data collection.
- Though eligible for inclusion in PMSS, capacity challenges related to consistent and timely submission of death certificates, linked birth records, and linked fetal death records may impede island representation within PMSS datasets.
- Definitions of "pregnancy-related death" vary, often differing in the time frames of maternal deaths postpartum. While PMSS defines pregnancy-related deaths as up to one year postpartum, T/FAS may use different definitions in their data collection and analysis may differ, which could impact participation in this dataset.

Next Steps and Recommendations

- T/FAS looking to increase their representation in PMSS datasets should connect with federal PMSS representatives and other island jurisdictions to learn about program processes, timelines, resources, and best practices.
- To improve maternal mortality data collection and quality, T/FAS should assess standards around death certificate completion to ensure accurate recording of pregnancy-related deaths as maternal deaths and alignment with defined PMSS criteria. Federal agencies and partners should offer technical assistance and targeted training to support these efforts.
- · Naphsis provides technical assistance and support to the 57 jurisdictions that participate in the Vital Statistics Surveillance System. FAS are not currently members in Naphsis but may benefit from Naphsis expertise. FAS vital statistics staff and partners should engage with Naphsis to determine opportunities to include FAS within the scope of Naphsis technical assistance.
- Territories interested in implementing MMRCs to support their ability to identify, review, and characterize pregnancy-related deaths can apply to the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program, supported by CDC. The next round of applications is in 2029, though partners may wish to explore whether to make exceptions to incorporate island participants before then.

Summary

The PMSS illuminates national maternal mortality trends and includes data from all states and territories but not FAS. To improve T/FAS maternal mortality data collection and assessment, island leaders should seek out peer connections and federal/partner technical assistance—including through Naphsis—to support jurisdictions in increasing their capacity to identify, review, and characterize pregnancy-related deaths. T/FAS may also wish to consider establishing MMRCs through the ERASE MM program supported by CDC.

T/FAS in the National Youth Tobacco Survey

Overview

NYTS differs significantly from the first five datasets in this report. This school-based survey collects data on tobacco use behaviors and risk factors in middle school (grades 6-8) and high school (grades 9-12) aged youth. The survey is a collaboration between CDC's Office on Smoking and Health and FDA's Center for Tobacco Products. These agencies agree on a core set of questions for annual inclusion in the survey. NYTS is administered through public and private schools to students using a self-administered, electronic survey. The methodology includes a sampling design that creates a nationally representative sample of students in grades 6-12 from all 50 states and Washington, D.C. Data adjustments and weights are used to describe national prevalence estimates of measures within NYTS.

Factors Affecting Island Representation in NYTS

There are currently no T/FAS participating in the NYTS. Information on youth tobacco use currently comes from other sources. For example, all six USAPI currently work with the Global Occupational Health and Safety organization and WHO to implement the Global Youth Tobacco Survey every four years. CNMI, Palau, and PR also participate in YRBSS, which contains measures on tobacco use and behaviors.

- For T/FAS that participate in YRBSS, the public school system and health agencies may not prioritize NYTS because YRBSS contains measures on tobacco. Similarly, USAPI participate in the Global Youth Tobacco Survey.
- Small numbers are a barrier to inclusion in NYTS.

Next Steps and Recommendations

- The first recommendation of the subgroup is to identify any benefits of island participation in NYTS that go beyond the benefits provided through participation in alternative sources such as YRBSS or the Global Youth Tobacco Survey. Potential benefits may include the development of benchmark data on other youth tobacco use and related risk factor measures, which help to design, implement, and evaluate comprehensive tobacco prevention and control programs. NYTS data also functions as a source to track tobacco measures within Healthy People 2030.
- If island leaders identify additional benefits, they should explore (1) the methodology of other national surveys to identify strategies to address methodological issues associated with small case counts and (2) options to expand FAS representation in NYTS based on FAS residents' special relationship with the United States through the Compacts of Free Association and through HHS inclusion of FAS in other national datasets.

Summary

The NYTS contains measures on tobacco behavior and risk factors for youth (grades 6-12) in 50 states and Washington, D.C.; however, there are currently no T/FAS participating in this dataset. Islands appear to rely on alternative sources of information for youth tobacco measures (e.g., all six USAPI participate in the Global Youth Tobacco Survey, and CNMI, Palau, and PR participate in YRBSS, which contains youth tobacco measures. Benefits of conducting NYTS in addition to these surveys may include aligning measures with large U.S. health initiatives such as Healthy People 2030 or increasing the timeliness of the data. If T/FAS decide that participation in NYTS is warranted, additional barriers such as small number methodology and inclusion of FAS in NYTS would need to be explored.

Conclusion

Public health datasets inform effective policymaking, guide intervention planning and resource distribution, and make the case for services and programs. As established in the 2022 "Including Island Areas in Federal Public Health Datasets" report, there are significant gaps in island representation across common public health datasets. These findings were further amplified in a May 2024 GAO report titled "U.S Territories: Coordinated Federal Approach Needed to Better Address Data Gaps." These gaps in federal public health datasets obscure the pronounced health disparities in island jurisdictions and undermine efforts to address these community health challenges.

This addendum seeks to help IAW participants understand the structures shaping gaps in island representation in NVSS, NNDSS, BRFSS, YRBSS, PMSS, and the National Youth Tobacco Survey. The recommendations in each section of this report are intended to support stakeholder efforts to build capacity and increase the availability and visibility of island public health data. This data will help leaders at the local, regional, and national levels to understand and address islands' most pressing public health priorities.

The IAW Data Capacity Subgroup also proposes the following overarching recommendations, which apply to all six datasets prioritized in this report and benefit broader island data collection, research, and coordination efforts. Appendix A summarizes all recommendations, including dataset-specific solutions.

1. Federal partners should clearly define which jurisdictions are included in a dataset in public-facing materials (e.g., technical documentation, web pages). At present, subgroup members often need to comb through data to identify which, if any, islands are included.

2. A lack of representation in one dataset may have ripple effects across other national datasets when one federal data system feeds into another. Federal partners should take steps to map out how federal data systems connect and draw on each other, particularly as it relates to island representation or lack thereof.

3. To support situational awareness and planning efforts within jurisdictions, partners should create an easy reference guide with the expected application deadlines associated with funding to support island participation in federal public health dataset. This task may be a future area of focus for the IAW Data Capacity Subgroup.

4. The conversations, connections, and knowledge gained this year in support of island participation in these six datasets have been invaluable. To continue these conversations and expand their reach, subgroup members and interested stakeholders should seek opportunities to conduct similar research with other datasets (e.g., those based within HRSA or the Census Bureau).

5. In collaboration with partners, island health agency staff should expand their collaboration with public health researchers, with an end goal of increasing the amount of island population health data available in the academic and "grey" literature. These collaborations should be undertaken with respect for island data ownership: Publications should include island authors, methods should contribute to long-term local data stewardship, and research findings should be communicated back to, and benefit, the communities they serve.

6. The IAW Data Capacity subgroup commends the GAO's recommendation in its May 2024 report that, "The Director of OMB should ensure that the Chief Statistician develops a coordinated, government-wide approach for federal statistical agencies to use, in consultation with the U.S. territories and other stakeholders, to examine the costs, benefits, and feasibility of including territories in statistical products and, as appropriate, identify ways to address any data gaps." The IAW Data Capacity subgroup stands available as a resource to support this effort, including feasibility studies, focus groups, and more. The IAW Data Capacity subgroup also seeks updates regarding any progress toward this recommended course of action from OMB, including documentation of the island leaders consulted throughout this process.

Appendix A: Summary of Recommendations

Cross-Cutting Recommendations

1. Federal partners should clearly define which jurisdictions are included in a dataset in public-facing materials (e.g., technical documentation, web pages). At present, subgroup members often need to comb through data to identify which, if any, islands are included.

2. A lack of representation in one dataset may have ripple effects across other national datasets when one federal data system feeds into another. Federal partners should take steps to map out how federal data systems connect and draw on each other, particularly as it relates to island representation or lack thereof.

3. To support situational awareness and planning efforts within jurisdictions, partners should create an easy reference guide with the expected application deadlines associated with funding to support island participation in federal public health dataset. This task may be a future area of focus for the IAW Data Capacity Subgroup.

4. The conversations, connections, and knowledge gained this year in support of island participation in these six datasets have been invaluable. To continue these conversations and expand their reach, subgroup members and interested stakeholders should seek opportunities to conduct similar research with other datasets (e.g., those based within HRSA or the Census Bureau).

5. In collaboration with partners, island health agency staff should expand their collaboration with public health researchers, with an end goal of increasing the amount of island population health data available in the academic and "grey" literature. These collaborations should be undertaken with respect for island data ownership: publications should include island authors, methods should contribute to long-term local data stewardship, and research findings should be communicated back to, and benefit, the communities they serve.

6. The IAW Data Capacity subgroup commends the GAO's recommendation in its May 2024 report that, "The Director of OMB should ensure that the Chief Statistician develops a coordinated, government-wide approach for federal statistical agencies to use, in consultation with the U.S. territories and other stakeholders, to examine the costs, benefits, and feasibility of including territories in statistical products and, as appropriate, identify ways to address any data gaps." The IAW Data Capacity subgroup stands available as a resource to support this effort, including feasibility studies, focus groups, and more. The IAW Data Capacity subgroup also seeks updates regarding any progress toward this recommended course of action from OMB, including documentation of the island leaders consulted throughout this process.

T/FAS in NVSS

1. Improve capacity: Island health leaders can strengthen local capacity for high-quality, timely vital statistics collection, analysis, and reporting by leveraging technical assistance from non-profit partners and federal agencies, training staff, and addressing administrative bottlenecks that currently impede vital statistics processes within jurisdictions.

    a. The subgroup recommends vital records staff from USAPI engage with the Pacific Island Health Officer's Association's (PIHOA) Civil Registration and Vital Statistics System Technical Work Group, and that partners offer equivalent support to vital records staff in PR and USVI as needed. The current momentum around data modernization provides an opportunity to target vital statistics capacity within Public Health Infrastructure Grant activities. This could include feasibility analyses and pilot work in collaboration with federal agencies.

2. Improve visibility: CDC Wonder is a publicly available and powerful visualization tool for accessing vital statistics data (e.g., underlying and multiple causes of death). The subgroup recommends that island vital statistics leaders work collaboratively with NCHS and other partners (e.g., academic institutions, research programs, etc.) to ensure the platform includes data from all T/FAS.

3. Address the "international" issue: FAS inclusion in NVSS will require various changes, beginning with FAS use of U.S. standard certificates for mortality and natality data. The IAW recommends FAS leaders first decide whether to use U.S. standard certificates. If FAS elect to use U.S. standard certificates and want inclusion in NVSS, island representatives and partners can collaborate with NCHS to analyze legislative authorities and agency policies to identify opportunities to include the FAS within NVSS's domestic portfolio, as is done with other HHS federal datasets. If they choose not to use U.S. standard certificates and/or do not value NVSS inclusion, partners can pursue alternative solutions to improve visibility into island vital statistics data (e.g., through WHO datasets). Ideally, alternate solutions would identify ways to support coding and storage of vital statistics data, as NVSS currently does for states and territories.

4. Address the "privacy" issue: Island leaders must determine whether geographic markers in vital records data present a privacy concern and, if so, take steps to address this through partnership with NCHS. Stakeholders value the NCHS confidentiality guidelines as a means to address privacy concerns.

T/FAS in BRFSS and NYTSS

1. Federal partners should consider alternative methods to support locally tailored adult chronic disease data collection in the USAPI (e.g., regular funding for the PIHOA NCD Hybrid Survey).

2. Island health leaders should secure additional sustainable funding opportunities through grants or health organizations to implement YRBSS or BRFSS in T/FAS if jurisdictions have missed the deadline for the five-year cooperative agreement to fund participation in BRFSS or YRBSS.

3. Islands looking to leverage YRBSS to evaluate youth chronic disease risk factors should consider:

    a. Engaging with their local departments of education to collaborate on the YRBSA grant application.

    b. Leveraging CDC's free guide, "A Guide to Conducting Your Own Youth Risk Behavior Survey," to support creation of a locally-relevant tool for youth data collection and assessment.

T/FAS in NNDSS

1. Additional resources are needed to support the implementation and interoperability of electronic case record (ECR) systems in T/FAS. This could include technical assistance from CDC and CSTE, who are increasingly focused on improving electronic case reporting for NNDSS. Territories have had mixed success implementing ECR systems.
   a. Steps to improve ECR systems may include connection to other T/FAS that have successfully implemented or improved their ECR systems, partnerships with technology providers to address the costs of these systems, or training programs from national organizations or federal agencies for health agencies and officials.
2. National and federal partners should clearly identify and monitor situations in which NNDSS system requirements are updated, understanding that while the change is intended to improve overall data quality and access, it also may cause integration challenges within island jurisdictions.
3. Funding and in-kind support to strengthen the local data infrastructure, such as cloud services or improved internet capacity, will be necessary to make full NNDSS participation feasible in some island areas.
4. Federal partners should explore opportunities to leverage nested datasets for NNDSS representation. For example, FAS submit tuberculosis (TB) data to CDC through NTSS—could CDC connect FAS TB data submissions with NNDSS to represent FAS TB data in NNDSS?

T/FAS in PMSS

1. T/FAS looking to increase their representation in PMSS datasets should connect with federal PMSS representatives and other island jurisdictions to learn about program processes, timelines, resources, and best practices.
2. To improve maternal mortality data collection and quality, T/FAS should assess standards around death certificate completion to ensure accurate recording of pregnancy-related deaths as maternal deaths and alignment with defined PMSS criteria. Federal agencies and partners should offer technical assistance and targeted training to support these efforts.
3. Naphsis provides technical assistance and support to the 57 jurisdictions that participate in the Vital Statistics Surveillance System. FAS are not currently members in Naphsis but may benefit from Naphsis expertise. FAS vital statistics staff and partners should engage with Naphsis to determine opportunities to include FAS within the scope of Naphsis technical assistance.
4. Territories interested in implementing MMRCs to support their ability to identify, review, and characterize pregnancy-related deaths can apply to the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program, supported by CDC. The next round of applications is in 2029, though partners may wish to explore whether to make exceptions to incorporate island participants before then.

T/FAS in NYTS

1. The first recommendation of the subgroup is to identify any benefits of island participation in NYTS that go beyond the benefits provided through participation in alternative sources such as YRBSS or the Global Youth Tobacco Survey. Potential benefits may include the development of benchmark data on other youth tobacco use and related risk factor measures, which help to design, implement, and evaluate comprehensive tobacco prevention and control programs. NYTS data also functions as a source to track tobacco measures within Healthy People 2030.
2. If island leaders identify additional benefits, they should explore (1) the methodology of other national surveys to identify strategies to address methodological issues associated with small case counts and (2) options to expand FAS representation in NYTS based on FAS residents' special relationship with the United States through the Compacts of Free Association and through HHS inclusion of FAS in other national datasets.

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