Multi-State Network of Linked Pregnancy Risk Assessment Monitoring System (PRAMS) and Clinical Outcomes Data for Patient-Centered Outcomes Research

Report for the Office of the Assistant Secretary for Planning and Evaluation

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Introduction

Between 2021 and 2023, ASTHO, with support from the CDC's Division of Reproductive Health and HHS' Office of the Assistant Secretary for Planning and Evaluation (ASPE), convened the Linking Pregnancy Risk Assessment Monitoring System (PRAMS) and Clinical Outcomes Data Multi-Jurisdiction Learning Community. Twelve state health department teams participated in this project, eleven of which were able to conduct linkages between PRAMS data and maternal and infant health clinical or administrative datasets. ASTHO provided on demand technical assistance (TA) throughout each linkage project and hosted several capacity building webinars on topics ranging from Data Linkage 101 to Data Validation and PRAMS weighting techniques. This report highlights the data linkage activities from each state, capacity building and TA offerings from the project, lessons learned, and future recommendations.

Background

Building Data Capacity for Patient-Centered Outcomes Research

ASPE oversees a portfolio of projects funded through the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) to build data capacity for patient-centered outcomes research (PCOR). OS-PCORTF projects improve the collection, linkage, and analysis of data to support PCOR studies that generate high-quality evidence on the effectiveness of treatments, services, and other health care interventions to address questions identified as important by patients, caregivers, clinicians, and policymakers.

Under the OS-PCORTF Strategic Plan (2020-2029), ASPE has prioritized efforts to build data capacity for national health priorities, including improving the linkage of clinical data and other health data for maternal health research. Ensuring relevant, comprehensive data, which can often only be accomplished through linkages, is essential for assessing programmatic and clinical interventions and improving maternal health outcomes.

Read more about OS-PCORTF's work in building data capacity to support patient-centered outcomes research in maternal health.

PRAMS Overview

Since 1987, CDC has worked with state, territorial, and local health departments to implement the Pregnancy Risk Assessment Monitoring System (PRAMS), a population-based survey capturing the lived experiences of persons with a recent live birth. PRAMS samples from 50 participating jurisdictions, and these jurisdictions represent 81% of total live births in the United States. As the only surveillance system collecting data on experiences before and after live birth and during the first few months postpartum, PRAMS provides a unique tool to gain insights into maternal behaviors, perceptions, and other social determinants of health impacting

maternal and infant health outcomes. PRAMS data can be used to inform programs and policies that respond to the needs of mothers and their infants and identify groups at high risk for adverse health outcomes.

PRAMS uses mixed-mode methodology and consists of two components: a set of core questions asked by all sites and a second list of CDC-developed or jurisdiction specific questions. Supplemental questionnaires can also be administered on special topics such as social determinants of health, COVID-19, and prescription opioid use. PRAMS data collection methodology is standardized, allowing for comparisons between sites.

Data Linkage with PRAMS

While PRAMS is an essential data resource on maternal and infant health, linking these self-reported responses with other maternal and infant health data would provide fuller context of the complex system under which outcomes occur. Linkages between clinical or administrative outcomes data and PRAMS can provide PCOR researchers and jurisdictions with more comprehensive data to study the effects of interventions and social context during the perinatal period and postpartum period. PRAMS provides patient-reported experiences before, during, and after a live birth that can be linked with clinical and/or administrative data sources to assess opportunities for improvement of care and services for mothers, infants, and families. There is considerable interest in using linked data to conduct maternal and infant health longitudinal research to plan and evaluate interventions, inform funding priorities, and target interventions. Despite this interest, linkage efforts vary greatly by state, and there is not a consistent set of standard methodologies to make these data available for research at the national level.

PRAMS Data Linkage Learning Community

To address this gap in PRAMS data linkage capacity across jurisdictions, ASPE partnered with CDC to develop a first-of-its-kind project, "Developing a Multi-State Network of Linked PRAMS and Clinical Outcomes Data for Patient-Centered Outcomes." This project centered around the following objectives:

- Launch a coordinating center to assist a multi-state learning community in connecting PRAMS and clinical outcome data and catalog project activities to support replication and sustainability.
- Create standardized methodology for developing linked datasets and offer technical assistance to participating states in utilizing the methodology to link data.
- Carry out priority analyses for patient-centered outcomes research, using the linked dataset, to improve maternal and infant health.
- Develop a process to host linked data and allow external researchers access to these datasets.

The approach and development of the multi-state learning community and activities of participating states are described below.

Establishment of a Coordinating Center

In 2020, CDC's Division of Reproductive Health identified ASTHO as the coordinating center for a multi-jurisdiction learning community representing health departments that linked PRAMS data with clinical outcomes and administrative datasets (hereinafter referred to as the PRAMS Data Linkage Learning Community). The coordinating center's purpose was to identify state, territorial, or jurisdiction health

departments with access to vital records, PRAMS, and clinical outcomes and administrative datasets with the capacity for data linkages to form a multi-state learning community network through a competitive process. Over the course of the PRAMS Data Linkage Learning Community, the coordinating center was to focus on the following:

- Identify appropriate linking methodology in each state based on the availability of the linking variables in that state and promote use of standardized linkage methodologies.
- Provide TA to states to refine the standardized linkage methodology to fit the state's specific needs and to create de-identified linkage datasets that can be shared with CDC and outside researchers.
- Provide TA to the states to design and maintain linked data in a standardized format and work with CDC and the states to identify the appropriate mechanism to host the data for access by CDC and external researchers.
- Provide TA to conduct analyses addressing state-specific priorities for PCOR for maternal and child health.

Project Implementation Challenges and Adaptations

Portions of the original coordinating center aims were unable to be completed for a variety of reasons. The initial goals of the coordinating center and the learning community included creating and promoting standardized linkage methodologies, creating a de-identified linked dataset that could be shared with CDC and external researchers, and identifying an appropriate mechanism for hosting the linked data.

The request for proposals process allowed for states to determine which datasets they would link to PRAMS data to ensure linkages that could inform their programs and priorities. However, the multi-state network couldn't establish standardized methodology because each state came into the learning community seeking to link different data sources to PRAMS or focus on different outcomes. It was therefore not feasible to create a standardized methodology for the variety of different linkage projects. As a result, ASTHO created the Data Linkage Framework (discussed in additional detail on page 11) that seeks to fill this gap by providing linkage resources to assist states no matter their data source or outcomes of interest.

Due to legal barriers at the state level, it was also not feasible to host de-identified linked datasets that could be shared with CDC and external researchers. In addition, states who did not experience legal barriers in data sharing with ASTHO faced time constraints due to the short performance period. In response, ASTHO created an instructional guide for researchers interested in accessing any of the state's linked datasets. The guide details step-by-step instructions that need to be taken, based on specific state rules, to engage with the program data. (For more information, see Appendix A.)

Establishment of an Interagency Workgroup

To inform and support the PRAMS Data Linkage Learning Community, ASTHO convened an interagency workgroup of experts from federal, academic, and nonprofit partner organizations. ASTHO and CDC identified and recruited these experts to assist PRAMS Data Linkage Learning Community teams as they identified focus areas and determined the most appropriate data connections. Workgroup members also responded to TA requests, hosted, or participated in webinars on a variety of data linkage topics (which are detailed on page 8) and contributed to the overall body of knowledge expanded upon by the project. Members convened

quarterly to receive project updates and provide input on activities and future deliverables. (See Appendix B for a complete list of workgroup members.)

Multi-State Network of 9-12 States

In April 2021, ASTHO released a request for proposals inviting states, territories, and jurisdictions that participate in PRAMS to apply to join the PRAMS Data Linkage Learning Community. The goal of the PRAMS Data Linkage Learning Community was to create a network of states as they build capacity to link PRAMS and clinical and administrative datasets to support maternal and child health PCOR and quality improvement initiatives. States could receive up to $135,000 in funding to support this work. In July 2021, four states were selected for the initial cohort: Alaska, New Mexico, Texas, and Washington state.[i] In January 2022, ASTHO released another request for proposals for a second cohort. An additional eight states joined the learning community in May 2022: Georgia, Massachusetts, Montana, Nebraska, Rhode Island, South Dakota, Tennessee, and Virginia. (See the Cohort 2 Request for Proposals in Appendix C.)

Cohort 1 (October 2021—September 2022)
The **Alaska Department of Health** built upon the Alaska Longitudinal Child Abuse Linkage Project (ALCANLink), which previously linked Phase 6 PRAMS data with vital records birth and death records and Medicaid billing data. During the funding period, Alaska linked those same datasets to two years of PRAMS Phase 8 data (2016-2018) through a deterministic linkage with a probabilistic linkage enhancement and deduplication method. Through this linkage, Alaska hoped to learn more about pre-birth familial stressors reported on PRAMS and injury-related healthcare visits during the first two years of life. The linked data and associated longitudinal data linkages continue to inform state initiatives by identifying pre-birth familial stressors that impact injury-related healthcare interactions after birth.

The **New Mexico Department of Health** linked 2018-2019 data from the Help Us Grow Strong (HUGS) survey, a toddler follow-up to the PRAMS survey, to the New Mexico State Home Visiting Database to assess factors contributing to postpartum challenges. These factors include maternal depression, breastfeeding, and other aspects of maternal and child well-being. Throughout the project, the team conducted a combined deterministic and probabilistic linkage using an open-source Fine-Grained Records Integration and Linkage tool (FRIL), matching predetermined variables decided upon in collaboration with state partner agencies.

The **Texas Department of State Health Services** proposed a deterministic linkage of 2016-2020 PRAMS data to birth files through birth certificate numbers, followed by a probabilistic linkage to the Texas Health Care Information Collection inpatient research file of patient identifiers. This linkage sought to inform programs and partners on the individual-level factors and behaviors related to Severe Maternal Morbidity (SMM). Unfortunately, due to acute staff turnover and the competing demands of the COVID-19 pandemic response, the Texas team was unable to complete its linkage activities.

The **Washington State Department of Health** linked PRAMS data from 2011-2020 with the state's Comprehensive Hospital Abstract Reporting System (CHARS) to learn more about maternal morbidity. The team revamped its process of creating an intermediate linked database between birth certificate data and CHARS, known as the Birth Event Records Database, through a new machine learning algorithm. The team then

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[i] Texas was ultimately unable to accept the funding.

linked PRAMS to this birth events database through a deterministic matching method of birth certificates, resulting in the final PRAMS-CHARS linkage. The final linked dataset includes data at the time of birth for both mother and infant and additional hospitalization data (for both the mother and infant) for 10 years before and/or 10 years after the birth.

Cohort 2 (April 2021—July 2022)

The **Georgia Department of Public Health** linked its 2017-2020 PRAMS data with vital records data and to the Georgia Discharge Data System, which includes hospital discharge and emergency department data. The team also had vital records data (including birth, fetal death, death, and marriage data) from 1980-2021 and COVID-19 laboratory and surveillance case reports from 2020-2022. Georgia created a standardized methodology to automatically exchange, transfer, and load all the data, prioritizing analyses of racial disparities in healthcare before, during, and after pregnancy. Throughout this project, the team used a combined deterministic and probabilistic linkage method with machine learning and artificial intelligence.

The **Massachusetts Department of Public Health** linked its 2007-2020 PRAMS data to the state's Pregnancy to Early Life Longitudinal (PELL) data system. Massachusetts developed and has maintained PELL since 2002, which links delivery records (including birth certificates and fetal death records) to their corresponding hospital discharge records for the delivery event for birthing individuals and their infants. Massachusetts used a deterministic linkage methodology through LinkPro using multiple linkage variables, followed by an assessment of agreement between the linked files. The team then used the linked data to evaluate the associations between health behaviors and outcomes for birthing individuals and their infants.

The **Montana Department of Public Health and Human Services** linked its PRAMS data files from 2017-2020 with multiple key population and programmatic datasets for children and youth with special healthcare needs, including those related to newborn screening (hearing and bloodspot result data); vital records (conditions of the newborn data); Department of Child and Family Services child maltreatment (suspected and substantiated case reporting) data; and the state's Maternal, Infant, and Early Childhood Home Visiting program. The team's analysis was designed to produce population estimates for children and youth with special healthcare needs including assessing geographic and racial composition. A combined deterministic and probabilistic linkage method was used with the Link Plus record linkage tool to identify populations with the greatest service needs, specifically looking at the prevalence of children with a reported case of maltreatment by age five and the prevalence of children with a known special healthcare need by age five.

The **Nebraska Department of Health and Human Services** linked 2017-2021 PRAMS data with vital birth records and hospital discharge data (HDD) using a probabilistic linkage methodology, through Match*Pro. The team sought to link these data sources together to analyze the burden of severe maternal morbidity (SMM) in the state. Previous efforts to examine SMM in Nebraska have primarily used unlinked, de-identified HDD, which were subject to extensive missingness and misclassification of race and ethnicity data. By using linked PRAMS-HDD, the race specified on the birth certificate can be used to reduce both misclassification and missingness, thus facilitating more accurate SMM analyses by race in addition to the patient perspectives to help understand racial disparities of SMM.

The **Rhode Island Department of Health** linked PRAMS data from 2021 to its hospital discharge data to improve its understanding of maternal complications such as maternal mental health and hypertensive disorders. Rhode Island initially conducted a deterministic linkage between PRAMS and its vital records data before conducting a second combined deterministic and probabilistic linkage of the PRAMS-vital records file with hospital discharge records using multiple variables. While the project examined maternal mental health and hypertensive disorders more broadly, there was a specific focus on the prevalence of postpartum depression among women who were diagnosed with severe maternal morbidity and health disparities.

The **South Dakota Department of Health** linked 2018-2020 PRAMS data to Medicaid claims data. The team used a deterministic linkage methodology via the SQL programming language. Throughout its project, South Dakota sought to learn more about maternal mental health and the percentage of women in the linked dataset who self-reported symptoms of postpartum depression and received mental health services.

The **Tennessee Department of Health** linked PRAMS data files from 2019-2020 to the Tennessee Birth Statistical File and Hospital Discharge Data System using a deterministic linkage methodology. By linking the hospital discharge data, Tennessee gained a better understanding of record level data on individual hospitalizations during and up to 12 months following pregnancy. More specifically, the team was exploring prenatal or postpartum hospital encounters for hypertension and the differences between birthing parents that had had prenatal care and those that did not.

The **Virginia Department of Health** linked 2017-2021 PRAMS data to hospital discharge data. The team utilized a deterministic linkage methodology in SQL to examine relationships between PRAMS indicators, such as prenatal care experiences to medical diagnoses, to support an increased understanding of the prevalence and cost burden of specific diseases in perinatal populations.

For more information, an overview of the learning community projects, linkage methodologies, outcomes of interest and other important information can be found in Appendix D. Find a list of completed publications with the linked datasets in Appendix E.

PRAMS Multi-State Analysis

As part of the final project year (2023-2024), ASTHO and a data linkage subject matter expert began conducting a multi-state analysis with four previous learning community states: Massachusetts, Tennessee, Virginia, and Washington state. During their learning community participation, each state linked PRAMS data with hospital discharge data. The research aims to investigate factors that contribute to racial and social disparities of severe maternal morbidity and pregnancy-related hypertension. Using deidentified data, each state applied a standardized algorithm to its individual hospital discharge dataset. Once each state had a completed research dataset, they will be combined into a single multi-state PRAMS-linked dataset. By completing this multi-state analysis and better understanding the complex web of determinants, ASTHO hopes to provide insights into developing targeted interventions, improving healthcare policies, and refining clinical practices to reduce the burden of these conditions.

ASTHO aims to complete the analysis by August 2024 and disseminate results of the study through publication in a peer-reviewed journal.

Capacity Building and Technical Assistance

Kickoff Meetings

ASTHO held a kickoff meeting on Oct. 13, 2021 to launch Cohort 1 of the PRAMS Data Linkage Learning Community and held another meeting on May 3, 2022 to launch Cohort 2. Attendees for each kickoff meeting included state team members participating in the learning community, ASTHO staff, CDC project staff, and members of the Interagency Workgroup. The goals of the kickoff meetings were to:

- Build relationships and deepen connections between and across state teams and project partners.
- Identify synergies and opportunities for collaboration across state teams.
- Increase state health agency subject matter expertise on how to successfully link data or conduct patient-centered outcomes research.

To meet these goals, each kickoff meeting included an overview of learning community activities, time for intentional networking and conversation across state teams, and a presentation on high level strategies for conducting successful data linkages. The meetings also included structured interactions between the ASTHO team, the CDC project team, the Interagency Workgroup members, and state teams.

Action Planning Sessions

ASTHO met individually with state teams following their kickoff meeting for 90-minute facilitated action planning sessions to frame their projects. ASTHO staff led state teams through a series of questions designed to identify the status of each team's linkage activities and the necessary steps they would need to take to achieve their future goals. As part of this exercise, the teams identified their potential challenges, barriers, and opportunities. State teams were asked to establish a project vision, a project equity statement, goals, strategies, and activities to build their linkages and promote sustainability. Each team created as many goals as they felt they needed to stay on track, which ranged in specificity. The teams regularly updated their action plans to track their progress toward these goals.

Technical Assistance

Throughout project implementation, ASTHO met with state teams once a month, providing TA in the form of process mapping and subject matter expertise through the Interagency Workgroup. ASTHO collected technical assistance requests from learning community teams and responded by connecting state teams to interagency workgroup members, outside experts, and each other to identify best practices for coding and linking data, discussing project challenges related to small sample sizes, and other activities. ASTHO staff also facilitated process mapping exercises to identify areas where states could increase efficiency in data sharing and analysis.

In November 2022, after identifying the need for more technical data linkage expertise, ASTHO hired Dr. Jared Parrish to serve as a consultant for Cohort 2 teams. Dr. Parrish has extensive experience in data linkage activities and served as the team lead for the Alaska project in Cohort 1. Learning community states in Cohort 2 received on-demand TA from Dr. Parrish in the form of monthly (or bi-weekly) one-on-one meetings, data analysis support, or troubleshooting.

Specific examples of TA that Dr. Parrish fulfilled include providing consultation to all Cohort 2 states on data linkage methods and tools, such as supporting software selection, methodology, setting thresholds, and setting routines and documentation to facilitate replication. The level of support he provided for each state ranged from providing publications, linkage examples, and code, to offering tailored recommendations on linkage tools and data management processes. For one state experiencing hiring issues, Dr. Parrish conducted linkage activities himself. In addition, Dr. Parrish reviewed state benchmarking and validation plans during calls with entire state teams and individual epidemiologists. As most states did not have benchmarking plans, Dr. Parrish provided guidance on both simple and more complex approaches. He also encouraged robust validation efforts, such as linking at least one full birth cohort to validate estimates against, conducting simulation studies and sensitivity analyses, and respondent to non-respondent comparisons. (See Appendix F for a complete list of the TA requests.)

Capacity Building Activities

In addition to on-demand TA, ASTHO developed several resources to build the data linkage capacity of the Cohort 1 and Cohort 2 teams. These capacity building resources include ASTHO*Connects* webinars, ASTHO*Experts* podcasts, ASTHO*Briefs,* and ASTHO*Blogs,* which are all available on ASTHO's [PRAMS Data Linkage Learning Community webpage](#). State teams identified capacity gaps, needs, and priorities during kickoff meetings, action planning sessions, and other one-on-one meetings and conversations. All program resources were developed to support the immediate needs of learning community teams and future needs of other jurisdictions conducting data linkages.

ASTHOConnects

In January 2022, ASTHO launched a webinar series covering the major data linkage themes identified during the Cohort 1 kickoff meeting and the learning community state action planning sessions. This series features information about data use agreements and partnerships, legal barriers, and evaluating a data linkage project. These webinars, listed below, were open to the public but were required activities for learning community participants.

Data Linkage 101
In this first session, Russell Kirby, PhD, MS, FACE, provides a high-level overview of the purpose and processes of linking data, as well as factors to consider throughout.

Asking the Right Questions
In session two, Khaleel Hussaini, PhD, and Milton Kotelchuck, PhD, MPH discuss how to successfully establish data use agreements and engage partners in the process.

Legal Barriers with Data Sharing
In session three, Lillian Colasurdo, JD, and Shae Sutton, PhD, discuss national and state legal barriers to data sharing.

State Share Session
In session four, Lizzie Harvey, PhD, MPH, shares successes and challenges with maternal and child health data linkages in Tennessee while Kara Zivin, PhD, MS, MA, MFA, discusses conducting data linkages of Michigan's PRAMS and Medicaid data from the perspective of an external partner.

Evaluating Your Data Linkages
In session five, Cheryl Clark, DrPH, RHIA, discusses connections between data quality and equity, the impacts of linking equity, and ways to ensure and optimize linking equity.

Between February 2023 and June 2024, ASTHO conducted five additional webinars based on needs identified while working with Cohort 2 of the learning community.

From Benchmarking to Documenting: How NCHS Links and Assesses the Quality of Their Data
In this session, Lisa Meril, MS, provides an overview of the National Center for Health Statistics Data Linkage program and its end-to-end linkage methodology.

Don't Wait, Validate: Estimating Population Outcomes with PRAMS Linked Data
In this session, Ama Bikoko, MPH, MHA, Abigail Newby-Kew, PhD, MPH, and Jared Parrish, PhD, MS presented on the importance of validation and benchmarking during a data linkage project. Experiences from Nebraska, Oregon, and Alaska were shared.

It's a Weighty Matter: Exploring PRAMS Weights
In this session, Phil Hastings, PhD, and Joe Pirozzolo, PhD, from Far Harbor, and Jared Parrish, PhD, MS provided thoughts and methods for checking assumptions of PRAMS subgroup estimations and potential bias risks and discussed how re-weighting is sometimes used for smaller subpopulation assessments.

Accelerating Patient-Centered Comparative Clinical Effectiveness Research to Prevent Maternal Morbidity and Mortality
In this session, Erin Holve, PhD, MPP, MPH, Nik Koscielniak, PhD, MPH, and Elizabeth Shenkman, PhD, provided an overview of PCORI's PCORNet and how to increase community involvement in PCOR.

Enhancing PRAMS with Data Linkages: A Framework for Effective and Efficient Integration and Sustainability
In this session, Shannon Vance, MPH, Stephany Strahle, MPH and Jared Parrish, PhD, MS presented ASTHO's PRAMS Data Linkage Framework.

ASTHO*Experts* Podcasts

Data Strategies to Improve Health Outcomes for Indigenous Communities
In this episode, three experts—Ed Ehlinger, MD, MSPH, Minnesota's former commissioner of health and a past president of ASTHO; Janelle Palacios, PhD, CNM, a nurse midwife and researcher; and Katelyn Strasser, MPH, RN, administrator of South Dakota Department of Health's Office of Child and Family Services—discuss the Federal Advisory Committee on Infant and Maternal Mortality's most recent report on health outcomes among American Indian and Alaska Native populations and the data-focused recommendations for states and territories.

[What I Wish I Knew Before Linking Data: A Conversation with Dr. Emily Putnam-Hornstein and Dr. Jared Parrish](#)

This episode features a conversation between two data linkage experts—Jared Parrish, PhD, MS, and Emily Putnam-Hornstein, PhD—highlighting their lessons learned and sharing recommendations for those seeking to use data linkage projects to examine key public health issues, such as:

- The thought process behind choosing which datasets to link, which linkage tools and methods to use, and how to bring intentionality to these choices when considering a research question.
- The benefits of using data linkage to enhance datasets and build a comprehensive and robust collection of information for new insights.
- Lessons learned for navigating data linkages with important considerations for preparation, analysis, and the uses of data linkage.

ASTHO*Briefs* and ASTHO*Blogs*

[Overcoming Common Barriers to Data Linkage](#)

This brief examines themes that emerged from conversations with learning community states—Alaska, New Mexico, Texas, and Washington—during the Cohort 1 kickoff meeting. Individuals shared challenges they encountered during previous data linking activities and discussed lessons they learned in the process. Although state teams were the main contributors to these conversations, interagency workgroup members consisting of federal, academic, and industry partners also offered advice based on their expertise.

[Leveraging Data Linkage to Address Adverse Childhood Experiences](#)

This blog discusses how surveillance data allow public health practitioners and researchers to track changes in the burden of adverse childhood experiences by collecting data on previous exposure, health conditions that may impact or be impacted by exposure, and other related topics.

[Linking Datasets to Address Racial Equity in Maternal and Child Health Outcomes](#)

This brief examines strategies for promoting racial equity in maternal and infant health through data linkages. Examples from Massachusetts and Georgia are explored.

[Strengthening Material and Infant Health Data in Territories](#)

The historical exclusion of territories in U.S. surveillance systems has limited our understanding of maternal and infant health outcomes and associated risk factors in these jurisdictions. This brief will highlight recent PRAMS implementation and relevant data linkage activities in Puerto Rico and the Commonwealth of the Northern Mariana Islands (CNMI) to resolve this gap and identify research areas where data linkage with PRAMS can be leveraged.

(See Appendix G for a list of all subject matter experts engaged throughout the learning community.)

PRAMS Data Linkage Framework

Based on the experiences from the PRAMS Data Linkage Learning Community teams, input from national experts, and a review of published research, ASTHO developed the *Framework for Linking PRAMS with*

Administrative Data and a series of supportive tools. This framework can serve as a tool for states, territories, and external researchers to use when preparing, conducting, and analyzing linked PRAMS data and building a sustainable linkage environment. The narrative of the framework describes the linking of PRAMS data in five phases, detailed below.

- **Phase I: Linkage Preparation** highlights the need for a clear and defined linkage purpose, to shape the linkage process, and a narrative that fosters buy-in among partnerships. It also discusses assessing internal capacity to conduct linkages and obtaining all necessary data sharing agreements and Institutional Review Board (IRB) approvals.
- **Phase II: Data Preparation** describes the process of identifying administrative sources to link PRAMS to, conducting an exploratory analysis of this data to establish common identifiers, and harmonizing the administrative data source with the PRAMS data through data cleaning, standardizing, and aligning.
- **Phase III: Data Linkage** details how to design a linkage approach (i.e. linkage tool and methods) appropriate for the needs and capacity of the project, establishing acceptance thresholds, and conducting validation.
- **Phase IV: Research Dataset Creation and Analysis** describes how to create a linked research dataset and a comprehensive analysis plan for the narrowed variables and outcomes of interest.
- **Phase V: Sustainability** covers how to document processes and ensure secure storage of linked data for future use and replication.

As part of the PRAMS Data Linkage Framework, ASTHO developed four supportive tools. While the tools could be used as standalone resources, they are meant to be used within the bounds of the framework to fill additional gaps in knowledge.

- **The Template Data Use Agreement** is an example of a generalized sharing agreement specific to public health data linkage projects.
- **The Data Linkage Readiness Assessment** provides a guide for states to assess their capacity and infrastructure for conducting PRAMS data linkage before carrying out a linkage project.
- **The Data Linkage Process List** outlines the five phases of the framework by providing a synthesized overview of the various processes that may need to be accomplished within each phase of a linkage project.
- **The Data Linkage Process Map** provides a visual depiction of each phase of the Framework and its main components.

Conference Presentations

Association of Maternal and Child Health Programs (AMCHP) Annual Conference | April 14, 2024
ASTHO presented on the PRAMS Data Linkage Framework during a one-hour virtual workshop during AMCHP's annual conference. This presentation covered five key phases of PRAMS data linkage and will showcase the four tools that ASTHO created to assist states in this work.

Council of State and Territorial Epidemiologists (CSTE) Annual Conference | June 10, 2024
ASTHO presented on the PRAMS Data Linkage Framework during a one-hour roundtable discussion at CSTE's annual conference. This presentation covered the five key phases of PRAMS data linkage and will showcase the four tools that ASTHO created to assist states in this work.

PRAMS National Grantee Meeting | Sept. 6, 2024
ASTHO will present at the PRAMS National Grantee Meeting on the PRAMS Data Linkage Framework and PRAMS Multi-State Analysis. This presentation will cover the five key phases of PRAMS data linkage and will discuss the results of the completed multi-state analysis.

City MatCH Leadership & MCH Epidemiology Conference | Sept. 9, 2024
ASTHO's abstract submission was accepted for a ninety-minute symposium at the CityMatCH conference on the PRAMS Data Linkage Framework. This presentation will cover five key phases of PRAMS data linkage and will showcase the four tools that ASTHO created to assist states in this work.

Lessons Learned

Throughout the PRAMS Data Linkage Learning Community, several common lessons learned were observed across five main categories. State teams found that having a clear purpose, leadership buy-in and internal capacity, partnerships and data sharing, preparation and execution of linkage activities, and dissemination and sustainability was crucial to data linkage success. Below are examples from each of these categories from the perspective of the learning community state teams.

Having a Clear Purpose

States entered the PRAMS Data Linkage Learning Community with various levels of expertise and staff capacity to perform linkages and at various starting points on their linkage journeys. Prior to the start of the project, some states already had existing linkage environments to work within, while others had never conducted linkage projects. Additionally, states entered with different ideas for linkage activities. Some teams sought to answer specific research questions, while others were interested in building a linkage environment to pave a path for future analysis and research.

In identifying primary indicators of success, having a well-defined and clear linkage purpose emerged as a central theme. By defining the project's purpose, state teams could consider which linkage activities would allow them to explore a specific research question. Learning community teams with specific research questions to guide their linkage projects experienced fewer barriers in identifying appropriate linkage approaches, conducting their linkages, assessing linkage quality, and establishing sustainability plans than other teams. This portion of the linkage process also requires considering how the state will obtain and manage data and reviewing any internal politics surrounding these processes. Without these considerations, linkage projects risk potentially encountering unintended barriers, an unstructured approach, and incorrect or low-quality analyses.

Leadership Buy-In and Internal Capacity

It is important to have support from leadership early in the data linkage process. This not only helps minimize delays in gaining access to data or receiving and administering funding, but it also ensures that the linkage activities remain top of mind for key partners. It is crucial for staff interested in linking data that the team is clear on its research questions, purpose of linkage, and how the linkage work will fit into leadership or organizational priorities. Upon applying to the PRAMS Data Linkage Learning Community, state teams were required to submit a written letter of support from the state health official giving project support and pledging to champion data access and sharing agreements. This required the state teams to communicate with their leadership the intent and direction their linkage activities were heading. Having this leadership buy-in prior to starting the learning community activities meant that none of the state teams encountered issues with prioritization during their project period.

Coupled with leadership buy-in is internal staff capacity to conduct the linkage. One of the Rhode Island team's primary facilitators of success in the PRAMS Data Linkage Learning Community was having staff already in place who were seasoned epidemiologists with exemplary data and analytical skills. This ensured their team was adequately prepared when it came time to link their data and analyze their research dataset. Unfortunately, this was not a common experience for most learning community teams. Many teams grappled with staff capacity issues, both with having adequately trained staff and having enough people to complete the project. As was seen across the country, due to competing demands of the COVID-19 pandemic and response, state health departments experienced significant challenges related to staff turnover and burnout. While they began the learning community with a fully staffed team, the Texas team suffered from acute staff turnover, losing more than half the members of their team to new positions. Consequently, they were unable to complete their linkage activities during the project period. Of note, Texas also did not have the internal capacity to receive and administer funding for the short performance period, which may have impacted their ability to have dedicated staff for this project.

Data linkage projects are labor and time intensive projects that can be difficult for state teams to begin and complete, even with a fully staffed, adequately trained team of epidemiologists and initial leadership buy-in. Having external resources and dedicated funding allowed state teams to outsource additional support and reduce delay when beginning linkage activities. Several learning community teams planned to use funding to hire temporary staff or contractors to complete the initial linkage activities to offset the workload. The Virginia and Tennessee teams were able to hire an external consultant to lead the linkage, conduct the analysis, and ensure that permanent staff were properly trained for sustainability purposes. These examples illustrate the importance of having both fully trained staff and enough bandwidth to take on new projects, especially those with short timelines. Given that the PRAMS Data Linkage Learning Community cohorts lasted only one year, it was imperative for the teams to be well-prepared at the beginning of the project to achieve a successful linkage.

Partnerships and Data Sharing

Many linkage projects across the PRAMS Data Linkage Learning Community included datasets (i.e., Medicaid, hospital discharge) that the health department did not own. As a result, several state teams learned the value of strong partnerships during their time in the learning community, and some were able to form new relationships or bolster existing connections. The Georgia team had a longtime relationship with the state registrar, who needed to approve the use of any vital records, which was a primary driver of success for their

linkage. This history, coupled with the Office of Vital Records' location within Georgia Department of Public Health, made obtaining the necessary data a relatively simple process. The Nebraska team also successfully improved and strengthened their relationship with the Nebraska Hospital Association during their time in the learning community by involving them throughout their linkage planning and implementation.

Even with the strongest partnerships in place, linkage activities still take time. Some state teams experienced unanticipated delays that pushed back their timelines. The Washington state team needed institutional review board (IRB) approval to complete their linkages between birth certificates, hospital discharge data, and PRAMS. While going through IRB review, concerns were raised around consent to share data, putting any linkage activities on hold. The state was unable to complete its full PRAMS linkage during the project period due to this delay. However, this review provided the opportunity for the Washington State Department of Health to do an in-depth assessment of its internal data sharing protocols, resulting in new agreements that protect and support the sharing of linked data and any new linkage activities in the future. The Washington state team ultimately completed their linkage activities in November 2023.

Preparation and Execution of Linkages

One key facet of states' successes in their linkage projects was determining the appropriate linkage approach. Some states did not have common identifiers (e.g., social security numbers or similarly formatted birth certificate numbers between datasets) readily available for linkages, which made it challenging to perform linkages or resulted in discrepancies upon analysis. Overcoming linkage-related issues often involved states building or relying on strong partnerships both within and external to their agencies, adopting a flexible approach to try multiple solutions or iterations, and utilizing ASTHO's technical assistance.

While a few PRAMS Data Linkage Learning Community teams encountered challenges prior to linking their data, many encountered unexpected issues once they got into the data. These issues included selection of variables for linkage, sufficient time for validation, and challenges with name homogeneity and matching. When preparing for a linkage, it is important to allocate ample time to familiarize one's team with the datasets prior to linking them. Some learning community teams were linking PRAMS to intricate datasets, such as Medicaid or hospital discharge data, that were unfamiliar to them. Knowledge of what is within each dataset is essential to ensure smooth variable identification and to effectively answer the research question through linkage. The South Dakota team had limited experience with the Medicaid dataset they were linking to PRAMS, leading to challenges in understanding how Medicaid eligibility affected the data's numerator and denominator and issues determining which Medicaid claims data fields could answer their research question. Consequently, the team relied heavily on their Medicaid data analyst to answer these questions.

During their linkage, the Nebraska team identified quality issues with one year of their linked data. While they identified the issue quickly, it took several process iterations from the team and ASTHO-provided TA to work through potential fixes. This iterative process, while necessary to ensure a complete and accurate linkage, delayed the team's timeline by several weeks.

Dissemination and Sustainability

While some states entered the PRAMS Data Linkage Learning Community with a loosely defined dissemination plan, most indicated that they planned to use the data internally for future program implementation or other surveillance activities. Ideally, a linkage project should start with the end in mind. When states could identify

precisely how they intended to use the linked data at the beginning of their project, they encountered fewer delays, as they were better positioned to navigate the intricacies inherent in sharing potentially sensitive information. From the beginning of their project, the Georgia team planned to work alongside other maternal and child health surveillance project teams to improve existing workflows. This allowed them to address issues with data sharing or other permissions in real time and make future linkage work easier. Planning dissemination prior to linkage also helped the Nebraska team, as they were able to develop priority areas for their analysis in collaboration with their state Maternal Mortality Review Committee.

States had few explicitly defined plans for external dissemination. The Washington state team indicated that it was important to have the ability to share the linked PRAMS dataset. Early in the state's planning process, the team agreed to disseminate their results through a statewide newsletter. The Alaska team was able to share the results from the linked dataset with several external groups, including the state legislature and child welfare advocacy groups. For some states, dissemination became a bigger challenge than they had anticipated. Some sought to share the information from the linked analysis externally only to run into issues with small numbers (preventing them from reporting out at all) or a mismatch in priorities across key partner groups (delaying the release of key data briefs). The New Mexico team had a lower match rate than they anticipated, which prevented them from sharing any of their results from the linked analysis, while the Montana team was unable to share a brief they had prepared due to leadership decisions regarding the results.

When it comes to sustainability, continued funding is critical to support data linkage activities. Without sufficient funding, innovative linkage activities such as automating the PRAMS-hospital discharge data-linked environment in Georgia will be unable to continue. In Rhode Island, the federally funded Title V and Social Security Disability Insurance programs oversee all routine data linkage activities. Now that Rhode Island has created the PRAMS linkage through learning community activities, these programs will be able to easily manage routine efforts for surveillance and research purposes.

Maintaining the linked datasets also requires dedicated staff who understand the process and are properly trained. Before the end of the learning community, the South Dakota team hired a health informatics analyst who was able to work alongside Dr. Parrish to discuss a plan for sustainability and necessary software needed to continue this work. Relatedly, the Montana maternal and child health epidemiologist left before the linkage activities were completed. The remaining team members worked with Dr. Parrish to ensure that a new staff person was trained in the linkage software and knew the steps to maintain the linked dataset in the future.

Another key theme around sustainability included ensuring that proper data governance structures are in place through robust protocols and collaboration with internal and external key partners. This integration will require establishing secure data-sharing agreements and protocols to ensure ongoing access to the necessary data. Setting up this structure is something the Virginia team made a priority at the end of their learning community participation. In addition to the above steps, Virginia began creating standard operating procedures that include how to responsibly access data and what quality assurance and control measures the state should take. Having these procedures and policies in place will ensure the sustainability of their PRAMS data linkage moving forward.

Future Recommendations

The PRAMS Data Linkage Learning Community was created to expand the data capacity for patient centered outcomes research (PCOR) by linking PRAMS to clinical outcomes and administrative datasets. Throughout this learning community experience, the challenges and successes outlined in the previous section led to the development of several recommendations pertaining to the future of PRAMS data linkage to improve the quality of maternal and infant care and services.

Recommendation 1: Develop a clear and defined purpose for all linkage-related activities to inform PCOR.

Data linkage activities of all sizes require a clear understanding of the end goal and need clearly defined research questions to minimize delays and confusion during the process. Furthermore, while community involvement is not traditionally considered a part of data linkage activities, it is integral to include community partners in the development of the patient-centered research question the data linkage activities are intended to answer. Community involvement extends beyond mere participation; it is a critical component in crafting questions that are not only relevant but also reflective of the community's health priorities. Despite historical tendencies to deprioritize community engagement due to limited resources, logistical hurdles, or the absence of established trust or formal relationships, early and proactive engagement facilitates the development of patient-centered research questions that resonate with community needs, thereby enhancing the relevance and application of the data linkage outcomes.

Recommendation 2: Increase the data capacity for PCOR by prioritizing linking available databases within federal agencies and across state institutions.

The learning community provided a unique opportunity for states to explore the steps necessary to conduct PCOR with linked PRAMS data. Due to a variety of reasons including health department priorities and decreased staff capacity due to turnover, many states focused on solidifying the linked datasets instead of conducting PCOR activities. These linked datasets offer the potential for a deeper understanding of the factors influencing maternal and infant health outcomes, as well as the effectiveness of interventions to improve these patient outcomes. Due to the standardized collection of PRAMS data and the health indicators it collects, using PRAMS surveys can serve as a foundation within states and jurisdictions to center maternal and child health for future PCOR.

The success of this project relied on the collaboration between state partners, CDC's Division of Reproductive Health, and ASTHO, focusing on building capacity for data linkage at the state level. In the future, continued collaboration between federal agencies (CDC, HRSA, and others), state partners, and other groups is needed to support states and prioritize the linkage of available databases across states and institutions. Building additional capacity for data linkages should be prioritized both at the federal and state levels. Future grant funding for data linkage opportunities and for developing data linkage infrastructure can support continued capacity building for PCOR. Furthermore, engagement with professional societies and national organizations is essential to promote data linkage, provide training for state teams, and build connections to data partners across states, federal agencies, and educational institutions.

Recommendation 3: Develop data infrastructure to promote hosting, sharing, and access to linked data for PCOR.

Due to several legal barriers and privacy concerns, the PRAMS Data Linkage Learning Community was unable to host state-linked datasets for sharing with external researchers. To support hosting and sharing linked data, states and territories should prioritize important data infrastructure developments. Developing a universal agreement to support data sharing across states and other entities, as well as adopting best data practices among states, may help minimize risk and privacy concerns and promote data sharing. Engaging partners to promote the benefits of data sharing could also help garner support for future data linkages that expand the capacity for PCOR and provide opportunities for researchers to access these data.

The states in the learning community utilized a variety of tools and techniques to link their data. Leveraging existing data tools and services for data linkages can build upon the success of previous projects and create sustainable capacity for future progress. Developing open-source data linkage tools may be particularly useful, especially at the state level, where resources are often limited. In the PRAMS Data Linkage Learning Community, the lack of standardized data elements across the state linked datasets, due to differences in clinical and administrative datasets linked and numerous legal barriers, kept the program from creating a shareable multistate linked dataset. Developing data standards can improve the quality of available administrative data. By enhancing overall standardization and data quality at the state level, the utility of these data for linkage can be improved to generate multistate or multisystem datasets.

Recommendation 4: Promote data linkage sustainability through long-term collaborations and financial support.

To assist states in linking their PRAMS data to clinical outcomes and administrative datasets, the PRAMS Data Linkage Learning Community provided funding to support state teams. In addition to funding, ASTHO and CDC offered training and TA to support state teams and build their capacity for data linkage. However, while some learning community states were able to link multiple years of PRAMS data and create plans to continue linking PRAMS to administrative datasets in the future, not all states are able to continuously prioritize these data linkages without additional support. For these programs to be sustainable at the state level, ongoing sources of funding are needed. Future funding opportunities can also incentivize programs to integrate PRAMS data linkage into routine data analysis workflows and foster long-term financial sustainability by strategically integrating funding via braiding and layering approaches. Additionally, developing longitudinal data can enhance the utility of linked datasets to support PCOR, as these datasets can be leveraged to understand the impact of interventions and policies on patient outcomes over time. However, without continued economic investment and collaboration between states, federal agencies, and national partners, there is no guarantee that states will have ongoing capacity for this future work.

Appendix A. Guidance for Accessing State PRAMS Data Linkages as an External Researcher

As part of their Final Reports, PRAMS Learning Community teams provided an overview of the process for external researchers seeking access to their linked datasets. For those that did have an existing process or plans to implement one, the processes often involved a combination of the following requirements:

- State Department or Agency retains ownership of the dataset(s)
- Requestors must obtain a data-sharing agreement (DSA), a data use agreement (DUA), a memorandum of understanding (MOU), a memorandum of agreement (MOA) with the State Department or Agency
- An Institutional Review Board (IRB) application and approval, which requestors can obtain via IRBNet
- Requestors may need to go through a state's specified online portal
- Contacting the State Department, Agency, or other entity holding data ownership
- A secure file transfer software or method specified by the state
- An associated cost for the requested dataset
- A timeline of request approval and duration of access to the dataset

Inquiries regarding state contacts for data requests or other general information can be directed to prams@astho.org.

Alaska

All ALCANLink data sharing requires an approved DSA and approved IRB between the external researcher and the state. The breadth, scope, frequency, and use of access to the dataset requested will need to be articulated clearly for review by the administration. The state retains data ownership, and not all linked elements may be available to external researchers without additional approval (e.g., the ALCANLink dataset integrates with education and the permanent fund dividend, each of which would require additional approvals from those sources before releasing information).

Georgia

To ensure a known timeline and related specifications, requestors must contact the PRAMS principal investigator before submitting a data request. Data may then be requested through the Public Health Information Portal (PHIP), an online system that requires creating a user account and completing the data request form. The PHIP link provided above will result in a standard DUA, inclusive of IRB approval. Data provided through PHIP are made available in a secure file transfer portal. Ensuring data are appropriately handled is detailed in the PHIP DUA. The estimated time to process requests and share linked data depends on the request. More leeway with time to speak with requestors is always preferred. Public agencies and students may receive data without being charged, but there may be a cost for grant-funded researchers.

Massachusetts

Data are managed by the Massachusetts Department of Public Health's (MDPH) Division of Maternal and Child Health Research and Analysis (DMCHRA). Access to the linked dataset can be requested using an IRB application. DMCHRA works with the applicant to securely transfer data using transfer. This process takes an estimated 90 days after the IRB application is submitted. Requestors should anticipate an associated cost dependent on the size of the dataset requested.

Montana

Because this was a pilot project, Montana has not yet established a protocol for sharing data with external partners. However, Montana PRAMS plans to work with leadership to develop a process for future data requests and further data integration.

Nebraska

External research requests and public records requests can be directed to dhhs.publicrecords@nebraska.gov. Requests including PRAMS data must adhere to Nebraska PRAMS Guidelines for Proposals to Receive Datasets to Conduct Analyses. All requests using PRAMS data must also complete the Nebraska PRAMS Proposal Application Form.

New Mexico

New Mexico does not currently have a defined process for external researchers to access the linked datasets. Data owners would likely include MCH Epidemiology at the New Mexico Department of Health (NMDOH) and the Early Childhood Education and Care Department (ECECD) Home Visiting program for future dataset applications.

Rhode Island

RI PRAMS has developed guidance for granting external researchers access to PRAMS data for requests that come directly to their state. The sharing agreement requires a draft proposal that summarizes the project, which is reviewed by the staff before approving access, as well as providing comments and suggestions given the limitations of the data. The same DSA will be used for the linked dataset. However, verbiage will be modified to reflect the data linkage information. In addition, the Office of Vital Records requests that external researchers interested in using their data complete a data request form for approval.

South Dakota

The project team will continue to work on a process to make this dataset available to external researchers. Permissions from the Department of Health, the Department of Social Services, and vital records must be granted first. The process will then resemble the current process for providing external researchers with the PRAMS datasets.

Tennessee

All data requests to the Tennessee Department of Health are submitted through a central data request portal managed by the Office of Informatics and Analytics. The requestor must submit an IRB application if Protected Health Information or Personal Health Information is requested. The time required to process requests varies based on internal reviews by the entity governing the data, the need for IRB review, and data fulfillment. If IRB

approval is necessary, the request will be processed in six to eight weeks. If IRB approval is unnecessary, the request will be processed in approximately two weeks. Upon data steward and IRB approval, records are transmitted electronically via secure email.

Texas

Due to a severe staffing shortage over the past couple of years for the MCH Epidemiology Unit at the Department of State Health Services, linkage activities were paused in Fall 2021 and a linked dataset was not created.

Virginia

Requesting the linked data starts with contacting the Virginia Department of Health Office of Family Health Services (VDH OFHS) Division of Population Health data team members via email here or DPHD data request Red Cap link. The researchers must obtain an IRB from their institution and an IRB from VDH. After both IRBs have been approved and completed, researchers will complete a DSA. Next, the codebooks and dataset will be distributed to researchers. These steps address our current processes for PRAMS data, pending updated MOUs with the Virginia Health Information (VHI) system to share data.

Washington

Data sharing approvals for the PRAMS-CHARS are shared between the Center for Health Statistics (CHS) and PRAMS. CHS leads the development of each DSA, following the agreed-upon processes for communication and approval with PRAMS. A similar, abbreviated process will be developed for internal data sharing with DOH. While it has yet to be formalized, the below steps indicate the anticipated process.

Process for requesting linked PRAMS-CHARS data:
- A description of the linked dataset, including a list of variables, will be included on the WA PRAMS and CHS web pages. This description will contain a link for those interested in requesting a dataset. The link will take the user to the Health Statistics data page, which includes a link to the CHS *Data Request Application*.
- Those who propose using the data for research will submit an application to the WA IRB.
- The requestor will submit a *Data Request Application* via the CHS email account.
- Assuming IRB approval, the CHS Data Sharing Agreement Coordinator will respond to the requestor and begin the DSA development process. The PRAMS PI and Coordinator will be included in all correspondence and will review the request to determine the appropriate use of the data.
- The DSA for PRAMS-CHARS linkage will include CHS, PRAMS, and the requestor. All DSAs will be limited to five years.
- CHS processes electronic signatures for DSA; Division Deputy Assistant Secretary will approve for the Division.
- The final signed DSA is sent to the requestor and placed in a secure folder that is accessible to both CHS and PRAMS.

Appendix B. Linking PRAMS and Clinical Outcomes Data Multi-Jurisdiction Learning Community

Interagency Workgroup Overview

ASTHO has convened experts from the Federal, academic, and non-profit sectors to lend their expertise as a part of an interagency advisory workgroup (IAW). Workgroup members are divided into two arms, one providing direct technical assistance to state teams and the other providing high-level advisory support and direction to the overall project.

Workgroup Member List

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Appendix C. ASTHO Request for Proposal

Linking PRAMS and Clinical Outcomes Data Multi-Jurisdiction Learning Community Cohort 2

Summary Information

Purpose: The Association of State and Territorial Health Officials (ASTHO), with support from the Centers for Disease Control and Prevention (CDC), is launching the second cohort of the *Linking PRAMS and Clinical Outcomes Data Multi-Jurisdiction Learning Community* project to support states, territories, and jurisdictions as they build capacity to conduct data linkage activities between PRAMS and clinical outcomes data sets. These linked data sets will inform Patient-Centered Outcomes Research and clinical quality improvement initiatives in maternal and child health.

Proposal Due Date and Time: *Friday, March 25, 2022, by 11:59 PM EST.*
Selection Announcement Date: *Monday, April 11, 2022*
Monetary Assistance Available to Awardees: Funding will be available for states, territories, and jurisdictions to build capacity to conduct and advance data linkage activities between PRAMS and other maternal and child clinical outcomes data sets.
Maximum Funding Amount: Up to $135,000 per jurisdiction, scaled to the local position market.
Estimated Period of Performance and Final Report Date: April 2022-March 2023. The project period of performance may be extended if additional funding becomes available.
Bidder's Informational Call: Tuesday, February 8, 2022, 2:00 PM-3:00 PM EST

Eligibility: All states, territories, and jurisdictions that apply must:
1. Have a current PRAMS project.
2. Have met or have the capacity to meet the response rate threshold of at least 50% for at least one calendar year during Phase 8.
3. Have documented approvals (data sharing agreements) to link datasets at the state, territory, or jurisdiction level OR be able to obtain those approvals within 30 days of the project period start.
4. Have the authority to share de-identified linked data sets with CDC or outside researchers OR be willing to begin developing a process for sharing before the end of the learning community funding period.
5. Be in good standing with ASTHO to be eligible to apply.

ASTHO Point of Contact: Britta Cedergren, Director, Family and Child Health, PRAMS@astho.org. *Please include "RFP: PRAMS Multi-Jurisdiction Learning Community Cohort 2" in the subject line.*

Description of RFP

Background

ASTHO will provide 5-8 states or territories the opportunity to participate in a learning community focused on building improved data linkages for PRAMS data with clinical outcomes data (e.g., hospital discharge, vital records, Medicaid claims, Home Visiting, and All-Payer Claims databases, etc.) According to The Patient-Centered Outcomes Research Institute, "Patient-Centered Outcomes Research helps patients, and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value

of healthcare options." The goal of the ASTHO PRAMS Multi-Jurisdiction Learning Community (Cohort 2) is to support a network of states, territories, and jurisdictions as they build capacity to link PRAMS and clinical data to inform maternal and child health Patient-Centered Outcomes Research, and quality improvement initiatives.

Project Activities

ASTHO will launch a second cohort of the PRAMS Multi-Jurisdiction Learning Community through a competitive process with up to eight state, territory, or jurisdiction health departments. Selected applicants with _demonstrated capacity_ to access PRAMS, vital records, and clinical outcomes data (e.g., hospital discharge, Medicaid claims, and All-Payer Claims databases), will be provided technical support to further build and improve upon data linkages to improve patient-centered outcomes research in maternal and child health.

Applicants will be expected to participate and actively engage in the following activities, including:
- Attending a virtual kick-off meeting with ASTHO, CDC, and a multi-disciplinary interagency workgroup of federal, academic, and non-profit partners.
- Attending all Learning Community activities, including _ASTHOConnects_ virtual learning sessions, technical assistance calls, team-to-team learning opportunities, evaluation calls, and additional assessments.
- Developing and implementing an action plan, submitting regular progress reports, and participating in technical assistance site visits or conference calls with ASTHO staff, as needed.
- Providing information via needs assessments or key informant interviews to assist ASTHO in better understanding barriers to data linkage to inform and refine technical assistance needs.
- Obtaining all documentation needed for data dictionaries.
- Develop a standard methodology for linking data sets consisting of PRAMS and clinical outcomes data to inform future activities supporting Patient-Centered Outcomes Research in maternal and child health.
- Finalizing all documentation needed for data linkages and data sharing, such as Memorandums of Agreement, Institutional Review Board approvals, and/or data sharing and use agreements.
  - States, territories, or jurisdictions may also show documentation to demonstrate existing processes and templates for data sharing and linkages, and/or should include a timeline for finalizing these agreements with partners as part of the application.
- Conducting data linkages and analysis resulting in de-identified linked datasets.
- Collaborating with the project Interagency Advisory Workgroup to identify priority activities that facilitate improved data linkage, share successes, and build sustainability plans.
- Participating in partner activities throughout the Learning Community to troubleshoot barriers, share best practices, and build upon successes. Documenting strategies and lessons learned for sustainability and expansion of the project in the future.

Expected Outcomes

Learning Community applicants will build capacity to effectively grow and monitor the progress of data linkage activities to better inform future patient-centered outcomes research in maternal and child health. Applicants will receive direct support through a full-time equivalent (FTE) staff member or contractor. Funding may also go toward underwriting existing staff. Along with guidance from ASTHO and the Interagency Advisory Workgroup, applicants will work together across the Learning Community cohort to develop performance measures to track major milestones as they standardize and build consistency across data set linkages.

Learning Community activities will inform future ASTHO activities that support state, territory, or jurisdiction data linkage activities to build patient-centered outcomes research sites across the country. As an organizational final product, ASTHO will develop a technical report on protocols, processes, and lessons learned on data access; data linkage; data sharing; and sustainability. This report will document some of the step-by-step processes for duplication of similar activities and be made available to members nationwide.

Health Equity

ASTHO is committed to supporting state health agencies in their work to address health disparities and advance health equity. This commitment is evident in ASTHO's strategic goals and in the [Achieving Optimal Health for All by Eliminating Structural Racism](#) policy statement.

Technical Support

ASTHO will provide information and technical support to the awardee at no cost, including virtual site visits. Technical support may be provided by the project's Interagency Advisory Workgroup, other learning community teams, and partners. ASTHO will work with Learning Community applicants, and the Interagency Advisory Workgroup to develop a series of project indicators, and individual site performance measures to be updated quarterly to track and evaluate project progress and share best practice examples through storytelling activities.

Funding

Awardees will be eligible for up to $135,000 each for the project. All states participating in the Linking PRAMS and Clinical Outcomes Data Learning Community are eligible to receive funding for a full-time equivalent (FTE) staff member or contractor in accordance with the local position market, based on state needs. Funds may also be used to pay for acquiring datasets, linkage software, or other required items. Funding may not be used for equipment. Options for hiring through this funding opportunity, for at least 12 months:

A. The state, territory or jurisdiction participant site will underwrite their current workforce.
B. The state, territory or jurisdiction participant site will hire a full-time equivalent (FTE) staff member or utilize existing MCH assignees or CSTE MCH fellows, EIS Officers, or ORISE Fellows already available to them.
C. The state, territory, or jurisdiction participant will hire a contractor to provide support to applicants as deemed necessary by project needs and number of applicants.

Selection Criteria

Each application will be reviewed and rated by a review panel consisting of ASTHO PRAMS Learning Community staff and staff from the CDC Division of Reproductive Health. Proposals will be rated on the following evaluation criteria:

- Completeness of application.
- Written documentation from the state, territory, or jurisdiction health official stating project support and pledging they will champion data access and sharing (e.g., State health officials, Title V Directors, Medicaid Directors) agreements.
- Access to vital records files with identifiers linked to PRAMS, and at least one primary clinical outcomes dataset for linkage, including, but not limited to:
  o Hospital discharge data
  o Vital records

- - o   Healthy Start or Home Visiting clinical data
  - o   All Payer Claims Database data
  - o   Medicaid claims data
- Documented approvals to link datasets OR documentation that within 30 days of funding, there shall be a fully executed memoranda of understanding (MOA) or data-sharing agreement with custodians of data sets including descriptions of current and future partnerships. Description of capacity and experience linking vital records with clinical outcomes data, including linkages performed through HRSA SSDI, or publications using linked data.
- Capacity to analyze linked datasets and willingness to participate in multi-jurisdiction efforts.
- Appropriately documented budget request consistent with stated needs and resources.
- A proposed plan to sustain data linkage capacity and analyses to continue to monitor pregnancy-related outcomes into the future.

Requirements for Financial Award

Allowable Expenses
Funds may not be used for equipment purchases. Per HHS requirements, funds awarded under this RFP are prohibited from being used to pay the direct salary of an individual at a rate in excess of the federal Executive Schedule Level II (currently $203,700). Funding may be used for mini-grants, stipends, materials/supplies, staff/consultant time, and other project-related expenses (including software).

Period of Performance
April 2022 – March 2023, with August 2022 – March 2023 subject to project continuation and funding from the CDC. If additional funding becomes available, the project may be extended.

Reporting Requirements
Awardees will be required to:
- Develop a workplan in coordination with ASTHO and CDC and update the workplan progress at least quarterly.
- Participate in a virtual kickoff meeting, virtual learning sessions, and technical assistance activities.
- Complete a template for a final report detailing data linkage success stories, facilitators, and barriers to inform strategies and lessons learned for sustainability and expansion of the project.

Required Proposal Content and Selection Criteria

Required Sections: Applicant Worksheet, Cover Letter, Budget & Budget Narrative, and Response to Draft Contract/Contract Terms. Only the information provided in the applicant worksheet count toward the 6-page limit.

Required Language: For the Cover Letter, Budget & Narrative, and Response to Draft Contract/Contract Terms sections, the descriptive language should be included as stated below. For questions related to the application, a FAQ document has been included, and ASTHO will host an informational call using the information indicated in the submission section.

Proposal Content: Please include the following elements in your submission.

Proposals should be completed using the associated applicant worksheet. The worksheet itself may not exceed six (6) pages in length. Required appendixes do not add to the page limit and include the cover letter, any letters of commitment, budget, budget narratives and staffing CVs. Proposals must include all components listed below to be considered.

Applicant Worksheet with the following required items (70 points):

1. Proposed Approach (25 points)
   Provide a brief outline of the approach and strategy to accomplishing the requested project activities (maximum word count 250). Provide a brief outline of approach, strategy, identified data sets to be linked, how data would be used or potential priority analyses, proposed partnerships, and plans for sustainability to achieve the deliverables and meet the expectations noted above. A formal workplan will be completed as part of the learning community, after award.
2. Prior Experience, Performance, and Organizational Capacity (45 points)
   Describe experience and quality of performance on recent work completed with similar scope. Include information about familiarity with and understanding of the topic and information about the agency and its capacity to perform the services required within the timeframe. Suggested demonstrated prior experience includes:
   - Documented partnership with PRAMS grantee, vital registrars (vital records) and holder of proposed clinical datasets for linkage. Include state level team members responsible for assisting with this project, including data stewards of datasets for linkage.
   - Documented access to vital records file with identifiers linked to self-reported PRAMS data.
   - Documented access to at least one primary clinical outcome administrative dataset (e.g., hospital discharge, Medicaid claims, intervention services) and identifiers for linkage. The applicant should provide documentation for at least one primary clinical outcomes dataset(s) of interest, as well as indicate if additional clinical outcomes datasets are available for linkage.
   - Documented permission to share de-identified dataset with CDC and ASTHO. Please include an MOU/letter to denote permissions. If these permissions do not currently exist, please indicate processes and proposed timeline to complete MOU to be signed with a letter from an appropriate official (e.g., legal officer) within 30 days of funding award.
   - Demonstrated capacity to link data to inform maternal and child health program and policy, such as HRSA State System Development Initiative (SSDI), previous data linkages, or steps needed to build this capacity within the timeframe (e.g. needed software or personnel).
   - Demonstrated capacity to analyze linked datasets.
   - Describe experience and quality of performance on recent work completed with similar scope. Include information about the agency and key staff to address the ability and capacity to perform the services required within the specified timeframe.
   - Demonstrated capacity to participate in multi-jurisdiction efforts.

Inclusion of Health Equity (5 points): Throughout the proposal, incorporate the following: (1) describe the extent to which potential health disparities are evident within the health focus of the application, (2) identify the specific group(s) which could experience a potential disproportionate burden of the health condition, and (3) demonstrate how proposed activities could address health inequities (this also includes identifying social and/or

environmental conditions which are the root causes of health disparities). All information regarding health inequities must be supported with data.

Applicant Cover Letter/Letter of Support from State/Territorial Health Official (5 points)
Include the names of the learning community team members including name, title, and contact information (email and phone) that will attend the virtual learning sessions and virtual ASTHO Learning Community kick-off meeting. Please identify a point person for ASTHO correspondence. Additionally, please include a financial/contract contact with name, title, and contact information. If a team member is to be named (TBN), please specify a timeframe for when the representative will be named. Required team members must provide an attached CV. Required team members include:

    a. PRAMS Manager
    b. Clinical outcomes dataset manager
    c. Maternal and Child Health (MCH) department representative (e.g., MCH Title V Director, MCH epidemiologist, or similar)
    d. Informatics or IT representative
    e. Any additional participants as needed integral to the work of the project.

Attachment A: Budget & Budget Narrative (10 points)
Provide a detailed fixed-price budget, including detailed projected costs for the completion of the project. The budget should include salary, fringe benefits, other direct costs, and indirect costs, as appropriate. If indirect costs are included in your budget, please provide a copy of your approved Indirect Cost Rate Agreement. A budget narrative must accompany the budget and indicate the costs associated with each proposed activity. Funding may be used for funding a position within the agency, software, datasets, or other line items.

Maximum award requested for the application is $135,000 for one year. If additional funding is available, ASTHO may increase the award ceiling or extend the timeframe of the award. **Attachment A** outlines the general format in which the budget should be presented. Applicants should use **Attachment A** to develop their project budget for submission. Please see the submission information below, for more details.

Attachment B: Response to ASTHO Contract Terms & Conditions (10 points)
ASTHO and successful applicants will enter into a fixed price agreement with a detailed payment schedule, depending on the application category chosen. **Review the Terms and Conditions (see Attachment B)— including provisions related to publications; acknowledgement of federal support; conference, meeting and seminar materials; and logo use for conference and other materials with your contracts officer and/or legal team and confirm that if selected, you will enter into this agreement; or identify and submit any proposed changes to the terms along with your proposal application.** ASTHO reserves the right to accept or decline any proposed changes to the terms and conditions. Significant proposed changes, which could affect the agreement's timely execution, may impact your selection as a successful applicant.

Submission Information
Application Procedure
ASTHO must receive applications by **Friday, March 25, 2022, at 11:59 PM ET**. Please submit an electronic copy of the application to *Britta Cedergren, PRAMS@astho.org*. *Please include "RFP: PRAMS Multi-Jurisdiction*

Learning Community Application Cohort 2" in the subject line. Incomplete applications or applications received after the deadline will not be considered.

Application Timeline
- January 24, 2022: RFP released
- February 8, 2022, 2:00-3:00 PM EST: Informational Bidder's Call
- March 25, 2022, 11:59 PM ET: Application submission deadline
- April 11, 2022: Awardees announced
- April 2022: Project Period Commences, team action planning meetings with ASTHO begin
- May 3, 2022, 1:00-4:00 PM EST: Cohort 2 Kickoff Event (virtual)

Informational Bidder's Call
ASTHO will support interested applicants to offer guidance and address specific questions about the RFP. A bidders conference call will be held on Tuesday, February 8, 2022, from 2:00-3:00PM EST. Interested parties may contact ASTHO staff via e-mail at Britta Cedergren, Director, Family and Child Health PRAMS@astho.org. Q&A will be updated as questions arise on https://astho.org/funding-opportunities/ under the heading, "Linking PRAMS and Clinical Outcomes Data Multi-Jurisdiction Learning Community Cohort 2". Please register by following this link.

Frequently Asked Questions (FAQ) Document
ASTHO has included a FAQ document as part of the application package. Interested parties may also direct questions to Britta Cedergren through PRAMS@astho.org.

Disclaimer Notice:
This RFP is not binding on ASTHO, nor does it constitute a contractual offer. Without limiting the foregoing, ASTHO reserves the right, in its sole discretion, to reject any or all proposals; to modify, supplement, or cancel the RFP; to waive any deviation from the RFP; to negotiate regarding any proposal; and to negotiate final terms and conditions that may differ from those stated in the RFP. Under no circumstances shall ASTHO be liable for any costs incurred by any person in connection with the preparation and submission of a response to this RFP.

Appendix D. ASTHO PRAMS Data Linkage Learning Community Project Overview

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
Cohort 1											
Alaska	Medicaid Claims Database	2009-2020 for data linkage; used 2016-2020 for record information (ICD codes) for this specific project analysis	2009 - 2018; analysis was conducted only on birth years 2016 - 2018	First name* Last name* Middle name* Date of birth Sex Year of birth (exact match needed) *Name data obtained from prior linkage of PRAMS to birth certificate data.	Deterministic linkage with probabilistic linkage enhancement and deduplication	R (Packages used: RecordLinkage, RODBC, dplyr, tidyr, lubridate, tidyverse, reshape2, stringi)	59.90%	Child Medicaid injury claim data PRAMS demographic variables PRAMS household challenges data	Requires approved data sharing agreement, approved IRB, and submission of a request form.	Pre-birth familial stressors reported on PRAMS and injury related health care visits (collected in Medicaid) occurring during the first two years of life of the sampled infant	Generally, validation and benchmarking for linked outcome data is done by comparing PRAMS with full birth cohort estimates.
New Mexico	New Mexico State Home Visiting Database	2018 -2019	2018 - 2019, including data from the Helping Us Grow Stronger (HUGS) follow-up survey to PRAMS	Mother first name Mother last/ maiden name Mother date of birth Date of birth Child first name Child last name Child date of birth SSN when available	Deterministic linkage with probabilistic linkage and manual review	SAS 9.4 and Match*Pro	3%	Administrative home visiting data PRAMS variables HUGS variables	Unavailable	Postpartum depression and how home visiting would assess and refer for depression and offer support among people who present with their families for home visiting services	Intended to validate survey responses and demographics in PRAMS (or birth certificate) and HUGS to information collected in the administrative home visiting data.
Texas*	Birth Certificates Texas Health Care Information Collection Research Data File	2016 - 2020	2016 - 2020								

* Due to staffing shortages, some states were unable to complete or report on their data linkages during the timeframe of the learning community.

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
Washington**	The Comprehensive Hospital Abstract Reporting System (CHARS) Washington Health and Life Events System (WHALES)	2011 - 2020	2011 - 2020		Pairwise matching followed by machine learning and deterministic matching	R version 4.1.0 using RStudio 1.4.1717 (Packages used: tidyverse, DBI, odbc, janitor, stringdist, data.table, e1071, stats, mltools, doParallel, snow, fuzzyjoin, stringr, pbapply, geosphere, scales, IDPmisc)				Maternal morbidity	
Cohort 2											
Georgia	Vital Records (Births, Fetal deaths, Deaths, Marriage) Laboratory reports Surveillance case reports	Vital Records: 1980 - present Laboratory and surveillance case reports: 2020 - present	2017 - 2020	Birth Certificate number (BCN) Record Number (e.g. BCN) Current name (first, middle, last, suffix) Maiden name (first, middle, last) Base name (first and last) Date of birth Date of death SSN Resident address Gender Employer Email address Phone number	Deterministic and probabilistic matching with machine learning and artificial intelligence	Senzing	100% to birth certificates	Entirety of vital records data Resulting knowledge graph from Senzing PRAMS data dictionaries available via DPH PRAMS site	Access to linked datasets can be requested and go through an online process and be in contact with the specified data owner.	*In the process of conducting analyses*	Currently in the process of conducting validation activities according to the DPH's gold standard data for the "find the mom" question. Tests of sensitivity, specificity, PPV, and NPV will also be conducted.

** Due to delays in IRB processing, some states were unable to complete or report on their data linkages during the timeframe of the learning community.

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
Massachusetts	Pregnancy to Early Life Longitudinal (PELL) datasets, including: live birth certificates, fetal death records, delivery/birth hospital administration records, and non-delivery/birth hospital care (inpatient admissions, observational stays, emergency department visits), and other maternal and child health data systems linked to PELL	1998 - 2020	2007 - 2020	Birth Certificate number (BCN) Mother first name Mother last name Mother date of birth Date of delivery Zip code	Deterministic and probabilistic matching	LinkPro v3.0 (SAS-based)	100%	Vitals records, delivery hospital discharge, hospital care uses (inpatient admissions, observation stays, emergency department visits) prior to and after delivery for birthing individuals; birth hospital discharge and hospital care use after birth for infants.	Can be requested through IRB.	Analysis was beyond the scope of the project, but MADPH intends to evaluate the associations between health behaviors and outcomes for birthing individuals and infants cross sectionally and longitudinally	Validation will be conducted through comparison of the PRAMS-linked weighted estimates to those observed in the full birth cohort.
Montana	Vital Records (Birth Certificate and Death Certificate)/VSIMS Medicaid files (Montana's Program for Automating and Transforming Healthcare (MPATH)) Newborn Screening (metabolic/bloodspot and hearing/critical congenital heart defect)/CHRIS Child Maltreatment Reports from Child Protective Services (CPS) Evidence-Based Home Visiting Services/MTmechv Children's Special Health Services (CSHS)	2017 - present (vital records, Medicaid eligibility and claims) 2017 - 2021 (newborn screening, child maltreatment reports, evidence-based home visiting services, CSHS)	2017 - 2018	Birth Certificate number (BCN) Infant first name Infant last name Infant date of birth Infant sex Mother maiden/ last name	Deterministic and probabilistic linkage	Link Plus	12 - 25% (depending on the data year/ linked source)	Vital Records (Birth and Death): Vital records (Birth Certificate and Death Certificate) from VSIMS deaths through the child's 5th birthday-2017 and 2018 births. Medicaid Eligibility and Claims: Eligibility and claims up to the child's 5th birthday-2017 and 2018 births. Newborn Screening: Newborn Screening (metabolic/bloodspot and hearing/critical congenital heart defect) exported from CHRIS-2017 and 2018 births. Child Maltreatment Reports: Child maltreatment reports up to the child's 5th birthday exported from MPATH-2017 and 2018 births. Evidence-Based Home Visiting Services: Evidence-based home visiting service records up to the child's 5th birthday-2017 and 2018 births.	No process yet established.	Prevalence of children with a reported case of maltreatment by age 5 and factors associated; prevalence of children with a known special healthcare need by age 5 and which conditions are most prevalent	Intend to take a single birth year and look at the incidence proportions of child maltreatment before age 5 years and compare those estimated using PRAMS with those observed using vital records (the full birth cohort).

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
Nebraska	Vital Birth Records Nebraska Hospital Discharge Data	2017 - 2021	2017 - 2021	Mother first name Mother last name Mother date of birth Age Zip Code	Probabilistic linkage	Match*Pro	87.6 - 92.74% (depending on the data year)	Hospital Discharge Data (HDD): Last name, first name, sex, age, zip code, ethnicity, race, language, primary source of pay, principal procedure, additional procedures, state, length of stay, birth weight in grams, total charges, patient linking ID. Birth Certificate: Maternal and infant demographics, pregnancy characteristics, characteristics of labor and delivery, newborn medical information.	Requests must be directed to the DHHS public records and a form specific to Nebraska PRAMS must be completed.	Severe maternal morbidity	Intend to conduct cross-validation using external validation from other credible sources/ datasets, sensitivity analyses, calculation of confidence intervals and statistical tests, use of gold standard subsets, expert review.
Rhode Island	Vital Birth Records Hospital Discharge Data	2020 - 2022	2021	Patient first name Patient last name Mother date of birth Medical record number Discharge date Zip code	Deterministic linkage and probabilistic linkage	Match*Pro and SAS	99.30%	Diagnostic and procedure ICD-10 codes for hospitalizations occurring between October 2020 to December 2022 including flag indicators for delivery status and severe maternal morbidity Maternal demographic information including race/ethnicity, education level completed, and residence	Sharing agreement requiring draft proposal for PRAMS linkage and a data request form to the Office of Vital Records.	Prevalence of postpartum depression among women who were diagnosed with severe maternal morbidity and health disparities	Compared estimates for variables of interest in the linked dataset to the full birth cohort.

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
South Dakota	Vital Records- Birth file South Dakota Medicaid Claims Data	2018 - 2020	2018 - 2020	Mother social security number Mother first name Mother last name	Deterministic linkage	SQL	49.10%	**Medicaid Claims Data** Demographic data (Patient name, birth date, address, bogus patient identifier added for both birth certificate ID and Medicaid ID so if needed the information could be linked back to the initial patient claim, coverage begin and end date along with the two prior coverage begin and end dates, current and previous level of care descriptions) Hospital Inpatient and Outpatient data (ICD-10-CM admitting diagnosis, principal (primary diagnosis), up to 20 secondary diagnoses, and DRG information for inpatients, ICD-10-PCS principal procedure and up to five additional procedure codes) Clinic visit data (ICD-10-CM primary diagnosis, up to 20 secondary diagnoses, and CPT-4 procedure codes with up to two modifiers) Claims data (for institutional, professional, dental, and pharmacy claims) including service from and through date, admit source, admit type, discharge disposition, claim type, service provider, billed amounts and, four levels of denial reasons at the claim level. Pharmacy claims data including the demographic and claims data above plus NDC codes, categories, names, and the supply of drugs purchased. Dental claims data including the demographic and claims data above and CDT procedure codes. **PRAMS** Demographics (summarized/categorized), preconception care, preconception health, pregnancy intentions and birth control use prior to pregnancy, nutrition and maternal weight, medical risk factors, prenatal care entry and adequacy, prenatal care barriers, flu vaccinations, oral health, abuse, tobacco use, tobacco quit status and relapse after pregnancy and barriers to quitting, environmental smoke exposure and actions of the health provider, alcohol use, drug use, breast feeding, infant health, infant safe sleep, postpartum health and birth control use, adverse childhood experiences (ACEs)	Working on PRAMS linkage-specific process that will be like	What percent of women in the PRAMS/Medicaid linked population who self-reported	Comparison of the PRAMS-Medicaid linked population to a state birth cohort-Medicaid linked population.

State	Data Sources Linked with PRAMS	Years of Available Data (Linked Dataset)	Years of Available Data (PRAMS)	Identifying/ Matching Variables	Linkage Method	Software Used for Matching/ Linkages	Proportion of Records Linked	Type of Data Elements Available in Linked Dataset (Research Dataset)	Availability of Linked Dataset to External Researchers	Outcome(s) of Interest	Validation or Benchmarking Method
Tennessee	Vital Birth Records Hospital Discharge Data System	Birth Statistical Data (BSD): 2019 - 2020 Hospital Discharge Data System (HDDS): 2018 - 2021	2019 - 2020	Mother social security number Two-name components and DOB or one-name component, DOB, and address	Deterministic linkage	SAS 9.4	100% to BSD 38.06 - 97.49% to HDDS depending on years linked and prenatal, birth, and postpartum hospital encounters	Hospital Discharge Data including diagnosis codes (ICD-10), procedure codes, payor information, length of stay, elements related to treatments occurring during hospitalization	Data requests must be submitted through a central data request portal managed by the Office of Informatics and Analytics, and an IRB must be obtained if requesting protected health information or personal health information.	Prenatal or postpartum hospital encounters for hypertension and differences between birthing parents that had prenatal hospital encounters from those that did not.	Compared the overall prevalence of hypertension related disorders in the full HDDS dataset of women aged 10-50 to the weighted prevalence obtained after linking.
Virginia	Vital Birth Records Hospital discharge data from the Virginia Health Information (VHI) system	2017 - 2021	2017 - 2021	Mother social security number	Deterministic linkage	SQL	67.90%	Patient level database system includes patient demographic, administrative, clinical, and financial information on every discharge that occurs in Virginia licensed hospitals, with over 850,000 discharges a year, including: Administrative: where the patient originated, the urgency of the admission, when the patient was treated and the hospital in which care was provided. Clinical: up to 18 diagnoses and 6 diagnostic or surgical procedures effective with discharges. Demographic: patient age, gender and race (when available), zip code and state of residence. Financial: total charges for the stay as well as a series of 14 calculated groupings by type of care. Physician: National Provider Identifier (NPI) of the attending and operating (where principal procedure is reported) physicians who are primarily responsible for the care received by any individual patient"	Contact the VDH OFHS Division of Population Health data team through email or DPHD data request Red Cap link. IRB will be needed from requestor's institution and from VDH, followed by a Data Sharing Agreement.	Birth outcomes, prenatal care, experiences of discrimination and stress, and substance use with VHI outcomes such as primary and secondary diagnoses, length of hospital stay, and patient status	Did not perform one.

Appendix E. Publications & Presentations Using Linked Data

Throughout the PRAMS Learning Community, state teams used their linked dataset and related analyses for a wide range of written and verbal products. Below is a list of the publications and presentations from both cohorts.

PRAMS Learning Community Written Publications

Date	State	Title	Author	Type of Article	Journal
10/22/2021	Alaska	Breastfeeding Duration and Reported Child Maltreatment in a Population-based Alaskan Birth Cohort	Helena Hutchins	Peer Review	Journal of Family Violence
12/01/2021	Alaska	State actions to prevent and mitigate adverse childhood experiences	Sweta Haldar	Project Highlights	NGA Website
01/20/2022	Alaska	Replicating the Alaska Longitudinal Child Abuse and Neglect Linkage (ALCANLink) Methodology	Jared Parrish	Report/Brief	US Department of Health & Human Services
03/15/2022	Alaska	Pre-Birth Household Challenges Predict Future Child's School Readiness and Academic Achievement	Robyn Husa	Peer Review	Children Journal
09/01/2022	Alaska	Summary of Findings from the ALCANLink Project: Education Outcomes	Robyn Husa	Report	Circulated via email
11/01/2022	Alaska	Adverse Childhood Experiences Among 3-Year-Olds, Alaska	Robyn Husa/Riley Fitting	Brief	Circulated via email
01/21/2023	Alaska	Changes in Household Challenges and Subsequent Child Welfare Report	Robyn Husa	Peer Review	American Journal of Preventive Medicine
02/01/2023	Alaska	Pre-Birth Challenges Impact Early Childhood Experiences	Jared Parrish	Analysis Brief	Circulated at Legislative Session

Date	State	Title	Author	Type of Article	Journal
05/03/2023	Alaska	Replication and Validation of a State-Wide Linkage Method to Estimate Incidence Proportion of Child Maltreatment	Abigail Newby-Kew	Peer Review	Annals of Epidemiology
09/2023	Montana	Children with Special Health Care Needs (CSHCN) in Montana, 2017-2018	Kara Hughes/Maren Weber	Data Brief	Circulated via email
02/2024	Nebraska	Nebraska Pregnancy Risk Assessment Monitoring System (PRAMS) Linkage to Hospital Discharge Data (HDD)	Celeste Illian/Ama Bikoko	Linkage Methodology Report	Circulated via email.

PRAMS Learning Community Presentations

Date	State	Title	Author	Location	Type	Audience
9/14/2021	Alaska	Dynamic Risk and Prevention in Child Maltreatment	Robyn Husa	ACT Board	Presentation	Board Members
10/14/2021	Alaska	The Alaska Child Abuse & Neglect Linkage Project: Implementing a mixed-design strategy for child wellbeing research in the health department	Jared Parrish	CDC DVP ADS Training Series webinar	Presentation	CDC DVP staff

Date	State	Title	Author	Location	Type	Audience
10/15/2021	Alaska	Trauma-Engaged Schools – Moving beyond awareness to engagement	Sharon Fishel, Pat Sidmore, Jared Parrish, Heather Coulehan, Vanessa Salmon	Annual conference on Advancing School Mental Health	Presentation	Educators/Researchers
10/26/2021	Alaska	When Having More Isn't Better The Relationships Between Household Challenges, ACEs, and Poor School Readiness	Robyn Husa, Pat Sidmore	Alaska Chapter AAP Grand Rounds	Presentation	Pediatricians/Academics
11/4/2021	Alaska	When the headwaters are a glacier: Moving upstream for maltreatment prevention requires addressing big challenges	Jared Parrish, Pat Sidmore, Matt Hirschfeld	Alaska Child Welfare Conference	Presentation	Caseworkers, parents, social workers
12/8/2021	Alaska	When More is Not Better: Changes in Household Challenges Between Pre-Birth and Childhood and Subsequent Child Welfare Contact.	Robyn Husa, John Prindle, Jared Parrish	CityMatCH Leadership and MCH Epidemiology Conference	Poster	Academics, professionals, healthcare workers, researchers
12/13/2021	Alaska	Building a clinical decision making tool - ACES	Jared Parrish	APHA Final grant report out	Presentation	Funder and other project sites

Date	State	Title	Author	Location	Type	Audience
12/15/2021	Alaska	Youth Mental Health	Jenny Baker, Pat Sidmore, Leah Van Kirk, Robyn Husa	Public Health Science ECHO	Presentation	Public
1/20/2022	Alaska	Integrating Pediatrics & Public Health in Alaska Through Data	Pat Sidmore, Jared Parrish, Matt Hirschfeld	Alaska Health Summit	Presentation	Public health professionals
2/23/2022	Alaska	Suicide Prevention Through Maternal Support	Robyn Husa, Katey Soellers	MCHI Conference	Presentation	Educators, researchers, health care professionals
2/24/2022	Alaska	Transforming Schools	Sharon Fishel, Pat Sidmore, Jared Parrish	MCHI Conference	Presentation - Plenary	Educators, researchers, health care professionals
4/5/2022	Alaska	Moving Upstream to Predict and Promote Children's School Readiness and Academic Achievement	Robyn Husa & Jared Parrish	All Alaska Pediatric Partnership Meeting	Presentation	A2P2 Staff
4/13/2022	Alaska	MCH-Epi & ALCANLink Publication Updates	Robyn Husa	State Epidemiology Workgroup (SEW) Meeting	Presentation	SEW Members
5/23/2022	Alaska	Changes in Household Challenges Between Pre-Birth and Childhood	Robyn Husa & Jared Parrish	Association for Maternal & Child Health Programs Annual	Poster	Academics, professionals, researchers, public

Date	State	Title	Author	Location	Type	Audience
		Predict Subsequent Child Welfare Contact		Conference (AMCHP)		
6/9/2022	Alaska	Moving from Reacting to ACEs to Preventing Them: Introducing a [in development] new pre-birth assessment tool	Jared Parrish, Riley Fitting	9th Annual Alaska Advanced Trauma Training Institute	Presentation	Professionals
9/21/2022	CDC	Linking the Pregnancy Risk Assessment Monitoring System (PRAMS) and Clinical Outcomes Data: Lessons Learned from a Multi-Jurisdiction Learning Community	Lauren Kipling	CityMatCH Leadership and MCH Epidemiology Conference	Poster Presentation	Academics, professionals, healthcare workers, researchers
9/30/2022	Alaska	Pre-Birth Household Challenges and Effects on Early Childhood Experiences in Alaska	Robyn Husa	Alaska Nurse Practitioner Association 2022 Annual Conference	Presentation	Nurse Practitioners & Health Care Professionals
11/3/2022	Alaska	ALCANLink data and early childhood indicators	Jared Parrish	ROCK MatSu	Presentation	Steering Committee
11/10/2022	Alaska	Unconditional Cash-Transfer and child abuse and neglect	Lindsey Bullinger	NYU Cash Transfer Lab Webinar	Presentation	Researchers
2/6/2023	Alaska	The connection between supporting healthy development and applying	Jared Parrish, Joshua Arvidson	Reducing Recidivism and Reentry Conference	Presentation	Professionals/lived experience

Date	State	Title	Author	Location	Type	Audience
		effective trauma treatment: Prevention along a continuum				
2/20/2023	Alaska	Adverse Childhood Experiences	Trevor Storrs, Jared Parrish, Linda Chamberlain	Alaska House Judiciary Committee	Presentation	Legislature
3/22/2023	Alaska	State of the child	Cathy Baldwin-Johnson, Jared Parrish, Pam Karalunas	Alaska Legislative Lunch and learn	Presentation	Legislature
6/13/2023	Alaska	Adverse Childhood Experiences Surveillance: A life course approach	Jared Parrish	ASTHO building capacity to prevent ACEs convening	Presentation	State learning community, ASTHO, CDC
09/21/2023	Tennessee	Characteristics of Tennessee Mothers with Prenatal Hospital Encounters	Sarah Shaffer	CityMatCH Leadership and MCH Epidemiology Conference	Oral Presentation	Academics, professionals, healthcare workers, researchers

Appendix F. Technical Assistance Requests Overview

Technical assistance (TA) requests were solicited in several ways over the course of the Learning Community. Primarily, TA requests would come in during the monthly check in meetings ASTHO held with each state. Occasionally, requests would come to the prams@astho.org inbox. Requests for Jared Parrish were sent directly to his inbox. All requests were responded to within 36 hours unless they required additional investigation. Most of the TA requests from Cohort 1 were logistical or training-related whereas the requests from Cohort 2 tended to be more statistical and linkage-related (likely due to the engagement of Dr. Jared Parrish as a consultant on the Learning Community).

ASTHO Technical Assistance Requests

TA Request	State	LC Cohort	Project Year	Notes
Connect Lizzie Harvey to subject matter experts re: creating common coding	Tennessee	Cohort 2	Y4	Connected Lizzie & Angela Miller (TN) with Jared to discuss the creation of common coding.
Connect w/ state teams who have follow up surveys (specifically OR, AK, NM)	Montana	Cohort 2	Y4	Connected MT team to OR, AK, and NM PRAMS teams.
Create background document/overview on DSA processes	Washington	Cohort 1	Y3	WA team retracted request so it was never completed.
Data analysis plan template	Texas	Cohort 1	Y3	Template was completed for Texas and adapted for use with Cohort 2.
Develop ASTHO PRAMS Data Linkages Research Scan datasheet	Texas	Cohort 1	Y3	TX team retracted request so it was never completed.
Connect team w/ AK re: equity review during linkage process	Tennessee	Cohort 2	Y4	Connected TN team to AK team members (Robyn Husa) to discuss equity review.
National Inventory of Follow Up (Toddler) Surveys	Montana	Cohort 2	Y4	Provided full list of follow up surveys to MT team.

TA Request	State	LC Cohort	Project Year	Notes
Connect w/ TN team re: defining the pregnancy period	Rhode Island	Cohort 2	Y4	Connected RI team to TN team to discuss how to define their pregnancy period.
Data to action language	Alaska	Cohort 1	Y3	Completed a template PRAMS success story about the LC activities. Repurposed this template and shared with all LC teams.
Biases in home visiting datasets	New Mexico	Cohort 1	Y3	Connect NM team with internal ASTHO staff to discuss biases in their data.
Process Mapping of data request and linkage	New Mexico	Cohort 1	Y3	Completed a process mapping exercise of specific data requests that fell outside of DOH jurisdiction.
Connect NM to PRAMS staff, and another state epi to identify standard variables for analysis	New Mexico	Cohort 1	Y3	Connected NM Epi to CDC PRAMS staff and AK Epi to discuss standard variables.
Set up meeting with AK re: partnerships	Washington	Cohort 1	Y3	Connected WA and AK teams to discuss potential data linkage partnership.
Identify trainings for Matchpro/Linkplus	Texas	Cohort 1	Y3	Identified trainings for TX staff to learn linkage software.
Connect AK with Susan Manning/MDPH team re: Roadmap	Alaska	Cohort 1	Y3	Connected AK team to MDPH team to discuss equity reviews and Racial Equity Data Roadmap.
Data Linkage Follow Up Meeting w/ AK	New Mexico	Cohort 1	Y3	Set up meeting between AK and NM to discuss barriers to data linkage.
Identify ways to promote state job/contract opportunities	Texas/Tennessee	Cohort 1/Cohort 2	Y4	Identified several ways for states to promote job or contract opportunities.
ICD-10 Codes	Alaska	Cohort 1	Y4	Connected AK team to CDC and held a meeting to discuss updated ICD-10 codes.
Process map for internal and external data sharing	Washington	Cohort 1	Y4	Completed a process mapping exercise for data sharing internal and external to WADOH.

TA Request	State	LC Cohort	Project Year	Notes
Connect with Dr. Kirby re: training for linkage software	Texas	Cohort 1	Y4	Connected TX team with Dr. Kirby re: trainings for linkage software.
Connect team with Washington re: machine linkage processes	Alaska	Cohort 1	Y4	Connected AK to WA to discuss their machine learning processes.
PRAMS MMM Data Request	Non-LC State (MO - UMKC)	N/A	Y4	Shared resources to inform UMKC's MMM research using PRAMS data and connected them with SMEs. Helped expedite UMKC's PRAMS data request with CDC.
Connect team w/ Nebraska re: onboarding of contractor	Tennessee	Cohort 2	Y4	Connected TN to NE team about how they successfully onboarded a contractor hired for data linkage activities.
Legal issues around state IRB	Montana	Cohort 2	Y4	Held a meeting with MT team and ASTHO Legal team to discuss state IRB barriers.

Dr. Jared Parrish Technical Assistance Requests (only applicable for Cohort 2)

TA Request	State	Project Year	Notes
Documented data linkage methods, purpose, analysis and sustainability plans, plan for validation and/or benchmarking, and identified specific state team needs.	All Cohort 2 States	Y5	Included calls with state teams and/or epidemiologists, working sessions, and providing templates and coding examples.
Review state evaluation/benchmarking plans.	All Cohort 2 States	Y5	Often no benchmarking plans existed. Provided guidance on simple to more complex approaches.
Supported development and consultation for validation methods.	All Cohort 2 States	Y5	Encouraged at least one full birth cohort linkage to validate estimates against. Also suggested simulation studies, sensitivity analyses, and respondent to non-respondent comparisons.

TA Request	State	Project Year	Notes
Consultation on data linkage methods and tools.	All Cohort 2 States	Y5	Provided support on software selection, methodology, setting thresholds, and setting routines and documentation to facilitate replication. Encouraged capture recapture or duel research linkage to create inter and/or intra rater reliability measures.
Provide publications, linkage examples using R, and other integration documentation.	Multiple States	Y5	Provided linkage examples and code to Montana, Rhode Island, and South Dakota.
Supporting one state w/ addressing a linkage anomaly.	Nebraska	Y5	Worked with the researcher conducting the linkages to identify coding error. By following my suggestion to link an entire birth cohort to benchmark against this error was detected. Solved by approaching it through compartmentalized code evaluation and testing.
Identified new linkage tool and data management process.	Montana	Y5	Sent recommendations and options that MT team could adopt.
Conducted linkage activities.	Virginia	Y5	Due to hiring issues, linkage activities were completed by Jared. Provided recommended SQL data structure and ID linkage storage.
Linkage validation support.	Nebraska/South Dakota	Y5	Resolved questions around validation of linked dataset.
Sustainability and Analysis Plan creation	Montana	Y5	Discussed options for sustainability and analysis plans with linked child welfare data. Provided R code and statistical support in analysis.
Weighting and Benchmarking	Rhode Island	Y5	Multiple discussions about subset analyses and accounting for partial cohort linkages and how to evaluate if re-weighting is necessary. Determined for their specific research question not necessary to re-weight.
Support end of grant reporting, assessments, and sustainability.	All Cohort 2 States	Y5	Provided review and clarification around final reporting.

TA Request	State	Project Year	Notes
GSEP Intern Support	Montana	Y5	Established weekly meetings to help them create an analysis dataset for a GSEP intern. Reviewed SAS code, provided data structure templates, and supporting them in developing analysis plans and long-term planning for using the linked data.
Identification of errors in code	Nebraska	Y5	Helped the analyst identify errors in code and walked them through a process for avoiding these issues in the future.

Appendix G: Data Linkage Subject Matter Experts List

Brenda Le Bauman, MSPH
PRAMS Epidemiologist
Division of Reproductive Health
CDC

Maria "Paz" Carlos, PhD, MBA
Senior Public Health Advisor
Program Officer, State Systems Development
Initiative Program (SSDIP) Tier 1 and Tier 2
Maternal & Child Health Bureau
HRSA

Juanita J. Chinn, PhD
Program Director
Demography of Health, Mortality &
Population Composition
NIH/NICHD

Lilian Colasurdo, JD
Director, Public Health Law & Data Sharing
ASTHO

Ann Davis, PhD *
Director, Perinatal Data Center
March of Dimes

Wanda Barfield, MD, MPH, FAAP
Retired Assistant Surgeon General, USPHS
Professor of Pediatrics, Uniformed Services
University
Director, Division of Reproductive Health
National Center for Chronic Disease
Prevention & Health Promotion
CDC

Nahida Chakhtoura, MD
Medical Officer/Physician
Executive Secretary, HHS Panel on Treatment
of Pregnant Women with HIV Infection &
Prevention of Perinatal Transmission
Chief, Pregnancy & Perinatology Branch
NIH/NICHD

Cheryl L. Clark, DrPH, RHIA
Associate Director
Equity, Epidemiology & Evaluation
AMCHP

Shanna Cox, MSPH
Associate Director for Science
Division of Reproductive Health
CDC

Renee Fox, MD
(Replaced Kristen Zycherman, RN, BSN)
Medical Officer
Division of Quality and Health Outcomes
Children and Adults Health Programs Group
Center for Medicaid and CHIP Services
CMS/CMCS

Lizzie Harvey, PhD, MPH *
Epidemiologist assigned to the
Division of Family Health & Wellness,
Tennessee Department of Health
Maternal and Child Health Epidemiology
Program
Division of Reproductive Health
CDC

Erin Holve, PhD, MPP, MPH
Chief Officer, Research Infrastructure and
Innovation
PCORI

Russel S. Kirby, PhD, MS, FACE
Distinguished University Professor &
Marrell Endowed Chair
College of Public Health
University of South Florida

Milton Kotelchuck, PhD, MPH
Professor of Pediatrics, Harvard Medical
School
Senior Scientist, Maternal Child Health
Center
Center for Child & Adolescent Health Policy
Massachusetts General Hospital

Lisa Mirel, MS *
Chief, Data Linkage Methodology &
Analysis Branch
Division of Analysis & Epidemiology
National Center for Health Statistics
CDC

Ekwutosi Okoroh, MD, MPH *
Commander, USPHS
Team Lead, Maternal and Child Health
Epidemiology Program

Phil Hastings, PhD
Founder & Principal
Far Harbor

Khaleel Hussaini, PhD, MS, MSW (equiv.)
Epidemiologist & Senior Service Fellow
assigned to the Delaware Department of
Public Health
Maternal and Child Health Epidemiology
Program
Division of Reproductive Health
CDC

Nik Koscielniak, PhD, MPH
Program Officer,
PCOR Infrastructure and Innovation Program,
PCORI

Joyce Martin, MPH
Lead, Birth & Infant Health Team
Reproductive Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
CDC

Abigail Newby-Kew, MPH
Epidemiology Doctoral Candidate
School of Public Health
Oregon Health Science University
Portland State University

Jared Parrish, PhD
Senior Maternal & Child Health
Epidemiologist
Division of Public Health

Division of Reproductive Health
CDC

Joe Pirozzolo, PhD
Research Statistician
Far Harbor

Elizabeth A. Shenkman, PhD
Department Chair and Professor,
University of Florida College of Medicine

Shae R. Sutton, PhD
Senior Director of Programs
NAPHSIS

Keriann Uesugi, PhD, MPH
Health Scientist
Division of State & Community Health
Maternal & Child Health Bureau
HRSA

Kristen Zycherman, RN, BSN
(Replaced by Renee Fox, MD)
Maternal Infant Health Initiative Lead
Maternal & Infant Health SME
Division of Quality and Health Outcomes
Children and Adults Health Programs Group
Center for Medicaid and CHIP Services
CMS/CMCS

Alaska Department of Health & Human
Services

Emily Putnam-Hornstein, PhD, MSW
John A. Tate Distinguished Professor for
Children in Need
School of Social Work
University of North Carolina, Chapel Hill

Holly B. Shulman, MS
PRAMS Statistician & Program Manager
Division of Reproductive Health
CDC

Megan Toe, MSW
Epidemiology Program Manager
Substance Use & Injury Program
CSTE

Kara Zivin, PhD, MS, MA, MFA
Professor of Psychiatry,
Professor of Obstetrics & Gynecology,
University of Michigan Medical School
Professor of Health Management & Policy,
University of Michigan School of Public
Health
Faculty Associate, Survey Research Center,
Institute for Social Research
Research Career Scientist, Center for Clinical
Management Research (CCMR), VA Ann
Arbor Healthcare System

* Indicates that individual is no longer in the role listed as of June 2024.