

Strengthening Maternal and Infant Health Data in the U.S. Territories

The U.S. territories—Puerto Rico (PR), U.S. Virgin Islands (USVI), Guam, Commonwealth of the Northern Mariana Islands (CNMI), and American Samoa—are <u>largely excluded from most statistical</u> <u>data systems in the United States</u>. This gap leaves island health leaders, national partners, and federal agencies without the surveillance necessary to inform timely and robust public health programs and policies. This is also seen in critical maternal and child health surveillance programs like the <u>Pregnancy Risk Assessment Monitoring System (PRAMS)</u>, <u>Maternal Mortality Review</u> <u>Committees</u>, and the <u>Pregnancy Mortality Surveillance System</u>, which either do not include or only recently included territories in their scope of coverage. This incomplete information creates challenges in identifying the aspects health systems need to address to reduce adverse maternal and infant health outcomes.

Applying a <u>life course perspective</u> to maternal and infant health data reveals gaps in public health systems that impact outcomes before, during, and after birth. PRAMS provides vital insights into these lived experiences and pregnant people's interactions with healthcare services. PRAMS data can also be linked to other administrative datasets, such as <u>Medicaid</u>, <u>child welfare services</u>, and <u>Community Healthy Start programs</u>, to provide a broader understanding of determinants of health across the life course for both the birthing parent and their child. With the breadth of contextual experiences that PRAMS captures in its data and the potential for data linkage projects to explore outcomes and their contributing factors, U.S. territories can leverage this wealth of information to assess the needs of their pregnant communities and their children.

Despite its development in 1987, PRAMS has been implemented in only two territories, PR and CNMI, within the past decade. This brief highlights the work of these two islands and the potential to gain further insights into maternal and infant health outcomes using data linkage methods.

Island Expansion of Maternal and Infant Health Surveillance Using PRAMS

Since beginning PRAMS data collection in 2017, **PR** has made considerable strides in providing their communities with comprehensive reports on various topics. In 2021, <u>one in eight live births was</u> <u>preterm</u> in PR—the U.S. average is one in 10 live births. This outcome is one example of a potential research area in PR that could leverage PRAMS linkages to clinical administrative data sources to investigate contributing factors.

In a special project conducted from 2016 to 2018, PRAMS served as an avenue for assessment of <u>Zika</u> <u>awareness among pregnant people</u> and their partners. Moreover, PRAMS informed numerous <u>reports</u> <u>and educational materials</u> on topics ranging from dental care to lactation and opioid use during pregnancy. Linking PRAMS to other administrative datasets could illuminate more information about healthcare utilization and access among pregnant people in PR.



Although limited research exists on maternal and infant health outcomes in **CNMI**, available evidence reveals <u>disparities in preterm birth</u> among the territory's indigenous Chamorro and Carolinian communities and Asian and Pacific Islander groups. Since CNMI started administering PRAMS in 2021, strong relationships with entities outside the territory (e.g., the Hawaii Department of Health) have facilitated PRAMS implementation by helping navigate Internal Review Board regulations and applications—both of which are necessary to conduct PRAMS collection and potential research using PRAMS data, like data linkage projects. Moreover, the CNMI PRAMS team's deep familiarity with their communities could help identify local administrative data sources that, when linked to PRAMS, capture priority areas for improved healthcare and social service delivery.

Considerations for Future Maternal and Infant Health Data Exploration

With the existing gaps in surveillance data available for maternal and infant health, this recent implementation of PRAMS and the potential for data linkages to other data sources could provide enhanced insights for U.S. territories. The following considerations can inform best practices to optimize this data.

Building Partnerships to Support a Linked Maternal and Infant Health Data Network

To build capacity for further data exploration, building partnerships with other agencies and PRAMS jurisdictions can facilitate the information-sharing necessary to <u>navigate data use agreements and</u> <u>other considerations</u> before successfully linking data. Leveraging these connections can also supply more avenues to administer educational tools about PRAMS and perinatal services, linking their pregnant populations to the services they need. A robust web of partnerships can create a network of linked data capturing the life course perspective to inform high-quality programs for the ongoing care of pregnant people and their infants.

Leveraging Community Input and Data on Social Determinants of Health

Territories are uniquely positioned to leverage closer community ties to examine how data linkages can inform initiatives that improve experiences surrounding pregnancy and the life course after birth. As with PR, integrating the voices of pregnant people, their families, and the people providing their care into their advisory committees allows for better identification of what communities need. Active engagement ensures agencies can be efficient with their linkage efforts by tailoring their projects to high-priority maternal and infant health outcomes.

Moreover, to foster community awareness about PRAMS and possible linked data sources, territories could create dashboards such as those created by <u>Washington D.C.'s PRAMS</u> program to provide a comprehensive and interactive view of the data. Data on social determinants of health collected through PRAMS—such as insurance coverage throughout pregnancy and postpartum as well as access to social support and a wide range of services—can also be leveraged for potential data linkage to identify inequities in health outcomes and the delivery of care.

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